

*Perceived Diagnostic Status, Pain-Related Guilt
and Their Association with Mood and Disability
in Low Back Pain*

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Declaration of Authorship

I, Danijela Serbic, hereby declare that this work was carried out in accordance with the Regulations of the University of London. I declare that this submission is my own work, and to the best of my knowledge does not represent the work of others, published or unpublished, except where duly acknowledged in the text. No part of this thesis has been submitted for a higher degree at another university or institution.

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Abstract

In the majority of low back pain (LBP) patients a clear diagnosis cannot be established. This may relate to how patients perceive and manage their condition, and to the development of pain-related guilt. This thesis presents a series of studies investigating the relationship between perceived diagnostic status, pain-related guilt and mood and disability in LBP. In Study 1 semi-structured interviews were conducted with LBP patients to explore their understanding, feelings and behaviour in response to their diagnostic status. Several participants experienced a state of diagnostic uncertainty which was associated with their social, emotional and cognitive functioning, and with seeking further treatment. Pain-related guilt emerged as a major theme and was further examined in Study 2 and 3, in which a pain-related guilt scale was developed and validated. Three subscales were identified: social guilt, managing condition/pain guilt and verification of pain guilt, and each subscale was positively correlated with pain, mood and disability. Study 4 aimed to amalgamate the findings from the first three studies and test a theoretical model in which diagnostic uncertainty predicted pain-related guilt, which in turn predicted mood and disability in LBP. The model provided a reasonable-to-good fit with the data, but the alternative models in which reversed relationships between guilt, mood and diagnostic uncertainty were tested were slightly better. Finally, Study 5 examined cognitive mechanisms underlying the relationship between diagnostic uncertainty and mood and disability; to this end an experimental study was conducted in which two groups of LBP patients were compared (certain vs. uncertain about diagnosis) on their selective recall of negative health stimuli. Only the group with diagnostic uncertainty displayed a recall bias towards negative health stimuli. Overall, the findings from this thesis suggest that diagnostic uncertainty and pain-related guilt are common and important experiences in LBP and are associated with mood and disability.

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Based on Study 5:

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Chapter 1

Introduction

This chapter provides a brief overview of the thesis. It outlines the thesis aims, structure and methodology, and it provides a summary of each study. Its aim is to introduce the reader to the thesis rather than provide a comprehensive review of these aspects.

Aims and Structure of the Thesis

The thesis examines the relationship between perceived diagnostic status and disability and mood in low back pain (LBP). In the majority of LBP patients a clear diagnosis cannot be established; as a result patients are given unclear labels such as non-specific LBP. Past research (reviewed in the next chapter) suggests that this may impact on patients' perceived diagnostic status; many patients are unhappy with their diagnosis, they believe that a clear diagnosis is needed for their pain and feel their pain is not legitimised without it. Research reviewed in the next chapter also shows that there is some evidence to suggest that perceived diagnostic status impacts on how LBP patients cope with their pain. It also relates to heavy use of medical services by these patients in an effort to find medical answers to legitimise their symptoms. However, the impact of perceived diagnostic status on LBP patients' outcomes is not entirely clear.

The thesis also examines the concept of pain-related guilt and it is the first to systematically examine it in the context of LBP. Research reviewed in the next chapter suggests that LBP patients sometimes report feeling guilty for things they cannot do because of their pain, but this research is scarce. Therefore, an examination of pain-related guilt, and primarily its relationship to perceived diagnostic status, is a secondary aim of the thesis.

In Study 1 (qualitative) in-depth semi-structured interviews were carried out with 22 LBP patients in order to explore how patients understand, feel and behave in response to their perceived diagnostic status, and whether they experience pain-

related guilt. Sampling, data collection and analysis were driven by a grounded theory approach. Categorisation for perceived diagnostic status was also derived from this study for use in Study 4 and 5 of the thesis. In Study 2 a pain-related guilt scale was developed (from Study 1 interviews using guidance for methodologically sound survey items) and tested with exploratory factor analysis; the aim was to identify an interpretable factor structure for use in the assessment of pain-related guilt of LBP. The aim of Study 3 was to test if this structure could be confirmed in a new sample of participants using confirmatory factor analysis, and to validate the scale by correlating it with clinical measures of pain, mood and disability. Study 4 aimed to bring the findings of the previous three studies together and test a theoretical model using structural equation modelling, which examined relationships between perceived diagnostic status, pain-related guilt, and disability, depression and anxiety in LBP. Finally, Study 5 aimed to gain a better understanding of the cognitive mechanisms underlying the relationship between perceived diagnostic status and these clinical measures in LBP; to this end an experimental study was conducted in which participants were categorised into groups according to their perceived diagnostic status and compared on their susceptibility to recall bias towards negative health stimuli. The thesis structure is illustrated in Figure 1:1.

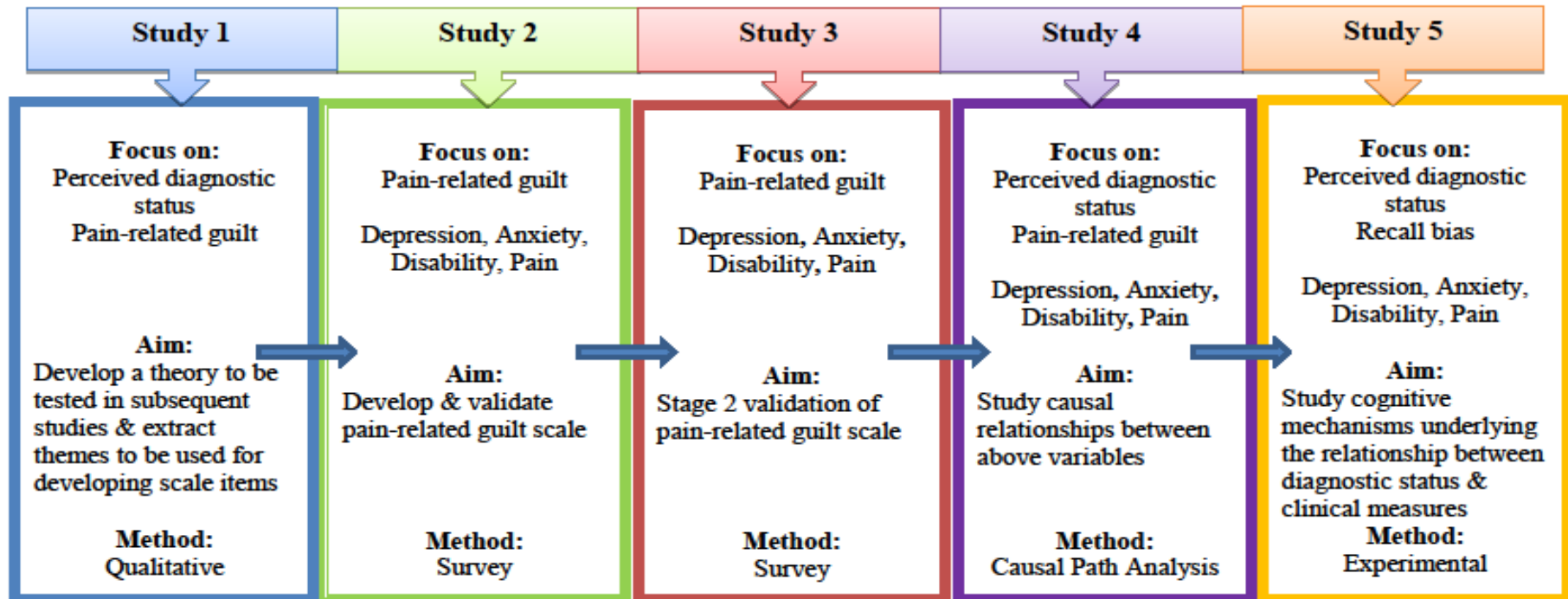


Figure 1:1 *Structure of the Thesis*

Methodology

The following is an introduction and a brief outline of the methodology used in the present work. Because each study of the thesis employed different methodology and statistical analysis, detailed descriptions of those will be provided within each chapter. Therefore, the aim of this section is to introduce and signpost the reader to key methodological aspects, rather than provide a comprehensive summary of those.

Main Variables Examined in the Thesis

Perceived diagnostic status is the main variable under investigation in the thesis. An aim of Study 1 was to develop a categorisation for perceived diagnostic status; this measure is described in Study 1 (Chapter 3). To understand the impact of perceived diagnostic status on LBP patients, the thesis examines its relationship to several other variables, most notably pain-related guilt.

The thesis focuses on guilt as a psychological construct and a psychological factor in the context of pain; it does not address guilt from other perspectives such as sociological, philosophical and theological. An aim of the thesis was to develop, test and validate a measure of pain-related guilt. This process is described in Study 2 and 3 of the thesis. A comprehensive review of the main variables is provided in the literature review (Chapter 2).

Secondary Variables Examined in the Thesis

The present work uses four clinical measures, which are widely used in pain research: depression, anxiety, disability and pain intensity. Existing and validated measures of these outcomes are used in the thesis and they are described in Study 1 - 3.

It should be noted that although the term distress would be more appropriate to use in the context of pain research (Pincus & Morley, 2001), the term depression is used in this thesis because it is the label used in the Hospital Anxiety and Depression Scale (which is implemented in the thesis). The reader should keep in mind that it

does not indicate the presence of clinical depression. Additionally, the current work is interested in the relationship between perceived diagnostic status, pain-related guilt, and mood and disability, but the relationships with pain intensity are also examined for exploratory purposes.

An additional aim of the thesis was to gain a better understanding of the cognitive mechanisms underlying the relationship between perceived diagnostic status and the above mentioned clinical measures in LBP. This was achieved by examining participants' susceptibility to recall bias for negative health stimuli. Recall bias is a type of cognitive bias, and there is a substantial body of research (summarised in Chapter 2) showing that it is an important cognitive mechanism that contributes to the maintenance of depression symptoms. The measure of recall bias used in the thesis is described in Study 5 (Chapter 6).

Design and Analysis

Chapter 3 presents Study 1 which employed a qualitative methodology in order to explore participants' experiences and understanding of their diagnosis-related beliefs and construct a theory that would explain the perceived impact these may have on their life and coping with their pain. It also aimed to develop a categorisation for perceived diagnostic status for use in the subsequent studies of the thesis. To this end, a grounded theory was employed, which is the most suitable qualitative method for deriving theories from the data.

Chapter 4 presents Study 2 and Study 3 which both used survey method and employed exploratory and confirmatory factor analyses respectively. Exploratory factor analysis was used to explore the underlying structure of the pain-related guilt measure. Confirmatory factor analysis was used to statistically validate this measure, and examine if this underlying structure can be confirmed in a new sample of participants.

Chapter 5 presents Study 4 which employed structural equation modelling in order to examine pathways between perceived diagnostic status, pain-related guilt, and mood and disability.

Finally, Chapter 6 presents Study 5 which employed experimental methodology to examine cognitive mechanisms underlying the relationship between perceived diagnostic status and clinical measures in LBP.

Participants

Figure 1:2 shows the data collection flow chart. For each study different participants were recruited; apart from Study 4 which included all Study 2 and Study 5 participants, Study 3 British College of Osteopathic Medicine (BCOM) participants and 67 new National Health Services (NHS) participants. Detailed information about participants and institutions where recruitment was carried out are provided within each chapter.

All five studies were ethically approved by Royal Holloway, University of London, institutions where recruitment took place, and by the NHS for Study 4 and 5.

Additional Notes and Explanation of Terminology

Term ‘diagnosis-related beliefs’ and ‘perceived diagnosis status’ both refer to participants’ perceptions about their diagnosis. They are very similar in meaning, although within the context of the present work, ‘diagnosis-related beliefs’ is used as a more general term and is therefore used to refer to broad diagnosis-related beliefs. For example, it may refer to beliefs about one’s diagnosis (presence/absence of it), but it could also refer to beliefs about how that diagnosis should be treated or talked about. It is a broader term than ‘perceived diagnostic status’ which mainly refers to one’s diagnostic status, such as presence/absence of clear diagnosis/evidence/causes /understanding of one’s pain. Both terms are used in the thesis, and their use depends on the context (in some cases both terms are appropriate to use). Term ‘diagnostic uncertainty’ is used to denote an outcome of ‘perceived diagnosis status’, and is regularly used in the thesis from Study 1 Results section onwards as it was identified as an (overall) outcome of Study 1 interviews. Terms ‘diagnosis’ and ‘diagnostic labelling’ will be defined and discussed in Chapter 2 and 3.

Study 1, 4 and 5 included chronic LBP participants; Study 2 and 3 included both acute and chronic (>3 months) LBP participants, although the vast majority (about 90%) of participants in these studies had chronic LBP. These two studies were correlational and their aim was to statistically validate the pain-related guilt scale, therefore it was not necessary to specifically focus on chronic LBP. Study 1 was qualitative and focused on participants' experiences, understanding, feelings and behaviour in response to their diagnostic labels, thus it was necessary to include participants with a prolonged experience of LBP. Study 4 examined pathways between perceived diagnostic status, pain-related guilt, and mood and disability hence it was also necessary to focus on chronic LBP. Study 5 was experimental and focused on cognitive mechanisms that may underlie the relationship between perceived diagnostic status, and mood and disability. Cognitive mechanisms/responses may take time to develop, thus participants with chronic LBP were used in this study.

Term 'participant/s' is used in the thesis to refer to participants who took part in the study, even for those participants who were patients in the institutions where recruitment took place. Term 'patient/s' is used to refer to patients in general.

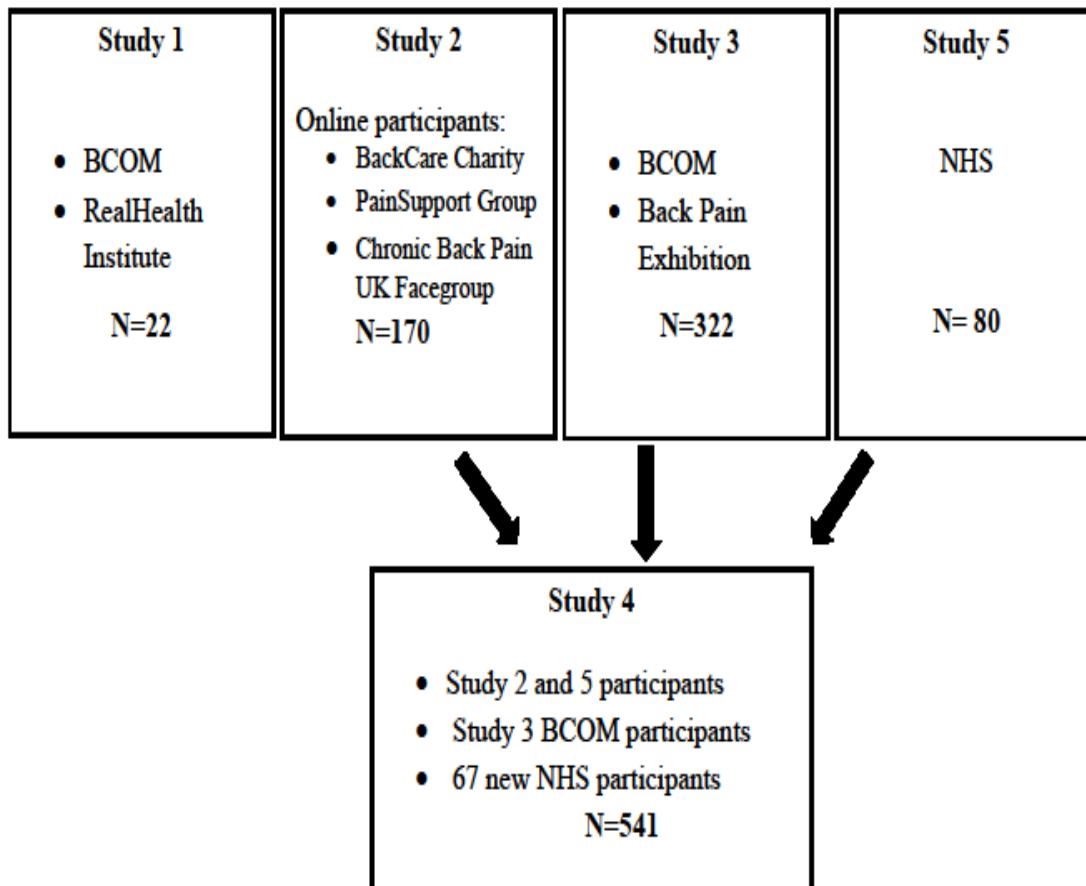


Figure 1:2 *Data Collection Flow Chart*

(N-total number of participants recruited; BCOM-British College of Osteopathic Medicine; NHS-National Health Services)

Chapter 2

Literature Review

This chapter provides a comprehensive overview of past research relevant to this thesis. The review begins with a brief introduction to pain and chronic pain, followed by an outline of research relevant to low back pain (LBP), mainly focusing on psychology of LBP. Next, past research relevant to the main variables examined in the thesis is reviewed: perceived diagnostic status and pain-related guilt, followed by a review of the literature relevant to the relationship between perceived diagnosis status and information processing in LBP. The review ends with a description of the aims of the research undertaken in this thesis.

Introduction to Pain

Defining Pain

The international association for the study of pain (IASP, 1994) defines pain as ‘An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’. Pain is a useful survival function of the body, it signals damage to the body or disease. However, chronic pain does not serve this same function; pain that persists after an injury has healed has many negative consequences for the individual (Melzack & Wall, 1996). This kind of pain is not useful to the individual in any way and becomes a considerable problem:

Pain such as this now becomes a problem in its own right. It is no longer the symptom of a disease but becomes a serious medical syndrome that requires attention for its own sake. Chronic pain can even be detrimental to survival in man (Melzack & Wall, 1996, p.12).

It is widely believed that the intensity of pain is comparative to the severity of the injury. Although this relationship in many instances holds true, there are many instances when it does not. For instance, how to explain chronic pain for which no observable cause can be found? Or, why does chronic pain following an injury often

continue long after the injury has healed (Melzack & Wall, 1996)? There are various theories that have attempted to provide answers to these and similar questions, and they are summarised later in this chapter.

Low Back Pain

Defining Low Back Pain

Low back pain (LBP) is defined as activity limiting pain and is localised between the 12th rib and the inferior gluteal folds; it can either include or exclude leg pain (Krismer & van Tulder, 2007). Acute LBP comes about abruptly and lasts for less than 6 weeks and the person must be at least 6 months without it before a new episode of LBP occurs. The same criteria apply to sub-acute LBP with the exception that an episode of sub-acute LBP lasts for at least 6 weeks to a maximum of 3 months. Chronic LBP lasts more than 3 months, or it occurs recurrently within a 6-month period (Krismer & van Tulder, 2007).

Diagnosing LBP

International guidelines for the management of LBP recommend the following classification in order to aid effective management of the problem: specific spinal pathology, nerve root pain and simple or non-specific low back pain (Koes, van Tulder, Ostelo, Kim Burton, & Waddell, 2001; Waddell, 2004). The main and very first concern in the examination of LBP is to establish that the problem is of musculoskeletal origin and to exclude non-spinal pathology. Excluding the possibility of serious spinal pathology is the next step, which is followed by inspection of evidence for nerve root pain. If such evidence cannot be found, the pain is categorised as non-specific LBP (van Tulder et al., 2006).

Only in about 5-10% of cases precise causes of back pain can be identified (Krismer & van Tulder, 2007), and non-specific LBP represents the majority (about 85%) of LBP patients (Wand & O'Connell, 2008). However, non-specific LBP is a heterogeneous group, and the remaining challenge is to classify non-specific LBP into clinically meaningful subcategories (Dunn, Jordan, & Croft, 2006); this would enable an understanding of causal mechanisms, prognostic factors and optimal

treatment. Thus, it is now recognised that a clearer classification system is needed. These issues are explored fully later in this chapter.

Epidemiology of LBP

Musculoskeletal pain is common, and has significant impact on individuals, their families, healthcare and socioeconomic costs (Maniadakis & Gray, 2000). During the course of one year around 15-20% of adults in the UK visit their GP about a musculoskeletal problem (Royal College of General Practitioners, 2006). Musculoskeletal problems are the second most frequent reason for consultation with GP after respiratory disease, and one of the most common musculoskeletal problems is LBP (Royal College of General Practitioners, 2006). Presumably it is a substantial health problem and affects 60-80% of the adult population (Nachemson & Jonsson, 2000). It was estimated that in the UK, treating all types of back pain costs the National Health Services (NHS) over £1000 million per year (National Institute for Health and Clinical Excellence, 2009). Lost work production as a result of LBP costs at least £3500 million per year in the year 2000 (Maniadakis & Gray, 2000) (in current times the equivalent cost would be approximately £5400 million). Thus, it is obvious that a reduction in the number of people with LBP will result in cost savings, although the size of these savings is not entirely clear (National Institute for Health and Clinical Excellence, 2009).

The high prevalence of LBP has been known for a long time, but the scope of its impact had not been known nor appreciated until very recently. According to the Global Burden of Disease (GBD) Project 2010 (Lim et al., 2012), LBP has the highest global impact as measured by the number of years lived with disability; and as such it is now recognised as the leading cause of disability worldwide. This study examined burden for 291 diseases and injuries in 187 countries in 1990, 2005 and 2010 (Lim et al., 2012). The lifetime prevalence of LBP is estimated to be 12%, and a one month prevalence is around 23% (Hoy et al., 2012). These figures seem to remain similar when adults, children and elderly are considered separately.

Psychological Treatments for LBP

A review of systematic reviews for the evidence of psychological interventions showed that the evidence for effectiveness is strongest for cognitive behavioural therapy (CBT), but the effect sizes across all meta-analyses and for all outcomes are modest (Eccleston, Morley, & Williams, 2013). Overall, psychological interventions produce small to moderate and mostly short term effects. For example, a review of evidence (van Tulder, Koes, & Malmivaara, 2006) found that they produce short term improvements in functioning and pain in LBP, and that no evidence exist to show they produce long term improvements. A more recent review (A. Williams, Eccleston, & Morley, 2012) examined CBT and the effectiveness of behaviour therapies on pain, disability, mood and catastrophic thinking; it found that CBT produced small effects in improving pain and small to moderate effects in reducing catastrophising and improving mood immediately after treatment. It also had small effects on disability. About 1/3 of studies examined in this review were with back pain patients.

Possible reasons for this could be the failure to understand the mechanisms that lead to chronic disability (Linton et al., 2011; Linton & Shaw, 2011; McCracken & Morley, 2014; Pincus & McCracken, 2013). Additionally, the majority of trials use heterogeneous groups of patients and do not sufficiently focus on matching patient problems with aspects of treatments that can tackle those problems (Pincus & McCracken, 2013). Furthermore, individualised treatment approach has also been proposed (Hartvigsen, Natvig, & Ferreira, 2013). For example large trials often show small treatment effects which can cloud variation in individual responses to certain treatments, while some individuals may not respond to a certain treatment, others may find it very beneficial (Eccleston et al., 2013; van der Windt, Hay, Jellema, & Main, 2008). Therefore, in order to improve patients' outcomes, identifying subgroups of patients with specific clinical profiles and needs is advocated. It has been argued that although psychological treatments give moderate effects, considering the complexity of chronic pain they still work, and that future research should focus on establishing when these treatments work and for whom they work best (Eccleston et al., 2013).

Acute vs. Chronic LBP

Back pain episodes have been regarded for a long time as independent events. However, this view is currently challenged and LBP is more and more perceived as a life-long condition (Dunn, Hestbaek, & Cassidy, 2013). It is a recurring and often persistent disorder. Cost and disability are associated primarily with chronic LBP, therefore it is important to understand which factors play a role in the transition from acute to chronic LBP. Short term LBP is usually brief, and the majority of patients get better. However, in the long-term LBP is a persistent condition with about two thirds of patients continuing to be in pain after 12 months (Weiner et al., 2008); hence the focus is on the lifelong 'course' of LBP, a chain of related episodes of LBP. Prognostic studies provide some guidance for understanding when back pain is likely to become chronic, but this guidance is often imprecise and dependent on a number of different factors (Hayden, Dunn, van der Windt, & Shaw, 2010). In most individuals with an acute episode of back pain, improvements are common within the first month after the initial consultation (Pengel, Herbert, Maher, & Refshauge, 2003). However, in about one quarter to a third of these patients, back pain reoccurs 6-12 months after the initial consultation (Henschke et al., 2008). Among chronic cases, the chances of recovery are low; around 80% of these patients will have pain after a year (Hayden et al., 2010).

Theories of Pain

A number of theories have been developed to explain the pain phenomenon. The following is not an extensive summary of pain theories; it is a brief overview of early pain theories followed by an overview of the gate theory of pain (GCT) and most important and relevant psychological theories of pain.

There is evidence that psychological factors play a role in the transition from acute to chronic LBP. For example, a systematic literature review of 25 publications (6 of which met acceptability criteria), (Pincus, Burton, Vogel, & Field, 2002) found strong evidence for the role of depressive mood in the transition from acute to chronic LBP and moderate evidence for the role of somatisation. More research is needed to understand change over time and one way of doing this is to study mechanisms by which acute LBP may develop into a chronic condition. For instance,

research has shown fear-avoidance beliefs to be such a mechanism (Linton, Buer, Vlaeyen, & Hellsing, 2000; Linton & Shaw, 2011; Vlaeyen & Crombez, 1999). However, the evidence for the role of fear of pain in LBP appears contradictory: another systematic review of nine studies did not find a link between fear of pain at early stages of back pain and poor prognosis, although there was evidence that fear may play a role when pain has passed the acute stage (Pincus, Vogel, Burton, Santos, & Field, 2006). Key psychological factors in LBP (including depression and fear of pain) are reviewed in the next section of his chapter.

Early Theories of Pain

Two early theories of pain are reviewed here: specificity theory and pattern theory.

Specificity Theory - The origins of this theory date back to the 16th century stemming from the French philosopher and mathematician Rene Descartes; it was expanded by Max von Frey in the late 19th century. Specificity theory of pain proposes that there is a specific pain system which is responsible for carrying messages from pain receptors in the body via pain pathways to a pain centre in the brain (Melzack & Wall, 1996). Both, Descartes and von Frey saw this connection as direct and automatic (Ogden, 2007). Although accurate in many respects, the theory cannot be supported by psychological evidence which conceptualizes pain as a perceptual experience dependent on a number of psychological factors. It also cannot be supported by clinical evidence, for instance phantom limb pain (Melzack & Wall, 1996).

Pattern Theory - While specificity theory proposed that pain was a specific sensation independent of the other sensations, pattern theory proposed that there is no separate system for perceiving pain, as pain receptors are shared with other senses. We feel pain when certain patterns of neural activity occur, and these patterns occur only with intense stimulation. However, this theory failed to recognize that physiological specialisation exists (Melzack & Wall, 1996).

Both of these theories are based on the assumption that pain is an automatic reaction to an external stimulus and that there is no need for further interpretation (Ogden, 2007). They offered a relatively simple relationship between tissue damage

and pain perception. These models also did not consider psychology as a possible causal factor. However, this view changed after it had been observed that medical treatments were useful in treating acute pain but not always successful in the treatment of chronic pain. It was also observed that individuals with the same tissue damage reported different levels of pain experienced. Finally, it was observed that phantom limb pain could not be explained by the existing theories of pain; external stimulus obviously does not play a role in this type of pain as the limb is missing. Additionally, phantom limb pain is not experienced by everyone and interestingly, some people who are born with a missing limb can also experience phantom limb pain (Ogden, 2007).

Gate Control Theory of Pain

Melzack and Wall (1965) developed the gate control theory (GCT) of pain. It proposed that a gate exists at the spinal cord which receives input from the site of the injury via peripheral nerve fibres but also from the brain, which then sends signals about psychological state. Both signals descending from the brain and sensory information ascending from the body can open or close neural gates in the spinal cord. The gate amalgamates all the signals received and produces an output; the more the gate is open the greater perception of pain. A number of different factors such as physical, emotional and behavioural can either open or close the gate (Ogden, 2007). Factors such as attention, expectations and past learning can impact on the gate and the level of pain perceived (Melzack & Wall, 1996). Therefore this proposition aids our understanding of why the same injury will produce different perceptions of pain between different individuals.

The gate control theory of pain differs from earlier theories of pain in that it incorporated psychology into our understanding of pain experience; therefore unlike earlier dualistic models it assumes an interaction between the body and mind (Ogden, 2007). Therefore, the GCT proposes that pain should not only be perceived as a result of a pain pathway from the site of injury to the brain where pain is experienced; instead it should be understood as a complex experience produced by the brain in collaboration with a number of other different processes. Furthermore, it conceptualises pain as a perception rather than just a sensation; this means that the

individual plays an active role in this process and s/he is involved in the interpretation of pain. The pain perception is not only influenced by physical factors as suggested by early theories of pain, but also by a number of different factors including individual variability. This also means that pain is never purely biological (Ogden, 2007) and that an integrated model of pain (including biological, psychological and social factors) is required to understand pain experiences and their impact on individuals' lives. This requires understanding of pain mechanisms, which may explain why and how chronic pain persists (Main, 2013).

Towards a Biopsychosocial Model of Pain

The gate control theory of pain has initiated examinations of peripheral and central pain mechanisms and there have been numerous investigations of its neurobiological foundations using modern techniques such as imaging. While these examinations help us understand vital neurobiological pain mechanisms, the experience of pain is perceptual and it also involves psychological processes (Main, 2013). Pain perception is a noisy process susceptible to biological, social and psychological influences (Apkarian, Baliki, & Geha, 2009; Apkarian, Hashmi, & Baliki, 2011). This process interacts with expectations, emotional states, memory and learning processes (Zaman, Vlaeyen, Van Oudenhove, Wiech, & Van Diest, 2015). For example, Apkarian et al. (2009) integrated evidence from human and animal studies of chronic pain which indicate that the human cortex continuously reorganises as it continuously experiences chronic pain, and distinct chronic pain conditions impact on the cortex in unique patterns. Findings from functional magnetic resonance imaging (fMRI) studies in chronic pain patients suggested that pain perceptions are influenced by memory networks which originate from automatic associative learning processes (Apkarian et al., 2009; Apkarian et al., 2011). Based on these findings it is proposed that that pain stimulates long-term memories via conditioning mechanisms, causing the reorganisation of limbic structures, which in turn impacts on sensory and cognitive processing areas. This is supported by psychological models of pain, such as the fear avoidance (FA) model (Vlaeyen & Linton, 2000, 2012). This model highlights the importance of associative learning (combined with catastrophising) in the development of chronic musculoskeletal pain, with avoidance behaviour (e.g. avoidance of potentially pain provoking situations) as a mediator to pain and disability. This model will be addressed in more detail later.

However, the neural mechanisms underlying the influence of associative learning in chronic pain conditions are still not understood very well (Zaman et al., 2015). Due to these research developments the biomedical model of pain, which is based on the premise that pain has an organic basis requiring a specific bio-medical treatment, has progressively given more way to biopsychosocial models of pain. Biopsychosocial models advocate a multidisciplinary approach to chronic pain and incorporate physical, psychological and social perspectives.

Psychological Factors and Models of Pain

The gate control theory has encouraged interest into the responsibility of several psychological factors such as beliefs and fears about pain in the processing of pain, as well as investigations into pain-related coping strategies and pain-related disability. In general, psychological theories suggest that pain should be perceived as a perception influenced by a number of interconnected biological, psychological and social processes. They also dispute the belief that the intensity of pain is comparative to the severity of the injury. This means that pain incorporates the entire person, their thoughts, hopes and fears (Melzack & Wall, 1996). Early psychological theories of pain mainly focused on rather broad factors such as age, gender and personality. However, research evidence into these factors and into pain experience is not convincing (Eccleston, 2001). More recent psychological research into pain has focused on more specific psychological factors, for example fear and depression.

Non-physiological prognostic factors of poor outcomes in LBP are referred to as 'yellow flags', and broadly speaking they include psychological, social and environmental factors (Nicholas, Linton, Watson, Main, & Decade of the Flags" Working, 2011). There is now substantial evidence that psychological factors play an important role in LBP. However, there is a lack of understanding about 'how' the psychological factors impact on patient outcomes and how they can be used to improve treatments (Linton & Shaw, 2011). A better understanding of these aspects may support the development of new treatments and the improvement of current treatments. This could also help reduce costs (Pincus & McCracken, 2013), by matching interventions to patients' specific needs (Morley, Williams, & Eccleston, 2013; Pincus & McCracken, 2013). Not only is it important to examine which psychological factors play a pivotal role in LBP and mechanisms by which they do

this, but it should also be examined how they should be addressed and treated (McCracken & Morley, 2014; Morley et al., 2013), and who should treat them (Pincus & McCracken, 2013). Additionally, awareness and understanding of these factors could improve communication between practitioners and patients, and subsequently improve adherence to advice and treatment (Darlow et al., 2012; Pincus & McCracken, 2013). Most relevant to this thesis are psychological factors that may be associated with patients' perceptions and expectations about their diagnosis and causes of their pain. A systematic review of evidence from studies with LBP patients on their expectations and satisfaction with treatment, suggests that LBP patients expected confirmation from their practitioners that their pain is due to biological causes (Verbeek, Sengers, Riemens, & Haafkens, 2004; this review is described in more detail later in this chapter). This review recommends that patients' expectations should be discussed during consultations and that they should be involved in the decision-making process. However, this may not be possible to achieve without an understanding of patients' psychological states, such as potential excessive worry about the causes of their pain.

It has now widely been acknowledged that an acceptable scientific model of pain should integrate key biological, psychological and social factors and offer an account of chronic pain with far-reaching applicability. Although there are several such models, currently, there is no all-encompassing theoretical model to address how these factors interact and change over time to impact on pain-related disability (Wideman et al., 2013). The next section will provide a review of psychological factors and models of pain that appear most relevant to this thesis' goal of enabling a better understanding of the relationship between perceived diagnostic status, pain-related guilt, and mood and disability in LBP. Psychological processes are highly interrelated and often interact to increase the impact on chronic pain; therefore this review will focus on the relationships between psychological processes rather than describe each in isolation.

Since the main focus of this thesis is on LBP patients' perceptions of their diagnostic status, this review will start with a discussion of the role of cognitions (beliefs and perceptions) in pain perceptions, emotions and behaviours.

Illness and Pain-Related Beliefs

Cognitive processes are used to interpret stimulus, including pain symptoms and they usually give rise to or interact with emotional processes. Both these processes affect behaviour (Linton & Shaw, 2011). Cognitive and behavioural models are arguably the most popular psychological models of pain (J. S. Beck & Beck, 2011). Since the 1970s, behavioural models have contributed to the analysis and understanding of pain experience. According to these models, both classical and operant conditioning play a role in pain perception and behaviour (Sharp, 2001). Since the 1980s, pain theorists started focusing on cognitive factors and the impact of beliefs and information processing on emotions and pain behaviours. Today, cognitive and behavioural models are often combined together into one broad model, the cognitive behavioural model (Pincus & McCracken, 2013). The basic principle of the cognitive behavioural model of chronic pain is that the way individuals view the world and think about it (beliefs), determines how they feel (emotions) and respond to it (behaviours). This process is important in understanding how individuals respond and adjust to chronic pain. Many other currently prominent models of chronic pain, such as fear-avoidance (Vlaeyen & Linton, 2000) and acceptance based approaches (McCracken, 1998) are perceived as versions or sub-models of the cognitive behavioural model (Pincus & McCracken, 2013). Some of these models will be briefly addressed later in this chapter.

People hold certain beliefs about various aspects of their illness and pain experience. Illness beliefs can be defined as ‘the organised cognitive representations or beliefs that patients have about their illness’ (Petrie, Jago, & Devcich, 2007, p.163). They also shape illness expectations and may have a considerable impact on one’s experience of the pain. Some of the well-researched cognitive factors are: catastrophising, which has been described as a tendency to misinterpret and exaggerate pain (Walton, Wideman, & Sullivan, 2013); fear-avoidance beliefs, which refer to beliefs that pain is extremely threatening and that potentially pain provoking activities should be avoided (Vlaeyen & Linton, 2000; 2012); and low acceptance, which has been described as the inability to accept the presence of pain (McCracken & Eccleston, 2005; McCracken & Vowles, 2008).

The origins of beliefs about back pain are not entirely clear, but there is evidence that they can be shaped by patients’ previous experiences, dominant social

views, health policy and legislation regarding sickness absences and compensation (Main, Foster, & Buchbinder, 2010). Patients' expectations about their condition are often not in line with those of their practitioners (Petrie et al., 2007), but there is some evidence that practitioners can also influence patients' beliefs. For instance, a systematic review of 17 studies from eight countries (Darlow et al., 2012) examined the attitudes and beliefs of a range of medical health practitioners and found strong evidence for practitioners' beliefs being associated with those of patients. However, only moderate evidence was found for the relationship between practitioners' beliefs and patients' behaviours.

Patients structure their beliefs of illness in a more or less consistent pattern: they commonly include information relevant to the identity of their condition such as its name and the type of symptoms associated with the condition. They also contain beliefs about the cause and the course of the condition (Petrie et al., 2007). Therefore, diagnosis-related beliefs and patients' perceived diagnostic status appear important; they are the main focus of the present work and will be fully reviewed later in this chapter. Furthermore, illness beliefs contain beliefs about the consequences of the condition and how it can be controlled by treatment and self-controlled. These beliefs shape how patients feel and act, and a number of beliefs have been found to be a significant predictor of outcomes such as pain and disability, in several medical conditions including back pain (Petrie et al., 2007). In an evidence-based review of pain beliefs, beliefs about the nature of pain, fears of hurting and further injury, and self-efficacy beliefs were shown to be the most important beliefs to consider (Main et al., 2010). For example, Foster et al. (2010) compared 20 factors in predicting pain-related disability; 1591 primary care LBP patients provided data at baseline and 810 patients at 6 months. They found that four factors were most predictive of outcome at 6 months: 1) pain perceptions that the problem will last well into the future, 2) pain perceptions that many symptoms are related to their back problem, 3) patients' weak beliefs about personal controllability and 4) low self-efficacy. These factors were better predictors of disability than fear avoidance, catastrophising and depression. These findings suggest that perceptions of low personal control over the pain and the certainty of a future with pain could lead to inactivity, reduction of coping efforts, avoidance of particular behaviours and poor

adherence with practitioners' advice to keep active. All of these can be mechanisms leading to increased disability levels (Foster et al., 2010).

Furthermore, a study by Turner, Jensen, and Romano (2000) examined 11 pain-related beliefs and their associations with depression and disability in 169 chronic pain patients entering a multidisciplinary pain treatment. These 11 beliefs were grouped into four scales using factor analysis: the first scale reflected that activity should be avoided and little belief that one can control one's pain; the second scale reflected the belief that the pain is not a permanent condition and that a medical cure for one's pain exists; the third scale reflected the beliefs that one is disabled; and the fourth scale reflected the belief that one is not responsible for one's pain. After controlling for age, sex, pain intensity, catastrophising and coping the four beliefs scores independently predicted disability (explaining an additional 7% of the variance), and depression (explaining an additional 5% of the variance). When examined as individual predictors of disability and depression, all four scales were significantly correlated with disability, while only the belief that one is disabled correlated with depression. There is also research evidence showing that patients' pain perceptions and expectations predict longer work absence. A large prospective population-based study of risk factors for work disability after back problems showed that patients' baseline recovery expectations predicted work disability at 6 and 12 months follow-up (Turner et al., 2008). Patients with very low baseline recovery expectations were 3 times more likely to be off work at 6 months.

Evidence of the relationship between expectations and outcomes such as pain and disability is also provided by neuroscientific evidence. For instance, expectancy can be used to explain the placebo effect which is now also supported by neuroimaging research. Neuroimaging techniques have improved our understanding of pain mechanisms and the processes influencing pain perception (Lee & Tracey, 2013). For example, Bingel et al.'s (2011) fMRI data showed that the effects of positive and negative expectancies of opioid analgesia involved different brain regions in healthy participants. This shows that expectancy effects have distinct functional neuro-anatomies and demonstrate an interaction between psychological and physiological processes.

In summary, illness-related beliefs and expectations have been shown to predict negative emotions and behaviours (Foster et al., 2010; Main et al., 2010;

Petrie et al., 2007; Turner et al, 2008). A model that can help explain the relationship between illness-related beliefs, emotions and behaviours is the misdirected problem solving model (Eccleston & Crombez, 2007) and it will be reviewed next.

The Misdirected Problem Solving Model of Chronic Pain - The misdirected problem solving model of chronic pain (Eccleston & Crombez, 2007) gives a central role to beliefs and cognitive processes in chronic pain. Worries about pain and cognitive evaluations are seen as problem solving efforts. When these efforts are misdirected towards goals that are difficult or impossible to achieve, rather than focus on more useful and achievable goals, this can lead to the persistence of pain and more worry. The misdirected problem solving model of chronic pain argues that pain-related worry, at a cognitive level, consists of thoughts and images about future pain events and is usually related to the perceived threat of pain (Eccleston & Crombez, 2007). The pain-related worry process usually involves an endeavour to engage in mental problem solving on an aspect of pain which is uncertain. For example, if pain is understood as a biomedical problem, problem-solving will solely focus on ways to eliminate or decrease pain. However, chronic pain is difficult to get rid of therefore these problem solving attempts might not be completely effective; and when they are not, they are likely to reinforce the initial worry, creating a vicious cycle. Therefore, trying to solve problems by solely focusing on pain relief is likely to result in a misdirected problem solving. These problem solving efforts can be redirected by changing the existing perceptions and expectation and redefining the problem towards goals that are more likely to be successful (e.g. less pain relief oriented, or non-biomedical solutions). Changing the existing pain perceptions may also lead to a greater acceptance of pain and pain experiences. Acceptance of pain is psychological factor and in the context of pain, it refers to psychological inflexibility to adapt to pain, and the inability to accept the presence of pain and carry on with normal activities (McCracken & Eccleston, 2005. Several studies showed that acceptance is associated with better physical and psychological functioning over time in chronic pain patients. (McCracken & Eccleston, 2005; McCracken & Vowles, 2008; McCracken, Vowles, & Gauntlett-Gilbert, 2007).

Another example of misdirected problem solving that is directly relevant to the issue of diagnostic labelling and providing physical evidence for the pain is the issue of patients' wishes and requests for additional diagnostic tests. Searching for a

specific biomechanical cause of LBP may encourage patients' misdirected problem-solving efforts to find a cause of their pain and reinforce the existing worry about it in some patients. Changing patient beliefs about pain may be more important than providing a cause of pain, especially where none is known (Linton & Show, 2011); it may help redirect the problem solving and decrease distress and worry.

The Role of Emotions

Emotion has an essential role as a mediator between the perception of pain and the behavioural response to it; the pain appraisals are influenced not only by specific illness beliefs but also by acknowledgement of its emotional consequences (Main et al., 2010). The level of distress is not simply explained by pain intensity, but appears to be mediated by cognitive factors. Therefore, emotion is not always a mediator between the perception of pain (cognitive aspect) and behavioural response, but can also be mediated by cognitive factors. The misdirected problem solving model of chronic pain illustrates this reciprocal relationship: pain-related worry usually initiates problem solving attempts, when these attempts are misdirected and not effective in eliminating or reducing pain, they are likely to generate more pain and worry (Eccleston & Crombez, 2007).

There is considerable evidence supporting the relationship between chronic pain and high levels of emotional distress, mainly depression and anxiety (Eccleston, 2001; Linton & Bergbom, 2011). Other common emotional reactions to pain are fear, anger, frustration and guilt. Guilt will be addressed specifically later in this chapter as it is a key factor in this thesis; the current discussion will focus on anxiety, depression and fear.

Anxiety - Anxiety is a dominant emotion in pain, and people with chronic pain have higher rates of anxiety disorders than those without it (Linton & Show, 2011). A more common type of anxiety in the context of pain is health-related anxiety or worry, where persons with chronic pain do not meet criteria for an anxiety disorder but they often contemplate negative pain and condition prospects. For example, Blyth et al. (2011) explored the relationship between pain status, anxiety and health-related anxiety (worry) at a population level, in 1217 community men. They found a strong relationship between worry about health and pain that remained after accounting for a number of other factors such as age, number of comorbidities,

depression and self-rated health status. These findings suggest that at a population level, worry about health and pain are strongly related, and that worry about pain is more common than general anxiety.

Health-related worry is also associated with increased care-seeking in LBP. For example, Jensen, Haahr, Frost, and Andersen (2012) examined the effects of previous pain, health anxiety, somatization and fear-avoidance beliefs on care-seeking in back pain and upper extremity pain in a prospective cohort study of 4325 participants. They found that previous regional pain was related to care-seeking for upper extremity pain and back pain among men and women. However, high levels of health anxiety and somatization were associated with care-seeking only among back pain patients, while this relationship was not found among patients suffering from upper extremity pain. The significant positive relationship between health anxiety and increased care seeking in back pain patients may suggest that health anxiety rather than symptoms drives consultations in this particular group of chronic pain patients. It may also suggest that they might be susceptible to misdirected problem solving in that their pain-related problem solving efforts (at cognitive and behavioural level) are largely directed towards a search for a cure and possible causes of their back pain (Eccleston & Crombez, 2007). Since in the majority of back pain patients cure and causes of back pain are unlikely to be found (Krismer & vanTulder, 2007), this may reinforce initial health anxiety, which in turn might result in more care-seeking.

Specific types of anxiety which could be a mechanism to maintain states of pain and pain-related disability are fear and hypervigilance. They are important concepts within the fear-avoidance model of pain, thus this model will be discussed next.

Fear-Avoidance Model of Pain - The fear-avoidance model has been defined as a cognitive-emotional-behavioural explanation that describes why some people with acute LBP progress into a chronic pain state (Vlaeyen & Linton, 2000). Fear is a form of anxiety that is common among chronic pain patients. Fear, however, is time limited while general health anxiety, in contrast to fear, is a future-oriented state without a clear focus and it is also less intense than fear (Jensen et al., 2012). The fear-avoidance model is one of the most influential models of pain. It was developed by Vlaeyen et al. (1995) and has been updated numerous times (Vlaeyen & Linton,

2000; Leeuw et al., 2007; Crombez, Eccleston, & Van Damme, 2012). The starting point in the original model is the pain experience, which sets in motion certain cognitive, emotional and behavioural responses, which in turn might worsen pain and disability. How patients interpret their pain is fundamental to the model. If pain is interpreted as a low threat, patients will usually continue normal activities after a pain episode. However, some patients may hold unhelpful and sometimes inaccurate beliefs about their pain and misinterpret pain as a catastrophe (Crombez et al., 2012). Examples of these beliefs are that pain is a signal of serious tissue damage and that it can only be treated medically. Pain catastrophising refers to the process during which pain is interpreted as being extremely threatening (Quartana, Campbell, & Edwards, 2009), and it has consistently been associated with pain disability in pain patients (Walton et al., 2013).

Unhelpful pain beliefs are likely to direct attention toward cues for pain and potential injury or re-injury, therefore attentional processes, such as hypervigilance also play an important role within the FA model. Patients actively engage in body scanning for potential sources of threat and selectively attend to threat-related rather than neutral stimuli. Although this was not explicitly outlined in the original FA model (Vlaeyen et al., 1995), the role of hypervigilance within the FA model of pain is now recognised (Crombez et al., 2012).

The model proposes that with catastrophic misinterpretations and hypervigilance as mediators, unhelpful pain beliefs can lead to an extreme fear of pain, and subsequently to a fear and avoidance of potentially pain provoking activities. Avoidance behaviours decrease fear intensity in the short term, but may reinforce it in the long run. This is because avoidance restricts patients' chances to adjust their expectations to actual experiences; this can strengthen their belief in the feared stimuli (hence interacting with the cognitive aspects within the FA model) (Leeuw et al., 2007), and overestimate their future pain and its negative consequences (Crombez et al., 2012). Avoidance behaviours can lead to a decrease in physical activity, which can in turn lead to physical deterioration, increased disability and lower patients' pain threshold (Verbunt, Smeets, & Wittink, 2010). Thus, fear and avoidance behaviours can exacerbate both pain and disability.

The FA model has been updated and reformulated numerous times since its conception (Vlaeyen et al., 1995). One of these most recent reformulations is that by Crombez et al. (2012), who proposed to extend the FA model by implementing a motivational perspective on chronic pain and disability. They proposed that the FA model should integrate the idea that pain-related fear and avoidance take place in a context of several and competing personal goals. Crombez et al. (2012) argue that pain is a disruptive experience that interferes with everyday tasks performance. For example patients may become fear-avoidant because of the repeated goal failures that occur due to pain. Therefore, a motivational analysis of FA opens new lines of research which will require a greater understanding of goals that are most important to patients (Crombez et al., 2012). Furthermore, selective attentional bias paradigms have been employed to further our understanding of hypervigilance within the FA (e.g. Keogh, Ellery, & Hunt, 2001). New formulations also suggest that the FA model should include examinations of a wide range of beliefs (not just unhelpful pain beliefs), such as those related to treatment and disability (Crombez et al., 2012). Research evidence suggests that unhelpful pain beliefs are common among patients, practitioners and the general population, hence they might be described as normative rather than unreasonable (Goubert, Crombez, & Bourdeaudhuij, 2004).

Research suggests that fear of pain and movement is a key predictor of how chronic pain patients adjust to persistent pain and has been linked to poor outcomes in numerous studies (Vlaeyen & Linton, 2000; Crombez et al, 2012). Findings from a prospective study (Linton et al., 2000) indicate that it is also important in the development of a pain problem. Fear avoidant behaviours are associated with negative outcomes, such as disability and depression and the FA model of pain is one of the most influential models in explaining psychological factors in chronic pain patients and the transition from acute to chronic pain (Linton & Shaw, 2011). A recent systematic review (Wertli, Rasmussen-Barr, Weiser, Bachmann, & Brunner, 2014) of 21 studies on the role of fear avoidance beliefs as a prognostic factor for outcome in patients with non-specific LBP showed that fear avoidance beliefs are prognostic for poor outcome in sub-acute LBP, with most convincing evidence found for work-related outcomes in patients with sub-acute LBP (4 weeks–3 months). There is also psychophysiological evidence for the fear-avoidance model of chronic pain. For example, a recent study by Glombiewski et al. (2015) examined

whether highly fearful chronic LBP patients show distinctive physiological response patterns compared with less fearful patients when expecting aversive back pain-related activities. They used two measures: one of which measured autonomic nervous system activation and the other measured muscle tension in the lower back. Their results showed that the patients showing the physiological pattern typical of fear also had higher scores on self-report measures of the fear-avoidance model.

In summary, the FA model gives dominant roles to fear, catastrophising, hypervigilance and behavioural avoidance as mediators between pain and chronic disability. Fear of pain develops as a result of a cognitive interpretation of pain as threatening, thus this model also enhances our understanding of how pain-related beliefs impact on emotions. Patients who are worried about the causes of their back pain and who think there is something else unexplained going on with their back might be fearful about activities and would avoid them. This, in turn would lead to never exposing themselves to the fact that their catastrophic fears about further damage are unsound, limit life and result in increased disability. These fears could therefore lead to disability and depression, in an on-going cycle.

The above summary shows that there are several interacting factors leading to pathways to disability. Misdirected problem solving leads to increased worry and anxiety and to more health care utilisation. In turn worry and anxiety lead to catastrophic interpretation of symptoms, hypervigilance and fear. These lead to avoidance of normal activities and increased disability. Avoidance behaviours may also lead to disengagement from social activities and social isolation, which may lead to depressive mood (Crombez et al., 2012).

Depression - Depression is a major and most prominent psychological factor in chronic pain; it is characterised by low mood, hopelessness, and despair (Linton et al., 2011). Depression can be present in chronic pain patients in two ways: as a comorbidity, where about 50% of chronic pain patients fulfil the criteria for major depression (Bair, Robinson, Katon, & Kroenke, 2003); while many more suffer from depressed mood but do not fulfil the diagnostic criteria for major depression (Linton et al., 2011).

There is substantial evidence that depression and pain are associated. For example, in a national survey (N = 91347) and two year follow-up survey (N =

55690) the findings showed that depression and LBP are correlated, and this correlation increased with intensity of back pain and severity of depression (Meyer, Cooper, & Raspe, 2007). This study employed cross-sectional and cohort-study designs. There is also evidence that depression predicts the transition from acute to chronic LBP (Henschke et al., 2008; Mallen, Peat, Thomas, Dunn, & Croft, 2007; Melloh et al., 2009; Okifuji, Turk, & Curran, 1999; Pincus et al., 2002). A systematic review of prospective cohorts that included psychological factors as predictors of negative outcomes (Pincus et al., 2002) has found depression to be the strongest predictor of long term disability in LBP. In order to examine the predictive power of baseline depression on the transition from acute to chronic back and neck pain and disability (3 months post-acute back pain), Young Casey et al. (2008) examined a prospective model evaluating the effects of trauma exposure, acute pain severity and disability, baseline depressive mood, and pain beliefs on chronic pain severity and disability. The model accounted for 26% of the variance in chronic pain and 58% of the disability at 3 months. Depressed mood was a prominent predictor in the model; depressed mood and greater exposure to past traumatic life events were most predictive of chronic pain, and depressed mood and negative pain beliefs were most predictive of chronic disability. Depression is also a predictor of work status, functional status and pain as found in the systematic review by Melloh et al. (2009). These findings are in line with the findings from studies that examined the impact of depression in other groups of pain patients (Bair et al., 2003).

Evidence suggests that depression is strongly linked to pain, but the link between the two is not entirely clear, and there is only limited evidence that direct causal links between depression and pain (Linton & Bergbom, 2011). Hence, more recent research has focused on examining mechanisms that may mediate this relationship. One such mechanism was proposed by Linton and Bergbom (2011) and it involves catastrophising and emotion regulation mechanisms. A systematic review by Linton et al. (2011) found that treating both pain and depression from early on may enhance treatment outcomes, but there is very little evidence that treating the pain alone will also result in the disappearance of the depression. Linton and Bergbom (2011) proposed the Örebro Behavioural Emotion Regulation Model for investigating the psychological mechanisms that might explain the relationship between depression and pain. This model proposed that catastrophising and

emotional regulation might be likely mechanisms in the depression–pain comorbidity because they are commonly found to play a role in both pain and depression (Linton et al., 2011). The following discussion will examine these mechanisms in more detail, starting with catastrophising.

Earlier in this chapter, catastrophising was introduced as a central concept in the fear avoidance model of chronic pain, but it is also a prominent concept in models of depression, such as the cognitive model of depression (A. T. Beck et al., 1961). In this model, catastrophising is understood as a form of cognitive error or a misrepresentation of reality, which can lead to negative affect which in turn can lead to more catastrophising. Recently, several studies examined the role of catastrophising in mediating the relationship between pain and depressed mood. For example, Wood et al. (2013) examined this relationship in a sample of 669 adults with persistent pain, who completed questionnaires measuring pain intensity, depressed mood, and catastrophising. Catastrophising significantly mediated the relationship between pain intensity and depressed mood. Another study (Goli, Asghari, & Moradi, 2014) experimentally induced negative mood (negative mood induced group, positive mood induced group and control group, by presenting different types of films) on 60 patients with chronic pain in order to investigate the role of pain catastrophising in the relationship between pain and depression. The results showed that the induction of depressed mood increased the pain intensity, while the induction of positive mood reduced it. When catastrophising scores were entered into the analysis as a confounding factor, the effect of mood on the pain intensity significantly reduced. These results suggest that catastrophising mediates the relationship between pain and depression. In comparison, the FA model of pain also includes depressed mood, and catastrophising is located earlier in the model suggesting that it initiates depression (Linton & Bergbom, 2011).

In summary, catastrophising may be an important mechanisms explaining how pain and depression impact on each other (Linton & Bergbom, 2011). This is relevant to this thesis because an extensive and persistent search for a clear diagnosis and causes of back pain (when a clear diagnosis and causes cannot be established) might be associated with catastrophic thinking (e.g. that something serious, unexplained is causing the pain) and misinterpretation of information received from health care professionals. This may in turn be related to increased distress and

disability in LBP patients. There is some evidence to suggest this and it is reviewed later in this chapter (Geisser & Roth, 1998).

Next, within the emotion regulation model of chronic pain, the possible role of emotion regulation is considered. Research shows that the experience of pain is accompanied by a variety of emotions such as anger, frustration and anxiety (Eccleston et al., 2001). Emotion regulation, also referred to as the emotion regulation system has a role of achieving emotional balance (McCracken et al., 2001) in circumstances that generate extreme emotions. Emotion regulation is proposed to be a mechanism that links depression and pain (Linton & Bergbom, 2011). The emotion regulation system comprises of many coping strategies (cognitive and behavioural), such as relaxation (e.g. taking deep breaths), distraction techniques (e.g. engaging in an additional activity/thought), etc. Thus, through these strategies this system enables a suitable response to emotions. However, some of these strategies will not work when emotions are extreme, such as during very intense episodes of pain, pain-related fear or distress (Linton & Bergbom, 2011). The Örebro Behavioural Emotion Regulation Model further proposed that flare-ups in pain initiate catastrophic thinking which in turn puts pressure on individual's emotion regulation system; negative emotion regulation leads to low mood, pain and disability. Within the model flare-ups are defined as episodes of either pain-related negative mood or increased pain intensity. Flare-ups stress the emotion regulation system and reinforce catastrophic thinking from previous pain-related experiences. If effective emotion regulation is not achieved this leads to increases in depressive mood, perception of pain intensity, disability and more flare ups, creating a vicious cycle and enhancing chronicity.

This model therefore places emphases on the role of emotions and the way they are regulated in chronic pain; poor self-regulation of emotions may lead to depressed mood. There is currently strong interest in the brain mechanisms that underlie cognitive self-regulation of pain and emotion (Ochsner, Silvers, & Buhle, 2012; Buhle et al., 2013), and this evidence shows that cognitive self-regulation can strongly modulate them. However, it is not entirely clear if cognitive self-regulation influences pain experience by affecting the primary representations of painful (nociceptive) stimuli in the brain, or if it regulates pain via a neural pathway that is distinct from the one that mediates nociceptive pain (so via an evaluative pathway).

Woo et al. (2015) examined this by engaging their participants in self-regulation to increase or decrease pain while being subjected to various levels of painful heat during fMRI imaging. During this scan, they were asked to imagine that the thermal stimulations are either more or less painful than they are. Heat intensity and self-regulation strongly influenced reported pain, and they did so via two distinct brain pathways. The effects of stimulus intensity were mediated by the neurologic pain signature, while the effects of self-regulation were mediated through functional connections between the nucleus accumbens and ventromedial prefrontal cortex. This pathway has been associated with emotional appraisal, and functional outcomes in pain. These results seem to suggest that cognitive self-regulation and emotion appraisal share same neural pathways supporting the emotion regulation model of pain, in which effective cognitive self-regulation is proposed to regulate pain-related emotions such as worry, frustration and anger.

Cognitive behavioural therapy is a successful treatment for depression. However, it has not been sufficiently assessed and adapted to pain patients with co-morbid depression (Linton et al., 2011). Better understanding of pain-related depression and its underlying mechanisms in LBP patients could potentially improve psychological treatments (Pincus & McCracken, 2013). The emotion regulation model suggests that the way emotions are self-regulated has consequences on coping with pain. This thesis focuses on pain-related guilt, an un-researched but likely emotion in the context of chronic pain. It is not known how it might be triggered and regulated, and how it might be linked to pain-related depression. Some of these questions will be addressed later in the chapter where literature on pain-related guilt will be reviewed.

The above discussion focused on several key psychological factors. It also focused on several models that integrate those factors and that explain how they might interact. It also included references to perceived diagnostic status and pain-related guilt, and how they might be understood using these psychological factors and models. The main aim of the next section is to review literature relevant to perceived diagnostic status and pain-related guilt in LBP.

Perceived Diagnostic Status in Low Back Pain

Non-Specificity of LBP: Explanation of Terminology

When a definitive cause and a clear diagnosis for back pain cannot be established, patients are given unclear labels such as non-specific LBP (Coste, Paolaggi, & Spira, 1992; Krismer & van Tulder, 2007). The vast majority of LBP patients seen by physical therapists are classified under this label (Wand & O'Connell, 2008) and it represents about 85% of low back pain patients seen in primary care (Deyo & Phillips, 1996).

Diagnosis is defined as the 'identification of a disease or condition by a scientific evaluation of physical signs, symptoms, history, laboratory test results, and procedures' (Mosby Inc., 2009). However, non-specific LBP is diagnosed by exclusion (Waddell, 2004) and is defined as non-specific or musculoskeletal back pain where underlying pathology cannot be found (Krismer & van Tulder, 2007). It has been described as an unclear diagnosis or label (Barker, Reid, & Minns Lowe, 2009), and it is often understood as a symptom or a syndrome rather than a diagnosis (Cedraschi et al., 1999). Diagnostic labelling is defined as 'the act of classifying a patient according to a diagnostic category' (Mosby Inc., 2009). In the case of non-specific LBP, labelling can be problematic and misleading because non-specific LBP is not a single diagnostic category; it represents a number of different subtypes of back pain (Waddell, 2004). In addition, the meaning of the label 'non-specific' seems ambiguous. For instance, a qualitative study (Barker et al., 2009) asked lay people what the label 'non-specific LBP' means to them; to lay participants the label suggested a number of different things, for example that practitioners do not understand the cause of the pain and how to treat it. It also suggested a need for further referral and that pain is not located in a particular place. In the same study, practitioners' understanding of the label was also explored; to them the label suggested that the cause for back pain cannot be established, or that there was no diagnosis.

In summary, it is apparent that in the absence of clear physical evidence the meaning of diagnosis becomes ambiguous, and it becomes questionable whether non-specific LBP should be seen as an official diagnosis or not. There are no consensus and clear guidelines in the literature on this question, but there is sufficient evidence to indicate that the non-specific LBP label is problematic and ambiguous,

and that it describes symptoms rather than the cause of pain (Cedraschi et al., 1999). Having taken this into consideration and the above definition of diagnosis, it seems reasonable to refer to it as 'no diagnosis', or at least as an 'unclear diagnosis/diagnostic label'.

Implications of Non-Specificity of LBP

Considering that the majority of LBP patients do not receive a clear diagnosis for their pain, it is surprising that there are relatively few studies that specifically focused on the absence of a clear diagnosis in LBP. One such study (Geisser & Roth, 1998) tested three groups of chronic neck and back pain patients: patients who did not know the cause of their pain (N=85), patients who did know the cause and agreed with their clinical diagnosis (N=83), and patients who identified a cause for their pain that was different from their clinical diagnosis (N=59). Patients who disagreed with their diagnosis were more likely to be diagnosed with musculoskeletal pain and reported the highest levels of pain and affective distress. Patients who were unsure of, or disagreed with their diagnosis tended to report a greater belief in pain being a signal of harm and reported being more disabled. Patients unsure of their diagnosis had the lowest levels of perceived control over pain. Lack of knowledge of pain aetiology significantly predicted increased disability, but not pain intensity. These results suggest that lack of knowledge about the causes of pain is associated with maladaptive pain-related cognitions such as catastrophising, and increased emotional distress. Additionally, Lacroix et al. (1990) found that LBP patients' (N=50) understanding of the origins of their medical condition, as determined by the Schema Assessment Instrument (SAI), predicted return to work. This finding suggests that patients' understanding of their medical condition is important for prognosis. However, the SAI (Lacroix et al., 1990) is restricted to measuring the objective accuracy rather than content of patients' interpretations and representations of their symptoms, and for this reason it has been used little since (Ayers, 2007). It is an open-ended interview which matches patients' description and interpretation of their symptoms to medical evidence (practitioners' descriptions) to obtain an overall understanding score.

However, the majority of relevant studies did not specifically focus on diagnostic status and aetiology of back pain; they primarily examined LBP patients' expectations and pain-related beliefs that indirectly address the issue of diagnosis and patients' perceived diagnostic status; lack of clear diagnosis emerged as a common theme in these studies. The vast majority of this research is qualitative, and it has been recently scrutinised in a systematic review of LBP and sciatica patients' experiences of health services (Hopayian & Notley, 2014). This review specifically focused on patients without clear diagnosis for their pain. They used thematic analysis to analyse 28 qualitative studies (most of which were judged to be of high quality, based on the high interclass correlation between reviewers). This review showed that the importance of a diagnosis and having pain legitimised were among the key themes extracted. Absence of a diagnosis made managing pain more difficult and some participants reported it led to 'delegitimation', a feeling of not being believed.

Another systematic review (Verbeek, Sengers, Riemens, & Haafkens, 2004) of both qualitative and quantitative studies summarised evidence from studies with LBP patients on their expectations and satisfaction with treatment. Twelve qualitative studies (N=490) were used to identify treatment features related to patients' expectations/satisfaction, while eight quantitative studies (N=3755) were used to calculate percentages of dissatisfied patients. The majority of the studies were judged to be of high quality. The review of quantitative studies suggested that patients were mostly dissatisfied with the amount of information provided by their practitioner, followed by the lack of pain relief. They also wanted more diagnostic information from general practitioners and more varied information from chiropractors. Overall, the findings across both qualitative and quantitative studies suggest that LBP patients want a clear diagnosis, they want to know the cause of their pain, and they desire clearer information and instructions from practitioners. Participants in these studies also expected more diagnostic tests, referrals to specialists and confirmation from their practitioners that their pain is due to biological causes (Verbeek et al., 2004). The review concludes that patients' expectations should be discussed during consultations and practice guidelines should include instructions on how to discuss the causes and diagnosis with the patient, who should also be involved in the decision-making process.

Findings from another review of 42 qualitative studies of people's experiences of LBP (Froud et al., 2014) support the above findings; overall, it showed that patients with non-specific LBP strive for a clear diagnosis for their pain. They conclude that social factors are insufficiently represented in the clinical measures of LBP, which should not only focus on pain and function, but should also include the impact of pain on 'identity and social participation, discrimination, and worries about the future' (p.11).

There is also evidence that patients' expectations are associated with anxiety and worry in LBP patients. For example, Eccleston, Crombez, Aldrich, and Stannard (2001) studied worry or anxiety in chronic pain patients. Over a 7-day period 34 chronic pain patients reported their pain-related and non-pain-related worry. Their results showed that the most common worry for participants was related to the medical uncertainty of their condition; they worried whether it would ever get better. However, worry for the future seems to be a common type of worry in chronic LBP patients and it does not seem to be related to non-specificity of physical evidence for their pain and to general anxiety (trait anxiety) in these patients.

Findings from the above studies clearly show that clear explanations about their pain are important to LBP patients. To some LBP patients, clear explanations are even more important than clear diagnosis. For example, a qualitative study by Dima et al. (2013) used thirteen focus groups which held group discussions on LBP treatments. Participants' main concern was to get a clear explanation for their LBP; an explanation that would enable an understanding of the cause of their LBP, and that would be delivered by an empathic and dedicated practitioner. Overall, these findings show that it is essential to help patients gain clear illness representations about their LBP before trying to engage them in shared decision making and adherence; and that this has potential of improving patient outcomes (Dima et al., 2013). This also relates to appropriately reassuring patients. A recent systematic review examined reassurance in primary care consultations for non-specific pain conditions (Pincus et al., 2013). They found that cognitive reassurance (involves giving appropriate information and specific advice to patients) is more effective than affective reassurance (involves empathy and offering basic reassurance) (Coia & Morley, 1998); it was also linked to improved outcomes. This appears to suggest that

the uncertainty surrounding non-specific LBP impacts on patients coping with their LBP and needs to be directly addressed during consultations.

LBP patients also often report feeling that their pain is not believed by other people, and that the absence of clear diagnosis suggests their pain cannot be justified and legitimised (Hopayian & Notley, 2014; Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999). In Rhodes et al. (1999)'s study 54 chronic LBP patients were interviewed, and their narratives were analysed with thematic analysis. They reported experiencing a series of negative outcomes, such as not being seen and heard, and shame and guilt. Another study examined narratives of 12 chronic LBP patients, using content analysis, and found that the patients associated practitioners' lack of explanation about their condition and practitioners' inability to deliver a clear diagnosis with a belief that they might believe them to be malingering (May, Rose, & Johnstone, 2000). Furthermore, a narrative review of the literature (Newton, Southall, Raphael, Ashford, & LeMarchand, 2013) on disbelief in chronic pain found that although the experience of being believed is regularly mentioned, there is only a handful of studies that specifically focused on it in chronic pain. They reviewed 17 studies and used grounded theory to analyse themes extracted from these studies. Three overarching themes emerged from the review: the experience of stigma, isolation, and distress. Patients whose pain is disbelieved report feeling isolated and experience the negative impact of this on their relationships with other people. This can make them distressed; they reported feeling depressed, angry and guilty. They also felt being stigmatised through either actual or perceived acts of stigma, for instance they linked stigma with psychological explanations of pain that others may use. However, a shortcoming of this study is that it did not address/comment on the quality of the studies included.

Until there is evidence to link diagnosis-related beliefs with negative outcomes in LBP they cannot be targeted by LBP interventions and properly addressed during consultations and treatment of LBP. For example, a qualitative study investigated how physiotherapists prescribe exercise for people with non-specific LBP (Slade, Molloy, & Keating, 2012). They interviewed 23 physiotherapists using focus groups methodology, and their responses were analysed with grounded theory. One of the findings showed that physiotherapists reported wanting to focus on causes of patients' pain (although these may be non-specific)

and that they want to observe speedy improvements in patients' health. When this does not happen, they sometimes respond negatively, for instance they may indirectly blame patients. This suggests that practitioners are perhaps poorly equipped to face the challenges of diagnostic uncertainty and may deal with it by trying to provide a diagnosis and suggest a cause of the pain (Slade, Molloy, & Keating, 2012). The findings also suggest that practitioners need clearer guidelines and training in order to advise and help patients and appropriately deal with diagnostic uncertainty. With no clear guidelines on dealing with the lack of specificity in LBP, it is not surprising that patients report that the information they receive from different practitioners is often conflicting; and this adds to the confusion and uncertainty about their condition (McIntosh & Shaw, 2003). McIntosh and Shaw (2003) interviewed two focus groups about patient information provision in primary care, one group consisted of 15 general practitioners and the other consisted of 35 LBP patients. Their narratives were analysed with framework analysis. A major cause of dissatisfaction in patients was that they were not given a concrete diagnosis for their back pain. The majority of GPs interviewed did not seem to be dealing adequately with the diagnostic uncertainty during consultations and were instead avoiding the problem.

There is also some evidence to show that when patient and doctor disagree about the identity and cause of illness, this is associated with more negative outcomes. For instance, Reesor and Craig (2003) compared two groups of 40 patients who displayed pain and symptoms either congruent or incongruent with the physical pathology provided by their clinicians. The incongruent group reported more pain intensity, depression and disability. Furthermore, a recent qualitative study (Darlow et al., 2013) used an interpretive description framework analysis to analyse responses from 22 LBP patients. They found that even though LBP patients were influenced by a number of different sources of information (Internet, friends, family), practitioners had the strongest impact on patients' beliefs and behaviours. They influenced their patients' understanding about the cause and meaning of symptoms, as well as their expectations. Hence, it is important that practitioners are aware of the impact their advice has on patients, and that they use it to positively influence patients' beliefs.

Overall, research evidence indicates that diagnosis-related beliefs are important in that they affect how patients understand and deal with their pain.

However, there are no studies that directly measured the relationship between perceived diagnostic status in LBP and patient outcomes such as depression and disability. This is partly due to the fact that the perceived diagnostic status has been primarily examined using qualitative methodology. Currently there is only one study (Wells, Pincus, & McWilliams, 2003) that used quantitative methodology, but it did not focus explicitly on patient outcomes. It explored the impact of diagnostic status on information processing biases in chronic pain. It also did not specifically focus on LBP; it used a heterogeneous group of chronic pain patients and ankylosing spondylitis patients. It separated participants into subgroups according to their physical condition and their perceived diagnostic status, and it used self-report answers to the following questions: 'Have you been given a diagnosis to explain your pain (yes/no)', 'Do you think the current diagnosis is correct? (yes/no/don't know)'. Participants answering 'yes' to both questions were categorised as having received a diagnosis (regardless of whether that diagnosis was accurate or not). This categorisation resulted in four groups: 15 chronic pain patients who had received a diagnosis and believed it, 24 chronic pain patients who had not received a diagnosis, 36 ankylosing spondylitis patients who had received a diagnosis and believed it and 34 control participants consisting of hospital staff. They compared groups (as part of descriptive analysis) and found the diagnosed and non-diagnosed chronic pain patients did not differ significantly on scores of depression. However, their information processing patterns (measured with recall for stimuli previously presented) did differ. Non-diagnosed chronic pain patients showed no significant recall biases towards any adjective type (illness, pain, depression and neutral). Diagnosed patients recalled fewer depression stimuli compared to the other two patient groups, suggesting a recall bias away from depression stimuli and therefore indicating differences between the diagnosed and non-diagnosed chronic pain patients in terms of their underlying cognitive processing, favouring diagnosed group. There was an association between receipt of a diagnosis and better psychological outcomes in terms of information processing biasing among diagnosed chronic pain patients. However, the cross sectional design of this study indicates that the causality cannot be assumed. The authors of the study proposed that a diagnostic label may validate patients' pain experiences and protect them from guilt and self-blame.

Studies like this one are necessary to gain a deeper and more complete understanding of how perceived diagnostic status affects LBP patients. Although this study categorised patients into diagnosed and non-diagnosed patients according to their beliefs, the categorisation was fairly simple and did not allow an insight into other aspects that may also be important, such as clear explanations about the causes of the pain, as described earlier (Dima et al., 2013).

Biomedical vs. Biopsychosocial Approach to Non-Specificity of LBP

Medicine has been at the heart of the creation of certain discourses that constructed meaning and experience of health and illness (Foucault, 1976). Discourse, as defined by Foucault, refers to ways of constituting knowledge and one of those discourses is that ‘pain must have a cause’; this means that pain must be a symptom of pathology. In the absence of a detectable cause, a possible outcome is that the practitioner views the patient as imagining or exaggerating the pain or seeking attention (Armstrong, 1984). This discourse is a characteristic of the biomedical model; in the absence of pathology LBP poses a threat to the foundations of biomedical thinking, which may help explain the difficulties that patients encounter in being believed when presenting themselves to clinicians (Eccleston, Williams, & Rogers, 1997; May, Doyle, & Chew-Graham, 1999). For instance, Eccleston et al., (1997) studied patients’ and professionals’ understandings of the causes of chronic pain using Q-factor analysis, their findings suggest that a common response by orthodox medicine in situations where no clear causes for the pain can be found is to shift the responsibility back to the patient. At the same time, patients expect to be cured and rely on the power of orthodox medicine to find the cause and provide the cure for their pain. Patients desire a medical diagnosis and physical evidence of their symptoms in spite of understanding that psychosocial factors impact on their pain (McIntosh & Shaw, 2003). Both parties try to protect their identities which may result in a power struggle (Eccleston et al., 1997) and pose a threat to the treatment.

In non-specific LBP a definitive diagnosis cannot be established by existing radiological methods. In fact, radiological evidence does not support a link between observable disc changes and LBP (Boos et al., 1995), and many LBP guidelines (e.g.

National Institute for Health and Clinical Excellence (NICE) guidelines, European Guidelines for the Management of Non-specific LBP) have recommended against carrying out x-ray and magnetic resonance imaging (MRI) tests in these populations (European Commission, 2002; National Institute for Health and Clinical Excellence, 2009). Chou, Fu, Carrino, and Deyo (2009) carried out a meta-analysis of six trials, which included 1804 LBP patients and compared immediate lumbar imaging (radiography, MRI, or CT) against clinical care without immediate imaging for LBP. The findings showed that immediate imaging in LBP patients did not improve clinical outcomes when compared with clinical care without immediate imaging in the short term, long term or follow up. Additionally, a recent review of five randomised controlled trials that included 1544 patients with various medical complaints (including LBP) found that there is very limited evidence for the view that diagnostic tests reassure patients in clinical practice (van Ravesteijn et al., 2012). Four out of five trials did not find a significant reassuring value of the diagnostic tests such as radiography of lumbar spine, laboratory tests and MRI of lumbar spine. One study reported a reassuring effect at three months, although this effect diminished after one year. The authors of this review advise an early exploration of the patient's fears and concerns instead of carrying out unnecessary tests. By making patients' concerns explicit, they may help patients to come to terms with aspects of their illness that they cannot control, heighten acceptance of their pain and lower their anxiety levels. However, as suggested by the results of studies reviewed above, (e.g. McIntosh & Show, 2003) many patients' concerns might not be properly addressed and they might be simply told that there is nothing wrong with their back. Instead of reassuring them, such statements may result in heightened anxiety, seeking further care and examinations, and mistrust in clinicians. An important theme emerging from a theoretical review of psychological theories of pain (Linton & Shaw, 2011) is that when practitioners primarily focus on searching for a specific cause of LBP and carrying diagnostic tests to find such a cause, they may encourage patients' 'misdirected problem-solving efforts' (p. 709) to deal with their pain and look for cause and cure for pain, instead of focusing on dealing effectively with their pain. This is supported by the results of a randomised control trial (Kendrick et al., 2001) with 421 LBP patients in which the control group received the usual care provided by their practice for patients with LBP, while patients in the intervention group were additionally given the opportunity to undertake a radiograph of the

lumbar spine. The intervention group reported more pain at three months, had a lower overall health status score and higher disability (an abnormal finding on radiography did not affect the disability outcome). The intervention group was also more satisfied with care at nine, but not at three months after randomisation. Additionally, 80% of participants in both groups (at three and nine months) said they would have radiography if this option was available to them.

The biopsychosocial model forms the basis of many LBP treatment guidelines (van Tulder et al., 2006). In spite of this, a recent review of 17 studies which examined the association between practitioners' attitudes and beliefs and the attitudes, beliefs and outcomes of LBP patients (Darlow et al., 2012) has found that many health care professionals continue to rely on the biomedical model, and this appears largely to be due to the lack of time and training. They found strong evidence that practitioners' beliefs about back pain are associated with the beliefs of their patients and moderate evidence that practitioners with a biomedical orientation are more likely to advise patients to limit work and physical activities, and are less likely to adhere to treatment guidelines. However, biomedical orientation is not associated with the number of sickness certificates issued for LBP. Therefore, in order to actually practice the biopsychosocial approach to LBP, it is necessary to raise awareness among practitioners and policy makers of the association between practitioners' attitudes and beliefs with attitudes and beliefs of their patients.

Perceived Diagnostic Status and Pain-Related Guilt

LBP patients constantly struggle with their pain and their distress, and suffering can have a major effect on them, their family and their friends. This in turn may result in conflicting emotions in the patients including resentment, sense of isolation and guilt. Not being able to provide physical evidence and diagnosis may cause some patients to feel guilty about having pain. There are no studies that explicitly examine pain-related guilt in LBP. However, there is some evidence (although very scarce) from other qualitative studies that LBP patients' experience pain-related guilt. Before these studies are reviewed it is necessary to define guilt and discuss its key aspects.

Defining and Measuring Guilt

Guilt is a type of emotional distress that is founded on the likelihood that we may be in the wrong, or that others may have such a view of us (Baumeister, Stillwell, & Heatherton, 1994). Kubany and Watson (2003) define guilt as ‘an unpleasant feeling with accompanying beliefs that one should have felt, thought, or acted differently’ (p.53). In addition, it is often limited to a particular situation or context (Tangney, Wagner, HillBarlow, Marschall, & Gramzow, 1996). Although guilt has also been described as an adaptive state (especially in studies with children), a review of relevant literature found that, in contrast, studies with adult populations mostly describe it as a maladaptive state as it prevents individuals from engaging in beneficial or adaptive behaviours (Tilghman-Osborne, Cole, & Felton, 2010). Guilt is a complex concept, and as a psychological process it has both affective and cognitive components (Kubany & Watson, 2003) including ‘a feeling of negative self-regard’ (Johnson et al., 1987, p. 359), and a ‘painful affect arising from the belief that one has or might hurt another’ (O’Connor, Berry, Weiss, Bush, & Sampson, 1997, p. 74). Guilt also involves moral aspects, a sense of responsibility and painful feelings of remorse (Tilghman-Osborne et al., 2010). Remorse may be minimised through behaviours which include apologising and seeking forgiveness (Tangney et al., 1996). This thesis adopted a pragmatic approach to studying guilt, and as such it focused on people’s individual understanding of guilt as a psychological process, rather than an examination of guilt as studied and understood within non-psychological domains, such as theological, philosophical and sociological domains.

Even though guilt embodies one of the most widely experienced emotions, research exploring the concept is scarce (Baumeister et al., 1994). It is especially limited in the research area of chronic pain, and it is almost non-existent in LBP research.

Many measurements of (general) guilt exist, for example (Harder & Zalma, 1990) developed Personal Feelings Questionnaire-2 (PFQ-2). It consists of a ten-item ‘shame’ subscale and a six-item ‘guilt’ subscale, rated by the respondents on a 4-point scale ranging from ‘you never experience the feeling’ to ‘you experience the feeling continuously or almost continuously’ (Harder & Zalma, 1990). Guilt items refer to regret, remorse and intense guilt, while shame items refer to feeling

embarrassed, feeling humiliated and self-consciousness. However, these items do not refer to a specific context, such as a pain experience, thus they are too general for use in the context of chronic pain.

However, no instruments have been developed to measure specifically pain-related guilt in LBP patients or in chronic pain in general. Measures of depression, such as the 'Beck Depression Inventory' (A. T. Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) include a single guilt item, and measures of self-perceived burden, such as 'Self-Perceived Burden Scale' (Cousineau, McDowell, Hotz, & Hebert, 2003) ('I feel guilty about the demands that I make on my caregiver') also include single guilt items. However, guilt is not a primary focus of investigation in these measures and they fail to capture comprehensively the full complexity and pain-specific focus of guilt.

Some instruments have only recently been developed to measure perceived burden in chronic pain patients, for instance Cousineau et al. (2003) developed a scale to measure perceived burden in haemodialysis patients ('Self-Perceived Burden Scale'). However, guilt, although related to self-perceived burden, is a distinct construct from burden (Tilghman-Osborne et al., 2010). Additionally, guilt is also different from shame, although they are both defined as moral and/or self-conscious emotions (Carni, Petrocchi, Del Miglio, Mancini, & Couyoumdjian, 2013; Teroni & Deonna, 2008), they are separate emotions with different consequences for psychological adjustment. Shame is strongly associated with feelings of worthlessness (Carni et al., 2013), and research evidence suggests that it is a stronger emotion than guilt; it is also more associated and prominent in depressive symptoms (Kim, Thibodeau, & Jorgensen, 2011). However, this evidence is contested by other older studies which found that in clinically depressed people, guilt predicts depression while shame does not (Alexander, Brewin, Vearnals, Wolff, & Leff, 1999). Depression is a prominent psychological factor in LBP, therefore exploring guilt as a possible contributing factor to pain-related depression is important.

A recent systematic review (Tilghman-Osborne et al., 2010) of 23 theory based definitions of guilt and 25 measures of guilt suggests that research on the relation of guilt to psychopathology is inconsistent, and that the main reason for this may be the lack of conceptual clarity. This review found that existing measures of

guilt do not relate well to their conceptual definitions, and both definitions and measures, often mirror other (unrelated) concepts such as anxiety, shame, worry, fear and anger. This can confound guilt research by inflating correlations between guilt and negative emotional outcomes.

The review reveals that contradictory findings are evident in studies of a number of psychiatric disorders, including depression and anxiety. In depression research, studies which defined guilt as a positive construct (which motivates reparation and reduces depression) found negative correlations between depression and guilt (Tangney, Wagner, & Gramzow, 1992; C. Williams & Bybee, 1994). Contrary to this, studies that defined guilt as a negative construct that involves painful feelings and tensions, found positive correlations between guilt and depression (Harder, Cutler, & Rockart, 1992). These studies used different measures of guilt, which reflected their definitions of guilt, for instance Harder's measure of guilt described guilt as a negative construct leading to negative consequences (Tilghman-Osborne et al., 2010). Similar discrepancies can also be found in anxiety research (Tilghman-Osborne et al., 2010). In order to avoid some of these problems, the authors of this review suggest that certain principles should be followed in the assessment of guilt, for example, measures of guilt should focus on guilt specifically, and other constructs should be avoided. For example, using terms such as sad, depressed, and anxious can confound the measurement, and subsequently the findings. Furthermore, explicit measures should be used and just asking 'How guilty do you feel?' is too vague, instead, each question should focus on a specific aspect. Additionally, guilt should be measured in context, addressing a specific event or scenario that should be in line with the research goals (Tilghman-Osborne et al., 2010).

Pain-Related Guilt

Guilt is a common symptom of depression (O'Connor, Berry, Weiss, & Gilbert, 2002; Tilghman-Osborne et al., 2010). However, studies into the presence of depressive symptoms in chronic pain rarely mention guilt. One study that did report on guilt is a cross sectional survey of the general population in five European countries (UK, Germany, Italy, Portugal and Spain) (Ohayon & Schatzberg, 2003).

The survey selected respondents with chronic painful physical conditions to examine whether chronic pain can predict depressive morbidity in the general population. It found that among other depressive symptoms feelings of worthlessness or guilt were frequently found with limb and back pain. However, this study included only one guilt question within a long list of depressive symptoms such as hopelessness, loss of interest and feeling sad. This particular question asked participants if they experienced 'feeling of worthlessness or guilt' (yes/no) within a measure that did not examine guilt specifically. Additionally, this question was double-barrelled as it inquired about two types of feelings, feeling worthless and feeling guilty.

Feelings of guilt have also been reported in qualitative studies that did not specifically set out to study guilt. For example, a qualitative longitudinal study of patients' experiences of chronic LBP by Snelgrove, Edwards, and Liossi (2013) explored the experiences of eight participants with chronic LBP using interpretative phenomenological analysis. In this study they reported participants' responses one and two years after the initial interviews. The main challenge for participants was managing constant unchanging pain experiences and loss across all areas of their lives, such as social loss and loss of family roles. Participants reported feelings of anxiety and guilt about letting their family down and about family members undertaking their responsibilities. In another qualitative study (Newton-John & Williams, 2006), 95 patient-spouse dyads completed questionnaires relating to marital satisfaction and communication, and 80 of those couples were interviewed about their perceived marital interactions and pain behaviours. In their findings and within 'participants affective responses' theme, guilt (in relation to marital interactions) was reported by participants. Spouses with chronic LBP reported feeling guilty for receiving constant assistance from their spouses. A third qualitative study by Rhodes et al. (1999) (described in more detail previously in this chapter) explored the meaning of diagnostic tests for people with chronic LBP and found that in cases of non-specific or absent findings LBP patients reported feeling guilty for 'letting the doctor down', especially when tests fail to identify the cause of their back pain. However, feelings of guilt were not explored and discussed in more detail in these studies.

One study that examined guilt specifically within the context of chronic pain is a study by Hochwarter and Byrne (2010). This study examined the interaction

between perfectionism, guilt and chronic pain at the work place. They used a non-clinical sample of 428 students and workers and employed regression analysis to analyse participants' responses. They modified Harder and Zalma (1990)'s eight-item scale to reflect guilt toward job duties. Example items included 'I experience regret about the way I do my job', and 'I experience remorse at work'. Guilt was measured and analysed as part of a composite measure of negative affect. They based their investigation on past studies such as that by Molnar, Reker, Culp, Sadava, and DeCourville (2006), which showed that negative affect and perfectionism are linked with the onset and responses to physical health problems, including chronic pain. Hochwarter and Byrne (2010) found that those who are suffering from chronic pain may attempt to overcompensate for their physical inability to perform and may feel guilty that they cannot. This is related to excessive stress in the form of heightened job tension and poorer job satisfaction. These findings suggest that people with chronic pain may feel guilty that they cannot do their job properly due to their pain.

Another study (Wynne-Jones et al., 2011) examined the beliefs and attitudes of 20 managers and 18 employees with musculoskeletal pain about sickness absence and return to work. Their narratives were analysed with thematic analysis. This study did not focus on guilt specifically, although guilt was identified as a component of the 'moral aspects of absence and attendance' theme within their results. Employees reported feeling guilty during periods of absence from work due to the impact of this on their work colleagues.

Finally, other constructs, such as self-perceived burden and worry have been studied within the context of chronic pain, but as discussed earlier, these constructs are different constructs from guilt and only provide indirect support to the understanding of pain-related guilt among chronic pain patients. For instance, the feeling of being a burden among chronic pain patients was reported by up to 70% of participants in a recent study (Kowal et al., 2012).

Importance of Studying Pain-Related Guilt in LBP

Although guilt is a symptom of depression, it has been suggested that symptomology of depression in chronic pain patients may differ from that found in

depressed non-pain patients (Morley, Williams, & Black, 2002; Pincus & Williams, 1999; A. Williams & Richardson, 1993). It has been argued that in pain patients there is a propensity for health related negative processing, without the self-denigration, shame and guilt, which are often related with clinical depression (Morley et al., 2002; A. Williams & Richardson, 1993). For example, Morley et al., (2002) used a sample (N=1947) of patients entering chronic pain management to examine the structure of the Beck Depression Inventory (BDI). They employed exploratory and confirmatory factor analyses and extracted a two factor solution: the first factor was named 'negative view of the self' and included items relating to failure, guilt, self-blame, self-dislike, punishment and body image change; the second factor, identified as 'somatic and physical function' included items relating to work difficulty, loss of appetite, loss of libido, fatigability, insomnia and somatic preoccupation. When they compared the extracted factor structure with published data from samples of clinically depressed (non-pain) patients the scores for items relating to the negative view of the self were consistently statistically lower than that observed in clinically depressed samples.

Research into specific components of depression associated with chronic pain is limited, the concept of depression in the context of LBP needs to be better defined and needs further research (Morley et al., 2002; Pincus & Morley, 2001; Pincus & Williams, 1999; Rusu, Pincus, & Morley, 2012). Different aspects and symptoms of depression in chronic pain should be examined and new measures should be developed to enable this (Pincus & Williams, 1999). No research has been conducted to examine pain-related guilt specifically (and its link to depression in pain patients); this thesis will address this aspect.

Depression is a strong risk factor for disability (Linton et al., 2011). Cognitive behavioural therapy is the main psychological treatment for distressed pain patients, and so far it has only had moderate success in treating pain patients (A. Williams et al., 2012). One of the main problems identified is that CBT lacks focus and past studies show that not all pain patients will benefit from the same psychological treatment. Although many LBP pain patients may have depressive symptoms, it is still unclear which symptoms they share with psychiatric depressed patients and which symptoms are unique to prolonged pain. If future research finds guilt to be an important chronic pain experience which is related to negative

outcomes in LBP, addressing and targeting it in psychological interventions may be beneficial for optimising management, of at least some patients with LBP. Past research suggests that several psychological factors (such as depression, anxiety, fear avoidance and catastrophising) are important obstacles to recovery from LBP. Although the research into these factors has advanced knowledge, psychological interventions have delivered only small improvements in trials (Williams et al., 2012); many of the factors overlap, and it is difficult to understand the mechanisms by which acute LBP develops into chronic LBP (Foster et al., 2010; Hayden, Chou, Hogg-Johnson, & Bombardier, 2009; Hayden et al., 2010). In light of the evidence that about 30% of people with an initial episode of non-specific LBP do not recover within a year (Henschke et al., 2008), it is imperative to identify components that comprise factors such as depression, and focus on understanding the mechanisms by which acute LBP might develop into a chronic problem. This is important for prevention and for improvement of interventions. Pain-related guilt resulting from perceived diagnostic status and pain-related guilt leading to pain-related depression might be potential mechanisms that compromise recovery in LBP.

Perceived Diagnostic Status and Information Processing in Low Back Pain

Patients with chronic pain often have negative expectations about their ability to control their pain and can perceive themselves as helpless. These expectations can impact on their behaviour, leading to reduced activity and increased distress (Hayden et al., 2010). But what are the underlying cognitive mechanisms that maintain this relationship? Research in anxious and depressed groups has unveiled cognitive mechanisms that appear to maintain both negative moods and avoidance behaviour (Pincus & Morley, 2001). Some of the mechanisms that have been proposed as underlying mechanisms are referred to as cognitive biases. The cognitive-behavioural approach to chronic pain proposes that chronic pain patients should be seen as active processors of information (Turk & Rudy, 1992). However, the processing of information is not always accurate and there is evidence for cognitive biases in chronic pain patients (Jones & Sharpe, 2014; Pincus & Morley, 2001; Schoth, Nunes, & Lioffi, 2012; Sharpe, 2014). Thus, the final objective of this thesis is to understand cognitive mechanisms that might underpin the relationship between diagnosis-related beliefs and mood and disability in LBP. One way to study

cognitive biases is through quasi-experiments observing cognitive processes, such as attention and recall for specific types of stimuli. This method has the advantage of being relatively free of self-awareness and demand characteristics that are typically found in interview and questionnaire based methods. Cognitive biases occur pre-consciously (Leventhal, 1984), and experimental studies of cognitive biases enable access to levels of cognitive structures that cannot be examined and accessed via other methods such as questionnaires (Pincus & Morley, 2001).

Research in chronic pain has mainly focused on three types of cognitive processes in which bias could occur: memory, attention and interpretation of information (reviewed in the next section). In chronic pain patients, the most robust evidence has been found for recall bias (Pincus & Morley, 2001), and it has been selected for this thesis because of its link with depression (Tilghman-Osborne et al., 2010), hence, theoretically it is more likely to be connected to guilt. In spite of this robust evidence, research into memory biases in LBP (and chronic pain in general) has been sparse in recent years; there has been more focus on attentional biases. Cognitive biases have been described as products of the activation of cognitive 'structures' or schemas. The cognitive theory, proposes that schemas are 'mental frameworks for representing knowledge that encompass an array of interrelated concepts in a meaningful organisation' (Sternberg & Mio, 2009, p. 583). Cognitive biases arise when the existing schemas selectively process certain types of information in preference to other types.

Schemas have been described as content specific domains in which information is linked by association (e.g. mood-related, pain-related, etc.) (Denton, Sharpe, & Schrieber, 2005), so activating any information within the domain will spread to linked information. This activation is dependent not only on past experience, but also on current circumstances, such as mood. In addition, and considerably less understood, it appears that selective processing is not only content and context specific, but also process specific. Thus, depressed patients exhibit memory bias for negative self-referent information (Segal, Gemar, Truchon, Guirguis, & Horowitz, 1995), whilst anxious patients exhibit attentional bias for anxiety-related stimuli towards threat or the focus of their individual concern (Keogh, Ellery, Hunt, & Hannent, 2001).

A substantial body of research on cognitive biases has suggested that anxiety (both clinical state and non-clinical trait anxiety), is associated with attentional bias. However, the relationship between depression and attentional bias is less clear (J. M. Williams, Mathews, & MacLeod, 1996). On the other hand, memory biases towards negative content have been found to have a robust link with depression, but less so with anxiety (J. M. Williams, 1997).

Chronic pain patients also exhibit pain-related cognitive biases, suggesting the existence of active pain schemas (Jones & Sharp, 2014; Pincus & Morley, 2001) (this research will be summarised in the next section). There is sufficient evidence to argue that patients with chronic pain process information differently to non-pain control participants, and there is also some evidence of variability among patients with chronic pain, but the basis of this variability is not entirely clear (Pincus & Morley, 2001). Attempting to identify subgroups of chronic pain patients may enhance the understanding of the role of cognitive biases in different groups of chronic pain (Denton et al., 2005; Pincus & Morley, 2001; Schoth et al., 2012). The current research addresses this issue by grouping chronic LBP patients according to their perceived diagnostic status, and examining if there are differences between them in terms of how they process information.

Attentional Biases in Chronic Pain

Attentional biases refer to the tendency to prioritise and selectively attend to the information that is most relevant to the individual (Sharpe, 2014). Therefore individuals tend to process and attend to certain types of information before others. In clinical populations, attentional biases have been found in individuals with anxiety, but also in individuals with depression and other clinical populations such as eating disorders (Schoth et al., 2012). The research into attentional biases present in individuals with chronic pain has focused on establishing whether they exhibit attentional bias for pain-related information. Models of chronic pain, such as models reviewed in ‘Psychological Factors in LBP’ section, e.g. Vlaeyen and Linton (2000), suggest that maladaptive interpretations of pain are harmful and they might also be important in the development of chronic pain. These interpretations result in anxiety and fear of pain, which in turn lead to hypervigilance and avoidance of potentially

pain-provoking stimuli and situations. Recent research on cognitive biases in chronic pain has focused mainly on attentional biases (Jones & Sharp, 2014). Such biases may be related to preoccupation with pain, and result in a propensity to unnecessarily avoid situations and activities erroneously perceived as threatening to them (Schoth et al., 2012). However, this research has produced mixed results. A number of studies have identified attentional biases in chronic pain patients (Dehghani, Sharpe, & Nicholas, 2003; Haggman, Sharpe, Nicholas, & Refshauge, 2010). However, they produced inconsistent findings (Schoth et al., 2012) and the effect sizes in these studies are small (Crombez, Van Ryckeghem, Eccleston, & Van Damme, 2013).

The first study to report a bias towards pain stimuli was a study by J. Pearce and Morley (1989). Attentional biases are explored with various methodologies and chronic pain studies predominantly use two classic methods, Stroop and Visual Probe tasks. J. Pearce and Morley (1989) used an emotional Stroop task to present sensory pain, affective pain, emotionally negative and neutral words to a group of chronic pain patients and pain-free control participants. Participants were asked to name the colours in which these words were written. It found that chronic pain patients display selective attention for pain-affective words and pain-sensory words in comparison to non-pain control participants, indexed by increased latencies to respond (although affective words did not produce greater interference than sensory words). Subsequent studies that tried to replicate this finding only found a bias towards pain words after controlling for depression (Snider, Asmundson, & Wiese, 2000) and in subgroups of chronic pain patients categorised by depression, anxiety and/or fear of pain (Keogh et al., 2001; Dehghani et al., 2003). Despite this early mixed evidence, a recent meta-analysis of ten studies that compared individuals with chronic pain to healthy controls (chronic pain participants N=515, control participants N=314), suggested that pain patients selectively attend to pain words (Schoth, et al., 2012).

Interpretation Biases in Chronic Pain

Interpretation biases occur when in the absence of external cues, ambiguous information is interpreted using existing internal schemas (Eysenck & Keane, 2010). Interpretation biases are less studied in the context of chronic pain than attentional

biases, although the evidence for interpretation biases is more consistent (Jones & Sharp, 2014). Existing research suggests that when chronic pain patients and non-pain control participants are presented with ambiguous stimuli, chronic pain patients are more likely to select a pain-related interpretation than control participants (Pincus & Morley, 2001). For example, Pincus, Pearce, McClelland, Farley, and Vogel (1994) compared pain patients, physiotherapists and control participants' responses on a task in which they were asked to generate a list of spontaneous associations to ambiguous cues (e.g. the cue terminal and the possible associations of train station, computer or cancer growth). They found that pain patients generated more pain-related associations than the other groups, and that this was independent of their anxiety and depression levels.

Memory Biases in Chronic Pain

For this thesis, which was constrained by time considerations, one of the biases had to be selected; recall seemed most pertinent (as explained earlier in this chapter). A memory bias occurs when individuals selectively remember specific information in preference to other types of information presented, usually information which is significant to them and their circumstances (Eysenck & Keane, 2010).

A review of experimental studies found that there is strong evidence for a memory bias towards pain and illness/health-related stimuli in patients with chronic pain (Pincus & Morley, 2001). Pain stimuli relate to sensory features of pain and contain immediate properties and features of pain, whilst illness/health related stimuli relate to illness aspects rather than sensory pain aspects and incorporate the consequences of illness relevant to patient's self-image. Research has mainly focused on the free recall of words and recall bias. In these studies the content of word lists and encoding instructions have been experimentally manipulated. Several studies have also examined recognition memory following the initial free-recall trial (Pincus & Morley, 2001). Research into memory biases in chronic pain patients has involved two key mediating variables: the type of the pain stimuli and the mood state of the patient (Denton et al., 2005). There is evidence for a recall bias for sensory pain words in pain patients (Edwards, Pearce, Collett, & Pugh, 1992; Koutantji, Pearce,

Oakley, & Feinmann, 1999; S. A. Pearce et al., 1990). For example, S.A. Pearce et al. (1990) compared two groups of participants: 25 chronic pain patients and 25 non-patient controls on a test involving both immediate and delayed recall of three types of words: pain-related, negative non-sensory pain words (relating to illness aspects rather than sensory pain aspects, e.g. suffering, vulnerable, ill) and neutral words. They found that pain patients recalled more pain-related words than non-patient controls. On the other hand, recall bias for non-sensory negative pain words has mainly been found in depressed chronic pain patients (Edwards et al., 1992; Pincus et al., 1995). For instance, Pincus et al., (1995) examined cognitive processing by comparing the responses of depressed pain patients, non-depressed pain patients and non-pain control participants. Endorsement of adjectives as descriptors of themselves and participant' best-friends and free recall of the presented words were measured in the study. Participants were presented with depression-related, pain-related and neutral control adjectives, and each category was split into negative and positive valence. Only depressed pain patients showed a bias towards self-referential negative pain words.

Evidence has suggested that recall bias in patients who are depressed is related to information encoded in reference to the self (participants are instructed to decide whether the presented material is self-descriptive) (e.g. Greenberg & Alloy, 1989); when self-referent instructions are present, a bias toward negatively valenced personal descriptors and illness/health-related stimuli (incorporate the consequences of illness relevant to patient's self-image) is displayed by patients with pain who are also depressed. In the absence of explicit self-referent instructions, a bias toward sensory pain descriptors is observed (Edwards et al., 1992; S.A. Pearce et al., 1990). This perhaps is not surprising as the impact of mood on memory is well established (Eysenck & Keane, 2010; Pincus & Morley, 2001), people have a tendency to memorise information that is congruent with their current state. Therefore, it seems that mood of the patient determines schema activation; furthermore, Pincus and Morley (2001) argue that the research evidence suggests that depression is the determining factor of recall bias in chronic pain patients.

Recall bias has also been explored in reference to future thinking in chronic LBP patients. Read and Pincus (2004) studied negative future thinking (common in depression) in relation to chronic pain and recall bias. They compared 25 depressed,

35 non-depressed chronic low back pain patients and 25 non-pain control participants (student osteopaths) on their recall for positive and negative ill-health, depression-related, and neutral (control) adjectives, encoded in reference to either current or future time-frame. Depressed pain patients displayed a recall bias for ill-health stimuli in the current negative thinking condition (confirming previous findings in the field (Pincus & Morley, 2001)), but not in the future negative thinking condition suggesting that negative future thinking may not be as prominent in chronic pain patients with depressive symptoms, as in depressed people without pain (Read & Pincus, 2004).

Overall, this research suggests that depression, which is a prominent characteristic in chronic pain patients, is also implicated in processing of information; it is implicated in specific selective processing of information congruent with the focus of pain-related depression (i.e. pain and ill health). A. T. Beck (1979) cognitive model of depression has been used and adapted to explain high rates of depression in chronic pain (Banks & Kerns, 1996). The model suggests that depressive symptoms are a product of negative schemas about the self, world, and future, that are characterised by self-denigration and self-worthlessness. It is suggested that chronic pain impacts on these negative schemas by reactivating them in already vulnerable individuals (Banks & Kern, 1996). However, this proposition has not found full support by research described above, for example Pincus, Pearce, McClelland, and Isenberg (1995) found that depressed pain patients recalled more non-sensory (illness/health-related) pain words, but not more depression-related words than non-depressed pain patients. This suggests that recall bias in chronic pain patients is more related to pain experience than depression, and as a result of this difference (and also due to the presence of other emotions in chronic pain such as anxiety, anger, frustration) Pincus and Morley (1991) suggest that affective distress is a more appropriate term to use in the context of chronic pain than depression. Additionally, although depressed mood is common in chronic pain patients, prevalence rates are not clear and depend on methodology used; for example measuring depression with scales not designed for patients with physical health problems may produce unreliable results (Pincus & Williams, 1999).

The Schema Enmeshment Model of Pain

One of the most prominent and detailed theoretical models of recall biases in pain is the Schema Enmeshment Model of Pain (SEMP; Pincus & Morley, 2001). Informed by empirical research findings, it proposed that the enmeshment of three cognitive schemas (pain, illness, self) is responsible for recall biases in some groups of chronic pain, typically distressed patients. Pain schemas contain sensory, intensity, spatial and temporal features of pain; illness schemas contain information about consequences of illness; and self-schemas contain organised information about the self. Although schemas are relatively stable, they can change due to new information associated with them being incorporated and irrelevant information being inactivated. This may result in the repeated simultaneous activation of information from different schemas and the information from one schema being incorporated into another; within the SEMP model this process is referred to as enmeshment (Pincus & Morley, 2001). Enmeshment may elicit new and unwanted reactions to events or information that were previously non-threatening.

Individuals with chronic pain may perceive themselves as being ill, which may contribute to an enmeshment of the (sensory) pain and illness schemas. Furthermore, depressed chronic pain patients may feel that their pain experiences will have detrimental implications for the self, which may result in enmeshment of self-schemas with pain and illness schemas (Read & Pincus, 2004). Processing of new information depends on salience to the existing content of schemas. In line with this, the model proposes that all chronic pain patients, irrespective of their emotional state preferentially process pain information. There is also a tendency to process information that is self-referent (explicitly refers to them, e.g. participants are asked if the information presented describes them/their pain as opposed to being asked if the information describes their friend/other people), especially when this information is congruent with their self-schema. Biases towards illness and affective pain information are proposed in distressed pain patients (without depression characterised by negative evaluation of the self), while patients with current depression characterised by self-denigration, tend to exhibit biases towards depressive information. Although interrelated, pain schemas contain immediate properties and features of pain, whereas illness schemas incorporate the consequences of ill health. When this ill-health schema becomes inter-connected

with the patient's self-image, it is hypothesised to be associated with poor coping (Pincus & Morley, 2001).

Pincus and Morley (2001) have proposed that the extent to which self, illness and pain schemas become enmeshed could be a way of understanding the pattern of biases seen in a range of cognitive tasks in people with chronic pain. Enmeshment is not a bias in its own right, but a structural attribute relating the self to pain experience (Read & Pincus, 2001) and an important task of therapy for people with chronic pain is to enable a separation of the self from pain and illness schemas (Pincus & Morley, 2001).

Perceived Diagnostic Status and Cognitive Biases

Research has shown that chronic pain patients who are uncertain about their condition continue searching for a diagnosis (Hopayian & Notley, 2014); this may prevent patients from focusing on other aspects of life, thus becoming overly preoccupied with their condition and pain. This may shape their schemas and bias their cognitive processing to selectively process information relevant to their concerns. As outlined above, the link between cognitive biases and negative emotional states, such as anxiety and depression has been identified in studies with chronic pain patients. Therefore, cognitive biases could be one mechanism underlying the relationship between patients' diagnosis-related beliefs and outcomes, such as depression and anxiety. The relationship between cognitive biases and diagnostic status/diagnosis-related beliefs has been previously explored in only one study (Wells, et al., 2003), (described in more detail in the 'Perceived Diagnostic Status' section above). It showed that diagnosed chronic pain patients recalled fewer depression stimuli compared to pain, illness and neutral stimuli, suggesting a recall bias away from depression stimuli, while non-diagnosed chronic pain patients did not exhibit better or worse recall towards any stimuli category. Overall, these findings suggest that recall patterns in the diagnosed and undiagnosed chronic pain patients vary and indicate differences in their cognitive processing. However, this study did not focus on LBP specifically; it included a heterogeneous group of chronic pain patients and their satisfaction with the labels and explanations they received was not measured. To date, there has been no direct comparison between recall bias in

people with LBP who perceived their condition to be unexplained and undiagnosed, and those who perceived their condition to have an acceptable diagnostic label.

Aims and Objectives of the Thesis

Chapter 1 broadly addressed the aims of the research undertaken as part of this thesis, and the aims of each study. The specific aims of the thesis are outlined next.

Research reviewed in this chapter shows that LBP patients often worry about their pain and that this is often related to the lack of clear diagnosis and physical evidence for their pain. Past research focused on various aspects of this issue, although, currently no theory exists that unifies these aspects.

Aims and objectives of the thesis are as follows:

1. The main aim is to explore LBP patients' perceived diagnostic status, mainly focusing on their understanding, feelings and responses to their diagnosis.

This will be achieved through the following steps:

- a. Participants' answers will be used to uncover the themes that underlie their responses.
- b. The themes will be used to develop a theoretical framework that would enable an insight into the relationship between perceived diagnostic status and patients' understanding, feelings and responses to their condition and pain.
- c. The themes and its categories will also be used to develop a set of items to allow categorisation which should enable subgrouping of individuals with LBP according to their perceived diagnostic status.

2. Past research suggests that LBP patients experience feelings of guilt and that in some cases this is related to their perceived diagnostic status, but this research is exceptionally rare. A secondary aim of the thesis is to explore pain-related feelings of guilt in LBP patients, especially in relation to the absence of clear diagnosis and physical evidence for back pain; this will be achieved through the following steps:

- a. Participants' answers will be used to extract themes for pain-related

- guilt from which a pain-related guilt measure will be developed.
- b. Psychometric properties of the new measure will be tested in large cross sectional samples.
 - c. The new measure will be used to examine the relationship between pain-related guilt and clinical measures of pain, mood and disability.
3. Finally, based on steps outlined under 1 and 2 above, a theoretical model will be developed in which pathways between perceived diagnostic status, pain-related guilt, and mood and disability in LBP will be examined.

An additional aim of the current research is to examine cognitive mechanisms underlying the relationship between perceived diagnostic status and mood and disability in LBP. To examine this, in the final study of the thesis participants will be grouped according to their perceived diagnostic status and compared on their susceptibility to recall bias for negative health stimuli.

Chapter 3

An Exploration of How Chronic Low Back Pain Patients Understand, Feel and Behave in Response to Their Perceived Diagnostic Status: A Qualitative Study

Abstract

In the majority of low back pain (LBP) patients a clear diagnosis cannot be established; as a result patients are given labels such as non-specific low back pain. There is some evidence that lack of a clear diagnosis is associated with negative psychological, clinical and behavioural outcomes. The main aim of this study was to examine LBP patients' understanding, feelings and behaviour in response to their diagnostic labels. In-depth semi-structured interviews were conducted with twenty two LBP patients who were recruited from one osteopathic and one pain management clinic. Sampling, data collection and analysis were driven by a grounded theory approach. Data were analysed through four stages of coding: open, selective, axial and theoretical coding. Data collection and coding continued until data achieved saturation. Results indicated that perceived lack of a clear diagnosis is associated with distress, further treatment seeking and uncertainty, and that legitimising the pain experience is of prime importance to them. It also influenced participants' perception of their social relationships; having visible evidence and a clear diagnosis gave participants' pain more social credibility. Participants reported feeling guilty about the consequences of their pain to themselves and others, and for failing to recover. Overall, participants' narratives suggest that diagnostic uncertainty is the fundamental issue for LBP patients, and that the absence of a clear diagnostic label is just one aspect of it. They tend to think whether there is something else, undiscovered going on with their pain. Overall, they are uncertain about the meaning and cause of their pain and how to deal with it in the future.

The work presented within Chapter 3 has been published in the Journal of Pain Management:

Serbic, D., & Pincus, T. (2013). Chasing the ghosts: The impact of diagnostic labelling on self-management and pain-related guilt in chronic low back pain patients. *Journal of Pain Management*, 6(1), 25-35.

Introduction

Chapter 2 provided a comprehensive summary of past research relevant to perceived diagnostic status in LBP patients, its impact on patients' coping with back pain and its relationship to pain-related guilt. This is a brief summary of the key issues identified in Chapter 2 which are relevant to the aims of this study.

Low back pain (LBP) is common; it affects about 80% of the adult population over a life span (Walker, Muller, & Grant, 2004) and has considerable impact on individuals. It also accounts for substantial socioeconomic costs, mainly in terms of number of work days lost (Krismer & van Tulder, 2007). When a definitive cause and a clear diagnosis for back pain cannot be established patients are often given unclear labels such as non-specific LBP (Coste et al., 1992). Diagnosis is defined as the 'identification of a disease or condition by a scientific evaluation of physical signs, symptoms, history, laboratory test results, and procedures' (Mosby Inc., 2009). However, non-specific LBP is diagnosed by exclusion (Waddell, 2004) and is defined as non-specific or musculoskeletal back pain where underlying pathology cannot be found (Krismer & van Tulder, 2007). In the case of non-specific LBP, labelling can be problematic and misleading because non-specific LBP is not a single diagnostic category; it represents a number of different disorders or subtypes of back pain (Waddell, 2004) for which a clear physical cause cannot be found. They are often described and are understood as a symptom or a syndrome rather than a diagnosis (Cedraschi et al., 1999). Non-specific LBP represents the majority of LBP patients, research shows that only about 5-10% of LBP patients receive a clear diagnosis and clear explanation of their back pain causes (Krismer & van Tulder, 2007).

Research reviewed in Chapter 2 suggests that in the absence of clear physical evidence the meaning of non-specific LBP label becomes puzzling to LBP patients,

and it does not represent their pain experiences (Froud et al., 2014; Rhodes et al., 1999; Verbeek et al., 2004). Practitioners and lay people find the label ‘non-specific’ ambiguous too. A qualitative study (Barker et al., 2009) reported that to lay participants, the label suggested that practitioners do not understand the cause of the pain and to practitioners the label suggested that there was no diagnosis. There is also no consensus or clear guidelines present in the literature, on how practitioners should deal with these issues.

To many back pain patients not knowing the exact cause of pain is unsettling. Having no clear physical evidence means that patients often feel that their pain is delegitimised and disbelieved (Hopayian & Notley, 2014; McIntosh & Shaw, 2003; Rhodes et al., 1999). In the absence of physical evidence a stigmatising, psychological cause for pain is sometimes proposed by practitioners as a plausible explanation (Newton et al., 2013). This results in heavy use of medical services by LBP patients in an effort to find medical answers to legitimise their pain experiences (Good, 1994). In terms of pain management, there is substantial evidence that communication between practitioners and patients is important and has potential of changing patients’ unhelpful perceptions of their pain (Darlow et al., 2013; Darlow et al., 2012). Lack of clear diagnosis is also associated with an increased belief in illness (Cioffi, 1991).

The majority of research in LBP has focused on long term outcomes such as disability and quality of life, and Chapter 2 outlined recent evidence that suggests that these outcomes are affected by a variety of psychological factors. However, the majority of research has focused on major psychological factors, such as depression and fear-avoidance. An objective of this study was to extend this line of research and enable an exploration of the relationship between perceived diagnostic status and clinical measures of mood and disability in LBP. This will be achieved by first, exploring LBP patients’ understanding, feelings and behavioural responses to their diagnosis, and by uncovering the themes that underlie their responses. These themes will then be used to develop a categorisation for perceived diagnostic status for use in quantitative studies. Currently no quantitative measure exists to measure LBP’s perceptions, adjustment and understanding of their diagnosis. The majority of studies that examined this issue are qualitative; one quantitative study (Wells et al., 2003) which examined susceptibility to recall bias in chronic pain patients classified

patients into those that were either diagnosed or non-diagnosed. However, the non-diagnosed patients were a heterogeneous group of chronic pain patients rather than LBP patients, and their satisfaction with the labels and explanations they received was not measured. Study 1 aimed to address this shortcoming by exploring the personal meaning of diagnosis to LBP patients and by constructing a set of items to allow categorisation of subgroups in terms of how patients perceive, accept and respond to diagnosis.

Some patients who lack clear physical evidence to justify their pain experiences also report feeling guilty, for example in the absence of positive findings from physiological tests some patients report feeling guilty for disappointing the doctor (Rhodes et al., 1999). Chapter 2 presented a detailed review of research on guilt and it defined guilt is a type of emotional distress that is founded on the likelihood that we may be in the wrong, or that others may perceive us that way (Baumeister et al., 1994). Guilt is also found to be a feature of depression, and it is recognised that many depressive symptoms are prevalent in chronic pain disorders (Eccleston, 2001) such as LBP. However, the role of pain-related guilt in chronic pain is not very well understood.

No instruments have yet been developed to measure pain-related guilt in LBP patients and in chronic pain in general, and overall it is poorly researched. Therefore, a secondary aim of this study was to explore pain-related feelings of guilt in LBP patients, especially in relation to unclear diagnosis and absence of physical evidence for back pain. Specific aims of this study are the following:

1. To explore LBP patients' understanding, feelings and responses to their diagnosis, and to uncover the themes that underlie their responses.
2. To develop categorisation for perceived diagnostic status for use in future studies; more specifically to construct a set of items to allow categorisation of subgroups in terms of how patients understand, accept and respond to diagnosis.
3. To explore whether LBP patients experience pain-related guilt and in which situations and contexts.
4. To explore how LBP patients' understanding and acceptance of diagnostic labels relate to pain-related feelings of guilt.

5. To extract themes for pain-related guilt from which a pain-related guilt measure will be developed in the next study.

Methods

Rationale for Using Qualitative Methodology

Qualitative research is founded on the belief that people will give best descriptions of their thoughts and feelings. Qualitative methods have potential for investigating new topics and discovering and studying new factors; they can also assist in theory building (Holloway, Wheeler, & Holloway, 2010). Within the context of the present work, a qualitative method was required to explore the personal meaning and understanding of diagnosis to LBP patients and pain-related feelings of guilt, and to develop a theory that would explain how these experiences influence LBP patients. It was also needed to develop a categorisation of subgroups for perceived diagnostic status and a pain-related guilt measure for use in Study 2-5 of this thesis.

Rationale for Using Grounded Theory

Sampling, data collection and data analysis in the study were driven by grounded theory. Grounded theory is a largely inductive approach, which employs an in-depth analysis to understand lived experiences and how participants themselves make sense of those. Grounded theory is particularly useful in applied and novel areas of research (Robson, 2002). It is a method in which theories develop from the data and it provides explicit procedures for analysis and generating theory. It is driven by the data in such a way that the final form of the theory is likely to provide a good fit to the data (Robson, 2002). Data collection and analysis are carried out simultaneously and data are analysed through several stages of coding, which are described in the data analysis section of this chapter. Analytical codes and categories are constructed from data, rather than preconceived ideas. For this reason, a thorough literature review is conducted after the analysis in order to prevent the researcher from bringing preconceived ideas to the research. These categories are compared with each other and contribute to the development of a theory; therefore theory development is an iterative process. A special type of purposive sampling is

used in grounded theory, called theoretical sampling. It is aimed towards theory construction rather than population representativeness (Robson, 2002).

In this study, grounded theory was chosen to explore how LBP patients understand their diagnosis, what it means to them, how they make sense of it, and how it related to their coping, emotions and subsequent behaviours. Perceived diagnostic status was also studied in relation to guilt, which is a poorly researched factor, so new theories and predictions need to be developed and then tested. As subsequent studies of this thesis are largely based on the findings of this study, it was also necessary to construct a set of items to allow categorisation of subgroups within perceived diagnostic status and a pain-related guilt measure, for use in these studies.

Other qualitative approaches also enable extractions of themes and categories that represent often huge amounts of data, for instance Interpretative Phenomenological Analysis is one such approach and it was considered initially as a potential method to be used in this study. However, grounded theory is wholly focused on the process of deriving a theory, and it provides very explicit and detailed procedures to achieve this. This was also a major contributor to the validity of the findings (validity of the study is discussed in the discussion section of this chapter).

Rationale for Selecting a Specific Grounded Theory Approach

There are a few versions of grounded theory and consequently various definitions of what constitutes a theory. Hence, it is important to clarify which grounded theory version is being used in this study; researchers regularly fail to do this (Tan, 2010).

Grounded theory could be carried out in a positivist or constructivist paradigm. A positivist grounded theory assumes that there is an unbiased verifiable reality and that concepts emerge from the data. On the other hand, a constructivist grounded theory is based on the premise that multiple and socially constructed realities exist, and concepts are created rather than discovered from data (Charmaz, 2006). Grounded theory was developed by Glaser and Strauss in 1967 (Glaser, 1967). After developing the original grounded theory, Glaser and Strauss went separate ways and developed their own versions of grounded theory. While Glaser tried to preserve grounded theory in its original format as much as possible, and continued to define it as a method of theory discovery, Strauss shifted grounded

theory from a method of discovery toward a method of verification and introduced additional procedures and stages of coding (Strauss & Corbin, 1990). Since then, in addition to these two versions, new versions of grounded theory have been developed, a prominent version of grounded theory is constructivist grounded theory, developed by Charmaz (Charmaz, 2006). Charmaz's grounded theory is based on the assumption that theories are not discovered, but constructed and that the researcher influences this process.

The grounded theory used in this study combines elements of both, Glaser and Strauss' approach; it also took into consideration Charmaz's notion that no research is value free and potential influences of the researcher were considered and outlined in the discussion section of this chapter. The original version of grounded theory strictly prescribed carrying out coding without having preconceived thoughts and skills about the phenomenon studied and recommend that literature review is conducted after the analysis of data. The author of this thesis did not carry out a thorough literature review until after the analysis was completed. However, familiarising oneself with the main issues was unavoidable as researchers cannot be free of prior ideas and skills (Charmaz, 2006).

Glaser's Grounded Theory - Glaser's approach to theory development comes from a strong positivist perspective; he places emphasis on the development of theoretical categories that can be viewed as variables. Glaser tried to develop the original grounded theory by proposing that the 'conceptual code', which was the end product of the coding process should be divided further by the means of substantive coding and theoretical coding (Glaser, 1978b). Substantive codes are 'first order' concepts that are most closely related to data, while theoretical codes were used to 'conceptualise' how the substantive codes may be related and amalgamated into the theory; these are more abstract than substantive codes (Glaser, 1978b). Both types of coding were employed in the present work. However, the process of converting substantive codes into theoretical codes is not sufficiently rigid in Glaser's grounded theory. Thus, this study aimed towards adopting a coding process which would provide a transparent transition from substantive codes to theoretical codes; for this reason Strauss and Corbin's axial coding was also adopted in the study (Strauss & Corbin, 1998)

Strauss and Corbin's Grounded Theory - Strauss and Corbin (1998)'s view of theory development also has some positivists characteristics. However, they place emphasis on the relationships among concepts, which should be integrated into an interpretative theoretical framework rather than deriving theoretical codes which can be treated as variables. Because an aim of this study was to study the relationships between different concepts, such as perceived diagnostic status and pain-related guilt, it was decided that these could be best explained by an integrated theoretical framework. This integrated framework represents the theory that has been developed.

They also placed emphasis on the use of complex and systematic coding techniques (Strauss & Corbin, 1990), which enable researchers to study the relationships between concepts and their properties. One such coding technique is axial coding (described in more detail in the data analysis section of this chapter); it emphasises relationships between concepts and was used in this study to explore how categories and subcategories were related.

In summary, Glaser's theoretical coding is employed in this study because by raising substantive codes to a more abstract level it enables the development of a theory that can be tested in new situations. However, Glaser's approach does not provide specific procedures for studying the relationships between concepts; to solve this issue Strauss and Corbin's axial coding was also employed. Two more stages of coding were used in the study, open (or initial) coding and selective (or focused) coding, which are used in both Glaser's, and Strauss and Corbin's grounded theory. These will be described in more detail in the data analysis section of this chapter. The study also implements Charmaz's view in that although it is important to maintain open mindedness, researchers cannot be free of prior ideas and skills, and it is important to acknowledge those (Charmaz, 2006).

Sample

Type and Size of Sample

Qualitative research does not require that the sample is representative and it normally uses small samples, one of the reasons being that data collection and analysis are usually very demanding (Howitt, 2010). Grounded theory has a very specific approach to sampling; it uses theoretical sampling which is adjusted to the

theory that is being developed and data saturation (Howitt, 2010). As there are no prescribed rules as to the ideal sample size for grounded theory, in this study data collection continued until comprehensive and in-depth descriptions of a variety of participants' views and actions had been collected. Analytic categories were closely watched and data were collected until these categories became full and saturated, and no new data contributed to their development (Charmaz, 2006). Examples of theoretical sampling are provided in the results section.

Inclusion and Exclusion Criteria

Inclusion Criteria - The following inclusion criteria were used in this study: patients with mechanical LBP seeking treatment; aged 18 and over; with pain duration of at least 3 months (Krismer & van Tulder, 2007), because the focus of the study was on participants' experiences it was important their LBP pain was not acute; fluent English (in order to interview the patient); and a range of different pain intensity. Pain intensity was measured using a single question, which used a numeric scale of 0 ('no pain') to 10 ('pain as bad as you can imagine') (Cleeland & Ryan, 1994).

Exclusion Criteria - Because the main focus was on simple or mechanical back pain, any conditions other than musculoskeletal back pain were on the exclusion list (e.g. rheumatoid arthritis, ankylosing spondylitis and back pain due to cancer; see Appendix A for the full list of excluded medical conditions), ascertained by self-report and by examining participants' medical notes with their practitioners.

Recruitment Procedures and Participants

Participants were recruited from two clinics in London, the British College of Osteopathic Medicine (BCOM) and RealHealth Instituted (RHI), which is a private pain management clinic. These two institutions were selected because the aim was to have a diverse sample with a range of disability levels. The RealHealth Institute is a pain management clinic and their patients are likely to be high in pain disability (Last & Hulbert, 2009).

The BCOM is an osteopathic clinic and their patients are likely to be relatively independent and low in pain disability. The majority of participants had experience of both private and NHS treatment and during the interview they were asked to reflect on their overall experiences. Information about participants'

diagnosis was obtained by examining their medical notes with practitioners. The researcher was allowed to view those together with a member of staff at the BCOM and RHI.

RealHealth Institute - Is an independent health institution in London which runs pain management programmes. The programme runs over four weeks and has up to 10 patients. Recruitment at the RHI took place over two consecutive pain management programmes in the spring of 2010. An information sheet with a short screening questionnaire and an opt-in slip (see Appendix A) were handed out to patients attending the RHI by the author of the thesis (henceforth referred to as 'researcher'). The questionnaire included data about age, sex, pain duration, average pain intensity, site of primary pain and a list of exclusion criteria. Data from the questionnaire were not used in the analyses; the only purpose of the questionnaire was to recruit participants and describe the sample. The opt-in slip required contact details for those who agreed to be interviewed and these were handed back to the researcher. The patients who fulfilled the inclusion criteria were contacted by the researcher via telephone after at least 48 hours to allow for a 'cool down' period in which patients could reread the information sheet, consult with family and friends and phone the researcher to ask questions. An interview was arranged at the convenience of patients, in terms of time and venue. Recruitment for interviews was based on aiming for a diverse but representative sample, based on age range, gender, range of different pain durations and intensities. Those who had expressed an interest in the research but were not interviewed received a verbal explanation from the researcher and were thanked for their time and interest in the study. Altogether, seven chronic LBP patients were recruited from the RHI.

British College of Osteopathic Medicine – The BCOM clinic sees on average 400 patients per week and approximately 35% of these are LBP patients. Recruitment procedure was identical to the one described above with the following exceptions, which were put in place due to a large number of patients visiting the BCOM clinic every week:

- a) At the times when the researcher was not present to disseminate copies of the screening questionnaire in person, copies of those were left at the reception for patients to take and a sealed box was provided for completed

questionnaires. Posters (see Appendix B) were placed in the waiting room in order to invite patients to participate in the study.

- b) Those patients who had expressed an interest in the research but were not interviewed received a thank you note by post.

All together 14 LBP patients were recruited from the BCOM.

Additional Measures

Two measures of patients functioning (described below) were also included in the study, these measures were in the form of a questionnaire and were given to the participants to complete after the interview was conducted. The purpose of this was to describe the sample and enable a better understanding of the characteristics of the sample, and these measures were not used in the analysis.

Anxiety and Depression - The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) consists of 14 items which evaluate the severity of anxiety and depression (7 items relating to anxiety; 7 items relating to depression). Scores range from 0 to 21 for each scale; higher scores indicate greater likelihood of depression or anxiety. Recommended cut-offs are: 8-10: mild cases, 11-15: moderate cases and 16 or above: severe cases (Zigmond & Snaith, 1983). The HADS has been widely used in studies of depression and anxiety in medical populations (Carroll, Kathol, Noyes, Wald, & Clamon, 1993).

Disability - Roland Disability Questionnaire (RDQ) (Roland & Morris, 1983) was used to measure back pain related disability. It is composed of 24 yes/no questions where 0 = no disability to 24 = maximum disability. This is a widely used and reliable measure of low back disability (Waddell, 2004).

Data Collection

Interview Schedule

Semi-structured interviews were used to collect data; this is a common data collection method in grounded theory (Howitt, 2010). Semi-structured interviewing includes questions that are open-ended and questions that identify areas that the researcher tends to explore. It also normally has a loose structure which means that

the order of the questions is not of prime importance. This approach was employed because the emphasis was on establishing rapport with the interviewee. The ordering and exact wording of the questions was less important and the interviewer explored interesting areas that arose during the interview (Robson, 2002). Probing questions were included in the interview schedule and verbal and non-verbal probes (such as nodding) were used throughout the interview in order to clarify understanding of participants' answers and explore them further. Therefore, the interview schedule was used as a guide rather than strictly followed. However, each interview started with the same opening question about participants' condition and how and when it all started: 'Can you tell me a little bit about how your pain started?' followed by the question about their first consultation: 'Can you tell me about your first consultation with the clinician?' The interview schedule (see Appendix C) included discussing areas such as participants' understanding of their diagnostic labels, their response to diagnostic labelling in the first consultation, in subsequent consultations, coping with their back pain and their relationships with others. Because of sensitivity attached to the terminology of guilt it was opted not to ask about this directly in the first instance, but it was used as a probe. Care was taken while constructing interview questions and probes to avoid leading questions (questions which suggest an answer), double barreled questions (items which consist of two questions), and offensive questions (e.g. worded in such a way to put blame on the participant) (Howitt, 2010).

The interview schedule was adjusted throughout the data collection process and this was in line with the grounded theory principles. For instance, the researcher's supervisor examined the first two interview transcripts in order to check the researcher's interviewing techniques and if the interview schedule should be adjusted further. She and the researcher discussed how the interview schedule could be improved. This process helped to adjust the interview schedule and direct theoretical sampling. For example, it was decided that it was necessary to include more probes on the relationships questions, especially in order to try to elicit more properties of the 'feelings of guilt towards other people' category, which was identified during the coding process. So the interview schedule was adjusted by adding probes such as: 'Can you think of an example and explain your feelings at the time?', 'How does it make you feel if you are unable to help a friend in need due to

your back pain?', 'How does it make you feel if you are unable to explain the cause of your back pain?'

Recording of Interviews

All the interviews were conducted by the researcher and tape recorded with a digital tape recorder. No notes were taken during the interview, to better focus on the interviewee and his/her story. However, immediately after the interview the researcher made written notes of any interesting and useful information and impressions, these were incorporated later on in the 'memos' kept by the researcher. Keeping memos is an important aspect of the grounded theory method (Charmaz, 2006) and it is described in more detail in the analysis section of this chapter. Additionally, notes about issues needing further clarification in subsequent interviews were taken after each interview was conducted. On few occasions participants started talking about important issues after the interview and recording were formally finished, in such cases the interviewer took notes.

Conducting Interviews

All interviews were conducted in the clinics, at the time convenient for the participants. Before the start of each interview it is important that the researcher develops a good rapport with the interviewee (Howitt, 2010). At the beginning of the interview the researcher made sure that each interviewee was informed about the purpose of the interview, this was done by going verbally through the information sheet (a copy of which was given to participants at the recruitment stage, see Appendix D). They were reminded that the interview would last about 30 minutes, they were also asked how much time they had available and the length of the interview was adjusted if necessary. Participants were informed that answering each question was voluntary, that they may withdraw at any time without giving an explanation and that there will be no effect on their care if they choose not to participate. They had the opportunity to ask questions about the study. All participants consented to being tape recorded by signing the first consent form (see Appendix D) and being verbally asked for permission before the interview started. At the end of the interview the participants were asked to sign the second consent form (see Appendix D) in which they were asked for permission to transcribe and use their data for analysis. They were debriefed about the study and were given the

opportunity to ask any questions. They were thanked for their time and for taking part in the study.

Developing a Rapport with the Interviewee - The researcher made sure that her use of language and her body language were appropriate and non-threatening for the participant. She maintained eye contact and was attentive to the participants. All interviews were conducted in the clinics, in the room with only the researcher and interviewee present. This was participants' choice and it appeared that all participants felt comfortable in this environment.

Length of Interviews - The first couple of interviews were short. However, the length of proceeding interviews gradually increased. Length of interview ranged from 9:02 to 34.58 minutes and the average length was 24.45 minutes.

Piloting the Study

This study was piloted with two people with LBP in order to establish comprehensiveness and clarity of questions and the exact duration of the interview. One pilot participant was a volunteer from the researcher's place of work and another was recruited from the BCOM. Only the first participant's data have been included in the analysis because the second interviewee reported having non-musculoskeletal back pain, and this could not be checked with their practitioner at the time.

Ethical Considerations

This study was approved (Appendix E) by the Royal Holloway Department of Psychology Ethics Committee (DEC). The RHI accepted DEC's decision and the BCOM's chair of research reviewed the application and agreed with DEC's decision.

Patients were reminded before the interview started that answering each question is voluntary, that they may withdraw at any time without giving an explanation, and that there will be no effect on their care if they choose not to participate. A consent form was also given to the participant to sign before the interview began. At the end of the interview the patients were asked to sign the second consent form in which they were asked for permission to transcribe and use their data for analysis. Participants were fully debriefed. Participants were also asked if they would like to receive a summary of the findings by email.

Only the researcher and her supervisor have been allowed to see participants' files, and their consent forms have been stored separately from the responses they provided. These have been kept in a locked filing cabinet at Royal Holloway, and all electronic data have been kept in a password protected computer. Participants' recorded interviews and interview transcripts were supplied with an ID number.

Data Analysis

Transcription of Recorded Interviews

All interviews were conducted and analysed by the principle researcher. The researcher transcribed 9 interviews, and the remaining 11 interviews were transcribed by a professional transcriber. Each audio taped interview was transcribed verbatim. The orthographic transcription was employed, which means that the focus was on the words that are being said and not on how they are said. This is the commonest method of transcription in qualitative research (Howitt, 2010). Additionally, only very obvious and very expressive forms of speaking and behaving were noted down, such as anger, laughter and distress. These were recorded in brackets. A sample interview transcript can be seen in Appendix F.

Coding in Grounded Theory

Coding means labeling segments of data with a concise name or label that summarizes and represents the data that it stands for. Codes should also have analytical properties to enable the development of conceptual ideas and theoretical categories for interpreting each piece of data. Codes should portray meanings and actions in participants' stories (Charmaz, 2006). Grounded theory is marked by simultaneous data collection and analysis (Glaser, 1978b; Strauss & Corbin, 1998); this enables the researcher to shape data collection to suit the emerging analysis (Charmaz, 2006).

All coding was completed by hand and Microsoft Word was used to keep record of the emerging categories and do the analysis of those. Whenever possible 'in vivo categories' (using words of the participants) were presented (Charmaz, 2006). Categories were supported by carefully chosen verbatim quotes, segments of texts from interview transcripts.

Using Comparative Methods

Constant comparative methods were used in the study to make comparisons at each level of the analysis (Glaser, 1967). First of all, data were compared with data in order to find similarities and differences. Comparisons of statements and incidents were made within the same interview and then these were compared with statements and incidents in other interviews. By using the method of constant comparison interviews were coded one by one, the second interview was coded with the first one in mind and subsequent interviews were coded with the emerging theory in mind (Glaser, 1967).

Keeping Memos

Keeping memos is an important aspect of grounded theory procedures; these capture the development of the theory. These were kept in a form of diary, where the researcher kept recording impressions, thoughts and possible relationships between the categories. These were approached as possible interpretation of data rather than definitive and final (Charmaz, 2006).

Stages of Coding

Open (or Initial) Coding - All interviews were coded, first by using 'open' or 'initial' coding; each transcript was analysed line by line in order to identify key words, phrases and eventually categories. This process continued by looking for concepts that encompass a number of more concrete instances found in the data. While doing the open coding the researcher tried to remain open minded, making sure codes are simple, accurate, short and they reflect actions (not only views of participants) (Charmaz, 2006). Codes are not definite, so they were changed and renamed as the coding advanced in order to better characterise meanings and actions emerging from the data.

After using open coding for the first two interviews, the researcher sought to identify and name participants' main concerns and possible core categories. Core categories explain the behaviour in the substantive area, and these were identified by asking the question 'What is this data a study of?' (Glaser, 1978a, p.57). After that, the researcher's supervisor examined the open coding process of the first and then of the second interview transcript and discussed with the researcher core categories and main concerns identified by the researcher. This process helped to direct theoretical

sampling and adjust the interview schedule (see Recruitment and Sampling section of this chapter).

Selective or Focused Coding - Selective or focused coding was the next stage of coding, and it means employing the most significant and/or recurrent codes to code large amounts of data. By contrast to open coding, selective coding involves restricting coding to only those categories that relate closely to the core categories (Charmaz, 2006). The data were subsumed into a core category which offered an explanation for the behaviour under study and it emerged with high frequency of mention.

Selective coding is neither an entirely independent nor linear process (Charmaz, 2006). For example, new participants and data sometimes made explicit what was implicit in earlier interviews. In such cases the researcher returned to earlier interview transcripts and explored those issues and topics again. Furthermore, simultaneously with the open coding, which involved searching for participants' main concerns and core categories; selective coding was employed in order to limit coding to those variables that were related to core categories (Glaser, 1978b). The most prominent initial codes were selected during this process and then checked against additional data. This process was examined by an independent examiner, who checked the categories developed by the researcher from the first five interview transcripts; their properties and verbatim quotes used to illustrate the categories were also examined. The examiner checked these against a sample of interview transcripts. The examiner's feedback was carefully considered and discussed with the researcher's supervisor. This process helped to establish a coding framework for the next phase of coding. It also shaped theoretical sampling.

Axial Coding - Strauss and Corbin (1990) developed a third type of coding, called axial coding, which role is to relate categories to subcategories. Open coding breaks data into separate categories, axial coding is employed to link these categories together. Axial coding analyses a category by studying its properties and dimensions. More specifically it studies conditions; these are the factors that lead the development of the phenomenon. In addition, it studies strategies that individuals carry out in order to deal with the phenomenon and their consequences (Charmaz, 2006).

Theoretical Coding - Data collection, analysis and coding were continued until theoretical saturation was achieved, at this stage the data added nothing about a specific category that was not known already, and this is the point when the theory emerged (Robson, 2002). During the entire process of coding statements were examined with the following question in mind: ‘Which theoretical categories do they represent?’ During the coding process the researcher tried to remain open and search for theoretical categories that emerged from the data rather than from an existing theoretical framework (Glaser, 1992). Theoretical categories were not treated as separate variables (as suggested by Glaser) but were intergraded into an interpretative theoretical framework (as suggested by Strauss & Corbin), which explains the studied phenomenon (see Table 3:1 for example coding, which includes all four stages of coding).

Data Triangulation

Validity of the study is discussed in more detail in the discussion section of this chapter. This is a brief summary of data triangulation in the study. The study used observer and theory triangulation (Robson, 2002). Observer triangulation was achieved by the researcher’s supervisor coding 10% of the interviews (blind to the researcher’s coding); and then by examining codes and categories (against interview transcripts) developed by the researcher; this was done throughout the coding process. Additionally, observer triangulation was achieved by an independent auditor, a health psychologist with considerable experience in qualitative research inspecting the coding process and categories developed against the interview transcripts. Theory validity was achieved by: a) returning to already analysed data to check if any instances could be found that contradict the emerging theory, b) collecting new data: five participants who reported having received a clear diagnosis were interviewed, four of these five participants experienced a prolonged period of being undiagnosed (between several months and 8 years) prior to being given a diagnosis. These cases enabled a direct comparison between absence and presence of a clear diagnosis.

Table 3:1 *An Example of Data Coding*

Data	Open coding	Selective coding	Axial coding	Theoretical coding
<p>'Yeah, I think they're a bit frustrated, 'cause I'm very very ... I was particularly, before, very sociable, like every night of the week, and every day of the weekend, I'm a big organiser, so things don't seem to happen, they don't organise, so that I've stepped out of the picture, I'm getting kind of pressure, like, are you doing this, and why aren't you doing this, and it's almost a kind of a bit of resentment in the fact that I have to kind of pace it...Cause they don't understand. I think that's the main thing. They don't know what the pain is, and for me, to keep using that, I can't come out tonight or stay out late because of my back pain, they're hearing that as an excuse that I don't mean it...' [RH4F28]</p>	<p>Thinks friends get frustrated</p> <p>Was very sociable before, not any more</p> <p>Getting pressure from friends</p> <p>Feelings of resentment from friends</p> <p>Friends don't understand your pain</p> <p>Friends think you are making excuses</p>	<p>Transformed relationships</p> <p>Skeptical others</p>	<p>Category:</p> <p>Transformed relationships- can be defined as a shift in how friends see you and how this makes you feel. It can also be defined as a shift in how LBP patients feel and behave towards other people as a result of their back pain.</p> <p>Subcategories and properties of this category:</p> <p>1st Subcategory: Pressure from friends to act the same way as before LBP started:</p> <p><u>Conditions that led to this:</u></p> <ul style="list-style-type: none"> • Change in patient's level of involvement in social activities, e.g. patient used to be very sociable before LBP, not any more • Friends don't understand your pain • Friends think you are making excuses <p><u>Consequences of this:</u></p> <ul style="list-style-type: none"> • Friends get frustrated with you • Feeling resentment from friends 	<p>Social consequences</p>

Results

Participants

Twelve participants were from an osteopathic clinic (one participant was excluded due to insufficient proficiency in English), 7 were on a pain management course and one pilot participant who fulfilled the inclusion criteria (the other pilot participant reported having non-musculoskeletal back pain, and as this could not be checked with their practitioner at the time and their data were excluded from the analysis). Therefore 20 participants' data were included in the analysis. The characteristics of the participants are summarised in Table 3:2. Because the study was qualitative these statistics are included only for descriptive purposes, and inferential statistics were not calculated. Fifteen out of 20 participants had mechanical non-specific LBP, and the remaining 5 participants had a clear cause for their pain (e.g. prolapsed disc). The information from these participants was analysed alongside the remaining 15 participants' data as part of theory triangulation. Four out of these 5 participants experienced a prolonged period of not knowing the cause for their pain (between several months and 8 years), they were asked about this period, and overall there were no apparent differences in their emerging themes. On a few occasions they were asked to make a direct comparison between undiagnosed and diagnosed state; these instances are clearly flagged in the findings.

Structure and Characteristics of the Theoretical Framework

The theoretical framework (see Figure 3:1) consists of five theoretical categories: 'lack of clear diagnosis and explanation about the back pain', 'social implications of lack of clear diagnosis', 'cognitive implications of lack of clear diagnosis', 'emotional implications of lack of clear diagnosis', and 'implication of lack of clear diagnosis on care seeking'. The structure of the framework explains how they are related to each other. Findings indicate that all categories are related, but the nature and direction of these relationships cannot be established using qualitative methodology. Theoretical categories consist of two or more first order categories. Theoretical categories are more abstract than first order categories; they

are used to conceptualise how the categories may be related and amalgamated into the theory (Glaser, 1978a).

Identification codes were used to represent the participants, these were created by using the first letter of their clinic name (R-for Real Health Institute, B-for British College of Osteopathic Medicine, P-pilot participant), followed by their participant number, gender (F-female, M-male) and age in years. For example R1F36 means that this is the first participant recruited in the Real Health Institute, female and 36 years old. Their verbatim quotes are labelled in italics.

Certain categories such as feelings of distress and inadequacy regularly appeared with several other categories, so they are reported alongside these categories rather than separately. Because research on pain-related guilt is sparse it will be analysed in relation to both perceived diagnostic status and LBP in general.

Table 3:2 *Sample Characteristics*

	Osteopathic* Clinic (N=12)	Pain Clinic (N=7)	Pilot (N=1)	Total (N=20)
Female (N)	8	5	1	14
Age (Mean/SD)	51 (17)	41 (8)	33	46 (15)
Pain >12months %	100	100	100	100
	1-2 years	8.3	14.3	10
	2-3 years	8.3		5
	4-5 years	16.7	42.9	25
	5+ years	16.7	14.3	15
	10+ years	50	25.6	45
Pain intensity (Mean/SD)	6.08 (2.58)	6.29 (1.80)	3	6.06 (2.30)
Anxiety (Mean/SD)	7.90 (4.77)	9.43 (5.09)	8	8.50 (4.67)
Depression (Mean/SD)	4.10 (1.73)	8.29 (6.90)	7	5.89 (4.76)
Disability (Mean/SD)	7.10 (4.43)	10.43 (6.21)	3	8.17 (5.33)

**Two patients from the osteopathic clinic did not provide data for depression, anxiety & disability*

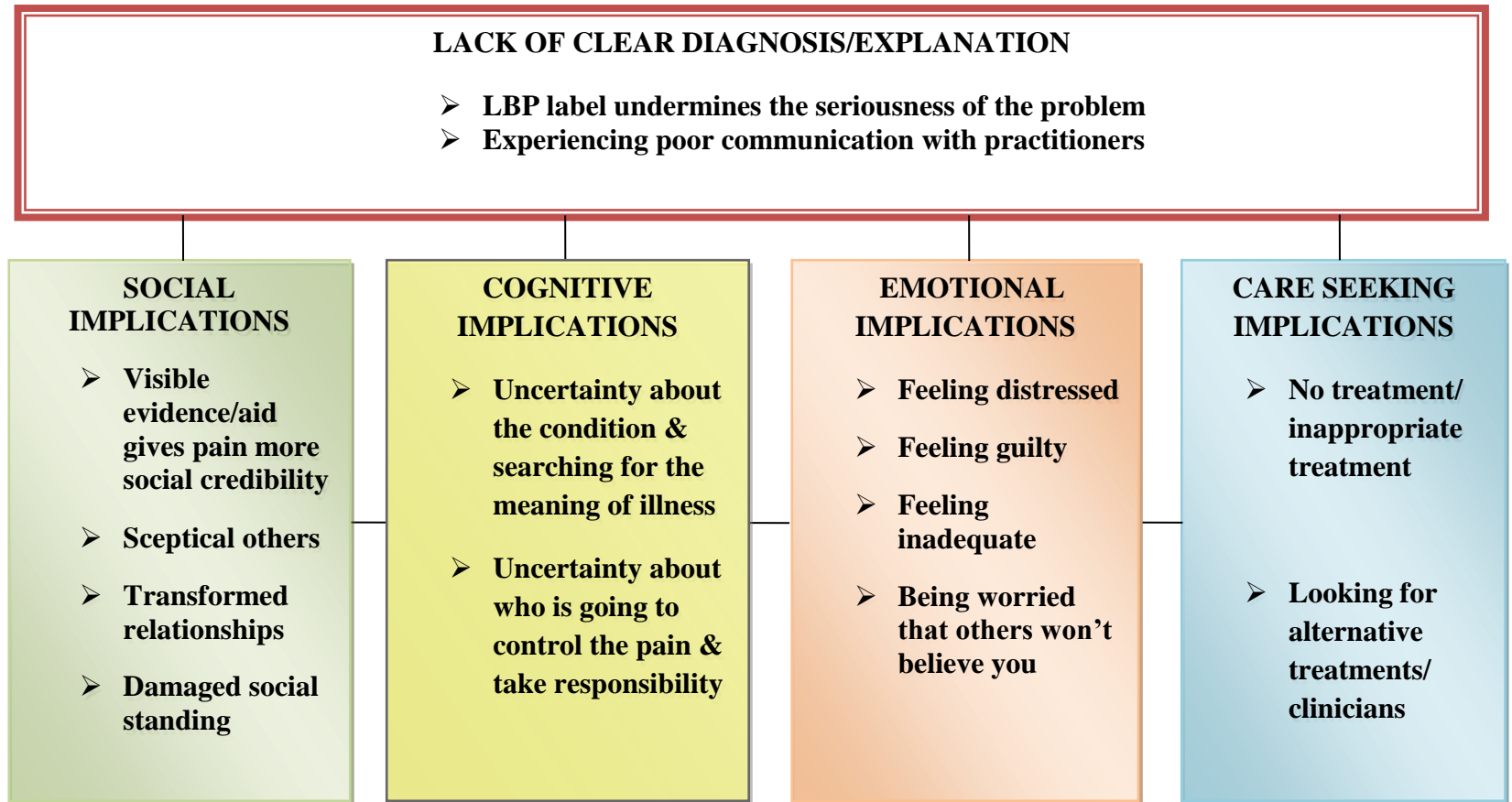


Figure 3:1 *Theoretical Framework Derived from Study 1 Interviews*

1st Theoretical Category: Lack of Clear Diagnosis and Explanation About the Back Pain

Interviews revealed that the meaning of not having a clear diagnosis can be understood as a prolonged state that is associated with how participants cope with back pain, how they perceive themselves and how they think they are perceived by others. This state does not normally come into existence in a single point of time in which the doctor is either able or unable to deliver a diagnosis to the patient; the findings suggest that this is a process characterised by a prolonged search for a diagnosis and an understanding of the experienced symptoms. This theoretical category consists of two first order categories: ‘LBP label undermines the seriousness of the problem’ and ‘experiencing poor communication with practitioners’.

LBP Label Undermines the Seriousness of the Problem

Sixteen out of 20 participants expressed concerns about their diagnostic status. Participants on the pain management programme were particularly unhappy with the LBP label and with what it represented. All seven participants on the programme expressed various degrees of dissatisfaction with their diagnosis.

None of the participants in the study defined their diagnosis with the prefix ‘non-specific’; most participants used the LBP label or just ‘back pain’ to describe their condition. Two participants reported having disc degeneration although there was no indication of this in their medical notes. Two participants used sciatica, either as their main diagnosis or in addition to the LBP label. This participant said she was not sure if she had sciatica or not; medical notes were not available for this patient to confirm this:

‘Now I say sciatica because most people recognise it’ [B7F55]

Participants’ accounts indicate that the LBP label undermines the seriousness of the problem:

‘...if I meet new people...just say I’ve got a bad back, but it’s negative anyway because you’re saying a bad back, what does that mean’ [R7M39].

It is also puzzling to practitioners:

'...cause I know the doctors and GPs and everyone kind of scoffs then, when you say those words [back pain] it means oh well we don't really know'
[PF33].

It is also assumed to be a short duration problem by others:

'I know they [new people she meets] won't understand because everybody at some time has back pain and they think it's over in days or weeks, but with mine it hasn't gone away ever, it always there. I get varying degrees of it'
[R6F39].

This indicates that in general other people misunderstand LBP and that they are not sufficiently informed about it:

'... because it's the whole system, does not lead you to kind of, um have this kind of very accurate understanding of it [back pain]' [B9F35].

The LBP label is associated by some people (even by medical professionals) with old age and acute back pain, which indicates that many people do not sufficiently understand what back pain is and how it affects people with back pain:

'...but then there is lower back pain and there is somebody bending over: ohh that's hurts and they go I've got back pain; I'm like hmmm maybe not'
[R1F36].

'I know they [new people she meets] won't understand because everybody at some time has back pain and they think it's over in days or weeks, but with mine it hasn't gone away ever, it always there. I get varying degrees of it'
[R6F39].

'Even one of the nurses said...you are a bit young for this' [R1F35].

Participants also said that their back pain is best understood by the people that suffer from back pain themselves; people who do not have back pain do not understand the nature of it:

'I've found its only people that have back pain do understand. My uncle understands totally what I'm going through. My aunt understands totally

what I'm going through because they all have terrible back pain, but other people, I just...they won't understand, no' [R6F39].

Some participants said that in general, people are not sufficiently informed about LBP:

'... because it's the whole system, does not lead you to kind of, um have this kind of very err accurate understanding of it [back pain]?' [B9F35].

'I think that's a question really that they're not...not educated enough, but they're not informed enough' [R3M54].

'I think it's understanding [of back pain that is needed]...because back pain has been one of these conditions that most people have but it's different severities...' [B14F38].

Even practitioners find it difficult to understand it; consequently no clear diagnosis can be given:

'I think it [diagnosis] was just lower back pain, and they were working on it, and they...they seemed like they didn't really wanna say in the beginning. I think I was quite inexperienced with dealing with people. I just thought they knew what they were doing. Maybe they're just not telling me stuff. But I realise now they probably didn't know very much, either way, and they were looking to put together like a picture of what was wrong with me' [PF33].

Experiencing Poor Communication with Practitioners

Participants reported several problems relating to their communication with practitioners, such as being given very little advice and being passed on from one practitioner to another:

'And I think I've seen about four different consultants by now, not one of them has offered any advice' [R6F39].

'...because the G.P.s when you go to them, they sort of just push you over to the physios, so that's how they help you [speaks sarcastically]...' [B14F38].

'...you know, it's a sausage factory going to the doctor...' [B7F55].

Participants also complained that practitioners do not take time to explain or listen to their descriptions of the symptoms and how they feel. Participants experienced this in both NHS and private settings:

'...and you feel like you're rushed, because it's only half an hour so even if they are late...' [B14F38].

'...they don't have much time [to explain]. You're in and out of the consulting rooms, even though it's private' [R4F28].

For a number of participants osteopaths seem to be an exception; they take time to explain which contributes to a better understanding of the condition:

'...it's been quite helpful being around me and having very good people [referring to osteopaths] explaining me and giving me proper advice...well to me it was a big step to understand things in a very clear and maybe in a mechanic way, like this is not happening because of that, you know? Your feeling this because of that and umm because all things kind of fall into places now' [B9F35].

'She [the osteopath] did...you know, the hour session, and wrote down what she thought it was my problem, and it was great because it was verbatim on my MRI [magnetic resonance imaging] scan, so it gave me a lot of faith in her [B8M44].

Practitioners want clear and simple explanations from patients about their symptoms. However, the participants said that they are not always able to produce them, due to the complexity of their symptoms:

'I had more problems trying to explain the kind of, the kind you know, the kind of pain I was having with the, you know, medical people, with the GP's you know [then other people]' [B9F35].

Not being able to explain their symptoms to practitioners, and not being listened to, made some participants feel 'stupid':

'...I mean it wasn't like how are you feeling and how are you coping...It was more like: okay so where does the pain go and is it piercing...a lot of, not technical, but stuff that I didn't really understand, and I tried my best to explain it, considering the pain changed a lot, and it moved around a lot. I

just felt pretty stupid because I couldn't pin point and describe my pain very well' [PF33].

Participants reported that practitioners use technical and complicated jargon, so they are often left puzzled:

'...so they tend to say there is nothing to see, it's is obviously mechanical, that's what they always say; what mechanical means you see, I don't know' [R2F46].

Participants also expressed appreciation for practitioners' use of simple language and taking time to explain:

'... [the clinician] broke it down, drew a picture and didn't use many large words, which is good...He did not know exactly what it was but it still did not matter because he was showing me, he was explaining a lot more' [R1F35]

'Yeah, so I think that even explaining with a graph, or a drawing, or even a small model, you know, that can help a lot, so like you have the thing in there, because it's so abstract, the way, you know...As long as you have visual aid in front of you...' [B9F35].

In order to understand the symptoms, the presence of visible evidence is perceived as necessary by both patients and practitioners. This indicates that the biomedical framework is used by both parties to interpret the symptoms:

'I think my doctor's very good, but on the same thing though, he's just saying oh we can't magic an MRI out of...you know, it [physical/visible evidence] should all be there...' [R6F39].

'..and in the first five years I just had back pain and it was getting worse and worse, and then with this x ray which didn't show anything so again I'm thinking what is it, it must be something...' [R2F46].

Patients approach practitioners with a belief that they could help them. This was expressed implicitly by a number of participants in the study and explicitly by one participant:

'...and I think the worst thing as well was I was given the run around 'cause you honestly believe, everybody that you go to see, is going to help you' [R6F39].

However, this can be a problem with LBP as a clear diagnosis cannot be given to such patients due to a lack of physical evidence. Being informed about the non-specificity of LBP from the beginning may help patients to lower their expectations:

'Having learnt or have learnt between now and then there is a massive difference between our perception of what can be done and what can actually be done, and how they can diagnose the pain, and fix the pain, so there's massive area in there where patients don't initially understand, so I think it should be made clear to patients, right out from the outset' [R3M54].

Making it clear to LBP patients from the outset that it may be impossible to give them a specific diagnosis may actually help patients lower their expectations and become less distressed:

'Err they (GP) explained that lower back pain in general, is a common ailment and often it's hard to put it down to a specific cause' [B13M32].

Participants reported that they are being exposed to contradicting messages from practitioners. This is a cause of frustration and confusion for the participants:

'Well umm I've only seen one physio and one consultant. I was back and forth from them. I've avoided my G.P. I've not been going back there and then what I found with seeing the physio and the consultant there's been a disagreement in treatment, so one's insisting on injection and the other is insisting I don't... so it's been like confusion I think in terms of what is best for my body, and no-one knows. I feel a bit of frustration' [R4F28].

When there is no clear explanation from practitioners, getting information outside the medical context (other people, Internet) adds to the confusion:

'...the first doctor at hospital said, I think he said something about that I'm having sciatica or something else or you just pulled something...So when I rang my mother, who is a nurse, she knows a fair bit, she goes but that doesn't sound like sciatica; so I am getting all sorts of messages...' [R1F35].

'Because it was just long winded and I think just getting one to say this is what is wrong with me, because when you read up on the internet there's so many suggestions, there's so many...it's like which one really affects me' [B14F38].

Participants also reported that practitioners ‘talk over them’ and ‘put pressure on them’. This leads to frustration and confusion. This is also linked to the ‘damaged social standing’ category (explored below):

‘He [consultant] kind of like talked over me, not to me, and everything was yes dearie, yes dearie, and every time I tried to ask him a question, it was like, no dearie, just leave it to me dearie...’ [R6F39].

‘So I said no to the consultant and he was quite insistent that that’s the thing I should do. I turned it down. But he literally has been putting pressure on me about two times, a lot of pressure, which pissed me off, because actually it’s just his opinion and what he has in his tool box...’ [R4F28].

Some practitioners create an atmosphere that discourages patients from asking questions:

‘I had a list of things I wanted to ask before I went in, then you get in there, you get down to like your kit, sometimes your underwear, and then you have to be pushed around, have your butt poked, like your buttock, and then things that are painful, all you want them to do is finish, so if you remember to ask the questions great, but usually you feel pretty intimidated and stupid, and you feel like have I done well this week’ [PF33].

Participants thought that practitioners focus more on treatment and do little listening and explaining:

‘...it [doctor’s appointment] was more treatment focused...’ [B14F38].

‘...but my experience is that I was given pain killers rather than being treated, and understanding the cause of that pain...’ [B4F62].

Poor communication does not enable patients and practitioners to share information, listen and understand each other. Several participants reported the feeling of their symptoms not being understood by their doctor, and the doctor relying on their preconceived ideas of what patients are experiencing and how they feel. This causes frustration in participants:

‘...I mean I got it to the point where I was getting very, very, very annoyed..., I mean they were telling me nothing is wrong. I was saying if nothing is wrong why I am in pain, you are not in pain for no reason’ [B2M77].

2nd Theoretical Category: Social Implications of Lack of Clear Diagnosis

Perceived lack of clear diagnosis appears to influence participants' relationships with other people and their social life in general. The analysis revealed that these problems are multiple; the ones that stood out most and appeared to be linked to participants' diagnostic status rather than just general characteristics of back pain are presented below. 'Damaged social standing' is identified as a separate category under this theoretical category (see Figure 5:1). However, its properties are in many ways closely related to the other two categories in this group: 'visible evidence gives your pain more social credibility' and 'sceptical others'. Therefore the 'damaged social standing' category is discussed in parallel with these two categories.

Visible Evidence/Aid Gives Your Pain More Social Credibility

LBP is invisible, thus hard to justify. Absence of a clear diagnosis complicates the justification of LBP further. Participants expressed a belief that visible evidence and having a concrete diagnostic label would give them more credibility, tolerance and sympathy:

'...if I broke an arm you could see it but you can't see that sort of thing [back pain]; but I could be making it up ...' [R1F35].

'...but if you had something more concrete [in terms of diagnosis] for them to go on, they'd look at you in a completely different light, like oh my God....' [R6F39].

'...if you break your leg, everybody knows what a broken leg is, so if I could say this is a back problem of some proportion, or whatever, then yeah, I would be quite happy to have that' [R6F39].

Other forms of visible evidence such as carrying a stick, telling others about being on painkillers and having positive results of serious tests (e.g. MRI scan) is another way of emphasising the seriousness of the condition and gives participants' pain more social credibility:

'...as soon as I said my MRI had come back to show my pelvis is tilted, completely different ball game, oh yes, there is actually something wrong, she isn't putting it on, so that, for me, was a great ... they're like, oh, that must be

so awful for you, well, yes, thank you very much, after this...you now believe in me and not thinking oh charlatan, trying to pull the wool over' [R6F39].

'..and of course no one outside can see what's wrong with you, well apart from the fact that now I have a stick but before that they wouldn't know, you know how bad it as, what was wrong, whatever; so that makes you even feel worse I think...' [R2F46].

'Yes, I just said [to her work colleagues] I've been in this big tube and it was really claustrophobic and they said ohh that's sounds serious' [R1F36].

One participant did not receive a clear diagnosis until an MRI scan (8 years later) showed three prolapsed discs. When asked whether having a clear diagnosis has made any difference, she said:

'Yes I think so...they have an idea of what that is, so at least it helps in that sense rather than just: 'ohh I've got a bad back'...I feel better for the fact that it sounds awful even though it isn't necessarily that bad, it's kind of stupid' [R2F46].

Sceptical Others

Lack of physical evidence and clear diagnosis presents a problem when participants need to justify their pain; participants reported feeling inadequate and being disbelieved by others, especially by their managers and work colleagues. Participants believed that a clear diagnosis was demanded and the inability to provide one made them feel like a failure:

'Yeah, there was no point [in explaining to work colleagues and managers the problem], absolutely no point because everybody else around you wants a diagnosis and when you can't give one you feel like you're a failure yourself' [R6F39].

'I wasn't happy [with GP's explanation] because I was in so much pain, from my neck, my shoulders, I couldn't walk and I kind of felt like he didn't believe me...' [R4F28].

'...and that was basically because some of the senior management basically didn't believe, so they tried to push me and I then went into total spasm...Um

they basically didn't believe I was as bad, like suffering as much pain as...'
[R5F46].

This made participants worried that they would not be believed; a consequence of this is that some participants go to work in spite of being in pain, all in an attempt to avoid scepticism and negative feelings associated with it:

'...sometimes if I take time off, and I phone to say I've got back ache, they don't tell you [that they do not trust you], but it's just sometimes when you go back to work, of how is your back, you know, did you manage to do anything... so from answers you give they will know you are just using backache as an excuse or whether you were out really sick ...why do I even have to think, when I'm sick, why do I have to go to work just to prove to them' [B14F38].

Participants reported feelings of not being believed when they need to take time off work due to back pain; they felt that in particular their managers and work colleagues expressed scepticism. The majority of participants acknowledged that they felt rather than experienced direct scepticism:

'No one actually said it but I've found like managers in particular felt that way or maybe 'really something else wrong?' [R2F46].

'I just said [to his managers] I've got this problem, that nobody seems to know what it is, so I said I'd go...we'll send you to the Occupational Health people. He said oh all you can do is go and see another specialist and see if you can get some kind of firm diagnosis for it...I don't actually think they believed me in the beginning. ..I think they just thought I wanted some time off...They didn't turn around and say, no, we think you're faking it, and you know...but you can tell by the way they behave towards you, that they don't believe you...' [R3M54]

Participants expected to be told that 'it is all in their head', and they reported a feeling of relief when other people believed and understood them.

*'It's nice to know that they believe because once you know they believe, and they understand your problems, it's like a big weight lifted off your shoulders...
'...because I was very sceptical when I came on the programme ...Cause I thought they're gonna tell me it's all in my head, and I'm a bit crazy and this*

is how to get over it, so it's nice for them to say, no, we understand, it is...there is something going on, we can't quite put our finger on it, but we know...'
[R6F39].

Transformed Relationships

Participants reported a number of issues in regards to their relationships with friends, family and other people. Participants overwhelmingly reported that they get understanding and support from family members, but their relationships with friends are more problematic. In terms of their relationship with friends, it was not always easy to distinguish between the issues that are specifically related to participants' perceived diagnostic status and absence of clear diagnosis, and those that may be related to general features of back pain. Because of the indistinctiveness of this category, participants' concerns are listed in Table 3:3.

Table 3:3 *'Transformed Relationships' Category*

Friends' responses	Participants' feelings/responses
<ul style="list-style-type: none"> • Friends don't understand your pain • Friends think you are making excuses • Friends and other people expect you should have been cured by now • Friends get frustrated with you • Pressure from friends to act the same way as before LBP started 	<ul style="list-style-type: none"> • Feeling frustrated/angry/miserable/bad that friends do not understand • Feeling resentment from friends • Do not care about what friends think and say • Letting friends down • Feeling inadequate • Not sharing feelings with friends • Avoiding friends • Will do anything to avoid disappointing friends

It is evident from Table 3:3 that a shift occurs in how friends see the participants and in how this makes them feel. A few quotations have been selected to illustrate the issues presented in Table 3.3 Some quotations illustrate participants' perceptions of friends, and some illustrate friends' beliefs and actions:

'Umm...well I think they [friends] probably think it's something that should have been cured by now. It's been going on for seven months' [R4F28].

'It [that people get frustrated when she can't do things because of back pain] makes me feel absolutely very, very frustrated, very impatient, and to the point of I just want to scream sometimes, or I just...it makes me very angry...And it makes me very frustrated and I put up a good fight I think' [B4F62].

'Well they accept and they sort of help me in a way, but sometimes when it goes on and on, they think oh you know this is going on too long you know, why don't you go to the hospital and whatever...' [B14F38].

'...friends, umm, they were okay with it you know because I used to put on a big front, yeah, I used to be...and I used to...They knew that I'd got a bad back, but not how I was feeling' [RH7M39].

Participants believed that having a clear diagnosis would change how others perceive them and that it would help them to be believed and taken more seriously:

'It would be brilliant if they had one [diagnosis], because I know they don't have one, umm, unless of course it was...unless they could narrow it down and give me something more specific, then, yes, I could go to my employer and say just so you know I need to work around this, or if I ever get sick it's because of this and it's not something because I'm not coping because my back's bad, and I haven't looked after myself, I've lifted too many heavy things, it's because I have this, and this is what it limits me with, so this is what it enables me to do sometimes, and it would mean my friends would know that I'm not being a rubbish friend because I'm being stressy and, I don't know, yes, I'd be taken a lot more seriously in many ways' [PF33].

A couple of participants said they did not experience significant problems in their relationship with friends and family:

'There is an understanding [among his friends and family]...lots of time I am not in pain so it does not matter' [B2M77].

Relationships with other people (particularly with work colleagues and managers) were also discussed by participants. The most reoccurring issues have been addressed above, under the 'sceptical others' category. Relationships with family members did not appear to be affected by a lack of diagnosis per se. However, participants expressed worries about their ability to care for their children and help their elderly parents, and about being cared for by their family:

With them [parents] it's just I can see them worry about my long term future...' [RH5F46].

These categories are not analysed further because of their seemingly minimal relevance to participants' diagnostic status.

3rd Theoretical Category: Cognitive Implications of Lack of Clear Diagnosis

Uncertainty About Who is Going to Take Responsibility and Control the Pain

Uncertainty was one of the most prominent categories in the study. Uncertainty about one's condition and its causes was reported to influence participants' relationships with others as well as their feelings, and overall it appeared to be an underlying factor for the distress they experienced:

'...I'd rather have an explanation than all this...and I felt the unknown sort of thing, I wasn't very happy with that...' [R1F36].

'It was very, very tough [being in so much pain and not being able to explain to herself and other people what really caused it], it was very depressing; I ended up extremely depressed...' [R2F46].

'You know, who's gonna take responsibility for it, if you like, who's gonna...put it in the correct direction...' [R3M54].

Having clear diagnosis means being able to control the illness and pain. To be able to identify the threat means being able to treat it and control it:

'So you know you've got this problem and this is how they're gonna fix it. That's what's in your mind' [R3M54].

'...so in my head I've got this picture of my back isn't working it needs to be fixed, it needs to go back and be fixed, I was constantly thinking and I'm still thinking now, I really do, I can't get it out of my head' [R2F46].

Not having a clear diagnosis made participants feel insecure:

'So, yes, a little set of words, a little title, would have made me feel a little bit more secure' [PF33].

Searching for the Meaning of Illness

Being able to identify the condition was important to the majority of participants interviewed in this study. There were several reasons for that: having a clear diagnosis would contribute to their well-being, and make them feel more accepting of themselves:

'...cause all I wanted was somebody to say this is it, this is what's wrong with you...and just for my own well-being, just to sort of confirm this is it, this is the problem...' [RH6F39].

Being able to identify the condition also means that there is a chance of getting better, a cure could be found and the problem fixed. Feeling uncertain about one's condition made some participants feel helpless:

'...I want answers, it can't be right to be in this position for so long, and there must be something that you can do to help me...and they did say about the nerves being shattered or pulled apart or whatnot, but to me, that wasn't good enough because I wanted to get better' [R6F39].

'Would've been much easier, much easier [with clear diagnosis]...because then at least you can say to people, right it's this, this is what we do for it and it will take x amount of time potentially to get it better or to be able to cope whatever it might be, but yes definitely' [R2F44].

'...so it's like nobody said and that's what it is and they're gonna have that and they're gonna feel better...' [R1F35].

Being able to identify the condition means that other conditions can be eliminated and they can stop worrying about it:

'I didn't get it, yeah, I wanted to be out of pain first and foremost, and then I figured that it seemed like they didn't know what they were doing, and I didn't know like what they were treating sometimes 'cause they kept going ooh, and that's interesting, and ohh, its moved there, as if it was like a surprise, so I'm like, well, what do I have then, is there something else wrong, and no, I wasn't happy, and I didn't understand what was going on' [PF33].

Participants wanted one clear diagnosis. However, it was not just about having a label, or naming their condition; it was also about what that label represents and what it means in terms of present and future care plans, their social standing and self-identity. Participants needed a label that would give a meaning to their experiences; the results show that the majority of the participants were searching for that meaning:

'...so it would be nice to just have one diagnosis and say this is what we think it is, and this is what they're going to do to relieve the pain or to help you' [B14F38].

'...I would love it if somebody said you have this, and these are the symptoms and these are the different problems that can occur, but you have this, there's none of that though' [PF33].

Managing patients' expectations about what is possible to achieve through consultations with health care practitioners appears to be one way to address this uncertainty. For instance, being informed about the non-specificity of LBP at early stages of the problem may help patients to have more realistic expectations. This category is related to the 'experiencing poor communication with practitioners' category:

'... so there's massive area in there where patients don't initially understand, so I think it should be made clear to patients, right out from the outset. So there is no big expectation that's then dropped through the hole in the middle. So...to start off with, and say: 'look it can't always be diagnosed specifically'...reduce their expectation level...and I think that'll help. Because you're not chasing these ghosts' [R3M54].

Seeking Information/Wanting Answers

Not all participants stressed the importance of having a clear diagnosis. Receiving satisfactory explanations regardless of being given a diagnosis or not is also helpful, it made the patients feel better:

'He [doctor] did not know exactly what it was but it still did not matter because he was showing me, he was explaining a lot more...Yeah I had some sort of reassurance as to say, this is what you've got but we can sort it out sort of thing, or we can go through procedures rather than...he made me feel better, yeah' [R1F35].

Participants wanted to understand what was in the background of the problem, they wanted an explanation, regardless of whether a label is provided or not.

'...yes for me it [having an explanation] was, for me it was definitely, rather than just saying the name of the disease, or the name of the problem' [B9F35].

4th Theoretical Category: Emotional Implications of Lack of Clear Diagnosis

A range of emotions that accompany other categories, or are a by-product of those, have been reported so far. For instance, participants reported feeling distressed, feeling inadequate and being worried that others would not believe their symptoms.

This section focuses primarily on the feelings of guilt because one of the aims of this study was to explore these feelings in more detail. This section describes both feelings of guilt related to perceived diagnostic status and general features of LBP. The analysis showed that feelings of guilt can be grouped into three subcategories: 'feeling guilty towards other people', 'feeling guilty towards yourself' and 'feeling guilty for not getting better'.

Feeling Guilty Towards Other People

Feelings of guilt towards other people can be split further into two subcategories: a) feeling guilty for what you cannot do; and b) feeling guilty for what you have done (actions):

a) Feeling Guilty for What You Cannot Do:

Participants reported feeling guilty for not being able to help and do things with their family and friends. A number of different situations were mentioned such as not being able to cook a meal for the family and attend birthdays and parties:

‘...you feel like you’re letting people down, like when you should be able to support yourself, you should be able to provide and go to work and be a good friend or be a good employee, then you feel guilty ‘cause you can’t and it sucks, and like this friend that they needed help or just someone to hang out, I can’t go to visit them because I ... my back’s bad and I can’t travel that day, and I know they give you support and they’re going through their own stuff, but you just can’t do it, so...’ [PF33].

‘...really guilty, and also not being able to go out, and missing birthdays’ [R4F28].

One participant reported feeling guilty for not being able to provide for his children (due to being out of work because of back pain):

‘...but I’m not working, I can’t do...I feel very guilty with my children’ [B6M34].

Some participants said they were feeling guilty towards their colleagues at work, when they are unable to go to work due to back pain. This puts extra pressure on work colleagues and results in feelings of guilty:

‘...and the pressure on my colleagues and you know you can see the stress in their faces. They have recruited a temp so that’s good to cover for the [inaudible 22:42]. That’s relieved my guilt actually’ [R4F28].

Participants also reported feeling guilty for not meeting friends’ expectations; friends expect them to be the same person as before back pain started, and they do not understand that this is not easy to achieve. Not understanding that back pain has brought about a change in their life, leads to friends failing to believe that their excuses are real. As a result participants feel guilty for disappointing their friends:

‘Why do you feel guilty for like you should be there but you can’t. Also they don’t believe that your excuse is real. You feel like you’d done something wrong and you haven’t’ [R4F28].

When friends do understand, for some participants the guilt does not disappear, they reported feeling guilty because others are trying to make allowances and be helpful.

'But then that has a knock down effect as well, that makes me feel guilty as well because they [friends] are making allowances' [R1F36].

How do patients deal with feelings of guilt related to other people? Some participants reported distancing themselves from other people because others cannot understand their situation. Other participants try to say 'no' more often and not feel bad about it, or they have learned to deal with it in their own way:

'...I've kind of given up on guilt...I think just because I got my head into a space where I just don't buy guilt any more. I've spent a lot of my life feeling guilty about one thing or another...And umm...it's just useless so I really don't go there' [B8M44].

Not all participants reported feeling guilty; about one third of all participants said they did not experience any feelings of guilt. Various reasons were put forward, such as living alone/not having a family to experiencing a different kind of feeling instead of guilt, e.g. feeling anxious rather than guilty:

'...maybe because I live alone, you know, I don't need to, you know, to, to do things for other people' [B9F35].

'... I'm a package, take me as a package, if you like the package, take the package, if you don't, don't bother. It's entirely up to you. This is how I am, this is where my life is, so, no, I don't worry too much about other people' [R3M54].

b) Feeling Guilty for What You Have Done:

Participants reported feeling guilty for their behaviour towards family members:

'Guilt, always saying sorry to everybody as if it's my fault, you know, didn't know what to say or do, just felt I was just apologising all the time. For my actions... Because they were...they [his children] said the other day that they used to come into the bedroom on a Saturday morning, when my wife She works at the weekend, for safety in numbers, you know what I mean, and that's a big, big shock like' [R7M39].

Feeling Guilty Towards Yourself (Personal Guilt)

Back pain causes disruption in participants' level of involvement in daily activities. For some participants this resulted in dissatisfaction with themselves and feelings of guilt. Back pain interferes with small daily tasks, such as doing shopping, going to the gym but also with being able to do one's job:

'...when I had these two...crises, err I couldn't do anything, even to myself, I couldn't go down to the shops, I couldn't do my work, and I had deadlines to follow, you know, so I felt like this is ridiculous, I should have been, you know? Doing something errs about this...I should....I felt guilty because I wasn't doing what I was supposed to be doing...' [B9F35].

'The guilt is big when it comes to money, and not being able to work, that's really bad, that's horrendous...' [PF33].

Feeling Guilty for not Getting Better

Some participants said they were feeling guilty for not getting better and for not being able to give a specific reason for their pain:

'Yeah, I've beaten myself up on a regular basis, why, I can't...why it's not better, why am I still getting episodes of pain, why hasn't it gone... I feel guilty that I can't tell anybody something concrete, that I cannot give a specific reason. I would have loved the doctor just to have gone that's what's wrong with you, and be happy, because then I've got something more concrete to say to everybody. I know I've got the MRI thing, but by then, it was too late, I was already in a spiral of despair and whatnot because you feel like you're getting fobbed off all the time' [R6F39].

However, when the back pain was caused by uncontrollable circumstances feelings of guilt were reduced:

'...but if any relief [from guilty feelings] because it's always been put down to my caesarean section. I always say it wasn't like I was just bungee jumping somewhere and then hurt my back' [B14F38].

5th Theoretical Category: Implications on Care Seeking

Inappropriate Treatment/Lack of Treatment

Participants reported a number of problematic issues with their treatment. Lack of diagnosis is related to lack of treatment or inappropriate treatment. In many instances participants made links between inappropriate or no treatment and absence of physical evidence and appropriate diagnosis:

'I had some x-rays, yeah, but the x-rays didn't show up anything, so I then [2 years after the problem started] was referred to a neurosurgeon...and they conducted a myelogram and that showed up a massive prolapsed disc touching the sciatic nerve and then I had the first operation' [R7M39].

'...well you have nothing too serious [GP said], there is no need for physiotherapy, there is no need for physiotherapy and things like that....well thank you very much for your time, but you know, at the time it was really needed...' [B9F35].

Participants also reported the continuation of treatment despite no improvement and/or feeling uncomfortable with it:

'I eventually got back to the physio and they just had me doing exercises that umm I wasn't very comfortable with' [B8M44].

Waiting for too long for treatment was also reported by the participants:

'... didn't really explain why I was in so much pain, and he just said I'd have to go on a waiting list which should take about two months to get physiotherapy, and he didn't have any immediate help, in the meanwhile, just told me to take some anti-inflammatories, and that it would maybe go away' [PF33].

'...and by the time I could see the GP was about 3 days after, the real crises and umm they say okay well we are going to be referring you to a physiotherapist, and it took me about two months to see the therapist...' [B9F35].

Participants said that treatment is often based on a 'trial and error' principle. This is upsetting for them:

'... [physiotherapist] just kept trying different things every time like, oh, we'll put a shoe insert or oh we'll try this, or try these exercises and see how it goes for the week, very trial and error, so it was very...it was pretty upsetting. I was happy 'cause I was getting some attention versus none, but obviously I had a lot of expectations, like they would be able to help me and make the pain go away, and they couldn't, and so they were just trying different things' [PF33].

Several participants expressed confusion with their treatment, which was often due to a lack of information and poor communication with practitioners:

'I feel I would have liked to have been able to ask more without being pushed into the injection room. I didn't feel like I was able to ask about the other therapy options and ask about that. He was a very nice guy, also, but he was very insistent about the epidural and I would have perhaps liked to have known more about why maybe the physio didn't work, or maybe...I had those questions, and would it be good to go to a chiropractitioner, and he was saying, oh, it's up to you, and I was really kind of unsure...so it's been like confusion I think in terms of what is best for my body, and no-one knows. I feel a bit of frustration' [R4F28].

Looking for Alternative Treatments/Clinicians

When current treatment does not work, participants reported looking for alternative treatments and seeing private clinicians:

'When I go to an osteopath I get looked at, and I get...it incorporates not just that specific pain, but you know, your lifestyle and also some other things, so you get even more to understanding the whole being, which is beneficial for me' [B4F62].

'I think psychologically you feel like they're here [osteopaths] more for me ... At least they make you feel like oh they care about me, not just once I'm here, but once I'm gone as well' [B14F39].

Discussion

Main Findings

This study explored the participants' perceptions of their diagnoses, the explanations they were given, their acceptance of these, and the perceived impact this had on their mood, behaviours, relationships and subsequent health care. The findings suggest that lack of clear diagnosis and lack of understanding about one's condition is associated with participants' social, cognitive and emotional functioning. It is also related to seeking further treatment. In addition, pain related guilt emerged as a major theme. Participants reported feeling guilty towards other people and themselves, and feeling guilty for not getting better. Overall, the findings suggest that a lack of clear diagnosis is associated with how participants cope and adjust to their diagnoses and their condition.

The LBP label was not perceived by many participants as a legitimised medical condition and they said that it undermined the seriousness of the problem. However, the problem cannot be simply defined as presence or absence of a clear diagnostic label; although the majority of participants indicated they wanted a clear diagnosis, it is a problem that encompasses much more than the mere absence of a clear diagnosis. An overarching theme in all the interviews was 'diagnostic uncertainty', which participants experience and have to deal with on a daily bases. They are uncertain about their diagnoses, about the meaning of their pain and condition, about its cause, their treatment and future prospects. Above all, they frequently contemplate whether there is something else going on with their pain that the doctors have not found yet. Participants spend much time and effort trying to understand their diagnoses and condition; they invest themselves in this process. This finding is significant, because the ability to find meaning is an important cognitive process and is an essential component of psychological recovery from stressful health related events (Taylor, 1983).

The findings therefore indicate that uncertainty and a conceptual search for the meaning of the condition are commonly experienced by LBP patients. The aim was to construct a simple categorisation that is straight forward to use in large samples and that is easy to understand and not confusing for participants. The perceived diagnostic status categorisation addresses three key aspects: a) patient's

perception and understanding of their diagnosis, and their agreement with this diagnosis; b) patient's perception and understanding of the explanation given by practitioners about why they have back pain, and their agreement with those; c) patient's (un)certainty that the diagnosis and explanation given provide them with acceptable understanding of their condition and that there is nothing else undiscovered going on. This last question addresses 'diagnostic uncertainty' which is, as discussed earlier, an overarching finding in the study. The first two questions can therefore be perceived as sub-questions or sub-components of the diagnostic uncertainty question.

The initial categorisation consisted of the following questions:

We are interested in what you think about your diagnosis for BACK PAIN. Please select either YES or NO answer.

a) I have been given a clear label/diagnosis for my back pain YES/NO

If YES:

Generally speaking, I agree with this label/diagnosis YES/NO

b) I have been given a clear explanation about why I have back pain
YES/NO

If YES:

Generally speaking, I agree with this explanation YES/NO

c) I think there is something else happening with my back which
the doctors have not found out about yet YES/ NO

This categorisation was slightly expanded later: in addition to the initial question, participants who said they were given a clear diagnosis for their back pain were also asked: a) what diagnosis they were given; b) who gave the diagnosis/explanation; and c) whether this diagnosis/explanation was given by the NHS or privately. These questions were asked in order to gain some understanding

of which LBP labels participants see as clear diagnoses and which practitioners are better at providing them.

For the majority of participants, their label provided a poor fit with their experience of the condition. This is important, because such a fit is necessary for acceptance of the diagnosis (Madden & Sim, 2006) and consequent adherence and care seeking. Additionally, it can be difficult to direct attention to non-pain aspects of life if one does not accept the presence of pain. Acceptance of pain is characterised by a willingness to have pain or other uncomfortable private experiences, and this has been linked to better function in several studies (McCracken & Vowles, 2006). The question these findings pose is whether acceptance of pain is possible in the absence of an acceptable diagnosis or explanation, and before the very identity of the pain and its causes is accepted?

The study also examined pain-related guilt in the context of unclear diagnosis and evidence for back pain and LBP in general. The analysis showed that feelings of guilt can be grouped into three subcategories: 'feeling guilty towards other people', 'feeling guilty towards yourself' and 'feeling guilty for not getting better'. Participants constantly struggle with their pain, and their distress and suffering made them feel guilty about their relationships with other people. Some participants reported feeling guilty for not getting better and for not being able to give a specific reason for their pain. When physicians cannot locate the problem, or express doubt about the cause of the problem, some participants feel that their pain is disconfirmed. Low back pain patients often report feeling that their pain is delegitimised (Hopayian & Notley, 2014; Rhodes et al., 1999) and feeling guilty for 'letting the doctor down' (Rhodes et al., 1999). Overall, these findings suggest a link between pain-related guilt and unknown aetiology/lack of physical evidence, although this should be confirmed by comparing reported guilt in pain populations with a clear diagnosis and physical evidence.

Pain-related guilt has not been specifically studied in relation to pain and disability in previous research; the findings of this study will therefore enable a construction of a pain-related guilt scale which will allow an examination of this relationship. The development and validation of this scale will be reported in Study 2 and Study 3 of this thesis, which will also provide a more in-depth discussion of pain-related guilt, in the context of both diagnostic uncertainty and LBP in general.

Diagnostic Uncertainty and (Perceived) Disbelief and Stigmatisation

Being worried about having one's symptoms disbelieved and being stigmatised was a recurring category in the interviews; this worry had perceived impact on participants' feelings and behaviour, such as going to work in spite of being in pain and avoiding discussing their pain with others, and it also made them feel guilty. This is in line with research described in Chapter 2 which reported that LBP patients regularly feel stigmatised due to the absence of clear physical evidence for their pain (Hopayian & Notley, 2014; Newton et al., 2013; Rhodes et al., 1999). When no physical evidence can be provided, a (stigmatising) psychological reason is often put forward as a plausible explanation by practitioners. Two types of stigma have been identified by Newton et al. (2013)'s review, felt and enacted stigma. Felt stigma refers to the fear of being stigmatised, while enacted stigma refers to the acts of discrimination experienced by persons who cannot provide physical evidence to justify their pain experience. In the present study, evidence of both felt and enacted stigma were found. For instance, the 'suspicious others' category encompasses both of them; it provides examples of explicitly expressed disbelief by other people, as well as participants' perceptions of other people's apparently stigmatising beliefs and judgements about their symptoms.

The findings also showed that in the absence of a clear diagnostic label and explanation about their back pain, participants put in immense effort in justifying their pain experiences and convincing practitioners and other people (especially work colleagues and managers) that they were not malingering. Participants' perception that others think they malingering is in line with findings from other studies, for instance Rhodes et al. (1999) explored the meaning of diagnostic tests for people with LBP, and found that in the absence of positive test results, many patients felt that practitioners did not believe their accounts of pain.

How do disbelief and attached stigma affect LBP patients? It appears to relate to conflicting emotions in the participants, including resentment and a sense of isolation. Participants found it difficult to meet social expectations and obligations, which in some participants appear to lead to withdrawal. This is in line with the findings from a systematic review by Newton et al. (2013) and a recent review of

forty two qualitative studies of people's experiences of non-specific LBP (Froud et al., 2014).

Diagnostic Uncertainty and Doctor-Patient Communication

When definitive diagnosis for LBP cannot be established it is sometimes described by practitioners as a consequence of somatisation, thus it is perceived as a product of mind rather than injury or degeneration. This may create tensions between patients and practitioners; without visible evidence patients may be confronted with doubt about their symptoms (May et al., 2000). The present study revealed that practitioners' doubt was in most cases expressed implicitly rather than explicitly, therefore participants expressed perceived scepticism.

Participants consistently reported that having visible evidence, such as MRI scan or x-ray positive results, actually serves as a long awaited proof of their symptoms. However, in most cases such tests are negative, and most guidelines now recommend that clinicians should not carry out testing for non-specific LBP. Research on diagnostic approaches for LBP that has centred on finding biological causes has been recently scrutinised. For instance, the use of early MRI scans has been employed as a means of providing earlier diagnosis and treatment, or reassuring LBP patients. However, it appears that this leads to an increase in unnecessary surgery and perceptions of poor health (Turner et al., 2008) and National Institute for Health and Clinical Excellence (NICE) guidelines for LBP in the UK now advise against carrying out x-ray and MRI tests (National Institute for Health and Clinical Excellence, 2009). Nevertheless, if not properly reassured about their pain, patients may misunderstand practitioners, mistrust them and seek further care and examinations (Linton, McCracken, & Vlaeyen, 2008). The present study findings suggest that many participants appeared to be in disagreement with their practitioners and they experienced problems in communicating their symptoms to practitioners, for instance they felt that were not listened to and that practitioners often did not understand or misinterpreted their descriptions of the symptoms. Participants said that treatment is often based on a 'trial and error' principle and reported the continuation of treatment despite no improvement and/or feeling uncomfortable with it. Findings also suggest that the information participants received from practitioners

was often conflicting, and this added to the confusion and uncertainty about their condition. This supports findings from other studies, such as McIntosh and Shaw's (2003) qualitative study who found that many LBP patients were dissatisfied with the information they received from their GPs about their diagnosis and treatment. They also found that GPs consider LBP patients having unrealistic beliefs and expectations about their back pain, for instance they may believe they have a disc lesion or they need an x-ray and other unnecessary examinations. It is not uncommon for LBP patients with absent findings to use other LBP diagnostic labels, such as degenerated disc, disc prolapse and trapped nerve (Waddell, 2004). Findings from the current study support this view; some participants believed they had degenerative disc disease or sciatica, although their medical notes did not confirm this. Such cases demonstrate a need to have a label that indicates real damage and the need to get fixed (Waddell, 2004). Additionally, a recent systematic review of LBP and sciatica patients' experience of health services found that personalisation and communication are important to patients with LBP (Hopayian & Notley, 2014). Practitioners should take into consideration the strain patients face when trying to provide illustrations of their pain; and in order to avoid being blamed for complaining, patients need to make sure these are sufficient but not exaggerated descriptions of their pain (Newton et al., 2013).

Some participants in the present study found it hard to understand practitioners' explanations about possible causes of their problem, this is line with the findings from Barker, Reid, and Lowe (2014)'s study which concluded that simplifying information for patients, avoiding complex medical jargon and checking understanding are essential to improve communication with patients.

An innovative study (Padfield, Janmohamed, Zakrzewska, Pither, & Hurwitz, 2010) was conducted in which photographs were used in pain consultations in order to establish whether visual images may help in understanding the personal experience of pain, and whether they may enhance doctor-patient communication. Patients were asked before their consultation to choose pain images which had represented their pain experiences and use them to describe their pain during the consultation. The photographs were not accurate images of different types of pain, but represented an array of pain features, such as temperature and sensation. The

outcome was that patients' pain experience was made more realistic and was better communicated (Padfield et al., 2010).

Additionally, findings from the present study suggest a misunderstanding and lack of communication between patients and practitioners, and that managing patients' expectations from the onset may help address this problem. Participants said that practitioners should provide much clearer and more detailed explanations, and advise patients that a definitive cause and diagnosis may not be possible to establish.

In summary, the findings from this and other studies suggest that poor communication and disagreements with practitioners are associated with distress in LBP patients. The above described responses from LBP patients should be seen as reasonable reactions to ambiguity that surrounds LBP. Patients' reactions should be taken seriously and an understanding of those is important for their recovery (May et al., 2000).

Interpretation of the Symptoms: Biomedical vs. Biopsychosocial Model of LBP

Participants believed that the pain had to be located in their bodies, not their minds; they believed that visible evidence was necessary and expected by others in order to justify their pain. Thus, it appears that the cause of this belief should not be located with the patient but the medical belief system that operates in society. It seems that many health care professionals stay faithful to the biomedical model, and as shown in a systematic review of evidence by Darlow et al. (2012), this is largely because they lack due time and training.

For practitioners, the failure to find an organic cause of the symptoms presented by the patient, and the failure of the implemented treatment to resolve the pain, often means that the pain must be a product of somatisation (Kenny, 2004). Therefore, they often use a psychogenic model to interpret the symptoms. However for patients, the same failure is understood as a deficiency of the doctor to find an organic cause and treatments and resolve the problem; this interpretation is based on the biomedical model (Kenny, 2004). Kenny's (2004) findings show that both doctor and patients 'were strongly invested in their positions, because to be otherwise would imply a failure of their respective roles of expert physician and good patient' (p.303).

Patients do not want to be classed as psychological cases and keep looking for evidence of biological or biomechanical malfunction. May et al. (2000) suggest that patients may be correct; their pain is normally a result of some biomechanical dysfunction, at the initial (acute) stage of the condition. There is also possibility that it may be a result of activity within the central nervous system. All of this puts extra pressure on practitioners to find a biological cause, and if unable to provide it, practitioners may use psychogenic causes to explain the invisible pain; which often stigmatises the patient (May et al., 2000).

Patients with no visible proof of pain normally deal with the situation in two ways; they either abandon self-respect and social acceptance; or they abandon medicine and turn to unconventional approaches which are approving of their beliefs and understanding of their pain, and they may assist the patient in legitimising the pain (Kenny, 2004). Participants in the present study who were recruited from an osteopathic clinic reported greater understanding from osteopaths, better communication and overall satisfaction with the treatment. Abandonment of self-respect and social acceptance are also evident in the findings, and in most cases were expressed by the participants on the pain management programme. They reported feeling inadequate and socially inapt due to the diagnostic uncertainty they had to face. Perhaps this is not too surprising as pain management programmes are usually the last avenue for many LBP patients (Last & Hulbert, 2009); it indicates that there are no other medical options and a change in beliefs and behaviour is needed.

Overall, the findings suggest that a shift in thinking about LBP is needed, not only within medicine but at societal level as well. The biopsychosocial model may be the best model so far, but its application by practitioners is to some extent controversial. Interactions between practitioners and patients should not rely on the biomedical model and should focus on the meanings of pain to patients (Kenny, 2004).

Clinical and Theoretical Implications

The findings show that participants invested themselves heavily in a search for biological causes of their condition. However, these efforts are often in vain, as such causes can rarely be found by modern medicine.

There is substantial evidence from this study and others that it is important to take LBP patients' responses to diagnostic uncertainty seriously and the next step should be to examine what could be done about it. The findings could be interpreted to suggest that there is a need for a clearer labelling system for musculoskeletal conditions with no apparent biological origin, and for a label that will give a new meaning to LBP and distance it from the current stereotypical view. However, the labelling issue is clearly problematic, for instance it is been debated that providing labels which indicate biological origin for conditions that do not seem to have one may strengthen the individual's belief that s/he is ill and encourage disability (Ehrlich, 2003). Instead, it is important to search for more helpful interactions between practitioners and patients that do not depend on the presence or absence of visible evidence (Darlow et al., 2013; Darlow et al., 2012; Hoffmann, Del Mar, Strong, & Mai, 2013; Kenny, 2004). The findings of this study provide supporting evidence to this view: diagnostic uncertainty encompasses much more than absence of a clear diagnosis; it incorporates lack of understanding of one's condition and symptoms, uncertainty about their origins, uncertainty about the pain management and the future in general. The current study's findings show that it is a state which is associated with emotional, social and cognitive functioning of LBP patients, and each of these aspects should be taken into consideration and addressed in consultations. Therefore, although the findings encourage practitioners to consider the importance of diagnoses and labels in LBP, above all they encourage practitioners to provide better and more acceptable explanations and consider the impact of those on patients. Some participants explicitly stated that they want clearer explanations about their pain and some even said that these are more important to them than clear diagnosis. This is supported by the findings of another qualitative study in which participants also stressed the importance of clear explanations about their pain (Dima et al., 2013). However, this may present a challenge to practitioners as currently there is no consistency and no clear guidelines for delivering diagnoses, explanations and reassurance for LBP.

Many participants reported feeling guilty and further research should examine if pain and diagnosis-related guilt is associated with mood and disability. Its relationship with depressive mood should be examined in order to establish if it is a feature of depression or perhaps an independent psychological factor. This may have implications for refining therapies, such as Cognitive Behavioural Therapy (CBT) by targeting specific emotional states and cognitive processes. Refining CBT to suit specific groups of patients is one of the most important priorities (Eccleston, 2001). But most importantly, pain-related guilt could also be explored, acknowledged and to an extent addressed during consultations.

The interviews also revealed that participants were highly aware that the public opinion and attitudes towards LBP also need changing. Re-education of the public about LBP has been suggested in other studies such as Link and Phelan (2001) who suggest that the deep-seated causes of stigma in society should be somehow addressed; these include attitudes and beliefs that lead to stereotyping.

However, health care is not only the result of doctor-patient interaction; proper pain diagnosis and management call for the joint efforts of both health care providers and health care organisations (Bertakis, Azari, & Callahan, 2004). Overall, current diagnostic system for LBP has limitations; it consists of diagnostic entities that do not provide sufficient explanations and treatment (Dankaerts & O'Sullivan, 2011), and the findings of this and similar studies could help reassessment of the current regulations. This could result in a reduction of suffering and distress in patients with LBP.

In terms of theoretical implications, apart from the theoretical framework that has been developed from this study, the findings also provide a basis for two categorisations/scales (perceived diagnostic status and pain-related guilt) which will be used in the further four studies of the thesis to test aspects of this theory. Study 2 and Study 3 will focus on the development and validation of the pain-related guilt scale; Study 4 will be testing causal relationships between diagnostic uncertainty, pain-related guilt, mood and disability; finally Study 5 will examine cognitive mechanisms underlying the relationship between diagnostic uncertainty and mood and disability in LBP. The findings of these studies should also shed some light on the relationship between pain-related guilt and depression and provide initial

evidence of whether pain-related guilt is an independent factor or a feature of depression.

Strengths and Limitations

This section addresses strengths and limitations of the study, and at the same time it provides a reflective analysis of how the research was conducted and of how this might have influenced participants' responses.

To the author's knowledge, this is the first study that carried out an in-depth exploration of pain-related guilt in LBP patients. A methodological strength of the study is that great care was taken to carefully tailor and justify every step of the analysis according to already well developed strands of grounded theory. Validity and reliability of the study are discussed in more detail next.

There are various ways to ensure the threats to validity are minimal in qualitative research. Triangulation is a strategy to confront threats to validity. Three types of triangulation have been used in this study; observer, methodological and theory triangulation (Robson, 2002). Observer triangulation was achieved by the researcher's supervisor checking coding of the interviews, throughout the coding process by first of all, doing her own coding of 10% of the interviews (blind to the principle researcher's coding); and then by examining codes and categories (against transcripts) developed by the principal researcher, this was done throughout the coding process. Additionally, observer triangulation was achieved by asking an independent auditor at the Department of Psychology, in Royal Holloway to inspect the process of coding by examining a sample of the interviews and the coding. The independent auditor was a health psychologist with considerable experience in qualitative research; her insights helped to open new possibilities for the interpretation of data and challenged the existing interpretations. The latter also contributed to theoretical triangulation, which refers to the use of various theories and perspectives in the analysis and interpretation of data (Robson, 2002).

The threat to theory validity is a failure to take into consideration alternative explanations and theories to explain the phenomenon being investigated. One way to prevent this is to look for negative cases/evidence, that is, to look for new or already collected data which is not in line with the emerging theory. This method was used in

the current study; a small number of participants in the study did not report experiencing distress or many negative consequences of diagnostic uncertainty. This method it is a good way to reduce researcher bias and often leads to a more developed version of the existing theory (Robson, 2002). Methodological triangulation will be addressed and achieved in the further four studies of the thesis, which will utilise quantitative methods to validate the pain-related guilt scale, and test hypotheses generated from this study.

Additionally, the study ensured that valid descriptions and interpretations are used, which are two important aspects of validity in qualitative research (Maxwell, 1992). A valid description of what has been observed should be provided and the threats to this type of validity are inaccurate and incomplete data. All interviews that were carried out in this study were audio recorded and transcribed verbatim. Valid interpretations of what has been observed are also necessary and the threat to this type of validity is in imposing an already established framework or meaning to the data, instead of this emerging from the data. This could be prevented by constantly checking and justifying the analysis and interpretation process. This study employed a transparent process of coding, which involves specific stage-like analysis and interpretation. This means that final categories and theories can be traced back to their roots by checking stages of the coding process.

In quantitative research, reliability is verified by checking the measures that are being used. However, qualitative research does not employ scales or other types of measurements (Howitt, 2010). In qualitative research, the concept of reliability applies only to some aspects of conducting the research, such as uniformity of transcriptions between transcribers (Howitt, 2010). In this study the transcription process was undertaken by the principle researcher and a professional transcriber, this is discussed in the analysis section of this chapter. It also means being meticulous and honest in conducting the research and demonstrating to others that you have been. This can be achieved by keeping a record of all stages of the research, including the raw data, memos and details of coding (Robson, 2002). The researcher has kept all of those.

The study has several limitations. As the inclusion into the study was limited to persons on the pain management programme and undergoing osteopathy treatment, the findings may not generalise to other LBP populations. For instance,

patients who manage their pain on their own or undergo other types of treatment were not included. However, the participants and their pain characteristics were sufficiently varied to represent LBP patients with various levels of disability, pain duration, intensity and age. In regards to gender there was a greater number of female than male participants (14:6) (Chenot et al., 2008), although there were no apparent differences in their answers to the interview questions.

In addition, the small sample of volunteers who agreed to be interviewed may have been subject to other biases. Future research should test the developed theory in large and diverse samples of LBP patients. It should be acknowledged that participants' accounts may be constructed through social processes and demands of the situation. Most importantly, the findings are limited to participants' perception and their own interpretation of their experiences. Exploring any link, especially causal, between receiving and accepting diagnostic labels and subsequent clinical status and health-related behaviours must be explored quantitatively and prospectively in appropriately large samples.

Conclusion

The interviews revealed that participants consistently experienced intrapersonal, interpersonal and social difficulties as a result of diagnostic uncertainty. The findings indicate that at least some LBP patients invest heavily in a search for biological causes of their condition, as such causes can rarely be found. Participants reported that they do not want to be classed as psychological cases and that they keep looking for evidence of biological or biomechanical malfunction. Their narratives suggested that many participants experienced difficulties as a result of the lack of understanding and acknowledgement of their suffering by practitioners and other people. They often experience a sense of guilt about their pain-related behaviour, and this may be linked to their perceived diagnostic status. The findings seem to suggest that diagnostic uncertainty is associated with how participants manage their back pain. However, this cannot be concluded based on qualitative methodology alone and further research is needed.

Overall, diagnostic uncertainty experienced by LBP patients poses a challenge to clinicians and further emphasises the importance of appropriate

communication, reassurance, and clear and acceptable explanations that may replace diagnoses based on physical evidence.

Chapter 4

Pain-Related Guilt in Low Back Pain: Exploratory and Confirmatory Factor Analysis of the Pain-Related Guilt Scale

Abstract

The findings from Study 1 suggest that diagnostic uncertainty is associated with feelings of guilt in low back pain (LBP). Examining the nature of this relationship and associations between guilt and clinical measures such as mood and disability, requires further investigation using quantitative methodology. Unfortunately, research on pain-related guilt is scarce, and reliable instruments to measure it are not available. Study 2 and 3 of the thesis addressed this gap by developing and testing a pain-related guilt scale (PGS). The studies used two different statistical procedures and two different samples of participants, although certain aspects of the newly developed scale were tested on the combined Study 2 and 3 samples. In both studies participants with LBP completed the scale and provided data on rates of depression, anxiety, disability and pain intensity. In Study 2 three factors were identified using exploratory factor analysis (N=137): ‘social guilt’ (4 items) relating to letting down family and friends; ‘managing condition/pain guilt’, (5 items) relating to failing to overcome and control pain; and ‘verification of pain guilt’, (3 items) relating to the absence of objective evidence and diagnosis. This factor structure was confirmed in Study 3 using confirmatory factor analysis in a new sample (N=288), demonstrating an adequate to good fit with the data. The PGS subscales positively correlated with depression, anxiety, disability and pain intensity. After controlling for depression and anxiety, the majority of relationships between the PGS subscales, disability and pain intensity remained significant, suggesting that guilt shared unique variance with disability and pain intensity independent of depression and anxiety. High levels of guilt were reported by over 40% of participants. The findings suggest that pain-related guilt is common and is associated with mood, disability and pain in LBP. The PGS is a reliable and valid measure of pain-related guilt.

The work presented within Chapter 4 has been published in the *Clinical Journal of Pain*:

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Introduction

Guilt is a common psychological factor (Tilghman-Osborne et al., 2010), but its role in LBP, and pain in general is poorly understood and researched. The findings from Study 1 (reported in Chapter 3) suggest that pain-related guilt is experienced by LBP patients who are uncertain about their diagnosis. It was found that the participants experienced feelings of guilt in relation to other people (e.g. partaking in social activities), in relation to themselves (e.g. doing daily tasks) and in relation to their pain management (e.g. for not getting better). These findings are in line with past studies (Hochwarter & Byrne, 2010; Ohayon & Schatzberg, 2003; Rhodes et al., 1999; Snelgrove et al., 2013) which found that guilt is experienced by chronic pain patients, but such studies are rare and they did not focus on pain-related guilt specifically (see Chapter 2 for a review of these studies).

In order to examine the relationship between pain-related guilt and different clinical measures in LBP it is necessary to use a valid and reliable measure of pain-related guilt. However, such a measure does not currently exist, and so the primary aim of Study 2 and 3 was to develop a measure of pain-related guilt.

A secondary aim of Study 2 and 3 was to begin to understand the relationship between pain-related depression and pain-related guilt in LBP. Low back pain is a leading cause of disability worldwide (Lim et al., 2012), and prevention of the transition to chronic states of pain depends on identifying predictors of long term disability, and intervening to change them. Research has been successful in identifying several psychological predictors of poor outcomes, notably depression (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Pincus et al., 2002) (see Chapter 2 for a review of key predictors). However, it focused primarily on key or overarching psychological predictors, and paid little attention to an array of other, less recognised factors (Foster et al., 2010; Pincus & McCracken, 2013), such as guilt. One key psychological factor is depression, and despite the robust evidence for an association

between depression and poor outcomes in LBP, the focus of depression in the context of pain remains poorly understood (Morley et al., 2002; Pincus & Morley, 2001; Rusu et al., 2012). This is to an extent due to the lack of understanding of what constitutes depression in chronic pain. A neglected aspect of pain-related depression, which appears to be prominent in the conceptualisation of clinical depression, is guilt (A. T. Beck et al., 1961).

The lack of conceptual clarity and measurement in reference to guilt has been highlighted in a systematic review of research on the role of guilt in psychology (Tilghman-Osborne et al., 2010), which suggests that guilt is conceptually different from concepts such as anger, shame and blame (see Chapter 2). This thesis adopted a pragmatic approach to studying pain-related guilt, and as such it focused on people's individual understanding of guilt as a psychological process, rather than an examination of guilt as studied and understood within non-psychological domains, such as philosophical and sociological. As a psychological process, guilt includes both emotional and cognitive aspects (Kubany & Watson, 2003), such as negative self-regard and painful feelings due to hurting other people. In depression, guilt is conceptualised as a perception of oneself as harmful to others, which results in attempts to minimize contact with others, or in becoming submissive to others' needs above one's own (O'Connor et al., 2002). Although guilt is commonly linked to depression, Study 1 findings seem to suggest that guilt in chronic pain extends beyond depression, and that the focus of guilt in groups with pain appears to be different from that of clinically depressed groups. Findings from other studies also show this, for instance, guilt has been found to exacerbate the effects of chronic pain on job dissatisfaction and tension (Hochwarter & Byrne, 2010). In a different study LBP pain patients reported feeling guilty for disappointing their practitioner (Rhodes et al., 1999). Crucially, Study 1 findings indicate that LBP patients associate guilt with their inability to provide evidence and a convincing diagnosis to justify their pain.

Overall, Study 1 findings suggest that guilt is an important factor that contributes to suffering. Therefore, examining if diagnostic uncertainty contributes to patients feeling guilty, and furthermore, examining the impact of such guilt on clinical measures such as depression, anxiety and disability, in large samples and using quantitative methodology is of primary importance. The relationship between

guilt, other known obstacles to effective coping, and long term outcomes in LBP remains unknown, and the investigation of predictive, moderating and mediating mechanisms is hindered by the absence of reliable and valid measures of pain-related guilt.

Study Aims

- a) Preliminary work (Study 1) to this study consisted of the identification of relevant themes from transcripts of semi structured interviews with LBP patients. The extracted themes will be used to derive items for a pain-related guilt scale (PGS).
- b) It will be examined if the PGS has a sound, parsimonious, and interpretable factor structure for use in the assessment of pain-related guilt in LBP.
- c) This structure will then be statistically validated in a new sample of LBP participants.
- d) Further validation of the PGS will be carried out by examining if it correlates with measures of depression, anxiety, disability and pain intensity.
 - a. Within the last study aim, due to the known link between depression and guilt the relationship between pain-related guilt and depression will be more closely scrutinised.

Methods

Participants

Study 2 participants (N=170) were recruited online and were members of three self-help groups for back pain (Back Care Charity, Chronic Back Pain UK Facebook group and Pain Support group). The use of online data is relatively common in pain research (Fish, McGuire, Hogan, Morrison, & Stewart, 2010; Johannes, Le, Zhou, Johnston, & Dworkin, 2010)

Study 3 Participants (N=322) were presenting for assessment and/or treatment in the British College of Osteopathic Medicine (BCOM) clinic (N=224) or were recruited at an annual Back Pain Exhibition (N=98).

Inclusion criteria in Study 2 and 3 were that participants be over the age of 18 years and have musculoskeletal LBP. No limit was imposed on pain duration and current pain intensity. Participants with non-mechanical back pain due to ankylosing spondylitis, osteoporosis, cancer and inflammatory conditions such as rheumatoid arthritis were excluded. The study received ethical approval from the university research ethics committee (see Appendix E) and BCOM accepted this decision. General ethical procedures were identical to those described in Chapter 3.

Materials and Procedures

Study 2

Participants were invited to take part in the study through the three self-help groups for back pain which hosted a link (see Appendix G) to the study questionnaire. Clicking on the link first opened the study information sheet (see Appendix H). By selecting 'continue' option (at the bottom of the information sheet) participants agreed to take part in the study and the questionnaire (see Appendix I) was presented to them. The questionnaire took approximately 15 minutes to complete and participation was anonymous. The questionnaire was presented using an online survey tool (SelectSurveyASP Advanced v8.6.4). It recorded the computer ID that each participant used to access the survey, and it did not allow completion of the questionnaire from the same computer more than once. Participants completed the study questionnaire between May and November 2011.

Study 3

Participants were given a paper and pencil version of Study 2 questionnaire, and they completed the questionnaire between May 2011 and December 2011. Questionnaire packs were left at the BCOM clinic reception and included an information sheet, consent form (see Appendix J), study questionnaire (see Appendix I) and postage-paid return envelope. The questionnaire took approximately 15 minutes to complete and participation was anonymous. A response box was placed in the clinic's waiting room for those participants who opted to complete the questionnaire while waiting for their appointment. In addition, when convenient, the researcher (author of this thesis) handed out questionnaire packs to patients who were waiting for their appointment in the clinic's waiting room.

The questionnaire packs were also handed out to the visitors of the 2012 Back Pain Exhibition in London on the 25th of February 2012, who could either post the completed questionnaire back or leave it in the response box provided. Passing visitors were asked if they had LBP and if they would like to take part in a brief anonymous survey. The questionnaire used at this exhibition slightly differed from the online and BCOM questionnaire; it was shorter (The Hospital Anxiety and Depression Scale was not included) in order to decrease the time required to complete the questionnaire and increase response rate (the main aim in this point of time was to increase sample size for the validation of the pain-related guilt scale (PGS))

Pain-Related Guilt Scale

The pain-related guilt scale was the primary measure under investigation. Items in the PGS were informed by the findings of Study 1. Transcripts were analysed using a grounded theory method, and resulted in three broad themes: ‘feeling guilty towards other people’, ‘feeling guilty towards yourself’ and ‘feeling guilty for not getting better’ (refer to Chapter 3 for theme contents). These themes provided bases for a pool of approximately 40 items constructed by the researcher. These items were discussed with the researcher’s supervisor in order to receive feedback and to check that the items truly reflected Study 1 interviews. After detailed discussions the scale was reduced to 24 items (see Table 4.2). It was ensured that all remaining items were not repetitive, represented a variety of participants’ responses and were as close as possible to the theme contents. For instance, many actual examples that participants used to describe their feelings of guilt were incorporated in these items (e.g. item 2 refers to an aspect that participants said made them feel guilty ‘About not being able to attend important events’).

In line with recommendation for methodological assessment (Furr, 2011; Robson, 2002), the following criteria were applied during the scale construction. It was ensured there were no overly sensitive and double-barrelled items (items addressing more than one issue). The scale was piloted: it was checked for face validity and appropriate wording by four people with LBP. These pilot participants provided valuable feedback in terms of item content and their wording, for example, many initial items started with this wording: ‘I feel guilty when/about...’. However, two pilot participants thought this wording was not entirely appropriate and implied

that LBP patients feel guilty all the time. They suggested that the wording is altered into: ‘I have experienced feelings of guilt when/about...’.

Additionally, the process of the scale construction was monitored by two independent expert health psychologists: the first expert overlooked the qualitative work and the themes extracted from it (refer to Chapter 3 for more detail). The second expert overlooked the process of the scale and individual items construction and checked for different aspects such as content validity, appropriate wording and comprehensiveness. For example, they identified that certain items were too similar in meaning and suggested only one item is kept in the scale or that the items are re-worded.

To address known limitations of measures of guilt (Tilghman-Osborne et al., 2010) which were reviewed in Chapter 2, it was ensured that all items focused specifically on guilt, rather than on other constructs, such as anger, shame and blame. It was decided that each item should include an explicit reference to guilt, to distinguish them from other concepts such as feeling bad, frustrated and ashamed, which are different from guilt. The qualitative work and piloting of the initial PGS showed that this explicit distinction was necessary, for instance some participants reported feeling anxious and frustrated rather than guilty. (Tilghman-Osborne et al., 2010). It was also ensured that all aspects of guilt were clearly related to experiencing pain, rather than guilt in general (Tangney et al., 1996).

The initial scale consisted of 24 items (see Table 4:2) and was later reduced (as a result of the exploratory and confirmatory factor analyses) to 12 items (see Table 4:3). It was headed by the phrase ‘Because of my back pain I have experienced feelings of guilt:...’. As this structure did not accommodate the use of negative items, all items were positively worded. This particular aspect was also discussed with the second expert who checked the scale and they agreed with this decision. Responses were on a Likert-type rating scale, ranging from 1 (‘never’ feeling guilty) - 5 (‘always’ feeling guilty).

Other Measures

The following measures were also included and were described in more detail in Chapter 3:

‘Demographics and pain details’: participants were asked to supply details about age, gender, duration of their back pain, and other health-related problems. ‘Anxiety and depression’: the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), the use of the HADS in a web sample has shown to provide valid data (Andersson, Kaldo-Sandstrom, Strom, & Stromgren, 2003). ‘Disability’: Roland Disability Questionnaire (RDQ) (Roland & Morris, 1983). ‘Pain intensity’ (Cleeland & Ryan, 1994).

Design and Analyses

The study design was correlational and the main statistical analysis in Study 2 was exploratory factor analysis (EFA), and in Study 3 confirmatory factor analyses (CFA); CFA was used for validation purposes of the PGS (Field, 2009).

Exploratory Factor Analysis

Exploratory factor analysis, using SPSS 19 (IBM, 2010) was carried out using direct oblimin rotation (because factors were expected to correlate) and principal components extraction methods. The selection of the number of components to be rotated was based on the Kaiser criterion and examination of the scree test of eigenvalues plotted against factors (Field, 2009). In addition, items that loaded $<.4$ (Stevens, 2002) on all factors were excluded as well as items that loaded across two factors (cross loadings) with a difference $<.3$ between the items (Matsunaga, 2010).

One rule of thumb for adequate sample size in EFA is that if there are sufficient high loadings ($>.8$) then a large sample size is not necessary, and a sample of approximately 150 should be sufficient (Tabachnick & Fidell, 2013). It is also recommended that a minimum sample of 100 is used or to have at least five times as many participants as variables (Dancey & Reidy, 2007). The guilt scale had 24 items, thus requiring a minimum sample size of 120 participants’ data sets.

Confirmatory Factor Analysis

Confirmatory Factor Analysis (CFA), using AMOS 19, (Arbuckle, 2010) was conducted to test the adequacy of the derived EFA structure, using the maximum likelihood estimation method. Most published studies reporting similar analyses

have a sample size of around 200 (Kline, 2005) and for a simple model, 200 cases are considered adequate (Harrington, 2009; Kline, 2011). Confirmatory factor analysis models were evaluated using a number of recommended goodness-of-fit indices. There are no set rules as to which indices should be reported (Harrington, 2009). First, the chi-square statistic (χ^2) was evaluated as the initial indicator of model fit. Because the χ^2 has a tendency to indicate significant differences, model fit was assessed by determining whether the observed chi square value was less than two times the model degrees of freedom (χ^2/df) (Tabachnick & Fidell, 2013). Although there is no consensus regarding this statistic, recommendations range to as high as 5.0 (Wheaton, 1977). The following goodness of fit indices were used: the Goodness of Fit Index (GFI >0.95 close fit; GFI >0.90 good fit); Adjusted Goodness-of-Fit Index, which adjusts for degrees of freedom (AGFI >0.90 good fit); Comparative Fit Index (CFI close to 0.95 close fit; CFI >0.90 adequate fit) (Byrne, 2010; Hu & Bentler, 1999; Kline, 2011); SRMR- Standardised Root Mean Square Residual (SRMR <0.08 good fit), Tucker Lewis Index (TLI close to 0.95 good fit), and Root Mean Square Error Approximation (RMSEA <0.06 good) (Hu & Bentler, 1999). When a model fit was poor, modification indices were inspected to indicate potential mis-specified parameters (Harrington, 2009). They were used only where it was theoretically plausible, such as error correlation within factors (Byrne, 2005).

Reliability Analysis

Analyses of Internal Consistency (Cronbach's alpha) were performed on both Study 2 and 3 samples separately.

Combined Analysis on Study 2 and 3 Samples

Since Study 2 and 3 had a common goal of statistically testing and validating the PGS, it made sense to compare the two samples and to conduct descriptive statistics of the final (validated) PGS on the combined Study 2 and 3 samples. The combined sample was also used for the final validation of the scale by correlating scores with measures of depression, anxiety, disability and pain intensity. Data were inspected for parametric assumptions; Kolmogorov-Smirnov tests will be reported in the results only for variables violating parametric assumptions. If Levene's test is significant, corrected (for equal variances) t tests will be reported.

Comparisons Between Study 2 and 3 Samples – The two samples were compared using t tests and Mann Whitney tests (when the data were not normally distributed). Because these analyses included measures besides the PGS (such as depression, anxiety, disability and pain intensity), participants with missing data were excluded on an analysis-by-analysis basis, which resulted in some variations in total sample sizes in these analyses (sample sizes are reported in Table 4:1)

Descriptive Statistics for the PGS - Calculated descriptive statistics were reported for the final subscales of the PGS. Percentages were reported for pain-related guilt rates across the two samples in the following five categories: participants with the mean score in the range of 1-1.9, 2-2.9, 3-3.9, 4-4.9 and the final category was the mean score of 5 (meaning that a participant scored 5 on all subscale items).

Correlations Between PGS Subscales and Depression, Anxiety, Disability and Pain Intensity - To examine the validity of the PGS, Pearson or Spearman tests (depending on violation of assumptions for parametric statistics for each pair of variables) were planned after conducting the CFA. First, zero-order correlations between the PGS subscales and depression, anxiety, disability and pain intensity, were conducted in order to explore the degree of association between these variables. However, as guilt is theoretically linked to anxiety and particularly to depression (A. T. Beck et al., 1961) partial correlations were also conducted to determine the degree of association between the PGS subscales and disability and pain intensity when impacts of depression and anxiety were removed. R^2 for all significant correlations were also reported, which show the amount of shared variability between each pair of variables (Field, 2009).

Results

Data Preparation

Response rates could not be calculated from Study 2 (online) sample. Response rate for Study 3 (paper and pencil) sample was 53.7 %; in total 322 out of 600 distributed questionnaires were completed and returned.

Participants who were missing more than 10% of responses (Bennett, 2001; Pincus, Greenwood, & McHarg, 2011) on the PGS were excluded, 19 from Study 2

sample (there were large sections of missing data where respondents stopped answering after only having answered the first few questions) and 15 from Study 3 sample). In Study 2 sample, missing data below 10% were replaced with the sample mean for that item in the EFA. Pairwise and listwise deletion methods were compared (Tabachnick & Fidell, 2013); all three methods yielded almost identical results in the EFA. For example, they all produced the same factor structure and the structure matrices were almost identical. Study 3 sample included no participants with missing data below 10%; therefore it was not necessary to deal with this further.

Participants who reported suffering from non-musculoskeletal back pain (osteoporosis, back pain due to cancer and inflammatory conditions such as rheumatoid arthritis and ankylosing spondylitis) were also excluded (14 from Study 2 sample and 15 from Study 3 sample). Scores for 4 participants in Study 3 sample were multivariate outliers, on inspection of these cases their scores indicated that these participants had extreme scores on multiple variables (Stevens, 2002); these participants were also excluded. Thus, the final Study 2 and 3 samples included 137 and 288 participants respectively.

Description of Samples

The two samples characteristics are reported in Table 4:1. The two samples were compared and tested for differences using t tests and Mann Whitney tests on a number of measures, including pain intensity, depression, anxiety and disability. Kolmogorov-Smirnov tests showed that across both samples, scores for disability in the paper and pencil sample $D(287) = .13, p < .001$, and scores for pain intensity in the online, $D(133) = .19, p < .001$, and paper and pencil sample, $D(287) = .14, p < .001$ were not normally distributed. Mann Whitney tests were used to analyse these scores. Homogeneity of variance was not assumed for age, $F = 6.89, p = .009$, pain intensity, $F = 9.23, p = .002$, and depression, $F = 5.93, p = .015$; corrected t tests are reported for these variables.

Study 2 sample was found to have significantly more pain, depression, anxiety and disability than Study 3 sample. However, these rates were broadly in line with other samples of LBP patients in the UK (Foster et al., 2010; Hill et al., 2011). Study 2 sample also had significantly more female participants, less co-morbidity

and more participants with pain duration >12 months (of note, in both samples >83% of participants had pain for >12 months).

Exploratory Factor Analysis of PGS on Study 2 Sample

All 24 items were included in the factor analysis; direct oblimin rotation and principal components extraction methods were employed. The Kaiser-Meyer-Olkin (KMO) statistic (a measure of sampling adequacy) was 0.92, defined as excellent (Field, 2009). This indicates that the data were appropriate for factor analysis. In addition to the overall KMO statistic, the diagonal elements of the anti-image correlation matrix were examined and all of them were between .85 and .96 (values above .50 are accepted (Field, 2009)). Bartlett's test of sphericity, $\chi^2(276) = 1354.68$, $p < .001$, indicated that correlations between items were sufficiently large and that the data were factorable. Taken together, these tests provide a minimum standard which should be passed before a factor analysis should be conducted (Field, 2009).

Oblique rotation was used because factors were expected to correlate with each other, and the structure matrix showed that this indeed was the case (Field, 2009). Communalities ranged between .42 (item 24 in Table 4:2) to .79 (item 5 in Table 4:2). This means that individual items shared between 42% and 79% of variance with the overall data set. The analysis resulted in three factors with eigenvalues greater than 1 (together accounting for 64.1% of the total variance), examination of the scree plot corresponded to this outcome. Factor 1 had an eigenvalue of 11.59 and accounted for 48.3% of the total variance; Factor 2 had an eigenvalue of 2.43 and accounted for 10.1% of the total variance; and Factor 3 had an eigenvalue of 1.36 and accounted for 5.6% of the total variance in the data.

Table 4:1 *Sample Characteristics*

	Study 2	Study 3	Inferential	Effect size	N
	Online sample	Paper & pencil sample	statistics	d/r/ odds ratio ^a	Study 2/ Study 3
			<i>t/U/X²</i>		
Age (Mean/SD)	48 (13)	45 (16)	-1.52		135/282
Female %	75.9	64.8	5.29*	1.71	137/287
Have co-morbidity %	26.3	39.5	6.18*	1.83	114/286
Pain >12 month %	92.7	82.9	7.47**	2.63	137/286
Pain intensity (Median)	8	6	-6.95*	.59	137/287
Disability (Median)	14	8	- 8.44*	.73	135/287
Depression (Mean/SD)	9.56 (4.64)	6.52 (3.81)	-6.28*	.72	135/196
Anxiety (Mean/SD)	11.24 (4.80)	9.05 (4.52)	4.21*	.47	135/195

*Effect size: d-for t test, r-for Man Whitney, odds ratio -for chi square; *p < .05, **p < .01*

The data were interpreted from both the pattern and structure matrix (Field, 2009); the latter was used to check for cross loadings. Items that loaded <.4 on any factor were excluded (Stevens, 2002) as well as cross loadings with a difference <.3 (Matsunaga, 2010). This criterion was strictly followed in all but one case; one of the items ('I have experienced feelings of guilt about not being able to visit my family and friends') met the criteria, but was excluded because it was very similar to another item in the scale ('I have experienced feelings of guilt when I have been unable to do things with my family and friends'). The item was removed because it was imperative to keep the scale short and minimize the burden on patients. Table 4:4 shows the structure matrix, which includes all 24 items with their factor loadings, cross loadings and item means and standard deviations.

The three factors (subscales) included 12 items (see Table 4:3). The first subscale was named 'social guilt'; it consisted of 4 items and related to letting down family and friends. The second subscale was named 'managing condition/pain guilt'; it consisted of 5 items and related to failing to overcome and control pain. The third subscale was named 'verification of pain guilt'; it consisted of 3 items and related to the absence of objective evidence and diagnosis. These subscales corresponded well with the three themes extracted from Study 1 (this is addressed in more detail in the discussion of this chapter).

The correlations between the three subscales were all positive and significant: between social guilt and managing condition/pain guilt, $r(135) = .55, p < .001$; social guilt and verification of pain guilt, $r(135) = .30, p < .001$; and between managing condition/pain guilt and verification of pain guilt, $r(135) = .53, p < .001$.

Analysis of Internal Consistency on Study 2 Sample

Cronbach's alpha values were either good or excellent for the subscales of the questionnaire (.94 for social guilt, .86 for managing condition/pain guilt and .83 for verification of pain guilt'). No items had to be removed to improve these values.

Table 4:2 *Structure Matrix and Descriptive Statistics for the Initial PGS*

Items	Factor	1	2	3	Mean (SD)
1.About not being able to go out more often	.88			-.48	3.42 (1.25)
2.About not being able to attend important events	.88			-.50	3.39 (1.32)
3.About not being able to visit my family and friends	.87			-.47	3.31 (1.32)
4.About not being able to help people close to me when they need me	.87			-.44	3.80 (1.21)
5.When I have been unable to do things with my family and friends	.89			-.49	3.80 (1.23)
6.About not meeting people's expectations	.73			-.71	3.64 (1.27)
7.When others make allowances	.77			-.65	3.46 (1.22)
8.About not being able to do my daily tasks	.80			-.53	3.91 (1.15)
9.About being impatient or frustrated with people around me	.55			-.57	3.79 (1.23)
10.About being unable to cope better with my back pain	.51	.40		-.80	3.65 (1.26)
11.When my therapist is not able to relieve the pain				-.73	2.92 (1.55)
12.About seeing a number of different practitioners in search of help	.46			-.76	3.06 (1.50)
13.About being unable to give a specific reason for what is causing my back pain				.76	2.95 (1.47)
14.About being unable to provide visible/physical evidence for my back pain				.77	3.46 (1.50)
15.When the pain does not seem to improve	.48			-.86	3.41 (1.42)
16.When I cannot stop worrying about my back problem	.43			-.81	3.33 (1.37)
17.About being unable to produce a clear diagnosis when asked				.82	2.95 (1.46)
18.About being unable to control the illness and pain	.50	.46		-.84	3.66 (1.34)
19.When my symptoms are not believed by other people	.45	.44		-.62	3.28 (1.53)
20.I apologise a lot for the things I cannot do because of my back pain	.70	.46		-.61	3.64 (1.20)
21.I apologise a lot for the things I do and say because of my back pain	.54			-.70	3.35 (1.30)
22.I do things (e.g. go to work) to feel less guilty in spite of being in pain	.47	.59			3.67 (1.33)
23.I feel like I am letting people down when I am in pain	.73			-.60	3.97 (1.17)
24.I have experienced feelings of guilt when my back pain has caused colleagues to do extra work	.51	.46			3.36 (1.49)

Factor loadings and cross loadings are presented for all 24 items; Items included in the final PGS are in bold; Descriptive statistics: score range for each item was 1-5 in this data set

Table 4:3 Pattern Matrix Showing Final 12 PGS Items

Item	Factor		
	Social guilt	Verification of pain guilt	Managing condition/ pain guilt
<i>Because of my back pain I have experienced feelings of guilt:</i>			
1.About not being able to go out more often	.86		
2.About not being able to attend important events	.86		
4.About not being able to help people close to me when they need me	.87		
5.When I have been unable to do things with my family and friends	.87		
13.About being unable to give a specific reason for what is causing my back pain		.67	
14.About being unable to provide visible/physical evidence for my back pain		.72	
17.About being unable to produce a clear diagnosis when asked		.75	
11.When my therapist is not able to relieve the pain			-.72
12.About seeing a number of different practitioners in search of help`			-.69
15.When the pain does not seem to improve			-.83
16.When I cannot stop worrying about my back problem			-.82
18.About being unable to control the illness and pain			-.74

Confirmatory Factor Analysis of PGS on Study 3 Sample

The derived three factor EFA model (containing 12 items) was entered into a CFA using data from a new sample of participants. Item means and standard deviations are reported in Table 4:4. Based on Mahalanobis distance, 4 cases were

identified as multivariate outliers, $p < .001$. These cases had several extreme values and were deleted from the analysis (Kline, 2011). The data fulfilled criteria for univariate (Kline, 2011) and multivariate normality (Bollen, 1989; Raykov & Marcoulides, 2008). The skew index ranged from -.01 to .58 and kurtosis index ranged from -1.23 to -.81. Following Kline's (2011) recommendations that the skew and kurtosis indices should be within 3 and 10 respectively, the data in this study are regarded as normal. There also was multivariate normality; the Mardia's coefficient was 31.06, which is lower than the computed value of 168 based on the formula $p(p+2)$ where p equals the number of observed variables in the model (Bollen, 1989; Raykov & Marcoulides, 2008).

Analysis of Internal Consistency on Study 3 Sample

Cronbach's alpha values were either good or excellent (.91 for 'Social guilt' scale, .91 for 'Managing condition/pain guilt' and .88 for 'Verification of pain guilt'). No items had to be removed to improve these values.

Table 4:4 *Descriptive Statistics for the PGS in Study 3 Sample*

Item	Mean (SD)
Social guilt	
1.About not being able to go out more often	2.41 (1.31)
2.About not being able to attend important events	2.24 (1.26)
4.About not being able to help people close to me when they need me	2.56 (1.30)
5.When I have been unable to do things with my family and friends	2.58 (1.31)
Managing condition/pain guilt	
11.When my therapist is not able to relieve the pain	2.23 (1.24)
12.About seeing a number of different practitioners in search of help	2.38 (1.34)
15.When the pain does not seem to improve	2.43 (1.33)
16.When I cannot stop worrying about my back problem	2.52 (1.40)
18.About being unable to control the illness and pain	2.81 (1.34)
Verification of pain guilt	
13.About being unable to give a specific reason for what is causing my back pain	2.69 (1.37)
14.About being unable to provide visible/physical evidence for my back pain	2.40 (1.31)
17.About being unable to produce a clear diagnosis when asked	2.77 (1.38)

Score range for each item was 1-5 in this data set

There are no set rules as to which indices of model fit should be reported and researchers typically employ different indices to determine model fit (Harrington,

2009). Table 4:5 shows the fit indices for the initial model. The indices indicated that the fit was good (e.g. GFI, CFI) or just short of adequate (χ^2/df). However, the RMSEA was poor. Table 4:5 also shows modification indices (in steps) which suggested that the model fit improved most (see model 4 in Table 4:5) when specifying the presence of a covariance for the error terms of two pairs of items on the first factor: error terms 4 and 3 (items 5 and 4), and error terms 3 and 1 (items 4 and 3); and for the error terms of one pair of items on the second factor: error terms 6 and 5 (items 12 and 11). Given that each pair of items contained related content and belonged to the same factor, it was considered appropriate to adjust the model such that the error terms of these items were allowed to covary. For example, error terms 4 and 3 belong to social guilt items which refer to feeling guilty: ‘About not being able to help people close to me when they need me’ and ‘When I have been unable to do things with my family and friends’. These two items refer specifically to family and friends. The correlation between the error terms of these two items indicates that there is something within these two items that is not only social guilt; it could be something more specific and related specifically to feeling guilty about important people in participants’ lives. Other social guilt items do not refer to this aspect; therefore it made theoretical sense to allow these two error terms to correlate.

All indicators of model fit suggested that the adjusted model had an adequate to good fit with the data. Model fit was significantly improved over the initial model, $\Delta\chi^2(3) = 69.13, p < .001$. All the items had high standardised regression weights (weights $>.5$ are considered good (Tabachnick & Fidell, 2013)), ranging between .78 and .92, and which were statistically significant ($p < .001$). Figure 4:1 shows the final CFA model, which also displays bivariate correlations (standardised regression weights) between the three PGS subscales, which were all positive and significant.

Table 4:5 *Fit Indices for the Confirmatory Factor Analysis*

Model	χ^2	χ^2/df	RMSEA	SRMR	GFI	AGFI	CFI	TLI
1. Initial	$\chi^2(51) = 168.63, p < .001$	3.306	.090	.034	.913	.867	.957	.944
2. Modified with covaried e4-e3	$\chi^2(50) = 126.59, p < .001$	2.532	.072	.035	.933	.895	.972	.963
3. Modified with covaried e4-e3, e6-e5	$\chi^2(49) = 107.91, p < .001$	2.202	.065	.033	.943	.909	.978	.971
4. Modified with covaried e4- e3, e6-e5, e3-e1*	$\chi^2(48) = 99.49, p < .001$	2.073	.061	.029	.946	.913	.981	.974

*N = 288; Model 2 included specified covariance between error terms: 4, 3 (items 5 and 4), Model 3: error terms 4, 3 and 6, 5 (items 12 and 11), Model 4: error terms 4, 3; 6, 5 and 3, 1 (items 4 and 1); *Model 4 produced the best fit; RMSEA- Root Mean Square Error Approximation, SRMR- Standardised root mean square residual, GFI-Goodness of Fit Index, AGFI-Adjusted goodness-of-fit index, CFI- Comparative fit index, TLI- Tucker Lewis index.*

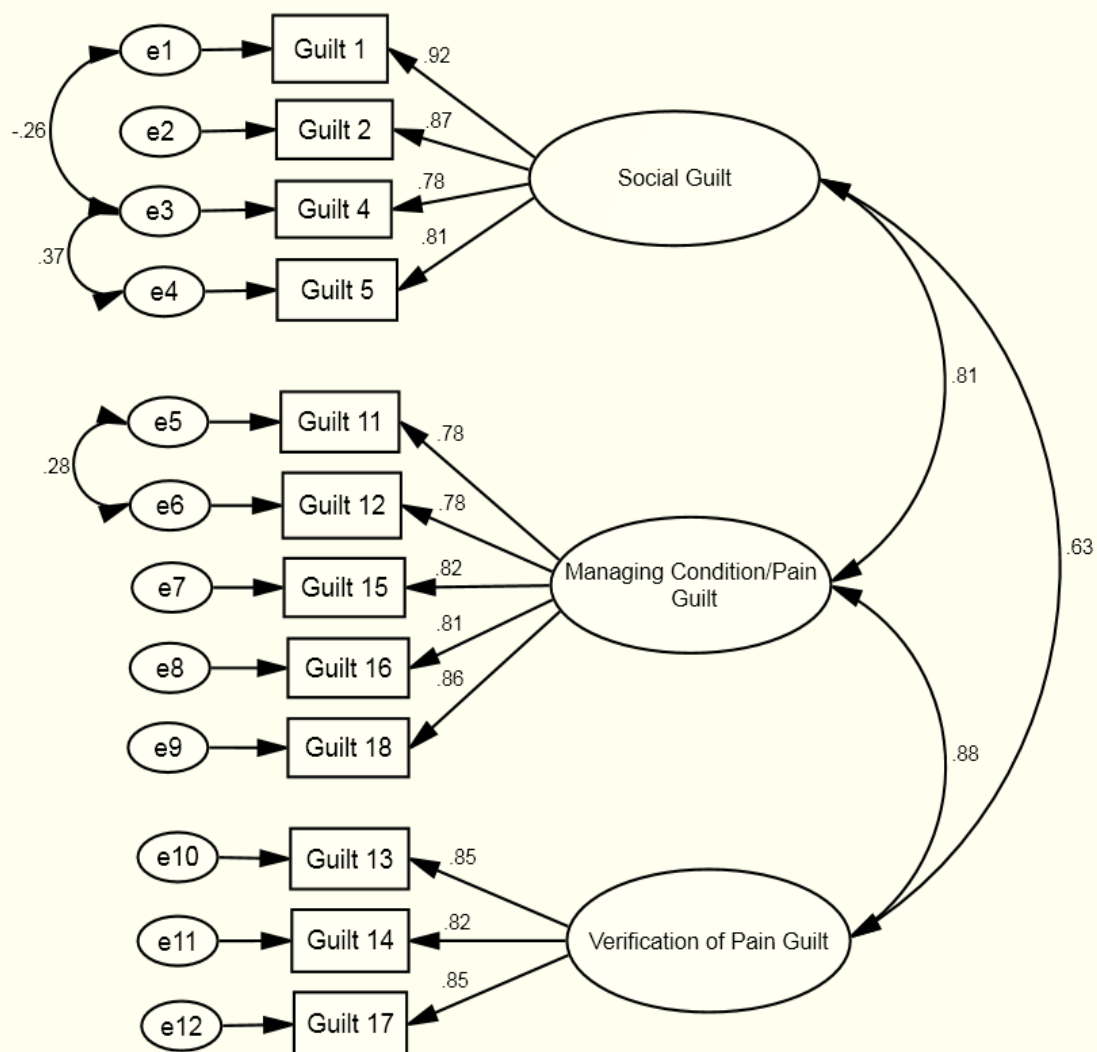


Figure 4:1 *The Final Confirmatory Factor Analysis Model with Regression Weights*

Full description of observed guilt variables can be found in Table 4:4.

Combined Analysis on Study 2 and Study 3 Samples

Descriptive Statistics for the PGS

Table 4:6 shows mean frequencies for the three PGS subscales for the combined Study 2 and Study 3 samples. High levels of guilt (participants with the mean score of 3 and above) were reported by over 40% of patients on each subscale and on the total guilt as measured by the new questionnaire. The maximum rate (scoring 5 on all subscale items) of social guilt was reported by 6.8% participants, managing condition/pain guilt by 4.7% and verification of pain guilt by 3.8% participants.

Table 4:6 *Frequency of Pain-related Guilt in the Combined Study 2 & 3 Sample*

Combined Study 2 & Sample (N=425)					
Mean score	1-1.9	2-2.9	3-3.9	4-4.9	5
Social guilt %	27.1	23.1	24.2	18.8	6.8
Managing condition/pain guilt %	27.8	23.1	27.5	17.9	3.8
Verification of pain guilt %	31.5	23.8	21.6	18.4	4.7
Total %	28.8	23.3	24.4	18.4	5.1

Correlations Between the PGS Subscales and Depression, Anxiety, Disability and Pain Intensity

Table 4:7 shows zero-order correlations between the PGS subscales and disability, pain intensity, depression and anxiety. It also displays partial correlations between the PGS subscales and disability and pain intensity after controlling for depression and anxiety. R^2 (shared variability) for all significant correlations is also presented. These correlations were conducted on the combined Study 2 and Study 3 samples.

Overall, the findings show that the zero order correlations between each guilt subscale and depression, anxiety, disability and pain intensity were all significant ($p < .001$) and positive with moderate to large effect sizes. All the relationships between pain-related guilt, disability and pain intensity remained significant independently of depression and anxiety, other than the relationship between verification of pain guilt and disability, when controlling for depression.

Table 4:8 shows the final three factor PGS scale that will be used in future research. The items have been randomised across the three subscales.

Table 4:7 *Correlations and Shared Variability Between the PGS and Clinical Measures on Combined Study 2 & 3 Sample*

	Correlations					
	Zero-order		Partial controlling depression		Partial controlling anxiety	
	r_s	R_s^2	r_s	R_s^2	r_s	R_s^2
Social guilt						
Disability	.66***	.44	.43***	.19	.57***	.32
Pain intensity	.45***	.20	.30***	.09	.39***	.15
Depression	.67***	.45				
Anxiety	.55***	.30				
Managing condition/pain guilt						
Disability	.46***	.21	.17***	.03	.34***	.12
Pain intensity	.41***	.17	.27**	.07	.29***	.08
Depression	.56***	.31				
Anxiety	.61***	.37				
Verification of pain guilt						
Disability	.29***	.08	.02		.13*	.02
Pain intensity	.34***	.12	.21***	.04	.27***	.07
Depression	.45***	.20				
Anxiety	.46***	.21				

$N=324$; * $p < .05$ ** $p < .01$ *** $p < .001$, all two-tailed

Table 4:8 *Final PGS with Randomised Items*

Directions: The following scale measures pain-related guilt. It includes a list of 12 statements and there are no right or wrong answers. Please rate the extent to which each statement relates to you over the past few weeks by circling a number. Use the following rating scale to make your choices.

Never	Seldom	Sometimes	Often	Always
1	2	3	4	5

Because of my back pain I have experienced feelings of guilt:

1. About not being able to go out more often	1	2	3	4	5
2. About being unable to control the illness and pain	1	2	3	4	5
3. About being unable to give a specific reason for what is causing my back pain	1	2	3	4	5
4. When I have been unable to do things with my family and friends	1	2	3	4	5
5. When the pain does not seem to improve	1	2	3	4	5
6. About being unable to provide visible/physical evidence for my back pain	1	2	3	4	5
7. About not being able to attend important events	1	2	3	4	5
8. When I cannot stop worrying about my back problem	1	2	3	4	5
9. About being unable to produce a clear diagnosis when asked	1	2	3	4	5
10. When my therapist is not able to relieve the pain	1	2	3	4	5
11. About not being able to help people close to me when they need me	1	2	3	4	5
12. About seeing a number of different practitioners in search of help	1	2	3	4	5

Note that Social guilt items = 1, 4, 7 and 11; Verification of pain guilt items = 3, 6 and 9; Managing condition/pain guilt items = 2, 5, 8, 10 and 12. There are no negatively scored items.

Discussion

Main Findings and Fit with Past Research

The primary aim of this study was to develop, test and validate a pain-related guilt questionnaire for use in the assessment of pain-related guilt in LBP. The findings provide evidence for the dimensionality, reliability and validity of the new PGS in two LBP samples. Exploratory factor analysis identified a three-factor structure which corresponded well with the three guilt themes extracted from Study 1: social guilt relates to the ‘feeling guilty towards other people’ and to ‘feeling guilty towards yourself’ (e.g. for not being able to help friends and family and for not being able to go out more often); managing LBP guilt and guilt related to absence of verification of LBP relate to aspects of both, ‘feeling guilty towards yourself’ and ‘feeling guilty for not getting better’ (e.g. for not managing the pain better and for not being able to give a specific reason for the pain). This factor structure was confirmed through CFA in a new sample of participants with LBP.

Reliability was demonstrated in both samples. Correlations between the PGS subscales and disability, pain intensity, depression, and anxiety were all positive and significant. After controlling for depression and anxiety, the PGS subscales still related significantly to disability and pain intensity, although these relationships were weakened. The only exception was verification of pain guilt, which no longer related significantly to disability. Partial correlations show that when controlling for depression the relationship between verification of pain guilt and disability is no longer significant. This indicates that there is a complex relationship (Field, 2009) between verification of pain guilt, depression and disability. Depression appears to be an important mechanism in both factors, but the causal direction of the relationship cannot be untangled in the current study.

The two samples were compared on various outcome measures; the online (Study 2) sample was significantly more depressed, anxious and reported more pain and disability. Given the slightly more heterogeneous nature of an online sample, it is reasonable to expect that means of these outcome measures may be higher when compared to the paper and pencil sample, in which at least two thirds of the participants were actively seeking treatment.

These findings support research evidence for pain-related guilt from other studies; although this evidence is scarce (see Chapter 2 for a discussion of this). The presence of social guilt in LBP has been reported previously. Studies have found that LBP patients' social life and relationships are compromised by LBP (Buchbinder et al., 2011; Snelgrove et al., 2013). The finding is also indirectly supported with research evidence from studies that addressed other similar concepts, for example, in a recent study up to 70% of pain patients report that they feel they have become a burden on others (Kowal, Wilson, McWilliams, Peloquin, & Duong, 2012). Guilt related to verification of pain focuses on not being able to provide clear observable evidence, diagnosis and explanations to verify pain. This is in line with a recent review which found that being disbelieved is associated with the sense of isolation and emotional distress, which can be manifested as guilt, depression and anger (Newton et al., 2013).

The measurement of the impact of having no diagnosis or objective evidence to justify pain is important, because only in about 5-10% of patients precise causes of back pain can be identified (Krismer & van Tulder, 2007). The presence of verification of pain guilt in LBP sufferers may indicate that they feel responsible for the absence of clear diagnosis and evidence for their pain.

Participants in the current study also reported feeling guilty for not being better able to manage and control their condition and for the failure of their treatments. This also included feeling guilty for being unable to control the illness and pain. This seems to reflect LBP patients' expectations of themselves to control aspects of their illness that in reality can be very difficult to control. This is to an extent supported by the findings from a recent qualitative study (Darlow et al., 2013) which suggest that chronic pain patients often feel responsible for the failure of their treatment rather than perceiving the treatment ineffective.

It is also important to address briefly items and aspects of the initial PGS that did not load highly enough on any factors. Other studies suggest that pain patients may feel victimised and may blame others (Linton & Bergbom, 2011) in contrast to psychiatric patients who tend to blame themselves. Findings of the present study support this view; the initial PGS scale included particular aspects of guilt, such as remorse and apology which involve the idea that guilt urges the person to apologise or confess. However, the factor analyses of the PGS did not find apology and

remorse items important suggesting that these are perhaps not key aspects of pain-related guilt. An explanation could be that the pain is perceived as the main ‘culprit’ which shifts the blame from one’s self. Additionally, work-related guilt was also reported in Study 1 of this thesis and other studies (Hochwarter & Byrne, 2010), but work-related guilt did not emerge as an important aspect of pain-related guilt in the current study. Further research should target working LBP patients and analyse the relationship between work and guilt further.

Finally, the literature on guilt in depressed groups also includes evidence that guilt may have a positive effect, by driving people towards behaviours that make reparation, thus increasing activity (O’Connor et al., 2002). However, the evidence for this is contradictory (Tilghman-Osborne et al., 2010).

Clinical and Theoretical Implications

Clarifying specific targets for interventions in order to improve outcomes depends on reliable and valid measurement of factors that are relevant to patients (Eccleston, Palermo, Williams, Lewandowski, & Morley, 2009; Morley & Williams, 2006). Amongst these factors, guilt may be a risk factor for poor outcomes and a promising target for interventions. Currently, the mechanism by which guilt impacts on patients’ outcomes is not known. It is possible that guilt affects outcomes through changes in behaviour that increase avoidance. Guilt may also moderate patients’ willingness to engage in treatment and comply with advice. Finally, reducing guilt through targeted interventions may be an important mediating mechanism to improve outcomes. The three roles (predictor, moderator and mediator) need to be explored in future research, which should include prospective designs, and sensitive measurement to elucidate change over time. The sub-classification provided by the current study in reference to guilt may help identify specific mechanisms that operate at an individual’s level. The findings confirm that all aspects of guilt are common and non-trivial.

The presence of high levels of verification of pain guilt in more than a third of the sample also highlights the difficulty that practitioners face when required to provide a clear explanation in the presence of uncertainty about aetiology and outcome. Practitioners are often under pressure to deliver a clear explanation even

when one cannot be given. Similarly, patients expect to receive a diagnosis. Consultations in which uncertainty is high are therefore difficult for both practitioner and patient, who may feel that they are each in their own way failing in their role. This in turn may contribute to patients feeling guilty for being unable to provide a clear explanation to others as to what causes their pain. McIntosh and Shaw (2003) found in their qualitative study that this is compounded by patients desiring a medical diagnosis and physical evidence that explains their symptoms, even after receiving and understanding explanations that emphasise the role of psychosocial factors in the pain experience. Providing negative diagnostic tests as a mean of reassurance is both contrary to current guidelines (Chou et al., 2009) and may have a negative, rather than positive impact by increasing guilt. A recent review (van Ravesteijn et al., 2012) found that there is no robust evidence for the view that diagnostic tests reassure patients with LBP; it advises an early exploration of the patient's fears and concerns instead. By making them explicit, they may help patients to come to terms with aspects of their illness that they cannot control.

These beliefs and behaviours might be addressed through education, treatment based on cognitive-behavioural principles, and interventions that aim to increase acceptance. An implication of these findings is that it is necessary to allow time and training to health care professionals to address these issues and help their patients to reduce feelings of guilt, unrealistic expectations and responsibility, rather than focus too much on diagnostic testing. It may also heighten acceptance of their pain and lower their anxiety levels. The positive associations found between all three pain-related guilt subscales and anxiety support this view.

Participants also reported feeling guilty for not being better able to manage and control their condition. This, along with verification of pain guilt, may be linked to increased health care utilisation, as patients search for a cure (Glenton, 2003) thus reflecting unrealistic expectations (McIntosh & Shaw, 2003).

In the current study, higher rates of guilt were associated with more negative clinical and psychological states: prospective research is needed to clarify how each subscale of guilt is related to subsequent behaviours, and ultimately to outcomes. For example, all three PGS scales were related to depression. Depression is a strong risk factor for disability (Linton & Bergbom, 2011). Cognitive-behavioural therapy (CBT) is the main psychological treatment for distressed pain patients, and so far it

has only had moderate success in treating pain patients (Eccleston et al., 2009). One of the main problems identified is that CBT lacks focus and past studies show that not all pain patients will benefit from the same psychological treatment. Although many LBP patients may have depressive symptoms, it is still unclear which symptoms they share with psychiatric depressed patients (Morley et al., 2002; Pincus & Williams, 1999). It has been argued that in pain patients there is a propensity for health related negative processing, without the self-denigration, shame and guilt which are often related with clinical depression (Pincus & Morley, 2001). However, little research has been conducted to confirm this and examine the presence of symptoms such as guilt in pain patients. Findings of the present study show that LBP patients have a tendency to feel guilty, that their guilt is health orientated, and that it is associated with high depression scores. Understanding the focus of pain-related guilt in LBP patients could improve detailed understandings of emotions and underlying cognitions and should assist the development of more focused cognitive-behavioural treatments. For instance, it has been argued that distressed pain patients may need psychological interventions which centre on self-concept in relation to their health (Pincus, Santos, & Morley, 2007). Self-focus has been recognised as a component of guilt in which one's sense of self (such as self-image or self-identity) is the focus of the guilt experience (Tilghman-Osborne et al., 2010). The relationship between the pain, guilt and self-identity could be examined in future research on pain-related guilt.

Strengths and Limitations

This research has several strengths. The PGS was based on qualitative data extracted from interviews with people with LBP, and therefore it has good face validity. Recommendations for good methodology for item construction were followed (Furr, 2011; Robson, 2002). This process was monitored by two independent experienced health researchers. During the process of the PGS construction it was ensured that all items addressed feelings of guilt specifically rather than other constructs, such as anxiety, anger, shame and blame. Tilghman-Osborne et al. (2010)'s systematic review suggests that research on guilt in psychology is greatly inconsistent and that a reason for this may be the lack of conceptual clarity. This review found that existing measures of guilt do not relate

well to their conceptual definitions and that they often mirror other concepts such as anxiety, shame, worry, fear, anger, and other constructs which confound guilt research; for instance they can inflate correlations between guilt and negative emotional outcomes (Tilghman-Osborne et al., 2010).

It is important that guilt is measured in context (Tangney et al., 1996; Tilghman-Osborne et al., 2010); in line with this view, each question in the PGS inquires about the guilt experience set in a reasonably specific event or scenario derived from Study 1 findings. Therefore, the PGS ties the experience of guilt to a specific situational context. However, theories of personality (Tilghman-Osborne et al., 2010) suggest that there are individual differences in people's predispositions to feel guilt, this was not controlled in the study and future research may consider controlling for this. Although the PGS explores the presence of pain-related guilt in musculoskeletal LBP patients specifically, an advantage of the scale is that it could be adapted for use in other pain populations where coping with pain is a prominent aspect.

The clinimetric qualities of the PGS are evaluated next using a checklist based upon the review criteria of the Scientific Committee of the Medical Outcome Trust (Lohr et al., 1996). The Medical Outcomes Trust is a depository and distributor of high-quality, standardised, health outcomes measurement instruments to national and international health communities. These attributes consist of the following: conceptual and measurement model; reliability; validity; responsiveness; interpretability; respondent and administrative burden; alternative forms; and cultural and language adaptations. Patient-assessed instruments should at least demonstrate validity, reliability and responsiveness before considering them to be useful in clinical practice (Eechaute et al., 2007).

In respect to the conceptual and measurement model, the PGS was developed from interviews with LBP patients and its underlying structure was examined by both exploratory and confirmatory factor analysis in Study 2 and 3.

The PGS' reliability was assessed by testing internal consistency of items using Cronbach's alpha analysis (Stangor, 1998). All three subscales of the PGS demonstrated good to excellent reliability.

There are several types of validity, and not all of them could be examined in the thesis. Lohr et al. (1996) suggest that the following three types of validity are most important: content, construct and convergent validity. The PGS was assessed for face and content validity. The scale was piloted: it was checked for face validity and appropriate wording by four people with LBP. Additionally, three expert health psychologists checked content validity of the scale (see the method section for a more detailed review of the scale construction).

There is no single method of establishing construct validity, and the more evidence a researcher can demonstrate for a measure's construct validity the better. It is generally established by correlating the measure with a number of other measures; the pattern of correlations should be in theoretically expected ways (Stangor, 1998). Study 3 results demonstrated construct validity by showing that the PGS was correlated with several other measures (e.g. with the HADS). The three PGS scales also seem to have a good level of convergent validity; the inter-scale correlations were sufficiently large. Other types of validity such as discriminant, concurrent and predictive validity could not be assessed in the current studies. Finally, it could be said that the PGS had a satisfactory external validity as it was used in reasonably large and two different samples of back pain patients.

Responsiveness has been described as the ability of a measure to detect important change of the health status over time (Eechaute et al., 2007); responsiveness of the PGS could not be assessed as the studies were cross sectional.

With respect to respondent burden (Lohr et al., 1996), the PGS placed fairly small physical strain on the respondent as it can be completed in a reasonably short amount of time. This will be minimised in the future studies as the scale has been shortened to 12 items. However, the scale does tap into a psychological construct that might be judged to have relatively high emotional load on the respondent. The questions were constructed with this in mind and very carefully worded (see the method section for more detail). Completion of the PGS did not need any special requirements, such as need to consult patients' health records. Administrative burden seems to be minimal, no particular level of training or expertise was needed to administer the scale, and it required minimal resources to administer, score, and analyse the scale (Lohr et al., 1996).

The study also has a number of limitations. First, self-reported feelings of guilt may not accurately represent actual feelings; although self-report has been the predominant method in this area of research.

The samples used in this study may not represent broader LBP patient populations within or outside of the UK. There is evidence suggesting that guilt is culturally defined (Tilghman-Osborne et al., 2010) and may be qualitatively different across different cultures. For instance, there is research suggesting that guilt is a qualitatively different concept in Asian as opposed to Western cultures (Bedford & Hwang, 2003). Related to cultural differences is the concept of guilt as studied and understood within non-psychological domains, such as theological, philosophical and sociological. However, the present research did not examine pain-related guilt from the viewpoint of any of these domains.

The survey was completed anonymously and information regarding participants' medical histories was based on self-report; it was not possible to check this information with their practitioner. The samples recruited for the current study included people subscribing to self-help groups, and those attending a LBP dedicated conference. This may indicate higher investment and involvement in their pain, and consequently rates of guilt may be elevated. Across the two samples, approximately half of the participants were osteopathic patients, although it could not be ascertained if they were treated elsewhere at the same time. Research is needed to establish levels of pain-related guilt in other populations. In addition, the differences between the online (Study 2) and paper and pencil (Study 3) sample may indicate a selection bias in the samples. The online sample participants might have been more self-motivated to take part in the study and express their pain related concerns. In contrast, many paper and pencil sample participants were approached by the researcher and asked to participate.

The sample sizes were moderate, but satisfied sample size criteria for both EFA (Dancey & Reidy, 2007) and CFA (Kline, 2011). As in all self-report measures, there is a threat of social-desirability bias (Stangor, 1998). In addition, the cross sectional methodology employed in the study does not allow for testing of the causal relationship between pain-related guilt and outcomes.

This three-factor structure was confirmed in a CFA, though good model fit was only achieved following the modifications of the initial model. These modifications included adding covariance between error terms of three pairs of items and were conceptually/theoretically plausible.

Conclusion

This study provides initial evidence for the underlying factor structure and good reliability and validity of the PGS. Although the scale items were developed from interviews with LBP patients and have good content validity, it is possible that there are other aspects of guilt, such as work-related guilt currently missing from the scale. Future research is also needed for additional validation and clinimetric assessment of this measure in new samples. The findings from this study suggest that pain-related guilt is a common experience among people with LBP. However, prospective methodology is needed to examine the relationship between pain-related guilt, prognosis and treatment outcomes.

Overall, this is an initial analysis of pain-related guilt and a work in progress; therefore further exploration of both pain-related guilt (psychological factor) and the PGS is needed.

Chapter 5

Diagnostic Uncertainty and Pain-Related Guilt are Related to Mood and Disability in Chronic Low Back Pain: Path Analyses

Abstract

The findings of the first three studies of this thesis showed that low back (LBP) patients experience diagnostic uncertainty and pain-related guilt, and that pain-related guilt is associated with mood and disability in LBP. However, the relationship between diagnostic uncertainty, pain-related guilt and clinical measures in LBP is currently unknown. This study tested several theoretical models to explore possible pathways between these factors. In Model 1, diagnostic uncertainty was hypothesised to correlate with pain-related guilt, which in turn would positively correlate with depression, anxiety and disability. Two alternative models were tested in order to ascertain that the hypothesised model was the most viable model: a) a path from depression and anxiety to guilt, from guilt to diagnostic uncertainty and finally to disability; and b) a model in which depression and anxiety, and independently diagnostic uncertainty, were associated with guilt, which in turn was associated with disability. Structural equation modelling was employed on data from 413 participants with chronic LBP. All three models showed a good fit with the data, with the two alternative models providing marginally better fit indices. Diagnostic uncertainty was correlated with pain-related guilt in all models. Unique pathways were observed between different types of guilt and disability and mood. Across all three models, social guilt was strongly correlated with disability and depression. Diagnostic uncertainty was moderately but significantly associated with guilt. Replication of the associations in studies that include a timeline is now required.

The work presented within Chapter 4 has been submitted to Health Psychology:

Serbic, D., Pincus, T., Schaw-Fife, C., & Dawson, H. (submitted). Diagnostic uncertainty, guilt, mood and disability in back pain. *Health Psychology*.

Introduction

Study 1 findings (reported in Chapter 3) showed that low back (LBP) patients report feeling uncertain about their diagnosis, accompanied by guilt. Study 2 and 3 findings (reported in Chapter 4) showed that LBP patients experience three types of pain-related guilt: social guilt, managing condition/pain guilt and verification of pain guilt. The aim of the current study is to examine the relationship between diagnostic uncertainty, pain-related guilt, and mood and disability in LBP, using a path analysis.

A plethora of tested predictors in prospective cohorts (Hayden et al., 2009; Hayden et al., 2010) suggests that psychological factors play an important role in the transition from acute to chronic LBP, among the most robust predictors are depression, catastrophic cognitions, fear of movement and activity, and beliefs about recovery (Pincus & McCracken, 2013). Despite this, psychological interventions have delivered only small improvements in trials (A. Williams et al., 2012).

Underdeveloped theoretical models have been blamed for small and short-term effects of psychological interventions in LBP (Pincus & McCracken, 2013). Identifying factors that mediate recovery in LBP using novel designs and advanced analysis, such as structural equation modelling has recently been highlighted as vital for improving outcomes in LBP patients (Hayden et al., 2010). These designs enable studying complex relationships between predictors in LBP. This study aimed to test one mechanism: guilt associated with diagnostic uncertainty, which may compromise recovery in LBP.

Past research (summarised in Chapter 2) has shown that LBP patients often feel uncertain about their diagnosis and explanations given by practitioners about the causes for their back pain (Hopayian & Notley, 2014), and in the absence of a clear cause for their pain they may feel that their pain is not legitimised (Rhodes et al., 1999). This may impact on how they feel and cope with their pain and they may continue searching for a diagnosis instead of focusing on more important aspects of their pain and lives. There is evidence that lack of knowledge about the cause of

pain is associated with increased emotional distress, disability (Geisser & Roth, 1998; Reesor & Craig, 1988), pain intensity (Reesor & Craig, 1988), unhelpful pain-related cognitions such as catastrophising (Geisser & Roth, 1998) and return to work (Lacroix et al., 1990). One mechanism via which diagnostic uncertainty might be associated with mood and disability is through feelings of guilt. Study 2 and 3 (reported in Chapter 4) showed that pain-related guilt is associated with mood (depression and anxiety) and disability, but the mechanism behind these associations remains unknown.

Therefore, the primary aim of the current study was to test a novel theoretical model (see Model 1 in Figure 5:1). The *a-priori* predictions for Model 1 propose that diagnostic uncertainty is related to the three types of guilt which in turn relate to depression, anxiety and disability. The rationale here is based on the cognitive dissonance between having insufficient evidence for the experience of pain, and the extent of the impact pain has on a patient's life, including their own experience and behaviour. This may result in patients feeling responsible for not being able to justify and manage their pain, and feeling guilty about it. These relationships are based on the findings of Study 1 (reported in Chapter 3) and previous research (Rhodes et al., 1999), which have shown that LBP patients who cannot provide a diagnosis and justification for their pain often feel guilty about this, as well as about being unable to control and manage their pain better and engage more in social situations. When feelings of guilt are extreme, a suitable response to these emotions may not be possible by the emotion regulation system (Linton & Bergbom, 2011), and they may in turn influence low mood and disability. Therefore, Model 1 predicts that the experience of guilt is associated with increases in depression, anxiety and disability.

This study also tested two alternative models (see Model 2 and 3 in Figure 5:1). These models are based on the body of evidence suggesting that depression and anxiety lead to increased disability (reviewed in Pincus & McCracken, 2013). The models test how guilt and diagnostic uncertainty may be placed within this process. Worry and low mood are common emotional reactions to pain (Blyth et al., 2011, Eccleston, 2001). Model 2 predicts that guilt may be increased by these emotions (Tilghman-Osborne et al., 2010), and in turn, decrease patients' ability to process and accept explanations from practitioners, thus impacting on patients' perceptions and concerns that something else, more serious, is going on with their back. Finally,

although the link between mood and guilt has theoretical underpinnings (A. T. Beck et al., 1961), diagnostic uncertainty may enhance guilt independently of mood, and this is examined within Model 3. In the absence of a visible cause for back pain, patients may feel that they are being perceived as imagining or exaggerating their pain or seeking attention (Armstrong, 1984). These perceptions are unhelpful but may often be justified as there is some evidence to suggest that a response by orthodox medicine, in situations where no clear causes for the pain can be found, might be to shift the responsibility back to the patient (May et al., 1999; McIntosh & Show, 2003). This may result in feelings of guilt that are not a direct outcome of negative affect.

In light of the evidence that depression and disability, and anxiety and disability are highly associated (Linton & Bergbom, 2011; Hayden et al., 2010; Pincus & McCracken, 2013) and that the direction of this association is not entirely clear, a reciprocal pathway was included between these variables in all three models. Finally, there is substantial research evidence that pain intensity is a predictor of disability in LBP (Hayden et al., 2010), thus the three structural models also included this pathway and it was connected indirectly to anxiety and depression via disability.

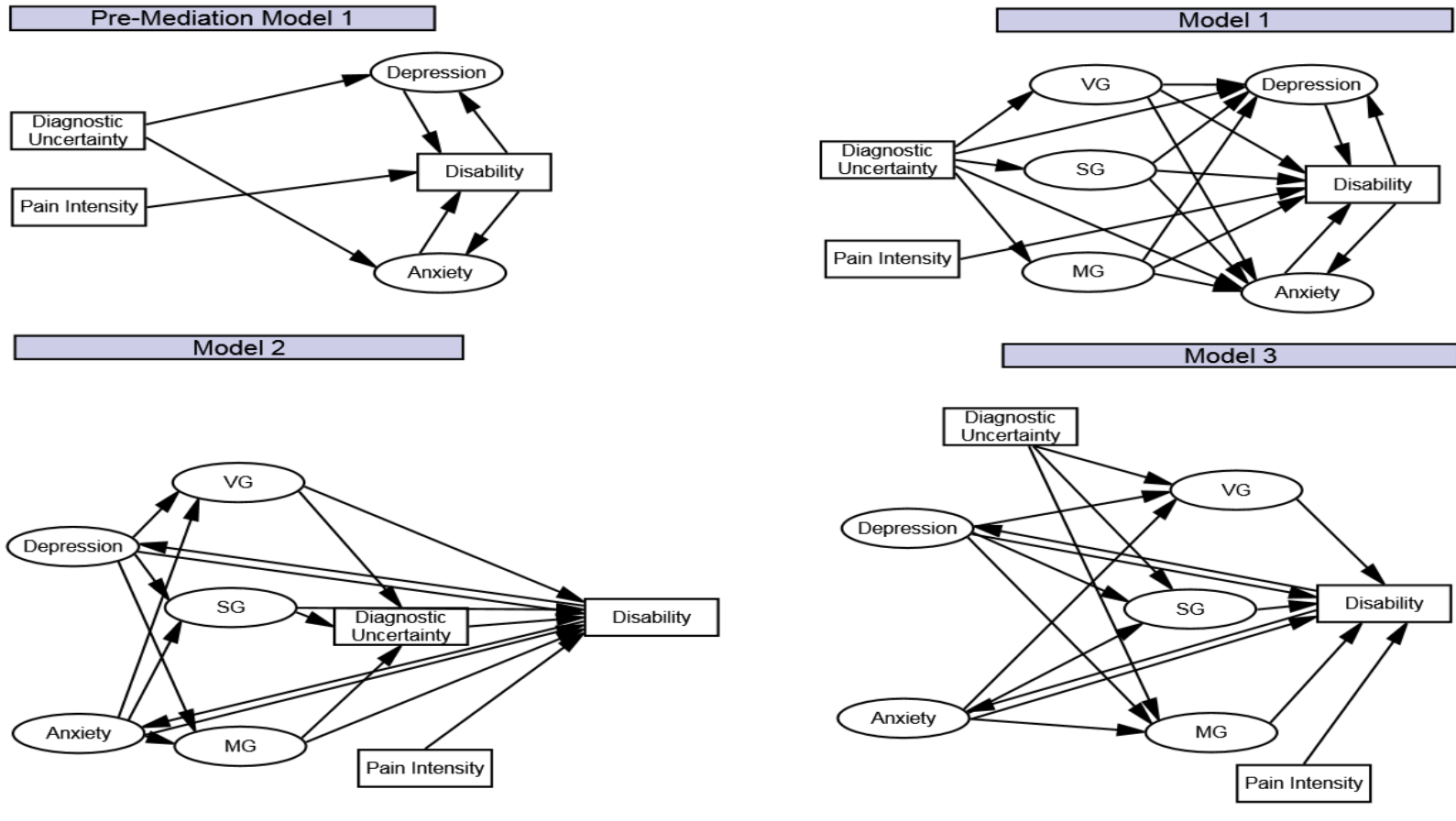


Figure 5:1 *Theoretical Models*

Methods

Study Design

The study was cross sectional in design and it examined relationships within three theoretical models using structural equation modelling (SEM). Structural equation modelling is used to evaluate whether theoretical models are plausible when compared to observed data, and it uses a complex form of multiple regressions to do this (Klein, 2011). There are numerous advantages of using SEM to conduct mediation analysis. One of advantages is that it is designed to test complex mediation models in a single analysis (Gunzler, Chen, Wu, & Zhang, 2013). This is an obvious improvement on standard regression analysis, in which ad hoc methods must be used for inference about mediation effects (Gunzler et al., 2013). The standard regression procedure initially recommended for testing mediation by Baron and Kenny (Baron & Kenny, 1986) has been shown to be low powered (Hayes, 2009). Terms ‘prediction’ and ‘mediation’ are used in this study as statistical terms (commonly used in regression analysis) and they do not imply causal psychological relationships.

As a process, SEM involves the following main stages: a) model conceptualization; b) parameter identification and estimation; c) data-model fit assessment; and d) potential model modification (Klein, 2011). All four stages were implemented in the current study.

Model 1

Model 1 (presented in Figure 1) was tested with diagnostic uncertainty predicting levels of three types of pain-related guilt: social guilt, managing condition/pain guilt and verification of pain guilt. Next, within this model the three guilt subscales were hypothesised to predict levels of depression, anxiety and disability. Thus, this model tests if diagnostic uncertainty and pain-related guilt might be part of the same mechanism, jointly relating to outcomes in LBP. A rationale for these relationships is provided in the introduction. Mediation is chosen because at this initial phase of the model testing it appears more plausible to expect that the (strength of) relationship between diagnostic uncertainty and outcomes variables can be explained by their relationship to pain-related guilt, rather than being simply moderated by it (moderation suggests two variables jointly relate to an

outcome) (Field, 2009). There are different ways of examining mediation (many of those are non-SEM approaches and not applicable to the current study), and one way of doing this in SEM is to compare competing or alternative models. Alternative models help to consider other explanations of the data (Kline, 2011). In the current study, the main theoretical model (Model 1) was first compared to a model that contains only direct paths between the predictor and outcome variable. Thus, mediation was examined by comparing the proposed theoretical model (with pain-related guilt as mediator) to a model not containing the mediator; this model will be referred to as ‘pre-mediation’ model (see Figure 5:1). Model 1 was then compared to two alternative models in which relationships between diagnostic uncertainty, pain-related guilt and mood were reversed.

Additionally, in order to clearly test the mediating role of pain-related guilt between diagnostic uncertainty and depression and anxiety, direct pathways from diagnostic uncertainty to depression and anxiety were included, anticipating that non-significant (or reduced in significance (Field, 2009)) pathways would confirm the mediating role of pain-related guilt in the model (Baron & Kenny, 1986). A direct path between diagnostic uncertainty and disability was not included because one of prerequisites for mediation is that the predictor and outcome variables are correlated (Baron & Kenny, 1986; Field, 2009); although this does not rule out the possibility of indirect association of the predictor with the outcome variable through the mediator (Hayes, 2009). The preliminary analysis using point-biserial correlations between diagnostic uncertainty and the three outcome variables, showed that diagnostic uncertainty was correlated with depression $r_{pb}(413) = .145, p = .003$, and anxiety, $r_{pb}(413) = .170, p = .001$, but not with disability, $r_{pb}(413) = .065, p = .186$. Also, there were no significant differences between the certain and uncertain about diagnosis group in their disability scores, but there were significant differences in their depression and anxiety scores (see Table 5:1). The preliminary analysis also showed that the two groups’ pain-related guilt scores (for all three pain-related guilt subscales) were significantly different supporting the relationship between diagnostic uncertainty and pain-related guilt and using pain-related guilt as a mediator in the model (see Table 5:1).

Finally, indirect effects between diagnostic uncertainty and the three outcome variables through each of the three types of pain-related guilt will be also calculated

and reported using Sobel tests (Klein, 2011) for all models in the study. However, indirect effects through two and more mediators cannot be hand-calculated (Klein, 2011) (for example, an indirect effect of this type would be the indirect effect of diagnostic uncertainty on disability through social guilt and depression). In such cases the following rule of thumb can be applied: if all component unstandardized path coefficients of an indirect effect through two or more mediators are statistically significant at the same level of alpha, then it can be assumed that the whole indirect effect is also significant at the same level of alpha (Cohen & Cohen, 1983; Klein, 2011).

Additional Features of Model 1 - The residuals of the three guilt scales were permitted to correlate; this can be justified as all three are subscales of the pain-related guilt scale (PGS) (described in more detail in the materials and procedure section below). The residuals for anxiety and depression were also permitted to correlate; this can be justified as both are subscales of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). Reciprocal pathways were included between anxiety and depression, and disability. A direct pathway from pain intensity to disability was also included and it was connected indirectly to anxiety and depression via disability. A rationale for these relationships is provided in the introduction.

Alternative Model 2 and 3

Two alternative structural models were also tested to examine whether Model 1 was the most viable model. The first alternative model tested if anxiety and depression precede both guilt and diagnostic uncertainty (see Model 2 in Figure 1). The second alternative model tested if the three types of pain related guilt are preceded by both mood (anxiety and depression) and diagnostic uncertainty independently (see Model 3 in Figure 1). These relationships are explained in more detail in the introduction. All additional features of Model 1 were also included in Model 2 and 3.

Participants

This study included 170 online participants from Study 2, 224 patients attending The British College of Osteopaths Medicine (BCOM), comprising the

participants from Study 3, and an additional 147 participants (patients) recruited from the National Health Services (NHS), from two pain clinics and a physiotherapy department in London. Therefore, a total of 541 participants were recruited for this study.

Inclusion criteria were that participants be over the age of 18 years and have chronic (> 3 months) musculoskeletal LBP. No limit was imposed on current pain intensity. Participants with back pain due to ankylosing spondylitis, osteoporosis, cancer and inflammatory conditions such as rheumatoid arthritis were excluded. For participants recruited from the NHS, these inclusion criteria were checked for each participant by their clinician; for non-NHS participants this was established by self-report. The study received ethical approval from the university research ethics committee, participating institutions and NHS (see Appendix E and K). General ethical procedures were identical to those described in Chapter 3 and 4.

Materials and Procedures

Online participants were invited to take part in the study through the three self-help groups for back pain which hosted a link to the questionnaire. The study procedure for Online participants is described in the method section of Chapter 4. Other participants were given a paper and pencil version of the questionnaire. The study procedure for BCOM participants is described in the method section of Chapter 4. For NHS participants the study inclusion criteria were checked for each participant by their practitioner before they were invited to participate in the study, if they agreed they were given a copy of the study questionnaire to complete.

Questionnaire packs included an information sheet, consent form, questionnaire (for Online and BCOM participants these were the same as in Study 2 and 3; for NHS participants see Appendix L and M) and postage-paid return envelope. The questionnaire took approximately 15 minutes to complete and participation was anonymous. The participants could either return the questionnaire by post or leave it a response box in the clinic. However, it was not possible to keep a record of how many NHS patients were approached, and how many refused to take part in the study; therefore response rates could not be calculated. Information related

to response rates for Online and BCOM participants is reported in the method section of Chapter 4.

Measures Used in the Questionnaire

Diagnostic Uncertainty – Diagnostic uncertainty was measured with a single categorical question, ‘I think there is something else happening with my back which the doctors have not found out about yet (yes/no)’. This categorisation created two groups of participants: those who responded with a ‘yes’ were in the ‘uncertain about diagnosis’ group, and those who responded with a ‘no’ were in the ‘certain about diagnosis’ group. This question was part of the perceived diagnostic status categorisation constructed from Study 1 (reported in Chapter 3). This question was constructed as a measure (categorisation) of diagnostic uncertainty, which was one of the major findings in Study 1 (see the results and method section of Chapter 3 for a detailed discussion of this finding)’.

Pain-Related Guilt - The pain-related guilt scale (PGS) was developed from Study 1 findings and validated in Study 2 and 3. It consists of 12 items and three subscales which represent three types of guilt: ‘social guilt’ (4 items) which relates to letting down family and friends; ‘managing condition/pain guilt’ (5 items) which is about being unable to overcome and control pain; and ‘verification of pain guilt’, (3 items) which relates to the absence of objective evidence and diagnosis. Initial validations of the scale (reported in Chapter 4) through exploratory and confirmatory factor analysis showed that the subscales had good validity and reliability. The scale items are headed by the phrase ‘Because of my back pain I have experienced feelings of guilt...’. Responses are on a Likert-type rating scale, ranging from 1 (‘never’ feeling guilty) to 5 (‘always’ feeling guilty).

The following measures were also included and were described in more detail in Chapter 3:

‘Demographics and pain details’: participants were asked to supply details about age, gender, duration of their back pain, and other health-related problems. ‘Anxiety and depression’: the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). ‘Disability’: Roland Disability Questionnaire (RDQ) (Roland & Morris, 1983). ‘Pain intensity’ (Cleeland & Ryan, 1994).

Planned Analyses

The main statistical analysis was SEM. A two-step modelling approach was employed (Kline, 2011) whereby the structural regression model was first specified as a measurement model before the structural components were examined. Therefore, the first step was to perform a confirmatory factor analysis (CFA) on the latent variables in order to examine the validity of the measurement model and its adequacy for use in the structural model. The following latent variables were examined using CFA: social guilt, managing condition/pain guilt, verification of pain guilt, depression and anxiety. Based on the findings of Study 2 and 3 (see Chapter 4), these latent variables were allowed to correlate within the measurement model. These latent variables were then entered into the structural models (explained in the study design section above) and examined with a SEM analysis.

Both CFA and SEM were performed using AMOS 21 (Arbuckle, 2012) and the maximum likelihood estimation method was used. Both analyses were evaluated using a number of established goodness-of-fit indices. Initially, the chi-square statistic (χ^2) was evaluated as the initial indicator of model fit. Because the χ^2 has a tendency to indicate significant ill-fit, model fit was assessed by establishing whether the observed chi square value was less than two times the model degrees of freedom (χ^2 / df) (Tabachnick & Fidell, 2013). Although, there is no consensus regarding this statistic, recommendations range to as high as 5.0 (Wheaton, 1977). The following goodness of fit indices were used: the Goodness of Fit Index (GFI > 0.95 close fit; GFI > 0.90 good fit); Adjusted Goodness-of-Fit Index, which adjusts for degrees of freedom (AGFI > 0.90 good fit); Comparative Fit Index (CFI close to 0.95 close fit; CFI > 0.90 adequate fit) (Byrne, 2010; Hu & Bentler, 1999; Kline, 2011); SRMR-Standardised Root Mean Square Residual (SRMR < 0.08 good fit), Tucker Lewis Index (TLI close to 0.95 good fit), and Root Mean Square Error Approximation (RMSEA < 0.06 good) (Hu & Bentler, 1999). When a model fit was below the set criteria, modification indices were inspected to indicate potential mis-specified parameters (Harrington, 2009), and they were used only when it was theoretically justified (Byrne, 2005). As the three models were not nested they were compared with AIC (Akaike Information Criterion, single sample cross-validation index), and EVCI (Expected cross-validation index, single sample cross-validation index) measures (Byrne, 2010). The lower the AIC and EVCI measure, the better the fit.

Results

Data Preparation

Forty nine participants who reported suffering from non-musculoskeletal back pain (osteoporosis, back pain due to cancer and inflammatory conditions such as rheumatoid arthritis and ankylosing spondylitis) and acute back pain were excluded. Participants who were missing more than 10% of responses on any of the scales were also excluded from the analysis (Bennett, 2001; Pincus et al., 2011). Because the scales used in the study were subscales of the PGS and HADS, they were short (3 to 7 items); this meant that if a participant missed only one item on a scale the responses already exceeded the cut-off of 10%. Participants missing data on the categorical (diagnostic uncertainty) and non-latent (disability and pain intensity) variables were also excluded. Altogether 79 participants were excluded due to missing data. Thus, the final sample included 413 participants, in both CFA and SEM analyses. Because a considerable percentage (14.6%) of recruited participants were excluded from this study due to missing data, and in order to examine that the attrition was not biased, the two groups of participants were compared: out of 79 recruited participants with missing data 21 (19 of which were in the online sample) stopped responding after having answered only a few initial question, therefore, the remaining 58 participants with missing data were compared to the 413 included participants. There were no significant differences between the two groups on age, $t(55.93) = .639, p = .525$), pain intensity, $(t(476) = .897, p = .370)$, and disability, $(t(474) = -.778, p = .437)$ scores.

Description of Sample

The sample characteristics are reported in Table 5:1, which also shows descriptive statistics for all variables used in the analysis. Participants who were uncertain about their diagnosis had significantly higher levels of pain, anxiety, depression and all three types of guilt. They also had pain for longer, although in both groups > 85% of participants had pain duration >12 months.

Table 5:1 *Sample Characteristics*

	<i>Certain</i> N=240	<i>Uncertain</i> N=173	<i>Inferential</i> <i>statistics</i>	<i>Effect</i> <i>size</i>
	Mean/ SD / %	Mean / SD / %	t/ χ^2 ^b	d/odds ratio ^c
Age^a	50 (15)	48. (14)	1.06	
Gender (female) %	67.9	69.9	.19	
Pain duration^a > 12 months %	87.9	94.2	5.54*	2.47
Co-morbidity^a %	32.6	35.8	.43	
Pain intensity	6.11 (2.38)	6.95 (2.10)	-3.74***	-.37
Depression	7.46 (4.43)	8.79 (4.40)	-.2.97**	-.30
Anxiety	9.18 (4.59)	10.77 (4.51)	-3.49**	-.35
Disability	11.52 (6.32)	12.34 (6.11)	-1.33	
Verification of pain guilt	2.41 (1.21)	3.34 (1.21)	-7.72***	-.77
Social guilt	2.91 (1.32)	3.29 (1.20)	-2.98**	-.30
Managing condition/pain guilt	2.78 (1.26)	3.34 (1.13)	-4.75***	-.47

^aN (sample size) for age, pain duration and presence of comorbidity was different: age - 236 & 172 for Certain & Uncertain respectively, pain duration for Uncertain was 172, comorbidity - 230 & 165 for Certain & Uncertain respectively; ^b t test, χ^2 - Chi Square; ^cOdds ratio is considered to be a more common and useful measure of effect size for categorical data than other effect size measure (Field, 2009); *p < .05, ** p < .01, ***p < .001

Confirmatory Factor Analysis of the Measurement Model

Cronbach's alpha values were either good or excellent for the latent variables/scales: .93 for social guilt, .91 for managing condition/pain guilt, .87 for verification of pain guilt, .84 for anxiety and .84 for depression. No items had to be removed to improve these values.

The data fulfilled criteria for univariate (Kline, 2011) and multivariate normality (Bollen, 1989; Raykov & Marcoulides, 2008). The skew index ranged from -.43 to 1.25 and kurtosis index ranged from -1.36 to .87. Following Kline's (2011) recommendations that the skew and kurtosis indices should be within 3 and 10 respectively, the data in this study are regarded as normal. There also was multivariate normality; the Mardia's coefficient was 74.36, which is lower than the computed value of 728 based on the formula $p(p+2)$ where p equals the number of observed variables in the model (Bollen, 1989; Raykov & Marcoulides, 2008).

Table 5:2 shows the model chi square and fit indices for the initial measurement model and for models re-specified as a result of specification search. The initial model showed evidence of reasonable fit, but there was evidence of some mis-specification. The table also shows 3 modified models which suggested that the model fit improved most when: a) specifying the presence of a covariance for the error terms of two related social guilt items PGS4: 'Because of back pain I have experienced feelings of guilt: About not being able to help people close to me when they need me' and PGS11: 'When I have been unable to do things with my family and friends'. Both items refer specifically to family and friends. The correlation between the error terms of these two items indicates that there is something within these two items that is not only about social guilt; it appears to be something more explicit and related specifically to feeling guilty about important people in participants' lives. Other social guilt items do not refer to this aspect; therefore it seemed reasonable to allow these two error terms to correlate; b) Making HADS7 ('I can sit at ease and feel relaxed') an indicator of both anxiety and depression (other chronic pain studies also found HADS7 to be a problematic item (Fish et al., 2010; Pallant & Bailey, 2005)); and c) allowing correlated error terms of two related managing condition/pain guilt items: PGS10: 'Because of my back pain I have experienced feeling of guilt: When my therapist is not able to relieve the pain', and PGS12: 'About seeing a number of different practitioners in search of help'. These two items seem to be measuring an additional aspect and something more specific than just managing condition/pain guilt, which is related to feeling guilty towards practitioners. Other managing condition/pain guilt items do not address this particular aspect (the model diagram is presented in Figure 5:2).

The model fit was significantly improved over the initial model, $\Delta\chi^2(3) = 145.65, p < .001$. All indicators of model fit suggested that the adjusted model had an adequate to good fit with the data. All the items had high standardised regression weights ranging between .50 and .92 and which were statistically significant ($p < .001$), apart from the standardised regression weight between HADS7 and Anxiety (.06), which was not significant ($p = .491$). However, it was significant in the initial and first model (see Table 5:2) in which HADS7 was an indicator of anxiety, but not depression. Correlations between the five latent variables were all significant ($p < .001$) and positive ranging between .41 and .80 (see Table 5:3).

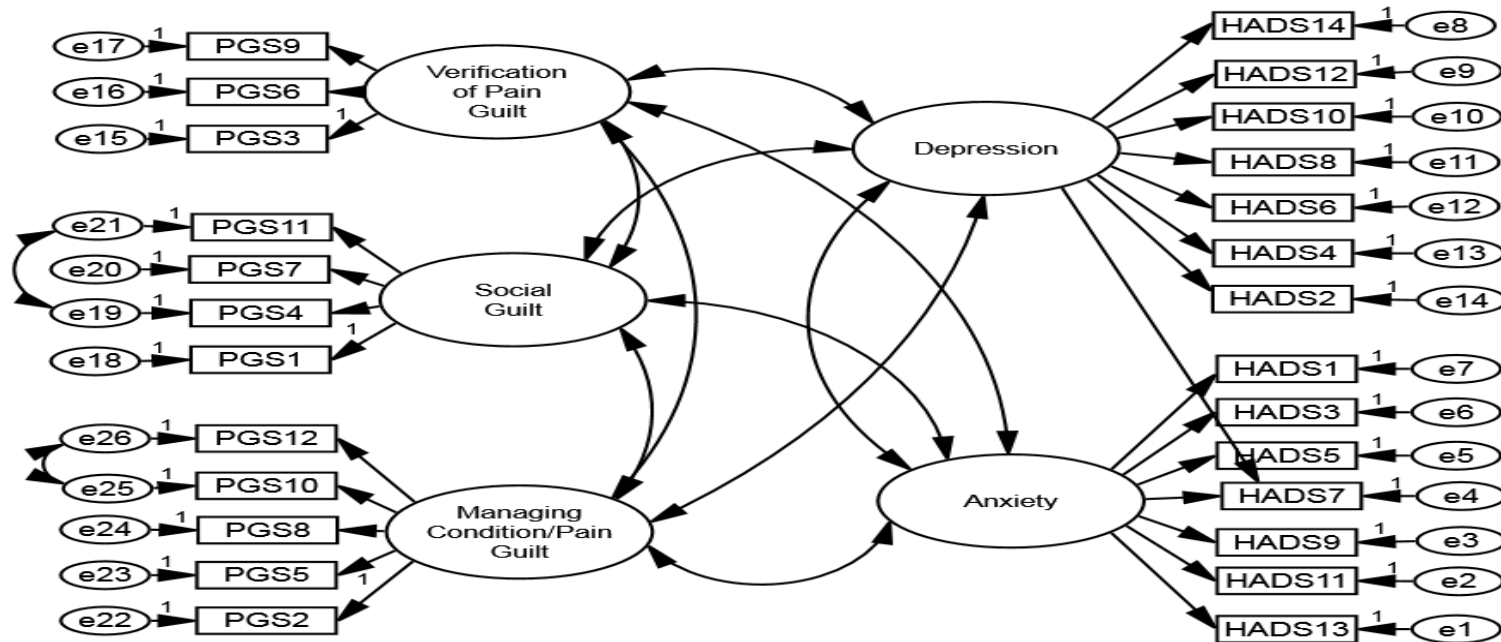


Figure 5:2 *Confirmatory Factor Analysis of the Measurement Model*

Standardised regression weights are omitted for clarity and these are summarised in the manuscript; PGS – Pain-related Guilt Scale, HADS – Hospital Anxiety and Depression Scale

Table 5:2 *Fit indices for the Confirmatory Factor Analysis*

Model	χ^2	χ^2/df	RMSEA	SRMR	GFI	AGFI	CFI	TLI
1. Initial	$\chi^2(289) = 791.05, p < .001$	2.74	.065	.056	.863	.834	.925	.915
2. As Model 1 with error terms of 2 social guilt items covaried	$\chi^2(288) = 727.44, p < .001$	2.53	.061	.056	.873	.845	.934	.925
3. As Model 2 with HADS7 as an indicator of both anxiety & depression	$\chi^2(287) = 627.05, p < .001$	2.34	.057	.050	.885	.859	.942	.934
4. As Model 3 with covaried error terms of 2 managing condition/pain guilt items	$\chi^2(286) = 645.39, p < .001$	2.26	.055	.050	.889	.864	.946	.939

N = 413; RMSEA- Root Mean Square Error Approximation, SRMR- Standardised root mean square residual, GFI-Goodness of Fit Index, AGFI-Adjusted goodness-of-fit index, CFI- Comparative fit index, TLI- Tucker Lewis index

Structural Models

Pre-Mediation Model 1

Confirmatory factor analysis of the measurement model showed that the modified model fit was adequate to good. This modified model was entered into the structural model which was tested next. In order to examine the mediation statistically, first a SEM analysis was conducted on the pre-mediation model presented in Figure 5.1, (which does not include pain-related guilt subscales as mediators; as explained in the method section).

The data fulfilled criteria for univariate (Kline, 2011) and multivariate normality (Bollen, 1989; Raykov & Marcoulides, 2008). The skew index ranged from -.62 to 1.25 and kurtosis index ranged from -1.89 to .86. Following Kline's (2011) recommendations that the skew and kurtosis indices should be within 3 and 10 respectively, the data in this study are regarded as normal. There also was multivariate normality; the Mardia's coefficient was 17.90, which is lower than the computed value of 323 based on the formula $p(p+2)$ where p equals the number of observed variables in the model (Bollen, 1989; Raykov & Marcoulides, 2008).

The model fit was marginally acceptable (see Pre-mediation Model 1 in Table 5:4). Significant standardised path coefficients (regression weights) can be seen in Table 5:4. Table 5:4 shows that standardised path coefficients between diagnostic uncertainty, and depression and anxiety were significant. Standardised path coefficients between pain intensity and disability, depression and disability, disability and depression and disability and anxiety were also significant.

Model 1

The full model (including pain-related guilt as mediating variables) was then tested with a SEM. The data fulfilled criteria for univariate (Kline, 2011) and multivariate normality (Bollen, 1989; Raykov & Marcoulides, 2008). The skew index ranged from -.62 to 1.25 and kurtosis index ranged from -1.89 to .87. Following Kline's (2011) recommendations that the skew and kurtosis indices should be within 3 and 10 respectively, the data in this study are regarded as normal. There also was multivariate normality; the Mardia's coefficient was 74.39, which is lower than the computed value of 899 based on the formula $p(p+2)$ where p equals the number of observed variables in the model (Bollen, 1989; Raykov & Marcoulides,

2008). Table 5:3 shows zero order correlations between all variables within the model, which were all positive and significant.

The model chi square and fit indices are reported in Table 5:4. Model fit was adequate to good. The inclusion of pain-related guilt variables as mediators between diagnostic uncertainty and outcome variables resulted in a significant improvement in the overall fit from the pre-mediation model, $\Delta\chi^2(241) = 496.42, p < .001$. Thus this model provided a significantly better fit with the data.

Correlation between the three PGS subscales, anxiety and depression residuals were also all positive and significant. All standardised path coefficients are reported in Table 5:5. Table 5:5 shows that diagnostic uncertainty was not directly correlated with depression, but the relationship was significant through social guilt. Diagnostic uncertainty was not directly correlated with anxiety, but it was through both managing condition/pain and verification of pain guilt (although the latter path was only marginally significant).

Standardized path coefficients between diagnostic uncertainty and the three PGS subscales were all positive and significant. Being uncertain about diagnosis positively correlated with all three types of pain-related guilt. These correlations were moderate but significant. Participants who experienced social guilt (about letting down family and friends) were more likely to have more anxiety, depression and disability. The correlation between social guilt and disability was particularly strong (.834). Participants who had guilt about absence of objective evidence and diagnosis were more likely to have less anxiety (although this zero-order correlation was positive). Managing condition/pain guilt was significantly correlated with anxiety; participants who had a guilt about being unable to overcome and control pain were more likely to be more anxious. Pain intensity, anxiety and depression were also significantly positively correlated with disability. Disability was significantly correlated with depression but not with anxiety.

Alternative Models 2 and 3

Fit indices for Model 2 and 3 were slightly better than for the hypothesised Model 1 and their AIC and EVCI were marginally lower (see Table 5:4). Fit indices for Model 2 were slightly better than for Model 3 and its AIC and EVCI were marginally lower. Direct and indirect effects for both alternative models are reported in Table 5:5. The table shows that in both alternative models anxiety was positively

correlated with managing condition/pain guilt. Depression was positively correlated with all three types of guilt, and it was positively correlated with disability through social and managing condition/pain guilt. Social guilt was positively correlated with disability while managing condition/pain guilt was negatively correlated with disability. Correlations between pain and disability, and disability and depression/anxiety were all significant.

Table 5:3 *Zero Order Correlations Between the Variables in the Models*

	Pain intensity	Anxiety	Depression	Disability	Verification of pain guilt	Social guilt
Certain about diagnosis (N=240)						
Anxiety	.29**					
Depression	.35**	.68**				
Disability	.55**	.48**	.60**			
Verification of pain guilt	.29**	.43**	.40**	.33**		
Social guilt	.38**	.54**	.63**	.62**	.58**	
Managing condition/pain guilt	.43**	.57**	.55**	.48**	.72**	.74**
Uncertain about diagnosis (N=173)						
Anxiety	.18*					
Depression	.35**	.60**				
Disability	.49**	.35**	.52**			
Verification of pain guilt	.37**	.21**	.31**	.21**		
Social guilt	.51**	.40**	.55**	.65**	.47**	
Managing condition/pain guilt	.46**	.44**	.41**	.42**	.69**	.64**

*Pearson correlations are reported, all two tailed and significant; * $p < .05$, ** $p < .001$*

Table 5:4 *Fit Indices for the Structural Models*

Model			χ^2	χ^2/df	RMSEA	SRMR	GFI	AGFI	CFI	TLI
Pre-mediation Model 1			$\chi^2(112) = 351.48, p < .001$	3.14	.072	.055	.903	.867	.909	.890
	AIC	EVCI								
Model 1	1011.87	2.456	$\chi^2 (353) = 847.87, p < .001$	2.402	.058	.086	.871	.841	.931	.921
Model 2	972.45	2.365	$\chi^2 (353) = 810.45, p < .001$	2.296	.056	.058	.873	.844	.936	.927
Model 3	979.66	2.378	$\chi^2 (355) = 819.70, p < .001$	2.309	.056	.064	.873	.844	.935	.926

N = 413; RMSEA- Root Mean Square Error Approximation, SRMR- Standardized root mean square residual, GFI-Goodness of Fit Index, AGFI-Adjusted goodness-of-fit index, CFI- Comparative fit index, TLI- Tucker Lewis index, AIC- Akaike Information Criterion, EVCI - Expected cross-validation index.

Table 5:5 Significant Direct and Indirect Effects for all Structural Models

Pre-mediation Model 1		(Hypothesised) Model 1		(Alternative) Model 2		(Alternative) Model 3	
Direct effects	β	Direct effects	β	Direct effects	β	Direct effects	β
DU→Dep	.122**	DU→SG	.144**	Anx→MG	.226**	Anx→MG	.246**
DU→Anx	.145**	DU→MG	.226***	Dep→SG	.586***	Dep→SG	.544***
Pain→Dis	.653***	DU→VG	.394***	Dep→MG	.532***	Dep→MG	.453***
Dis→Dep	.733***	SG→Anx	.292*	Dep→VG	.568***	Dep→VG	.437***
Dis→Anx	.400***	SG→Dep	.331**	VG→DU	.610***	DU→VG	.321***
Dep→Dis	-.477*	SG→Dis	.834***	MG→Dis	-.463*	DU→MG	.119**
		VG→Anx	-.222*	SG→Dis	.771***	MG→Dis	-.412*
		MG→Anx	.581***	Dis→Anx	.446***	SG→Dis	.744***
		Dep→Dis	-.493*	Dep→Dis	-.713**	Dis→Anx	.414***
		Pain→Dis	.466***	Pain→Dis	.725***	Dep→Dis	-.627**
		Anx→Dis	.610**	Anx→Dis	.441*	Pain→Dis	.650***
		Dis→Dep	.373**	Dis→Dep	.820***	Anx→Dis	.371*
						Dis→Dep	.757***
Indirect effects		Indirect effects		Indirect effects		Indirect effects	
Pain→Dis→Anx	.261***	DU→SG→Dep	.048*	Dep→MG→Dis	-.246*	Dep→MG→Dis	-.187*
		DU→SG→Dis	.120*	Dep→SG→Dis	.452***	Dep→SG→Dis	.405***
		DU→VG→Anx ^a	-.087*	Dep→VG→DU	.253***		
		DU→MG→Anx	.131**	Pain→Dis→Anx	.323***		
		Pain→Dis→Dep	.174**				

^a This indirect effect was marginally significant, $p = .0508$; DU-diagnostic uncertainty, SG-social guilt, VG-verification of pain guilt, MG – managing condition/pain guilt, Anx – anxiety, Dep- depression, Dis – disability, β – standardized coefficients; * $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

Main Findings

The study examined a theoretical model (Model 1) which hypothesised that diagnostic uncertainty predicts pain-related guilt which in turn predicts depression, anxiety and disability in chronic LBP patients. The group that included patients who were uncertain about their diagnosis had higher levels of depression and anxiety than the certain group, supporting to an extent prior research cited in the introduction (Geisser & Roth, 1998; Reesor & Craig, 1988); and, it adds to it by identifying one specific factor which together with diagnostic uncertainty is associated with mood and disability.

The study explored two additional models of pathways via which pain-related guilt and diagnostic uncertainty might fit into a mechanism associated with disability in LBP. Model 2 included pathways from anxiety and depression to guilt which are in turn associated with diagnostic uncertainty and finally with disability. Model 3 included independent pathways from depression and anxiety, and diagnostic uncertainty to guilt, followed by disability. All three models had a good fit with the data, but the best model was Model 2, emphasising the probable role of mood in mechanisms. Model 2 and Model 3 had significantly better fit with the data than the first hypothesised model, but in all three models fit indices were very similar, suggesting that all three models are viable. Despite the limitations associated with cross-sectional designs, the findings highlight the roles played by both guilt and diagnostic uncertainty.

Due to a large number of relationships examined within the three theoretical models (many of which are reversed), and in order to enable an easy to follow interpretation of these findings, the following section will be organised according to three major groups of variables examined within these models: pain-related guilt, diagnostic uncertainty and mood. It will discuss specific findings, fit with past research and theoretical and clinical implications relevant to these variables. However, in order to avoid repetition, these findings will be interpreted in light of

psychological models (reviewed in the literature review) in the final chapter of the thesis.

Pain-Related Guilt

Pain-related guilt in all three models was significantly correlated with mood and disability. Findings suggest that not all types of guilt are equally important and they highlight some specific relationships between the different types of guilt, disability and mood. Feeling guilty about letting down others because of pain (social guilt) was significantly correlated with (predicting) depression, anxiety and disability in Model 1. While depression appears to be closely linked with (predicting) all types of guilt in Model 2 and 3, anxiety appears to be associated most closely with guilt about failure to manage ones pain. The association between social guilt and disability is particularly high and promising; and both direct and indirect paths (from depression via social guilt to disability) in these models were significant. While the causal path between these two variables is unknown, the possibility of a 'vicious cycle' in which disability increases social guilt, and the response to social guilt is further withdrawal from social engagement, in turn increasing isolation, disability and depression, warrants further investigation.

Thus, the findings show that social guilt is associated with both depression and disability. This begs the question, through which other mechanisms social guilt may be associated to disability. One explanation could be through avoidance behaviours: in an attempt to reduce or avoid negative feelings of guilt people withdraw from social interactions, resulting in increased isolation and reduced daily activities. Study 1 findings showed that LBP patients reported distancing themselves from other people to avoid feeling guilty about their pain-related behaviours. This suggests that future research should examine how aspects of the fear-avoidance model of pain (Vlaeyen & Linton, 2000) may interact with pain-related guilt and lead to negative outcomes. This is discussed in more detail in the overall discussion in Chapter 7. Social guilt might also be addressed through education, and an implication of these findings is that it might be necessary to allow time and training to health care professionals to address these issues and help their patients to reduce

feelings of guilt, unrealistic expectations and responsibility. Overall, the current findings suggest that social guilt may be a risk factor for negative outcomes, and/or a negative outcome of pain-related depression, and therefore a promising target for psychological interventions.

Managing condition/pain guilt was predicted by both anxiety and depression in Model 2 and 3, suggesting that this type of guilt is associated with worry and depression in LBP patients. Study 1 and past research (Verbeek et al., 2004) suggested that this may be related to an increased search for remedy, unrealistic expectations and consequently increased health care utilisation. This study's findings seem to support this and may also suggest that a prominent focus of worry in these patients is on the treatment and management of their back pain (Verbeek et al., 2004). Therefore, it seems that this particular type of guilt could be largely addressed during consultations by discussing patients' concerns and providing appropriate advice and reassurance.

Of interest is the negative relationship between guilt about failure to manage pain and disability, evident in Model 2 and 3. The zero-order correlations between these variables were positive. This finding might be an artefact of the interaction between the three types of guilt in the model. On the other hand, this could be explained through a positive behavioural response to guilt, in which patients who feel guilty about their failure to respond to interventions increase their levels of activity and are more motivated to recover, resulting in lower rates of disability. Alternatively, high rates of guilt about failure to manage one's pain might affect responses to the disability questionnaire items, and result in lower scores. Future research should address this issue and examine if this pattern of results occurs in new samples. Furthermore, although the correlation between verification of pain guilt and anxiety was positive in Model 1, verification of pain guilt was a negative predictor of anxiety in this model. This finding is also difficult to interpret. However, it should be noted that verification of pain guilt accounted for only a very small percentage of variance in anxiety, which fits with a systematic review by Rolfe and Burton (2013) showing that getting negative tests does not reassure patients with high uncertainty.

Overall, the results support the findings from Study 1, 2 and 3 of this thesis and other studies (e.g. Snelgrove, Edwards, & Lioffi, 2013) which show that pain-

related guilt is a common experience among patients with LBP and is related to disability and mood. High levels of pain-related guilt were reported in Study 2 and 3 of this thesis by over 40% of participants with LBP. Several qualitative studies have suggested that an important focus of pain-related guilt is social. Thus, patients have reported feelings of guilt about letting their family down and about family members undertaking their responsibilities (Snelgrove et al., 2013) and feeling guilty in their marital interactions (Newton-John & Williams, 2006). In the context of uncertainty and absence of objective tests to verify their pain, patients report feeling guilty for 'letting the doctor down' (Rhodes et al., 1999). The results are also in line with another study findings (Harris, Morley, & Barton, 2003) which asked participants with chronic pain to identify four social roles in four domains (friendship, occupation, leisure, family) and identify two personal attributes in each role prior to pain onset. It found that both social roles and attribute loss were associated with depression. Controlling for demographic and clinical differences did not impact on this relationship.

Diagnostic Uncertainty

The relationship of diagnostic uncertainty to other factors appears more modest, although significant. Focusing specifically on the relationship between diagnostic uncertainty and pain-related guilt, the results from Model 1 and 3 could be compared to Model 2 (the best model). It was observed that in Model 2 out of the three types of guilt only verification of pain guilt predicted diagnostic uncertainty. When the relationship was reversed in Model 1, diagnostic uncertainty predicted all three types of guilt, while in Model 3 diagnostic uncertainty predicted verification of pain guilt and managing condition/pain guilt. These relationships were moderate, but significant, suggesting that the diagnostic uncertainty is associated with guilt. However, it should be taken into consideration that even modest associations should be considered informative in studies of LBP (Hayden et al., 2010), as they may contribute to our understanding of the mechanisms leading to poorer outcomes when used in longitudinal designs. The current study findings fail to offer definite evidence about whether mood and guilt result in diagnostic uncertainty, or whether diagnostic

uncertainty increases depression and anxiety, possibly through increased guilt. However, the findings propose that the first pathway may be more likely.

The findings are in line with the findings from Study 1. The findings also indirectly support other research, for instance, a recent systematic review based on 28 qualitative studies of LBP and sciatica patients' experiences of health services showed that the importance of a diagnosis and having pain legitimised were among the key themes extracted (Hopayian & Notley, 2014). This review showed that absence of a diagnosis made managing pain more difficult and some participants reported that it led to 'delegitimation', a feeling of not being believed. This review specifically focused on patients without clear diagnosis for their pain.

Mood

While the causal mechanisms linking depression and anxiety to guilt and to diagnostic uncertainty remain unclear, Model 2 and 3 suggest that mood plays a pivotal path in mechanisms leading to increased disability. Overall, the two alternative models show that depression is associated with all three types of guilt. Model 2, which was a marginally better model, suggests that depression drives pain-related guilt, and that certain types of pain-related guilt mediate (statistically) between depression, disability and diagnostic uncertainty. More specifically, Model 2 and 3, suggest that social and managing condition/pain guilt mediate between depression and disability. While Model 2 suggests that verification of pain guilt mediates between depression and diagnostic uncertainty.

Anxiety was positively correlated with guilt over one's inability to manage the condition and recover in Model 2 and 3. Past research (Verbeek et al., 2004) suggested that this may be related to an increased search for a cure, and consequently increased health care utilisation. This may also suggest that these patients have unrealistic expectations about the treatment and management of their back pain, which is in line with the results from Study 1 and other research (reviewed in Verbeek et al., 2004). The findings add to a large body of evidence suggesting that eliciting and addressing depression and anxiety should be a priority in LBP,

especially in light of evidence suggesting that current practice fails to do so adequately, especially in primary care (van der Windt, Hay, Jellema, & Main, 2008).

Strengths and Limitations

In order to improve the outcomes of interventions in LBP it is necessary to understand better the specific mechanisms that lead to poor outcomes (McCracken & Morley, 2014; Pincus & McCracken, 2013). Therefore, strength of the study is that the theoretical models it examined focused on two potential mechanisms, diagnostic uncertainty and pain-related guilt. The study used advanced statistical procedures to investigate the models. Structural equation modelling has clear advantages over other, less efficient approaches in that it can examine complex relationships between prognostic factors on outcomes in LBP (Hayden et al., 2010; Kline, 2011). According to McCracken and Morley (2014) theoretical models are useful in respect to at least three aspects: a) models should be practical and easy to understand; this can be achieved by integrating research findings into a reduced number of principles rather than introduce several variables without clearly organising them; b) a model should explicitly state goals; c) a model should continuously encourage progress, for example through constant revisions of the model and ability to influence treatments, methods and measures used. The models assessed in this study are parsimonious and integrative models and these were based on previous research; hence the models appear to have satisfied the first two recommendations stated above. Its theoretical implication (relevant to the third recommendation) is that it has produced clear hypotheses to be tested by future research. For example, it revealed that social guilt is a prominent type of guilt in LBP, closely linked to mood and disability; the next step is to examine the nature of these relationships and inspect their direction by using longitudinal and experimental methodology.

This is the very first study to examine the role of pain-related guilt in the context of diagnostic uncertainty and their relationships with mood and disability; therefore these findings should be retested and replicated in new samples. Finally, the sample was varied and representative of both participants who were treated and those

that were not seeking treatment for their back pain. It was also representative of both private and NHS patients.

There are also several limitations. Although the (causal) path models have been argued to assess causality between a set of variables, causality cannot be established in the absence of experimental design and a timeline (Klein, 2011). The study was cross sectional and therefore causation cannot be inferred from the findings. Prospective research should be employed in future to verify the direction of relationships, and subsequent trials can explore causal links by manipulation of hypothesised variables. The current study only examined statistical mediation; full mediation/moderation analysis should be carried out in future studies using prospective methodology. Should pain-related guilt prove to be a mediator/moderator of patient outcomes or perhaps an outcome of mood, it could potentially become an explicit target in interventions.

However, this research is in early stages and there is a need to be cautious about interpretation of the findings, for example, moderate correlations between diagnostic uncertainty and pain-related may suggest that the diagnostic uncertainty measure used in this study was not sensitive enough to capture participants' perceptions about their diagnosis, and that a continuous measure might have enabled a better insight into those. Alternatively, it may suggest that diagnostic uncertainty is strongly influenced by health anxiety. However, even though some associations were small they seem to be of sufficient size to merit interest.

While the findings may be due to limitations in the measure of diagnostic uncertainty, they also suggest that there are other factors that contribute to pain-related guilt, for example feeling guilty during periods of absence from work due to the impact of this on work colleagues (Wynne-Jones et al., 2011). Research on pain-related guilt is extremely limited, and is mainly reported in qualitative studies that did not specifically set out to study guilt. Thus, inclusion of other contributing factors in the model at this stage would be speculative. Additionally, research evidence suggests that guilt is culturally distinct (Bedford & Hwang, 2003; Tilghman-Osborne et al., 2010); therefore the current research findings may not be entirely applicable in non-western

cultures. The clinimetric qualities of the PGS were fully assessed in the discussion of Chapter 4 and will be summarised in Chapter 7.

Although the current models may appear to be restrictive, it provides directions for further research by identifying potential issues, and it points towards potential hypotheses to be tested in the future (McCracken & Morley, 2014). This may require a longitudinal designs as well as experimental manipulation.

Conclusion

This study is the first investigation to systematically examine relationships between diagnostic uncertainty and pain-related guilt, and mood and disability in chronic LBP patients. Taken together, these findings suggest that diagnostic uncertainty is moderately associated with pain-related guilt. However, a more sensitive measure may be needed to fully understand the strength and meaning of this association. The findings from this study indicate that the relationship between pain-related guilt, diagnostic uncertainty and mood is complex. Pain-related guilt, especially the social aspect of guilt, is an important factor closely associated with disability and mood. Future research should focus on further clarifying these mechanisms using longitudinal designs.

Chapter 6

Diagnostic Uncertainty and Recall Bias in Chronic Low Back Pain: An Experimental Study

Abstract

The previous findings (Study 1 and 4) suggest that diagnostic uncertainty can be perceived as a measure of perceived diagnostic status and that it is associated with mood and disability in low back pain (LBP). Past research showed that pain patients' beliefs and their cognitive processing of pain-related information have both been shown to be associated with poorer prognosis in LBP, but the relationship between perceived diagnostic status and specific cognitive processes is not known. The aim of this study was to study the relationship between perceived diagnostic status, more specifically diagnostic uncertainty and recall bias in two groups of chronic LBP patients, those who were certain about their diagnosis, and those who believed that their pain was due to an undiagnosed problem. Patients (N=68) endorsed and subsequently recalled pain, illness, depression and neutral stimuli. They also provided measures of pain, diagnostic status, mood and disability. Both groups exhibited a recall bias for pain stimuli, but only the group with diagnostic uncertainty additionally displayed a recall bias for illness-related stimuli. This bias remained after controlling for depression and disability. Sensitivity analyses using grouping by diagnosis/explanation received, supported these findings. Higher levels of depression and disability were found in the group with diagnostic uncertainty, but levels of pain intensity did not differ between the groups. Although the methodology does not provide information on causality, the results provide evidence for a relationship between diagnostic uncertainty and recall bias for negative health-related stimuli in chronic LBP patients.

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Introduction

The findings from the previous chapter suggest that pain-related guilt is an emotional mechanism that mediates the relationship between diagnostic uncertainty and mood and disability in chronic low back pain (LBP). The current study will examine recall bias, which is a specific cognitive mechanism that might also underlie this relationship.

Patients' beliefs and expectations about their pain have been shown to predict prognosis in chronic pain (Henschke et al., 2008; Iles, Davidson, & Taylor, 2008; Main et al., 2010). The identification of subgroups of people with (LBP) has been outlined as a priority, in order to modify interventions to match patients' obstacles to recovery (Dankaerts & O'Sullivan, 2011); thus it is important to conduct group comparison based on patients' beliefs about their pain. Amongst these beliefs, catastrophic thinking appears to be particularly important (Quartana et al., 2009). Research reported in Chapter 3 showed that diagnostic uncertainty is also important, specifically, the findings showed that diagnostic uncertainty predicted mood and disability through pain-related guilt. This is supported by past research reviewed in Chapter 2, overall this research provided evidence (mainly from qualitative studies) that the absence of a clear diagnosis and explanation are associated with negative social, cognitive and emotional functioning (Froud et al., 2014; Geisser & Roth, 1998; Hopayian & Notley, 2014). Additionally, Study 1 findings showed that patients who are uncertain about their condition continue searching for a diagnosis; this may place an extra burden on health services and prevent patients from directing their attention to other aspects of life. Study 1 findings also showed that cognitive implications of unclear diagnosis in chronic LBP relate to being uncertain and unable to attach a meaning to the condition, a process which is necessary to achieve psychological recovery from distressing health-related events (Taylor, 1983).

However, a better understanding of cognitive mechanisms underlying the relationship between diagnostic uncertainty and mood and disability is needed. Could cognitive biases, such as recall bias be one such mechanism? This study will specifically focus on recall biases. Recall bias has been chosen over other cognitive biases due to its link with depression (Pincus & Morley, 2001), thus, it is more likely to be also connected to guilt (O'Connor et al., 2002; Tilghman-Osborne et al., 2010). Chapter 2 provides a summary of research relevant to recall biases. Overall, it outlined that cognitive biases are due to individuals selectively processing certain types of information in preference to other types of information. Cognitive biases have been observed in pain patients and regarded as a risk factor for the development and maintenance of chronic disability (Pincus & Morley, 2001), and they have also been linked to higher health care costs in one study (Pincus & Newman, 2001). A review of evidence (Pincus & Morley, 2001) suggests that one of the methodologies that have yielded robust significant differences in cognitive biases between pain patients and other groups is memory (recall) for words encoded in reference to the self. Individuals show a tendency to recall material that is congruent with their existing state and their concerns. The key role in this process is played by schemas which can be described as mental frameworks that represent existing knowledge and provide a context for learning new knowledge (Sternberg & Mio, 2009). As memory is generally perceived responsible for constructing representations of the self (Eysenck & Keane, 2010), Pincus and Morley (2001) argued that memory biases can help explain representations of the self in chronic pain patients by examining the relationship between three schemas: self, pain and illness. Their scheme enmeshment model (SEMP) of information processing (described in more detail in Chapter 2) explains recall bias in chronic pain patients through the overlap or enmeshment of these three schemas. The authors propose that biases towards pain related information in pain patients might be a normal adaptation to pain, while biases towards illness or depressed stimuli are reflective of unhelpful schemas, may maintain distress and suggest that illness information is enmeshed with the self-schema.

To date, there has been no direct comparison between recall bias in people with LBP who perceived their condition to be unexplained and undiagnosed, and

those who perceived their condition to have an acceptable diagnostic label. The relationship between recall biases and diagnostic status has been previously explored in one study only (Wells et al., 2003) (see Chapter 2 for a description of this study). However, the participants in this study were a heterogeneous group of chronic pain patients and their satisfaction with their diagnosis was not examined. The findings showed that diagnosed chronic pain patients recalled fewer depression stimuli compared to pain, illness and neutral stimuli, suggesting a recall bias away from depression stimuli, while non-diagnosed chronic pain patients did not exhibit better or worse recall towards any stimuli category. These findings suggest that recall patterns in the diagnosed and undiagnosed chronic pain patients vary and indicate differences in their cognitive processing.

Previous research has demonstrated that recall bias towards illness-related stimuli is also associated with high rates of depression (Pincus et al., 1995). Because of the proposition (based on Study 5 findings) that diagnostic uncertainty is related to increases in depression, a set of stimuli related to depression is also included in the study.

The current study aimed to compare recall of specific stimuli sets in two groups of patients with LBP: those who perceive themselves to have a clear and acceptable diagnosis, and those who believe that there is something else unexplained going on with their condition and pain. It is hypothesised that both groups would replicate previous findings for a bias towards pain stimuli, but that only the group of patients high in uncertainty would selectively recall words related to illness, reflecting these patients' preoccupation with the meaning and consequences of their pain.

Method

Participants

A total of 80 participants with mechanical chronic LBP were recruited from the pain management services in two UK hospitals: St Mary's and Charing Cross hospital in London. Participants were presenting for assessment and/or treatment. Inclusion criteria were that participants be between ages of 18-65, speak fluent

English and have musculoskeletal chronic LBP with pain duration of at least 3 months. Participants with back pain due to ankylosing spondylitis, osteoporosis, cancer and inflammatory conditions such as rheumatoid arthritis were excluded. These inclusion criteria were checked for each participant by their clinician before they were invited to participate in the study and via a screening questionnaire (see Appendix N). However, it was not possible to keep a record of how many patients were approached, and how many refused to take part in the study; therefore response rates could not be calculated. The study received ethical approval from the National Health Service (NHS) ethics committee (see Appendix K) and the university research ethics committee (see Appendix E). General ethical procedures were identical to those described in Chapter 3.

Materials and Procedure

Participants were first screened by their clinicians in the two participating pain clinics. They were then given the screening questionnaire which included demographic questions and questions about their pain, other conditions and diagnosis. They also were asked to indicate if they agree to take part in the study.

The testing was conducted in the clinics, in a quiet room, and it took place either before or after patients' appointment with their clinician. The study began with patients being informed about the study and signing the consent form (see Appendix O). They were not informed of the study hypothesis and exact purpose of the study at this stage. They were informed of this after they completed the study. The testing began with a computer-based task. The task was created and delivered using DMDX software programme (Forster & Forster, 2003) and it included 32 words (all adjectives): 8 pain related which describe immediate properties of pain (pounding, sore, pricking, tingling, pounding, itchy, aching, hurting), 8 illness related which describe the consequences of illness (vulnerable, suffering, disabled, dependent, ill, uncomfortable, helpless, stiff), 8 depression related which describe salient aspects of depression (inefficient, inadequate, lazy, boring, guilty, withdrawn, unlovable, unlikable), and 8 neutral (nosey, obnoxious, crude, discourteous, ungrateful, phoney, thoughtless, uncivil). Depression and neutral adjectives were taken from previous research (Greenberg & Alloy, 1989; Pincus et al., 1995; Pincus, Pearce, McClelland,

& Turnerstokes, 1993), where the adjectives had been matched for social desirability, word frequency, and length. Illness and pain adjectives were taken from previous recall bias studies in chronic pain patients (Pincus et al., 1995; Pincus et al., 1993). The complete set of stimuli was also used in the Wells et al. (2003) study, which addressed the relationship between recall bias and diagnostic status in chronic pain (described in Chapter 2).

The words were presented in white letters (font type: Times New Roman; font size: 36) against a black background on a laptop computer (12.1 in.; 1280 x 800-pixel resolution) positioned approximately 50 cm in front of seated participants. Right and left shift keys were labelled with 'yes' and 'no' respectively. The task was preceded by written instructions on the screen, which participants were asked to read and then these were rephrased by the researcher (the author of this thesis) in order to ensure that the instructions were clear and understood:

You will be presented with some words that may describe you or your pain. Before each word is presented, the following question will appear on the screen: 'Does the following word describe you/your pain?'. Press the right SHIFT button if YES, that is if this word describes you or your pain. Press the left SHIFT button if NO, that is if the word does NOT describe you or your pain. Please respond as quickly as possible, the first response that comes to your mind is probably the most accurate. You will be presented with some practice questions first. Press SPACEBAR to start practice questions.

Words were presented on the computer screen in a random order (different for each participant), with the restriction that no two words from the same category were presented in succession. Preceding each 'pain' word was the cue question, 'Does the following word describe your pain?' Preceding all other words was the cue question, 'Does the following word describe you?' The cue question facilitated encoding of the words in relation to the self. It was presented for three seconds, followed by a delay of 500 milliseconds, before the appearance of the target word (Pincus et al., 1995). The participants were expected to respond to the target word by answering 'yes' or 'no' as quickly as they could, by pressing either right or left shift key on the

keyboard. As soon as a response has been made or after 3500ms, the next cue question was presented. The 32 words were preceded by 6 practice trials at the beginning, in order to familiarise participants with the procedure. Following the practice trials (these six words were used: careful, educated, short, disrespectful, exciting, lovely), an additional three adjectives (interesting, original, pleasant) were presented to control for primacy effects as well as three adjectives (honest, immoral, flexible) at the end to control for recency memory effects (Pincus et al., 1995).

On completion of the computer task, participants were asked to complete a filler task (Pincus et al., 1995) for two minutes in which they were presented with two nearly identical images (see Appendix P) and were asked to identify differences between them. The filler task was used to avoid short term memory effects and prevent participants from rehearsing the information. Participants then recalled as many of the previously presented words in a surprise recall test. No time limit was imposed on the recall task.

Finally, the participants were asked to fill in the questionnaire (see Appendix M) containing the following measures which were all described in the preceding chapters:

Perceived Diagnostic Status - the questions were developed from Study 1 findings and their development is described in Chapter 3. The main question was related to diagnostic uncertainty: 'I think there is something else happening with my back which the doctors have not found out about yet (yes/no)'. Two other questions were asked relating to being given clear labels and explanations for back pain: 'I have been given a clear label/diagnosis for my back pain (yes/no)'; 'I have been given a clear explanation about why I have back pain (yes/no)'. If the participants answered 'yes' to these two questions, they were also asked whether they agreed with the diagnosis/explanation given.

The following measures were also used in the study and they were described in more detail in Chapters 3 and 4:

'Pain-related Guilt Scale' (PGS, developed from Study 1 findings and validated in Study 2 and 3); 'Demographics and pain details': participants were asked to supply details about age, gender, duration of their back pain, and other

health-related problems. 'Anxiety and depression': the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). 'Disability': Roland Disability Questionnaire (RDQ) (Roland & Morris, 1983). 'Pain intensity' (Cleeland & Ryan, 1994).

Design and Analysis

The research design was a 2 (between-group, levels of certainty about diagnosis) x 4 (within-group, word type) mixed factorial design. In the primary analysis the two groups were a priori categorised on the basis of participants' self-report answers to the following question: 'I think there is something else happening with my back which the doctors have not found out about yet (yes/no)'. In a secondary sensitivity analysis groups were categorised on the basis of participants' answers to the following questions: 'I have been given a clear label/diagnosis for my back pain (yes/no)', and 'I have been given a clear explanation about why I have back pain (yes/no)'. The four levels of the within-group factor were word category (pain, illness, depression and neutral).

The primary outcome measure was the number of words recalled for each word category by each participant. In addition, the number of words endorsed as self-descriptors for each word category and mean reaction time (measured in milliseconds) for each word category were used as secondary measures with the purpose of establishing if they confound the recall data. Speed of response to stimuli is a by-product measure of the methodology used in this study. Response time was recorded in order to control for differences in exposure time to different stimuli (Greenberg & Alloy, 1989; Pincus et al., 1995).

Additional measures were pain intensity, disability, depression and anxiety self-report scores and they were used to compare the two samples.

Sample size calculation using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007) ($\alpha = .05$, $\beta = .80$) was set to achieve a medium effect size and it resulted in a minimum sample size of 62. The sample size in the present study was in excess of this value and therefore satisfied this criteria. The assumption of a medium effect size was based on other studies of recall bias in pain populations (Pincus & Morley,

2001). These were not identical to the current study in design, but in the absence of studies in cognitive bias that compared groups for diagnostic certainty this appeared the most informed assumption.

Data were first screened for outliers and parametric assumptions were inspected; Kolmogorov-Smirnov and Levene's test were reported only for variables violating parametric assumptions. When Levene's test was significant, corrected (for equal variances) t tests were reported. The following statistical analyses were conducted: First, patients' groups were compared on measures of pain intensity, disability, depression and anxiety. For the main (primary) analysis a two-way mixed analysis of variance (ANOVA) with simple planned contrasts was conducted, in order to test the two a-priori hypotheses relating to recall of the four word types in the two groups of chronic LBP patients.

Two sensitivity analyses were also conducted to investigate if the findings from the primary ANOVA could be confirmed, first by grouping participants by diagnosis received, and then grouping them again by the explanation received.

There is evidence (Pincus & Morley, 2001) suggesting that concurrent depression biases recall toward self-referent illness stimuli. Depressed mood is also associated with greater disability (Linton & Bergbom, 2011). This warranted the inclusion of depression and disability as covariates in order to control for their effects; and to this end, an analysis of covariance (ANCOVA) was conducted on recall data and using grouping by diagnostic certainty (which was the primary grouping and analysis).

Secondary two-way mixed analyses of variance were carried out on reaction time and endorsement data. This was done in order to test for the possible confounding effects of group differences on these factors, and if significant, these measures were planned to be entered as covariates in the ANCOVA analysis, together with depression and disability measures.

When the assumption of sphericity was violated, Greenhouse-Geisser correction of degrees of freedom was applied in all analyses of variance and covariance (Field, 2009).

Finally, bivariate correlations between pain intensity, disability, depression, anxiety and word recall were conducted in order to examine associations between these variables. Associations between pain-related guilt scales and word recall were also examined, for exploratory purposes. All analyses were conducted using SPSS statistical package, version 19.0 (IBM, 2010).

Results

Data Preparation

Eighty participants with mechanical chronic LBP were recruited. In the recall analysis, data for three participants were incomplete. On the inspection of outliers, a further nine participants' recall scores (> 5% of the sample) were > 2 standard deviations above the group mean (Field, 2009) and were excluded from the recall analysis. The final sample size for the recall analysis was 68.

In the reaction time and word endorsement analyses, data were incomplete for three and four participants respectively. A further five participants who had >3 (>10%) (Bennett, 2001; Pincus et al., 2011) 3500ms responses, and/or >2 3500 ms responses within the same word category were excluded from the reaction time and endorsement analyses. No further outliers had to be removed (Field, 2009). The final sample size for the reaction time and endorsement analyses was 72 and 71 respectively.

Only words that were either correctly recalled or included the root of the target word correctly (e.g. hurtful instead of hurting, or achy instead of aching) were included in the analysis, provided that the meaning of the word was not changed. Words that included endings that changed the meaning of the target word were excluded.

Description of Sample

Participants' characteristics are reported in Table 6:1. No outliers had to be removed (Field, 2009) and data were normally distributed. The assumption of

homogeneity of variance was met for all variables (Levene's test for all variables was $p > .05$). Independent samples t tests and chi squared tests (for frequency data) were carried out. No significant differences were found for gender, age, pain duration and the presence of comorbidity between the two groups. The only significant differences were found on measures of depression and disability; participants who were uncertain about their diagnosis were more depressed and disabled than those who were certain about their diagnosis.

Participants' responses to the diagnostic status questions are summarised in Table 6:2. Over 40% of participants who reported thinking that there was something else undiscovered going on with their back, also reported that they had received a clear diagnosis and clear explanation for their pain. All participants were screened by practitioners who excluded diagnoses other than mechanical LBP. In spite of this, the diagnostic labels that participants reported being given varied, and included both simple descriptions of their symptoms and concrete diagnostic labels, including several that had in fact been excluded.

Table 6:1 *Sample Characteristics*

	Certain about diagnosis (N=36)	Uncertain about diagnosis (N=32)	Inferential statistics t/X²	Effect size d/odds ratio
Age Mean (SD)	50 (11)	49 (11)	- .20	
Female %	63.9	53.1	.81	
Have comorbidity %	27.8	35.5	.46	
Pain duration>12 months %	91.7	96.8	.77	
Pain intensity Mean (SD)	7.08 (1.99)	7.75 (1.68)	1.51	
Disability Mean (SD)	12.82 (5.68)	16.23 (5.04)	2.61*	.64
Depression Mean (SD)	7.21 (4.29)	10.06 (4.30)	2.74**	.66
Anxiety Mean (SD)	9.89 (6.59)	11.23 (3.44)	1.02	

* $p < .05$; ** $p < .01$, two tailed

"Odds ratio is considered to be a more common and useful measure of effect size for categorical data than other effect size measures (Field, 2009).

Table 6:2 *Participants' Responses to the Diagnostic Status Questions*

	Certain about diagnosis (N=36)	Uncertain about diagnosis (N=32)
Believe clear diagnosis given %	91.7	46.9
Agree with this diagnosis %	100	100
What diagnosis have you been given?	hypermobility, degenerative disc, nerve pain, nerve damage, sciatica, piriformis syndrome, leg nerve damage L4/5 wearing away, trapped nerve, slipped disc at L5/S1 with spinal compression, a tear and something with my disc; scoliosis	nerve damage, LBP, mechanical back pain, scoliosis, OA, disc bulge, L4/5 and disc degeneration, chronic pain syndrome, prolapsed disc L5/S1, wear and tear between discs, narrowing between discs, spondilosis, degenerative wear and tear
Believe clear explanation given %	82.9	43.8
Agree with this explanation %	100	92.9

Analysis of Variance on Recall Data (Primary Analysis)

Homogeneity of variance was met (Levene's test for all variables was $p > .05$). However, data were not normally distributed in the uncertain about diagnosis group for: pain words, $D(32) = .21, p = .001$, illness words, $D(32) = .20, p = .003$, depression, $D(32) = .22, p < .001$, and neutral words, $D(32) = .35, p < .001$. In the certain about diagnosis group: pain words, $D(36) = .16, p = .023$, illness, $D(36) =$

.25, $p < .001$, depression, $D(36) = .30$, $p < .001$, and neutral words, $D(36) = .23$, $p < .001$. As ANOVA is regarded as a fairly robust statistical method (Tabachnick & Fidell, 2013) it was decided to proceed with this analysis. A 2 x 4 mixed ANOVA revealed that there was a significant main effect of word type, $F(2.38, 157.1) = 24.18$, $p < .001$, $\eta_p^2 = .27$). Simple planned contrasts showed that more pain words were recalled than illness words, $F(1, 66) = 25.60$, $p < .001$, $\eta_p^2 = .28$, depression words, $F(1, 66) = 31.20$, $p = .001$, $\eta_p^2 = .32$), and neutral words, $F(1, 66) = 57.55$, $p = .001$, $\eta_p^2 = .47$). There was no significant main effect of group, $F(1, 66) = 3.30$, $p = .074$). There was a significant interaction between word type and group, $F(3, 198) = 5.34$, $p = .001$, $\eta_p^2 = .075$), indicating that the recall for the four types of words differed between the two groups.

This interaction was examined further within each group and using participants' recall for neutral words as a comparison baseline. A repeated measures ANOVA showed that in the group with diagnostic certainty there was a significant main effect of word type, $F(2.16, 75.51) = 22.39$, $p < .001$, $\eta_p^2 = .39$. Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 35) = 32.13$, $p < .001$, $\eta_p^2 = .48$. However, there was not a significant difference between the recall for neutral and illness words, $F(1, 35) = .093$, $p = .76$ and between neutral and depression words, $F(1, 35) = 1$, $p = .32$, indicating that participants in this group selectively recalled pain words only.

In the group with diagnostic uncertainty there was also a significant main effect of word type, $F(2.29, 71.11) = 6.25$, $p = .002$, $\eta_p^2 = .17$). Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 31) = 33.70$, $p < .001$, $\eta_p^2 = .52$, and more illness words were recalled than neutral words, $F(1, 31) = 7.01$, $p = .013$, $\eta_p^2 = .18$. However, there was not a significant difference between the recall for neutral and depression words, $F(1, 31) = 3.93$, $p = .056$. Therefore, participants in this group selectively recalled both pain and illness words. Descriptive statistics are reported in Table 6:3.

Table 6:3 Means and Standard Deviations for Word Recall and Endorsement

	Recall			Endorsement		
	Certain about diagnosis N=36	Uncertain about diagnosis N=32	Total N=68	Certain about diagnosis N=41	Uncertain about diagnosis N=30	Total N=71
Mean (SD)						
Neutral words	.89 (.75)	.56 (.72)	.74 (.75)	2.61 (1.22)	3.63 (1.52)	3.04 (1.44)
Pain words	2.44 (1.48)	1.50 (1.19)	2.00 (1.42)	2.34 (1.39)	3.33 (2.01)	2.76 (1.74)
Illness words	.94 (.86)	1.09 (.93)	1.01 (.89)	2.73 (1.27)	3.97 (1.59)	3.25 (1.53)
Depression words	.72 (.78)	.94 (.80)	.82 (.79)	3.17 (1.50)	4.03 (1.88)	3.54 (1.71)
Total	1.25 (.50)	1.02 (.53)	1.14 (.52)	2.71 (.98)	3.74 (1.49)	3.15 (1.31)

Sensitivity Analyses Using Grouping by Diagnosis Received and Explanation Received

Sensitivity analysis was carried out by repeating the analysis of variance using group categorisation according to diagnosis received, and explanation received. The sample size in the groups reporting that they did not receive a diagnosis (N=20) or an explanation (N=24) was small. Nonetheless, the pattern of results confirmed the main findings in the primary analysis of variance.

Sensitivity Analyses Using Grouping by Diagnosis Received

A 2 x 4 mixed ANOVA revealed that there was a significant main effect of word type, $F(2.38, 198) = 15.08, p < .001, \eta_p^2 = .186$. Simple planned contrasts showed that pain words were significantly more recalled than illness words, $F(1, 66) = 12.88, p = .001, \eta_p^2 = .163$ depression words, $F(1, 66) = 17.45, p < .001, \eta_p^2 = .209$ and neutral words, $F(1, 66) = 39.26, p < .001, \eta_p^2 = .373$. There was no significant main effect of group, $F(1, 66) = .04, p = .85$. There was a significant interaction effect between the word type and group, $F(3, 198) = 4.49, p = .004, \eta_p^2 = .064$.

This interaction was examined further within each group and using participants' recall for neutral words as a comparison baseline. A repeated measures ANOVA showed that in the group with a clear diagnosis there was a significant main effect of word type, $F(2.15, 101.03) = 25.23, p < .001, \eta_p^2 = .35$. Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 47) = 44.46, p < .001, \eta_p^2 = .49$. However, there was not a significant difference between the recall for neutral and illness words, $F(1, 47) = .66, p = .42$ and neutral and depression words, $F(1, 47) = .083, p = .085$. Therefore, participants in this group selectively recalled pain words only.

In the group without a clear diagnosis there was also a significant main effect of word type, $F(3, 57) = 3.18, p = .031, \eta_p^2 = .14$. Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 19) = 18.42, p < .001, \eta_p^2 = .49$, and illness words, $F(1, 19) = 5.62, p = .028, \eta_p^2 = .23$. However, there was not a significant difference between the recall for neutral and depression words, $F(1, 19)$

= 2.27, $p = .15$), indicating that participants in this group selectively recalled both pain and illness words.

Sensitivity Analyses Using Grouping by Explanation Received

Again, the results in this analysis were similar to those in the previous two analyses. A 2 x 4 mixed ANOVA revealed that there was a significant main effect of word type, $F(2.34, 195) = 18.95, p < .001, \eta_p^2 = .23$. Simple planned contrasts showed that pain words were significantly more recalled than illness words, $F(1, 65) = 18.39, p < .001, \eta_p^2 = .22$, depression words, $F(1, 65) = 22.75, p < .001, \eta_p^2 = .26$, and neutral words, $F(1, 65) = 47.05, p < .001, \eta_p^2 = .42$. There was no significant main effect of group, $F(1, 65) = 162, p = .69$. There was a significant interaction effect between the word type and group, $F(3, 195) = 2.73, p = .045, \eta_p^2 = .04$.

This interaction was examined further within each group and using participants' recall for neutral words as a comparison baseline. A repeated measures ANOVA showed that in the group with a clear explanation there was a significant main effect of word type, $F(2.09, 89.84) = 20.66, p < .001, \eta_p^2 = .33$. Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 43) = 35.90, p < .001, \eta_p^2 = .46$. However, there was not a significant difference between the recall for neutral and illness words, $F(1, 43) = .47, p = .50$ and neutral and depression words, $F(1, 43) = .093, p = .76$. Therefore, participants in this group selectively recalled pain words only.

In the group without a clear explanation there was also a significant main effect of word type, $F(3, 69) = 5.43, p = .002, \eta_p^2 = .19$. Simple planned contrasts showed that more pain words were recalled than neutral words, $F(1, 23) = 27.60, p < .001, \eta_p^2 = .55$, and illness words, $F(1, 23) = 6.30, p = .020, \eta_p^2 = .22$. However, there was not a significant difference between the recall for neutral and depression words, $F(1, 23) = 1.96, p = .18$, indicating that participants in this group selectively recalled both pain and illness words.

Secondary Analyses of Variance on Reaction Time and Endorsement Data

Analyses of variance on reaction times revealed a significant main effect for word type, $F(2.72, 210) = 19.12, p < .001, \eta_p^2 = .22$. Simple planned contrasts

revealed that reaction times were slower for pain words than for illness, $F(1,70) = 27.28, p < .001, \eta_p^2 = .28$, depression, $F(1,70) = 20.11, p < .001, \eta_p^2 = .22$ and neutral words, $F(1,70) = 42.08, p < .001, \eta_p^2 = .38$. Main effect for group was significant, $F(1, 70) = 5.38, p = .023, \eta_p^2 = .071$, showing that the group with diagnostic uncertainty responded slower than the certain about diagnosis group. The interaction was not significant, $F(3,210) = .31, p = .82$.

Analyses of variance on endorsement data showed a significant main effect for word type, $F(3, 207) = 6.32, p < .001, \eta_p^2 = .084$. Simple planned contrasts revealed that participants endorsed fewer pain words than illness words, $F(1, 69) = 7.89, p = .006, \eta_p^2 = .10$, and depression words, $F(1, 69) = 16.43, p < .001, \eta_p^2 = .19$, while the difference between endorsed pain and neutral words was not significant, $F(1, 69) = 2.07, p = .16$. Main effect for group was significant, $F(1, 69) = 12.4, p = .001, \eta_p^2 = .15$, the group with diagnostic uncertainty endorsed more words across the four word types. The interaction was not significant, $F(3, 207) = .36, p = .79$. Descriptive statistics for word endorsement are reported in Table 6:3.

As the interaction was not significant in both analyses (there were no differences between the groups on their pattern of endorsement and reaction times) it was not necessary to use endorsement and reaction time variables as covariates in the ANCOVA analysis.

Analysis of Covariance on the Primary Analysis

A 2 x 4 ANCOVA was conducted on recall data and using grouping by diagnostic certainty (see the primary ANOVA analysis) with the total depression and disability scores entered together as covariates. Both covariates were non-significant: depression, $F(1, 63) = .065, p = .80$, disability, $F(1, 63) = .29, p = .59$, and the inclusion of these covariates did not change the pattern of results.

Correlations between Word Recall, Mood, Disability, Pain and Pain-related Guilt

Bivariate correlations between measures of depression, anxiety, disability and pain intensity, and word recall were all non-significant (see Table 6:4). Correlations between pain-related guilt scales and word recall were also non-significant, apart

from the correlation between verification of pain guilt and pain words, $r(36) = -.35$, $p = .037$ and verification of pain guilt and neutral words, $r(36) = .39$, $p = .018$, in the group with diagnostic certainty.

Table 6:4 *Correlations between Word Recall, Depression, Anxiety, Disability, and Pain Intensity*

	Pain Intensity	Disability	Depression	Anxiety
Uncertain about diagnosis (N= 32^a)				
Pain Words Recall	-.05	.18	-.09	-.17
Illness Words Recall	-.05	-.24	-.20	-.06
Depression Words Recall	-.20	-.11	-.18	-.10
Neutral Words Recall	-.01	.12	.02	-.11
Certain about diagnosis (N=36)				
Pain Words Recall	-.11	-.17	-.13	-.20
Illness Words Recall	-.29	-.29	-.09	.10
Depression Words Recall	.02	.10	.27	-.08
Neutral Words Recall	.10	.13	.20	.10

^a*Correlations including disability, Depression and anxiety variables had the sample size of 31 in the uncertain about diagnosis; * $p < .05$, all two tailed; All Pearson correlations*

Discussion

Main Findings

The objective of this study was to examine the relationship between diagnostic uncertainty and recall bias among patients with chronic LBP. The study hypotheses were supported: both groups displayed a recall bias for pain stimuli, but only the group with diagnostic uncertainty additionally selectively recalled illness-

related stimuli. These biases remained after adjusting for depression and disability, and were not found in endorsement or reaction time data. Secondary analyses using grouping by diagnosis/explanation received, were in line with the primary analysis findings, supporting the link between diagnostic uncertainty and recall bias. The group with diagnostic uncertainty had higher levels of depression and disability than the comparative group, but levels of pain intensity did not differ between the groups. The group with diagnostic uncertainty recalled fewer pain words than the certain about diagnosis group (although this was not tested explicitly to avoid multiple post-hoc testing). One explanation is that these patients allocate their memory resources more equally between pain and illness stimuli than patients with diagnostic certainty whose cognitions seem to be primarily pain focused. Overall, the results demonstrate an association between diagnostic uncertainty and recall bias towards negative health-related stimuli, which has been conceptualised as evidence for the presence of unhelpful schemas and poor coping (Pincus & Morley, 2001) (see below). The findings provide a plausible explanation for the association between diagnostic uncertainty and poorer prognosis.

Fit with Previous Research and Theoretical Implications

The only previous study (Wells et al., 2003) that examined the effect of diagnostic certainty on recall bias found significantly different patterns of results between diagnosed and undiagnosed chronic pain patients. In this study, however, the pattern suggested that perceived diagnostic certainty was associated with a reduction in the recall of depression-related words. Although the pattern of results is different, the conclusion stated by the authors is in line with the current study: diagnostic certainty is associated with healthier cognitive processes.

The findings also support the self-enmeshment model of pain (Pincus & Morley, 2001), which proposes that in the presence of chronic pain schemas of illness, pain and depression become enmeshed with self-schema. More specifically, the model suggests that biases towards pain-related information in pain patients might be a normal adaptation to pain, while biases towards illness or depressed stimuli are reflective of poor adjustment to illness. Such biases may maintain distress

and indicate that illness information is enmeshed with the self-schema (Pincus & Morley, 2001).

These results are in line with the findings from Study 1 and past research (Hopayian & Notley, 2014; Verbeek et al., 2004) which showed that diagnostic uncertainty matters, and it appears to be related to negative emotional, cognitive and social functioning (Geisser & Roth, 1998; Reesor & Craig, 1988). The current findings support this proposition by providing evidence that diagnostic uncertainty is associated with reports of higher disability and depression. However, this finding is not entirely in line with the findings from Study 4 in which diagnostic uncertainty was directly associated with depression and anxiety, but not with disability. This might suggest that the relationship between diagnostic uncertainty and depression is more stable than with disability. Thus, the recall bias towards pain and illness words in the group with diagnostic uncertainty is in line with previous evidence that depressed pain patients selectively process pain and illness-related information (Pincus & Morley, 2001). Past research has shown that pain patients exhibit a recall bias for sensory pain words (Edwards et al., 1992; Koutantji et al., 1999), but when controlling for depression or comparing subgroups of pain patients according to their mood state, a recall bias for non-sensory pain (illness-related) words has mainly been found in depressed chronic pain patients (Edwards et al., 1992; S. A. Pearce et al., 1990; Pincus et al., 1995). Surprisingly, in the current study correlations between recall of pain, depression and illness stimuli and measures of depression and disability were not significant. Recall bias has been shown to be related to disability and depression in past research (Pincus & Morley, 2001), but it is not without precedent (Denton et al., 2005). Denton et al. (2005) examined recall bias in systematic lupus erythematosus and rheumatoid arthritis patients; in their primary analysis, depressed patients did not recall more negative illness words than non-depressed patients and control group. However, splitting negative illness words into sensory and disability words in their post-hoc analysis showed that depressed patients recalled more disability words than comparative groups. They also found that recall for illness words was not correlated with depression (measured with HADS).

All correlations between pain-related guilt and word recall in the group with diagnostic uncertainty (and the majority of correlations in the group with diagnostic

certainty) were non-significant. This perhaps is not surprising considering that the correlations between depression and word recall were also non-significant. Earlier studies of this thesis showed that pain-related guilt was associated with depression, the relationship between social guilt and depression was particularly strong.

Depression and disability were not significant covariates (confounds) in the analysis of covariance, and hence did not confound the pattern of recall observed in the two groups. It should also be noted that the significance for the difference between the recall for neutral and depression words in the uncertain about diagnosis group was $p = .056$ in the primary recall analysis; suggesting that the inference that the recall bias in this groups is specific to illness words is perhaps premature and requires further testing. Overall, depression-related findings in the current study are somewhat perplexing and indicate a complex relationship between diagnostic uncertainty, depression and recall bias.

Past research has also suggested that recall bias in patients who are depressed is related to information encoded in reference to the self (Greenberg & Alloy, 1989); when self-referent instructions were included, a bias toward negatively valenced personal descriptors and illness/health-related stimuli was displayed by patients with pain who are also depressed. The impact of mood on memory is well established (J. M. Williams, 1997), people have a tendency to memorise information that is congruent with their current state. However, in the absence of explicit self-referent instructions, only a bias toward sensory pain descriptors was observed (Edwards et al., 1992; S.A. Pearce et al., 1990; Pincus et al., 1995).

In the current study all participants were asked whether presented stimuli described them/their pain. The group with diagnostic uncertainty endorsed more words across the four word types. Considering that all word stimuli (including neutral words) were negative descriptors, this suggests that diagnostic uncertainty may be associated with a more negative view of oneself. There were no differences between the two groups on their pattern of endorsement of the four word types, suggesting that word endorsement was not a potential confound of the pattern of results observed in the recall data, and for this reason it was not included in further analysis.

The same pattern of results was observed for reaction time data in the current study. The group with diagnostic uncertainty responded slower than the certain about diagnosis group, perhaps suggesting that the words grabbed their attention (all words were negatively valenced). This group was more depressed and disabled, which might have impacted on their reaction times. The interaction was not significant; there were no differences between the two groups on their pattern of the speed of reacting to the four word types, suggesting that reaction time was not a potential contributor to the pattern of results observed in the recall data.

Implications for Clinical Practice

The findings enable a better understanding of the variability of chronic LBP patients in relation to their cognitive processing; the distinct recall pattern between the certain and uncertain about diagnosis group indicates that the processing of information differs among chronic LBP patients according to their perceptions of their diagnosis and condition.

The different recall pattern between those certain and uncertain about their diagnosis may reflect patients' preoccupation with the meanings and repercussions of their pain. Even though these findings cannot provide evidence for a causal link between diagnostic uncertainty and unhelpful cognitions (or subsequent poor prognosis), they provide tentative evidence for the hypothesis that greater certainty may help patients to shift their attention to non-pain and non-illness aspects of life. However, how to provide acceptable explanations to decrease uncertainty in these patients remains unknown: diagnostic uncertainty does not appear to be linked to what patients think they were told about their pain and condition; instead it might be a product of their communication with practitioners and their prior beliefs and experiences: the findings suggest that patients can hold seemingly contradictory perceptions of their diagnostic status simultaneously, thus, over 40 % who thought there was something else going on with their back which was not found yet, also reported having received a clear diagnosis. This may be a function of unwillingness to contradict health professionals; it might refer to patients' belief that the diagnosis is correct but does not capture the true severity of their condition; or perhaps it represents a belief that the diagnosis is correct, but that it fails to capture something

else that is going on, in addition to the diagnosis. This is supported by other studies which suggest that improved doctor-patient communication, clear explanations, and manageable expectations might influence patients' beliefs, and subsequent behaviours (Darlow et al., 2013; Darlow et al., 2012). However, offering reassurance may be difficult in the context of uncertainty about aetiology and prognosis; chronic pain patients rarely receive labels that precisely explicate the causes of their condition (Krismer & van Tulder, 2007). The current study does not provide information on the most acceptable explanations or labels. In fact, the accuracy or clarity of such 'diagnoses' appears to matter little. All the patients in the current study had been seen by practitioners who excluded diagnoses other than mechanical LBP. Nevertheless, exploration of the 'diagnoses' that patients reported revealed high variability, ranging from very simple descriptions of patients' symptoms (e.g. 'problem with spine') to more concrete, but often incorrect labels (e.g. 'slipped disc').

Diagnostic uncertainty is also associated with higher disability and depression, indicating that patients' concerns about their condition may cause them to adapt unhelpful behaviours and emotions. A fundamental component of the schema enmeshment model is the self-schema (Pincus & Morley, 2001). It proposes that healthy levels of enmeshment in pain patients would include the self-schema fairly distant from illness schemas. The current study's findings demonstrate that chronic LBP patients who are uncertain about their diagnosis appear to have a greater level of enmeshment of these two schemas than patients who are certain about their diagnosis and pain. Whether a change in patients' diagnosis related beliefs could reduce the degree of the enmeshment is an important question which future research should try to answer. A key implication of these findings is the need to prioritise the study of effective reassurance in the absence of a concrete diagnosis. Screening for diagnostic uncertainty might also be a valid and relatively easy method to establish if a patient needs to be reassured further.

Strengths and Limitations

One strength of the current study is that it used clear and precise inclusion and exclusion criteria; clinicians explicitly excluded alternative diagnoses which

contributed to the validity of the categorisation of patients into groups. The identification of subgroups within LBP is a key to the understanding of how LBP patients differ in the way they feel and respond to their pain and condition, and for improving interventions (Dankaerts & O'Sullivan, 2011); the current study conducted group comparison based on patients' beliefs about their diagnosis and pain. The use of an experimental procedure enabled an insight into the information processing in chronic LBP patients and their pain-related cognitions uncontaminated by biases commonly found in self-report data. Additionally, the sample size was sufficiently large to find significant differences.

The study also has some limitations. The choice of stimuli was adapted from previous research, and might not have captured the specific qualities of participants' individual pain (Denton et al., 2005; Pincus & Morley, 2001). This limitation might have influenced the endorsement results; participants were asked to endorse pain words as self-referent or not and it was found that their endorsement of pain words was unexpectedly low (see Table 6:3), suggesting that some pain words might have been irrelevant. Additionally, no differences were found between the groups on their pattern of endorsement. Matching pain words to participants' descriptions of pain might have improved the validity of the stimuli used. Additionally, although the cues differed between pain words ('Does the following word describe your pain?') and other three types of words ('Does the following word describe you?'), in line with past research (Pincus, et al., 1995), encoding was identical between groups and should not have affected results.

Furthermore, the sample sizes in the sensitivity analysis were small in the groups reporting that they did not receive a diagnosis (N=20) or an explanation (N=24). However, the pattern of results was in line with the main findings in the primary analysis of variance.

In addition, the findings are applicable to chronic LBP patients who actively seek treatment; the extent to which these findings apply to other chronic LBP subgroups (such as those not seeking active treatment and/or primary care patients) is not known. In the absence of a control group the inference that only chronic LBP patients with diagnostic uncertainty show a bias towards illness words cannot be conclusively established. Lastly, the study was only powered to find medium effect

sizes (based on Pincus & Morley's (2001) review); a larger sample size might have allowed for small effect sizes to be detected.

Conclusions

Overall, these findings suggest that uncertainty about diagnosis in LBP is associated with recall bias towards pain and illness stimuli. Although the findings provide evidence of a relationship between diagnostic uncertainty and recall bias, the cross-sectional design of this study means that causality cannot be inferred. Future research should focus on the development and consequences of patients' beliefs about their diagnosis. It should also try to understand the nature of the relationship between diagnostic uncertainty, depression and recall bias as the current study produced inconsistent results in respect to this relationship. Finally, future research should examine whether and how different cognitive biases interact; this would enable a greater understanding of the cognitive mechanisms underlying the relationship between diagnostic uncertainty and patient outcomes in chronic LBP.

Chapter 7

Discussion and Conclusions

This chapter begins by summarising the aims and findings from the studies in this thesis. The discussion then focuses on how these aims and findings fit within previous research and theory, followed by the clinical implications. Finally, the limitations of the current research are discussed.

Summary of Research Undertaken in the Thesis

The primary aim of this thesis was to explore the relationship between perceived diagnostic status and mood and disability in low back pain (LBP). Research described in Chapter 2 shows that perceived diagnostic status has previously been studied. However, the majority of this research is qualitative and its relationship with mood and disability is insufficiently explored. Not having one's pain verified and legitimised may leave some patients feeling guilty about it; therefore, the thesis has also examined the concept of pain-related guilt within the context of LBP. This concept has long been neglected in LBP (and chronic pain in general); the research undertaken within this thesis is the first to systematically examine pain-related guilt in the context of LBP.

Chapter 3 reports Study 1, which aimed to explore LBP patients' understanding, feelings and behaviour in response to their diagnostic labels and explanations given about the causes of their pain, using qualitative methodology. Additionally, it aimed to develop a categorisation for perceived diagnostic status and a measure for pain-related guilt. Chapter 4 reports Studies 2 and 3, which describe the development and testing of a pain-related guilt scale (PGS) for people with LBP. Study 2 employed exploratory factor analysis in order to statistically validate the PGS and to understand its underlying structure. Study 3 aimed to validate this structure in a new sample of participants using confirmatory factor analysis. Study 2 and 3 samples were then combined to conduct further validation of the PGS subscales; to this end, correlational analysis were conducted between the PGS and

pain, mood and disability. Partial correlations were also conducted in which correlations between pain-related guilt and disability, and pain intensity were examined while controlling for depression and anxiety.

Study 4 (reported in Chapter 5) aimed to explore how diagnostic uncertainty and pain-related guilt might fit in the pathway to disability by testing several theoretical models, which were supported by research evidence from Study 1- 3, and past research and theory. It was hypothesised that diagnostic uncertainty would predict pain-related guilt, which in turn would predict mood and disability. Two alternative models were also tested in which reversed relationships were examined (to those tested within the hypothesised model) to establish whether the hypothesised model was the best model. Both models tested if guilt may be increased by low mood and if in turn it was associated with disability. While Model 2 described mood increasing guilt, which in turn resulted in diagnostic uncertainty, Model 3 described both mood and diagnostic uncertainty increasing guilt, independently.

Finally, Study 5 (reported in Chapter 6) aimed to examine possible cognitive mechanisms underlying the relationship between diagnostic uncertainty and mood and disability. There is evidence that pain patients selectively recall negative health information when compared with control groups (Pincus & Morley, 2001). Hence, the objective of this study was to examine if these biases were related to perceived diagnostic status. Specifically, the study tested whether there are differences in subgroups of LBP patients in their recall of pain, illness, depression and neutral stimuli. This study compared two subgroups of LBP patients, those that were certain about their diagnosis and those that believed their pain was due to unidentified causes. The two groups were also compared on measures of pain, mood and disability.

The thesis was planned to include diverse methodologies, and followed recent recommendation that research should test theoretical models using advanced analysis (such as structural equation modelling) that integrate and examine relationships between potential predictors of poor outcomes in LBP (Hayden et al., 2010; McCracken & Morley, 2014). Some methodologies were adapted from related research (e.g. experimental procedure for studying recall bias) in order to enable comparisons with past research and to test theories derived from established models such as the schema enmeshment model of pain (SEMP, Pincus & Morley, 2001), the

emotion regulation model of pain (Linton & Bergbom, 2011) and the misdirected problem solving model of pain (Eccleston & Crombez, 1997). The studies described in this thesis aimed to integrate and expand knowledge on the role of perceived diagnostic status in LBP, and examined its relationship with pain-related guilt, mood and disability.

Summary of Main Findings

Study 1 explored the participants' perceptions of their diagnosis and perceived impact this had on their feelings, behaviours, relationships and subsequent health care. The findings indicate that perceived lack of clear diagnosis and physical evidence for their pain is related to participants' social, cognitive and emotional functioning, and their use of healthcare services. The participants described LBP as an 'illegitimate' condition that failed to capture the seriousness of the problem. They also expressed concerns about the future management of their back pain. These findings support past (predominantly qualitative) research (Hopayian & Notley, 2014; Verbeek et al., 2004). Pain-related guilt emerged as a major category, supporting findings from only a handful of studies that indirectly addressed guilt in chronic pain (Newton-John & Williams, 2006; Rhodes et al., 1999). Study 1 provided the data for the construction of two new measures: the categorisation for perceived diagnostic status and the PGS.

The pain-related guilt scale was then validated in Study 2 and 3 using two different samples of LBP participants, and two different statistical analyses: exploratory and confirmatory factor analysis. Three types of pain-related guilt were identified: 'social guilt', relating to letting down family and friends; 'managing condition/pain guilt', relating to failing to overcome and control pain; and 'verification of pain guilt', relating to the absence of objective evidence and diagnosis. The three pain-related guilt subscales had good to excellent reliability and were positively correlated with pain, mood and disability. High levels of pain-related guilt were reported by over 40% of participants in the combined Study 2 and 3 samples.

The next study (Study 4) examined how pain-related guilt related to diagnostic uncertainty, and whether both pain-related guilt and diagnostic uncertainty were part of a distinctive mechanism relating to mood and disability in LBP. All

three models had a reasonable-to-good fit with the data and their fit indices were very similar, suggesting that all three models are feasible. Model 2 and Model 3 had marginally better fit with the data than the first hypothesised model, with Model 2 providing the best fit, highlighting the apparent role of mood in diagnostic uncertainty and pain-related guilt. In Model 1 diagnostic uncertainty positively predicted all three types of pain-related guilt. Social guilt predicted anxiety, depression and disability; verification of pain guilt and managing condition/pain guilt predicted anxiety. In both alternative models anxiety predicted managing condition/pain guilt, while depression predicted all three types of guilt. Social guilt and managing condition/pain guilt predicted disability.

The next study (Study 5) focused on a cognitive mechanism potentially underlying the relationship between diagnostic uncertainty and mood and disability. Both groups of participants, those that were certain and those that were uncertain about their diagnosis exhibited a recall bias for pain stimuli, supporting a body of past research reviewed in Pincus and Morley (2001). However, only the participants with diagnostic uncertainty displayed a recall bias for illness-related stimuli. The bias persisted after adjusting for depression and disability. Sensitivity analyses which used grouping by diagnosis/explanation received were in line with these findings.

In summary, the thesis explored two relatively new concepts, diagnostic uncertainty and pain-related guilt. It defined their content through qualitative work, and, despite the limitations associated with the lack of time-line inherent in cross sectional studies, it verified that they are important to patients both in terms of their prevalence and their relationships to mood and disability.

Two main questions remain:

1. How do these two factors fit into mechanisms leading to poorer outcomes? This includes their interactions with each other, and their associations with mood and disability. To answer these questions there is a need for research that includes time-lines. In their absence, and to inform future research, the following discussion will speculate on how these concepts might fit into the current research and theory.
2. What does the evidence suggest for interventions? This will be discussed in the clinical implications section.

Fit with Past Research and Theoretical Implications

The Relationship Between Diagnostic Uncertainty, Pain-Related Guilt and Mood

The perceived diagnostic status categorisation addresses three key aspects: a) patients' perceptions and understanding of their diagnosis, and their agreement with this diagnosis; b) patients' perceptions and understanding about the causes of their back pain, and their agreement with this; c) the first two questions can be perceived as subcomponents of the final question, which addresses patients' certainty that the diagnosis and explanations given provide them with an acceptable understanding of their condition. More specifically, this question asked if they believed that there was 'something else' going on with their back, above and beyond any diagnoses or explanations they had been given. This last question represents an overarching finding from Study 1, which is that LBP patients perceived diagnostic status should not be evaluated as a mere presence/absence of a clear diagnostic label. It is a more complex problem that is reflected in an overall state of diagnostic uncertainty. Participants expressed uncertainty about the meaning and cause of their back pain and kept looking for answers; finding meaning of one's pain and illness has been proposed to be crucial for psychological recovery from pain/health-related events (Taylor, 1983).

However, finding a meaning of a condition where clear causes of pain are not known may present a challenge to both patients and practitioners, and it may result in misdirected problem solving (Eccleston & Crombez, 2007). The misdirected problem solving model of chronic pain proposes that pain-related worry usually implicates problem solving efforts on an aspect of pain which is uncertain and is usually related to the perceived threat of pain (Eccleston & Crombez, 2007). Therefore, the presence of diagnostic uncertainty may suggest that patients worry that pain might be an indicator of serious tissue damage. When patients are focused on finding definitive causes of their pain (when in fact such causes cannot be established) their problem solving efforts can become misdirected towards goals that are difficult or impossible to achieve. This may for instance involve patients requesting additional diagnostic tests and overuse of healthcare services, both of which were frequently mentioned by Study 1 participants and have been related to

increased health-related anxiety in LBP in past research (Jensen et al., 2012). This might shift patients' focus away from more achievable goals, and it may lead to more worry, which in turn might result in more care-seeking. This is also supported by the findings of a study described in Chapter 2 (Geisser & Roth, 1998) which found that chronic pain patients who were unsure of their diagnosis reported a greater belief in pain being an indicator of harm and higher levels of affective distress than those who were sure about their diagnosis.

Thus, it seems plausible to suggest that health-related anxiety might be driving diagnostic uncertainty. This is supported by the findings of Study 5 where over 40% of patients who said they were given a clear diagnostic label for their pain still believed there was something else going on with their back. This might suggest that clear diagnostic labels do not always reduce diagnostic certainty in LBP patients, and that diagnostic uncertainty might stem from worry and beliefs about the pain, which may in some patients lead to catastrophic thoughts (Quartana et al., 2009). Additionally, the findings from Study 5 show that diagnostic certainty is associated with healthier cognitive processes. Biases towards illness (and depressed) stimuli observed in the group with diagnostic uncertainty have been interpreted by the self-entrapment model of pain (Pincus & Morley, 2001) as being reflective of poor adjustment to the condition and pain and patients' preoccupation and worry about their pain. These results suggest that recall bias might be a cognitive mechanism underlying the relationship between diagnostic uncertainty and mood and disability in LBP, but it may also suggest that patients susceptible to recall bias are less likely to accept reassuring explanations from their practitioners.

Taken together, Study 1, 4 and 5 findings suggest that diagnostic uncertainty is related to patients being overly worried and preoccupied with the meaning and consequences of their condition and pain, which in turn relates to how they process information. This is also supported by past research described in Chapter 2 (Eccleston et al., 2001) which showed that the most common worry in chronic pain patients was related to the medical uncertainty of their condition. This is further supported by the findings of Study 4 in which the model (Model 2) where anxiety and depression were entered as predictors of diagnostic uncertainty (with guilt as a mediator), provided a slightly better fit with the data than Model 1, in which diagnostic uncertainty preceded anxiety and depression. Within Model 2, the indirect

path from depression via verification of pain guilt to diagnostic uncertainty was significant, perhaps suggesting that depressed mood, which is commonly associated with catastrophic beliefs (Linton & Bergbom, 2011), might initiate feelings of guilt related to unknown causes of their pain experiences. It could be that those patients with less effective emotion regulation system (Linton & Bergbom, 2011) are more prone to experiencing guilt. Poor self-regulation of emotions such as guilt may result in further increases in depressed mood, creating a vicious cycle. Attempts to alleviate guilt might result in rejection of reassuring messages from practitioners, such as that LBP is common and nothing serious is happening. Patients may continue believing that something serious must be going on, so that pain and pain behaviours are justified, and thus reducing their guilt. Therefore, it could be argued that diagnostic uncertainty might be understood as a cognitive coping mechanism that has a potential of regulating verification of pain guilt, and in turn decreasing depressed mood. However, this cannot be established with cross sectional data.

Focusing further on the relationship between diagnostic uncertainty and pain-related guilt, the results across all three models in Study 4 show that these relationships were moderate, but significant, suggesting that the diagnostic uncertainty is associated with guilt, and the relationship with verification of guilt being most consistent. However, the current study findings fail to offer evidence about whether guilt results in diagnostic uncertainty, or whether diagnostic uncertainty increases guilt. Although, the findings suggest that the first pathway may be more probable, because Model 2 provided a better fit with the data. In comparison, the above analysis of theoretical models suggests that the relationship between diagnostic uncertainty and mood was more modest. However, the results of other analyses within the thesis, such as the between group comparisons conducted in Study 4 and 5 consistently showed that patients who were uncertain about their diagnosis were more distressed than those who were certain.

Overall, these results suggest that diagnostic uncertainty is associated with pain-related guilt and increased emotional distress. There is strong evidence suggesting that depression and anxiety lead to increased disability (Hayden et al., 2010; Mallen et al., 2007; Quartana et al., 2009). The next section will discuss how diagnostic uncertainty and pain-related guilt may be placed within this process.

The Relationship Between Diagnostic Uncertainty, Pain-Related Guilt and Disability

The above discussion suggests that there are a number of interacting factors and possible pathways that might increase disability in LBP patients who are uncertain about their diagnosis. The findings of Study 2 - 5 revealed several direct and indirect relationships between diagnostic uncertainty, mood, guilt and disability.

Worry about potential causes of pain and beliefs that something serious must be causing the pain might lead to misdirected problem solving attempts, which in turn could reinforce initial worry, and lead to rejection of reassuring messages from practitioners and increased health care utilisation. This cycle might also lead to catastrophic interpretations of symptoms and catastrophic beliefs the pain is a signal of harm. These beliefs may result in hypervigilance and excessive fear that certain movements might cause additional harm and that the unknown (and potentially serious) causes of back pain will be aggravated further. Therefore, the relationship between diagnostic uncertainty and disability in the current studies may be further interpreted by the fear-avoidance (FA) model of pain (Vlaeyen & Linton, 2000). Avoiding movements which are perceived by the patient as potentially detrimental for the condition and pain will result in more disability and distress (Crombez et al., 2012; Leeuw et al., 2007; Vlaeyen & Linton, 2000). Avoidance behaviours might also prevent patients from learning that their catastrophic fears about these movements causing further damage are unfounded. It may in fact, reinforce existing fears and lead to disability and more worry about potential causes of their back pain (Crombez et al., 2012).

Avoidance behaviours may also lead to disengagement from social life and isolation, which may lead to depressive mood (Crombez et al., 2012) and possibly guilt for not being able to lead a normal social life. Indeed, in Model 2 and 3 of Study 4 the indirect paths from depression to disability via both social and managing condition/pain guilt were significant. This is supported by other studies described in Chapter 2, such as that by Reesor and Craig (2003) who found that pain patients who displayed pain and symptoms incongruent with the physical pathology provided by their clinicians reported more depression and disability than the congruent group. Furthermore, Geisser and Roth (1998) found that chronic pain patients who were

unsure about their diagnosis were more disabled than those who were sure about it. Interestingly, this group of patients also had lower levels of perceived control over pain, suggesting that poor emotion regulation (Linton & Bergbom, 2011) may contribute to increases in disability. Findings from other studies such as Foster et al. (2010) (also described in Chapter 2) add to this evidence by showing that among other pain-related beliefs, weak beliefs about personal controllability were better predictor of disability at 6 months than fear avoidance, catastrophising and depression. In Model 2 and 3 of Study 4, social and managing condition/pain guilt mediated the relationship between depression and disability (in Model 1 social guilt was also a strong predictor of disability), which may suggest that poorly regulated emotions, such as depression and guilt may increase disability. Social guilt may also be associated to disability through avoidance behaviours. This is supported by the findings of Study 1 which showed that in an attempt to avoid feeling guilty about their pain-related behaviours some patients withdraw from social situations; this may result in increased isolation (hence possibly increasing depressive mood) and reduced daily activities. This is also in line with theoretical accounts of guilt which propose that that guilt motivates avoidance behaviours (Tilghman-Osborne et al., 2010).

Summarising the Relationship Between Pain-Related Guilt and Mood

Although the causal mechanisms linking depression and anxiety to pain-related guilt remain unclear, the above discussion suggests that mood plays a crucial role in the relationship between guilt and increased disability.

Pain-Related Guilt and Depression - Overall, the results of Study 2 – 4 showed that depression is associated with all three types of guilt. Social guilt emerged as a prominent factor in all three models of Study 4, strongly linked to both depression and disability and supporting past research showing that weakened social roles and reduced social contacts are common problems in LBP (Froud et al., 2014; Harris et al., 2003; Snelgrove et al., 2013). Both social guilt and managing/condition pain guilt were related to disability via depression and independently in Study 4. These independent relationships are also supported by the partial correlations conducted in Study 2 and 3 which showed that after controlling for depression and

anxiety, all relationships between social guilt and disability, and between managing condition/pain guilt and disability remained significant. This suggests that guilt shared unique variance with disability independent of depression and anxiety. However, the direction of these relationship is not clear; it could be that guilt increases avoidance behaviours which in turn will impact on disability; or it might mean that disability (with input from mood, pain and perhaps some other unmeasured factors, such as catastrophising) increases feelings of guilt about not being able to socialise more and manage one's pain better.

Pain-Related Guilt and Anxiety – The results of Study 4 show that anxiety appears to be in particular linked to managing condition/pain guilt and verification of pain guilt, which may be related to increased health care utilisation (Verbeek et al., 2004) and unrealistic expectations about the management of back pain, its causes and diagnosis. This is also supported by the findings of Study 1 where patients said that their expectations of how their back pain should be treated are often not met. However, verification of pain guilt accounted for a very small percentage of variance in anxiety, which fits with a systematic review by Rolfe and Burton (2013) showing that getting negative tests does not reassure patients with high uncertainty. Study 2 and 3 showed that after controlling for depression, the relationship between verification of pain guilt and disability was no longer significant. This suggests that depression might be an important mechanism in the relationship between verification of pain guilt and disability.

In summary, the findings about pain-related guilt indicate that in the context of LBP, pain-related guilt is a common psychological factor that is associated with mood and disability.

Future Research Directions

The findings of Study 1 inform about perceived impact of diagnostic status on LBP patients' social, cognitive, and emotional aspects of life and their care seeking. The findings also informed about pain-related guilt in LBP; an unexplored yet common experience among LBP patients. In Study 4 several theoretical models were tested in order to examine how diagnostic uncertainty and pain-related guilt relate to each other and to mood and disability in LBP. However, these findings do

not inform about causal relationship and do not clarify ‘how’ and via which mechanism these factors relate to poorer outcomes in LBP. Thus, future research should include a timeline in order to examine the nature of these relationships.

The current findings suggest that unhelpful pain beliefs might be related to diagnostic uncertainty, however it is unclear whether and how these beliefs might lead to catastrophising. This is important to study because catastrophising has been identified as a mechanism leading to poorer outcomes in LBP patients (McCracken & Eccleston, 2005; McCracken & Vowles, 2008). Catastrophic pain perceptions were not measured in the current studies, therefore prospective research could incorporate this measure and examine whether and how it relates to diagnostic uncertainty. Catastrophic pain perceptions may also potentially increase pain-related guilt or be increased by it, and indirectly place pressure on the emotion regulation system (Linton & Bergbom, 2011). Future research could also examine whether patients with less effective emotion regulation system might be more prone to experience diagnostic uncertainty and pain-related guilt. For instance, there is some research showing that perceived control over pain might be linked to diagnostic uncertainty, but further research is necessary to examine this relationship (Geisser & Roth, 1998). All these factors might interfere with how patients respond to practitioners’ explanations about their pain and reassuring messages that nothing serious is happening with their back, hence a greater understanding of patients’ health-related anxiety, pain-related beliefs and underlying cognitions might enable more helpful and productive consultations.

It is also necessary to identify behaviours through which both diagnostic uncertainty and pain-related guilt might increase disability. The current findings suggest that patients who experience pain-related guilt engage in avoidance behaviours, for example in Study 1 patients reported avoiding social interactions. It is important to understand whether and how this might impact on their engagement in treatment and physical activity. Thus, detecting avoidance behaviours (such as avoiding physical activity), through which pain-related guilt may increase disability, should be studied by future research. Acceptance and avoidance have been described as two extremes of the same concept (De Boer et al., 2014); patients who engage in avoidance behaviours are usually less acceptant of their pain and pain experiences. Acceptance of pain has been associated with less pain, pain-related anxiety,

avoidance, depression and disability (McCracken, 1998). Therefore, future research could examine whether changing pain and diagnosis-related perceptions may lead to a greater acceptance of pain and pain experiences.

The current findings suggest there is a link between diagnostic uncertainty and biased information processing in LBP patients; patients who were uncertain about their diagnosis displayed a recall bias for negative health information. Prospective research should examine if the pattern of results found in the current study could be found for other cognitive biases, such as attentional and interpretation biases. This research could additionally examine whether and how the three cognitive biases interact in this group of LBP patients. This may enable a greater understanding of the underlying cognitive process in patients who excessively worry about causes of their back pain and potential links of recall bias with hypervigilance and catastrophising, both of which have been identified as key mechanisms of fear avoidance (Crombez et al., 2012). Considering that recall bias has been suggested to be one mechanism that might explain the maintenance of disability and distress in chronic pain patients (Pincus & Morley, 2001), an important question for future research is to examine whether reducing diagnosis-related worry and changing unhelpful beliefs might result in reduction of diagnostic uncertainty and healthier information processing. Such research should use a longitudinal design.

Finally, this thesis enabled an insight into the relationship between pain-related guilt and mood. Depression is arguably one of the most prominent psychological factor in LBP (Linton et al., 2011; Linton & Shaw, 2011), but it is not entirely clear what constitutes depression in LBP. Although the current findings suggest that pain-related guilt and depression are associated, the nature of the relationship between pain-related guilt and depression in LBP is currently unknown.

Clinical Implications

Currently there is no consistency or clear guidelines for delivering diagnostic labels for LBP, especially in relation to non-specificity, and education and management of patients who cannot be provided with a clear diagnosis (Dankaerts & O'Sullivan, 2011; Slade et al., 2012). This appears to be a considerable problem, since in the majority of LBP patients a clear diagnosis cannot be given (Krismer &

van Tulder, 2007). However, the findings of Study 5 seem to suggest that clear diagnostic label seem matter very little to patients. Patients who said they were given a clear diagnosis for their back pain were also asked which diagnosis they had been given. They provided a variety of answers, these included simple descriptions of their symptoms, e.g. 'problem with spine', more concrete descriptions such as 'slipped disc', as well as vague diagnostic labels such as 'low back pain', indicating that the labels themselves might not be as important as the patients' acceptance of the label. Of note, all participants in that study had been seen by NHS practitioners who excluded diagnoses other than mechanical LBP. This suggests that the accuracy of diagnosis does not seem to be important, and that diagnostic uncertainty may not be a product of what patients think practitioners actually told them about their diagnosis and causes of their back pain. This is supported by another finding from Study 5: about 40% of the participants who reported being uncertain about their diagnosis and pain, also said they were given a clear diagnosis. This might appear to be a contradictory finding, but it also suggests that diagnostic uncertainty might be an outcome of patients' beliefs and worry about what their symptoms mean and the origins of their pain. Patients might think that their diagnosis is correct but it does not reflect the seriousness of their condition or that something else is going on, in addition to the existing diagnosis. These findings clearly suggest that providing diagnostic labels to patients will not reduce their worry. In fact, it has been argued that providing a diagnosis based on a biological cause to patients with non-specific problems may make them believe that they are ill and encourage worry and disability (Ehrlich, 2003). Therefore, discussions with patients would benefit from including information and advice that do not depend on the presence or absence of a clear diagnosis and visible evidence (Darlow et al., 2013; Darlow et al., 2012; Hoffmann et al., 2013; Kenny, 2004), but focus on patients' mood and pain-related beliefs.

The current findings show that diagnostic uncertainty is associated with mood and disability. Thus, changing patients' diagnosis-related beliefs and addressing their concerns could potentially reduce worry and distress, increase self-management and activity levels, and reduce unhelpful care-seeking and overreliance on practitioners (Linton & Shaw, 2011; Main, 2013; Main et al., 2010). The findings from this thesis suggest that diagnostic uncertainty does not always appear to be about what

diagnosis/explanation patients are given and what they are told by practitioners, but about their perception of what they have been told against their internal state of pain and beliefs about pain. Therefore, eliciting patients' unhelpful beliefs and especially catastrophic concerns is very important (Main et al., 2010).

However, practitioners might be confused and unclear about how to deal with the diagnostic uncertainty experienced by their patients and what advice to provide to them (Slade et al., 2012). The current guidelines advise practitioners to refrain from ordering diagnostic tests in non-specific LBP. However, many patients want to know the cause of their pain and often request such tests (Verbeek et al., 2004). This makes it difficult for practitioners to comply with guidelines and at the same time provide satisfactory explanations to their patients (Verbeek et al., 2004). Some practitioners might also be unaware of how diagnostic uncertainty might affect patients (Linton & Shaw, 2011; McIntosh & Shaw, 2003). Past research suggests (Verbeek et al., 2004) that practice guidelines should focus on establishing the best way of educating LBP patients about the diagnosis and causes of back pain, but in the absence of such guidelines it is still unclear 'how' to provide suitable explanations to decrease or accept uncertainty in LBP patients.

Based on this thesis' findings, three relatively simple steps could be implemented in clinical practice: a) screening for diagnostic uncertainty, and discussing with patients their diagnosis-related concerns; b) raising awareness that causes of LBP are often unknown, but that this does not mean that something serious is going on with their back; c) reassuring patients who are uncertain. Although the best way of reassuring patients is still not fully understood (Linton et al., 2008; Pincus et al., 2013), in the first instance patients' immediate concerns and expectations about their diagnosis might be addressed and discussed. For example, Study 1 findings showed that LBP patients often have unrealistic expectations about their diagnosis and management of their pain (such as that a cure for back exists and all back pain must have clear physical causes), as well as about the ability of practitioners to provide a coherent and acceptable diagnosis. Perhaps it could be explained to patients with unrealistic expectations that in the majority of LBP patients a clear diagnosis cannot be provided and that the absence of a concrete diagnosis does not invalidate their pain experiences. Validation of one's pain

experiences has been shown to produce significantly more positive affect, less worry and higher adherence (Linton, Boersma, Vangronsveld, & Fruzzetti, 2012).

The findings also provide an insight into the cognitive processing of chronic LBP patients. The recall bias towards negative illness-related stimuli, observed in patients who were uncertain about diagnosis may suggest that these patients are preoccupied with the implications and consequences of their pain. It may also suggest that these patients perceive themselves as being affected by their pain in a more personal way than the patients who have a clear diagnosis for their back pain (Pincus & Morley, 2001). Although these findings do not imply a causal link between diagnostic uncertainty, unhelpful cognitions and subsequent poor coping, they might suggest that feeling uncertain leads to ruminating behaviour and that being worried about something else more serious going on is important. Therefore, helping patients to decrease the worry and unhelpful beliefs could potentially help them to focus more on non-illness aspects of life and could potentially lead to healthier information processing.

In addition to perceived diagnostic status, the findings from this thesis suggest that pain-related guilt is associated with mood and disability in LBP patients, although they do not inform on 'how' they might be linked. Understanding the focus of pain-related guilt could enable a more detailed understanding of pain-related emotions and underlying cognitions. It could potentially improve reassurance and education of patients. If future research shows that guilt is a mediating factor and clarifies which aspects of guilt lead to poorer outcomes, it could become a target for psychological interventions such as Acceptance and Commitment Therapy and Cognitive Behavioural Therapy. Improving psychological treatments requires understanding of patients' specific needs (Pincus & McCracken, 2013); the thesis findings suggest that social guilt in particular, is a prominent psychological factor in LBP pain as it is closely associated with both mood and disability. As such, social guilt might be addressed explicitly by practitioners through patient education, with the aim of helping patients to reduce feelings of guilt and increase social interactions. This is supported by a recent systematic review and meta-synthesis of the impact of LBP on people's lives (Froud et al., 2014) which showed that it is necessary to focus more on the impact of social factors on patients' social interactions and worries about the future.

The thesis findings in relation to managing condition/pain guilt indicate that it may be related to an increased search for remedy, unrealistic expectations about the treatment and management of back pain and worry and disability in LBP. These aspects could be assessed and discussed during consultations and patients could be reassured about their symptoms, and helped to manage their expectations and pain without placing too much burden on themselves. Verification of pain guilt drives LBP patients to carry on searching for a diagnosis; this might impose a considerable burden not only on health services, but also on patients as they become preoccupied with their diagnosis, instead of focusing on managing their pain efficiently and improving their quality of life. One way to address this issue would be to discuss patients' concerns about not being provided with a clear diagnosis, explain that this is common in LBP and reassure the patient that the absence of diagnosis and physical evidence does not undermine their pain.

In summary, primarily focusing on searching for a specific cause of LBP and carrying diagnostic tests to find such a cause may encourage patients' misdirected problem-solving efforts to look for cause and cure for pain, instead of focusing on dealing effectively with their pain (Kendrick et al., 2001; Linton & Shaw, 2011). It may also result in further worry and increased disability. These problem solving efforts might be redirected by changing the existing expectations and beliefs, which might help patients to become more acceptant of their pain and pain experiences.

Therefore eliciting and addressing pain-related worry, unhelpful pain-related beliefs and potential catastrophic thoughts should be a priority in LBP patients who feel uncertain about their diagnosis and causes of their pain.

Limitations

There are several limitations of this thesis that have been addressed within each chapter; the following section will focus on the most prominent limitations that apply to the thesis as a whole.

A major limitation of the research presented within this thesis is that it is cross sectional, this means that it cannot inform on causal relationships between perceived diagnostic status, pain-related guilt, and mood and disability in LBP. The path analyses in Study 4 used structural equation modelling to examine the

relationships between diagnostic uncertainty, pain-related guilt, mood and disability. It is a powerful statistical analysis that enabled inclusion of several key variables simultaneously within the models (Hayden et al., 2010), but in the absence of a timeline it can only inform about associations between these factors. Prospective, longitudinal research should be employed to verify the direction of observed relationships, and causal links between them.

Additionally, pain-related guilt was found to be associated with diagnostic uncertainty, and mood and disability. However, full mediation / moderation analyses should be conducted in future studies using prospective methodology, so that the nature of these relationships could be better understood. The current research provides early evidence for the underlying structure and good reliability and validity of the PGS (this is discussed in more detail later). In spite of the fact that the scale items were developed from interviews with LBP patients it is possible that there are other facets of pain-related guilt currently not included in the scale, such as work-related guilt (Wynne-Jones et al., 2011).

It is evident from the results of Study 4 that diagnostic uncertainty explained relatively moderate amount of variance in the three types of pain-related guilt. It could be argued that this thesis would go a step further if it tested an expanded model in which other measures were included, for instance catastrophising, hypervigilance and measures related to emotion regulation. However, apart from the research undertaken within this thesis, research on pain-related guilt in LBP is almost non-existent; therefore inclusion of these and other potentially relevant variables is recommended for future research.

Some of the relationships within the models tested in Study 4 were not particularly strong, for instance diagnostic uncertainty predicted only a moderate amount of variance in pain-related guilt. However, this is still an important finding, especially in light of the evidence from the systematic reviews of prospective cohorts in LBP which showed that combining all known predictors explains only around 50% of the variance in outcomes (Hayden et al., 2010). This suggests that the high correlations between social guilt and disability and mood reported in this thesis are particularly informative. Furthermore, negative standardized coefficients between verification of guilt and anxiety, and managing condition/pain guilt and disability

within the models need further investigation; it should be re-examined if this pattern of results re-occurs in new samples.

It is important to re-emphasise that some of the samples used in this thesis (e.g. people with LBP subscribing to self-help groups used in Study 2) may not be representative of broader LBP patient populations within or outside of the UK. This may also suggest greater involvement in their pain, and thus their responses on any of the measures used may be elevated.

Another limitation that is relevant to the overall thesis and deserves revisiting is that relating to the perceived diagnostic status categorisation. Numerous studies and trials have heterogeneous chronic pain patient samples (Morley et al., 2013), and it has been argued that classifying patients by disorder may enable a better interpretation of research evidence to clinical practice. However, this process is not straight forward because patients' psychological states usually do not match their medical diagnosis (Flor & Turk, 2011). Therefore grouping patients according to their psychological characteristics might be more effective than grouping them according to their medical diagnosis (Morley et al., 2013). The research conducted within this thesis used a relatively unknown grouping of LBP patients: their perceptions of their diagnostic status. An advantage of this grouping is that it is based on an experience that is very common among LBP patients; and it may further enable a better understanding of the importance of diagnosis-related beliefs in LBP. But, the measure of diagnostic uncertainty used in the model may not be sufficiently sensitive for use in assessment of diagnostic uncertainty.

The aim was to construct a simple and easy to understand categorisation of perceived diagnostic status that could be used in large samples, but this categorisation might not have been able to capture all patients' concerns about their diagnosis and causes of their pain. Perhaps a more informative way of measuring perceived diagnostic status would be using a continuous measure, although this may not be possible for all questions within the existing categorisation. For example, the questions relating to the presence/absence of a clear diagnosis/explanation may not be suitable for a continuous measure. Nevertheless, the question relating to diagnostic uncertainty could potentially be measured using continuous scoring. However, the findings of Study 5 demonstrated that the three main questions

(relating to diagnosis/explanation/uncertainty) have good convergent validity as they produced the same pattern of results in respect to recall bias in LBP patients.

The clinimetric qualities of the PGS were fully assessed in the discussion section of Chapter 4. In summary, the PGS was developed from interviews with LBP patients and its underlying structure was examined by both exploratory and confirmatory factor analysis in Study 2 and 3 of the thesis. Prior to conducting the structural equation modelling in Study 4 the PGS was subjected to a confirmatory factor analysis to examine its latent structure and suitability for use in the structural equation modelling analyses (Kline, 2011). Its three factor structure was confirmed in all three studies. All three subscales of the PGS demonstrated good to excellent reliability (see Study 2 – 4). The PGS had good face and content validity (described in more detail in Study 2 and 3). Study 2 – 4 demonstrated that the PGS had good construct validity by showing that the PGS was correlated with several other measures (e.g. with the Hospital Anxiety and Depression Scale (HADS)) in predicted directions. The three PGS scales also seem to have a good level of convergent validity; Study 2 – 4 showed that the inter-scale correlations were sufficiently large. Other types of validity such as discriminant, concurrent and predictive validity could not be assessed in the current studies. The PGS also appears to have a satisfactory external validity as it was used in reasonably large and different samples of back pain patients (online, NHS and private) (Lohr et al., 1996). Responsiveness of the PGS could not be assessed as the studies were cross sectional (Eechaute et al., 2007). The PGS placed minimal physical strain on the respondent as it is a relatively short scale (12 items). However, the scale seems to have relatively high emotional load on the respondent as it taps into a sensitive construct. The administrative burden seems to be minimal as it required minimal resources to administer, score, and analyse the scale (Lohr et al., 1996). Finally, it should be re-emphasised that guilt is culturally distinctive (Bedford & Hwang, 2003; Tilghman-Osborne et al., 2010). The PGS did not undergo any cultural and language adaptations, thus the thesis findings relevant to pain-related guilt may not be fully applicable in other cultures

Other measures in the study, such as the HADS (Zigmond & Snaith, 1983) and Roland Disability Questionnaire (RDQ) (Roland & Morris, 1983) are prolifically used measures and have been validated numerous times. Although the HADS is a widely used self-report psychometric tool which has consistently demonstrated good

reliability (Bjelland, Dahl, & Haug, & Neckelmann, 2002; Herrmann, 1997), recent evidence suggest that its structure is not entirely clear (Cosco, Doyle, Ward, & McGee, 2012). Cosco et al. (2012) conducted a systematic review of 50 studies to examine the HADS' latent structure. Twenty five of fifty studies indicated a two-factor structure (anxiety and depression - originally proposed by Zigmond and Snaith (1983) and most commonly used by researchers). The remaining 25 studies either semi-confirmed (finding equal support for the two- and three- factor structure) or did not confirm this structure. The results were particularly inconsistent in studies with cancer patients and pregnant women. Although earlier systematic reviews (Bjelland, Dahl, & Haug, & Neckelmann, 2002; Herrmann, 1997) have demonstrated that the HADS was a suitable measure for the assessment of anxiety and depression, Cosco et al. argued that its subscales should be interpreted with caution, or alternatively that the total HADS score should be used. Interestingly, Cosco et al. (2012) found that Item 7 is in particular a problematic item as it had inconsistent load in 20 studies. The confirmatory factor analysis conducted in Study 4 of this thesis also found this item to be problematic, and the confirmatory factor analysis model (in which the latent structure of the HADS was examined) had to be re-specified allowing this item to load on both anxiety and depression latent factor.

Conclusions

The research presented within this thesis provides evidence that diagnostic uncertainty is a considerable problem for many LBP patients and that it is linked to mood and disability. It also showed it is related to pain-related guilt and recall bias for negative health stimuli. Future research should investigate which other factors are closely linked to diagnostic uncertainty. Ways to deal with this uncertainty during consultations have been discussed within this and other chapters.

The current research has also shown that pain-related guilt is an important factor in LBP, and that it is linked to diagnostic uncertainty, mood and disability. Social guilt is particularly prominent and closely related to depression and disability. Future research should clarify these relationships using longitudinal designs.

This research is novel and is in its early stages; therefore there is a need to be cautious about the interpretation of the findings. However, the associations found by

the current research between diagnostic uncertainty, pain-related guilt, and mood and disability are of sufficient size and importance to merit interest and encourage further examinations of the relationships found.

The current research examined associations between perceived diagnostic status, pain-related guilt, and mood and disability, but it does not provide evidence into the nature and direction of these relationships. Future research should examine 'how' these factors might form mechanisms leading to poorer outcomes in LBP, and it should use longitudinal design.

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Appendices

Appendix A: Study 1 Screening Questionnaire

How do chronic back pain patients understand and feel about their diagnosis?

What is this study about?

This study explores how chronic back pain patients understand and feel about their back pain and how they cope with it. Some patients with back pain receive a diagnosis from clinician, others receive an explanation without clear diagnosis, but many patients feel they receive neither. As currently there is no consistency and no clear guidelines for delivering diagnosis for chronic back pain, it is important to explore patients' experiences.

What is going to happen in the study?

- If you are interested in this study please fill in the attached brief questionnaire with your details and we will contact you within two weeks.
- We will then arrange an interview at your convenience in terms of time and venue. For instance it could be arranged before or after your next visit at the BCOM.
- The interview will last approximately 30 minutes and you will be asked questions about how you understand and feel about your diagnosis and about coping with your chronic pain.
- Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason. The information you give and your identity will remain completely confidential and in the study you will be known only by number. It will not affect or be linked to your treatment in any way

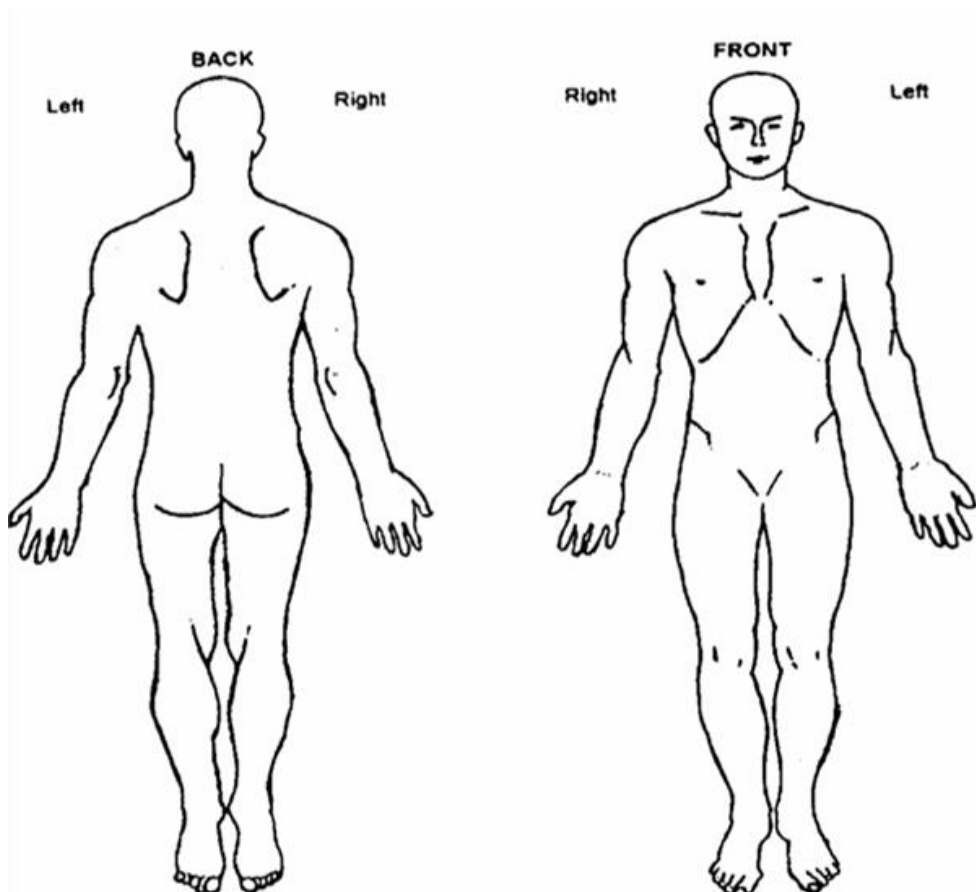
There is a detailed information sheet inside this pack; please read it before deciding whether to take part in this study or not. You can retain it for reference and use it to contact the researcher with any queries.

1. What is your age? _____years
2. What is your gender? Male Female
3. Do you have back pain? Yes No

4. How long have you had your pain? (please tick one)

0 - 3	0 - 6	7-12	1-2	2 - 3	4 - 5	More	More
months	months	months	years	years	years	than 5	than
						years	10
							years

5. This question is about any pain you have had in any part of your body over the past week. Please could you shade on this diagram all of the areas where you had pain.



6. How would you rate your pain <u>over the past week</u> on a scale of 0 - 10, where 0 is 'no pain' and 10 is 'pain as bad as could be'? (please tick one)										
No pain							pain as bad as can be			
0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Are you diagnosed with/have any of the following:

- Rheumatoid Arthritis
- Ankylosing Spondylitis
- Cancer
- Osteoporosis
- Fibromyalgia
- Infections
- Trauma
- Post spinal surgery
- Pregnancy
- Sciatica
- Whiplash syndrome
- Degenerative disc disease
- Disc prolapse
- Nerve root pain
- Facet joint syndrome

Thank you for completing this questionnaire. If you would like to take part in the study (described in the attached information sheet) I will arrange an interview at your convenience in terms of time and venue (for instance it could be scheduled before or after your next appointment at the BCOM). The interview will last approximately 30 minutes.

If you would like to take part in this study then please leave your contact details below and I will contact you within 2 weeks.

We are very grateful for expressing an interest in the study and for your time.

- I would like to take part in this study: YES NO
(If you answered YES please leave your contact details below)
- I would not like to take part in this study but may consider taking part in future related studies: YES NO
(If you answered YES please leave your contact details below)

First name: _____

Surname: _____

Address: _____

Home telephone number: _____

Mobile number: _____

Appendix B: Study 1 Poster Invitation

An invitation to
Back Pain Patients

to take part in a research study carried out by
Royal Holloway, University of London

**To discuss how you feel about
and understand your diagnosis
and how you cope with back
pain**

**If you are interested,
we would be delighted to hear from you**

**To find out more please collect an information sheet from
the reception or from your clinician**

Appendix C: Study 1 Interview Schedule

1. Can you tell me a little bit about how your pain started?
2. Can you tell me about your first consultation with the clinician?
 - a. Did they examine you physically?
 - b. Did you have any tests?
 - c. What did they tell you?
 - d. Did they explain the cause of your pain?
 - e. Did they give a name or label for your symptoms? What was it?
 - f. Do you think they got it right?
 - g. Were you satisfied with their explanation? Did you understand it?
 - h. Did you get a chance to ask questions about it?
 - i. How did you feel about it?
 - j. What was your initial response to it?
3. Can you tell me about your subsequent consultation/s?
 - a. Who did you see?
 - b. Did they examine you physically?
 - c. Did you have any tests?
 - d. Did you want them?
 - e. Did they discuss your symptoms with you?
 - f. Did they ask you about how you were coping with the pain?
 - g. Did they agree with the initial diagnosis?
 - h. If they did agree, were you satisfied with it?
 - i. (if not satisfied) Why were you not satisfied?
 - j. If they did not agree with the initial diagnosis, what diagnosis/label/explanation did they give you?
 - i. Do you think they got it right?
 - ii. Were you satisfied with their explanation? Did you understand it?
 - iii. Did you get a chance to ask questions about it?
 - iv. How did you feel about it?
 - v. What was your initial response to it?
4. What is your understanding of your back pain now?
 - a. What do you think is the cause of your pain?
 - b. Do you agree with the clinician/s in this respect?
 - c. What diagnosis do you use to explain your symptoms?
 - d. Is this in agreement with the diagnosis/label you received from the clinician?
 - e. (If not) Why don't you agree with it?

- f. Do you use this diagnosis to explain your symptoms to your friends and family?
 - g. In what ways does your own diagnosis help you?
 - i. In terms of coping with your pain?
 - ii. In terms of how you feel about your situation?
 - iii. In terms of how you communicate about your back pain with your friends and family?
 - h. (If you use the diagnosis your clinician has given you) Are you satisfied with it?
 - i. (If not) Why not?
 - i. How does it make you feel?
 - ii. Does it impact on your coping with your pain?
 - iii. Does it influence how you communicate about your back pain with your friends and family?
 - j. Would you like to discuss it with a professional and have it changed?
5. How has having back pain impacted on your relationship with friends and family?
- a. Do you think the way they see you has changed?
 - i. If yes, how has it changed?
 - ii. Why do you think it has changed?
 - b. How do you feel about it?
 - c. Has having back pain affected the relationship with them over time?
 - i. Why do you think this change has happened?
 - ii. What are positive aspects of this change?
 - iii. What are negative aspects of this change?
 - iv. How do you feel about it?
6. How do you think you are coping with your back pain?
- a. Has it changed over time?
 - b. If yes, how has it changed?
 - i. Would you describe this change as positive or negative?
 - ii. What has influenced this change most?
 - c. If it has not changed,
 - i. How do you feel about it?
 - ii. Why do you think it has not changed?
 - iii. Do you think that changing your diagnosis status would contribute to this change?

Appendix D: Study 1 Information Sheet and Consent Forms

Department of
Psychology
Royal Holloway,
University of London
Egham, Surrey
TW20 0EX

INFORMATION SHEET

How do chronic back pain patients understand and feel about their diagnosis?

My name is Danijela Serbic and I am a PhD student at the Psychology Department, Royal Holloway, University of London. This study is supervised by Dr Tamar Pincus.

I am carrying out a study to explore how chronic back pain patients understand their back pain and how they cope with it. Some patients with back pain receive a diagnosis from clinician, others receive an explanation without clear diagnosis, but many patients feel they receive neither. As currently there is no consistency and no clear guidelines for delivering diagnosis for chronic back pain, it is important to explore patients' experiences. We hope that the findings from this study will help clinicians to discuss back pain with patients better. If you would like to discuss any aspect of this study you can contact me by email: danijela.serbic@rhul.ac.uk or by phone 01784 443913.

If you are interested in this study or future related studies please fill in the attached questionnaire with your details and we will contact you within two weeks.

If you decide to take part in this study, you will be asked questions (in an interview) about how you understand and feel about your diagnosis as well as questions about coping with your chronic pain. I will arrange an interview at your convenience in terms of time and venue. The interview will last approximately 30 minutes. The interview will be recorded and transcribed but the transcript will not include your name and will be kept separately from your consent form.

Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason. During the interview you can decide not to answer any questions if you prefer not to. The information you give and your identity will remain confidential, nobody except myself and my supervisor will be allowed to see your files and in the study you will be known only by number. The information you give about your clinical treatment will be also kept confidential, it will not be linked to your name and will not affect or be linked to your current or future treatment in any way.

Your signed consent form will be stored separately from the responses you provide. This study has been reviewed and approved by the Psychology Department Ethics Committee at Royal Holloway, University of London, and by the ethics committee at the British School of Osteopathic Medicine
Thank you for taking the time to read this information.

Please retain this information sheet for reference and contact me with any queries.

CONSENT FORM 1

How do chronic back pain patients understand and feel about their diagnosis?

Researcher: Danijela Serbic

You have been asked to participate in a study which aim is to explore how chronic back pain patients understand and feel about their diagnosis.

Please circle yes or no:

I have read the information sheet about this study

YES/NO

I have had the opportunity to ask questions

YES/NO

I have received satisfactory answers to any questions

YES/NO

I understand that I am free to withdraw from the study at any time, without giving a reason

YES/NO

I agree to participate in this study YES/NO

I agree to be audio recorded YES/NO

Signed -----

Name (please print) -----

Date -----

NB: This Consent form will be stored separately from the responses you provide.

CONSENT FORM 2

How do chronic back pain patients understand and feel about their diagnosis?

Researcher: Danijela Serbic

The aim of this study was to explore how chronic back pain patients understand and feel about their diagnosis.

Thank you for taking part in the study. We would like to reassure you that the information you have given and your identity will remain confidential, nobody except myself and my supervisor will be allowed to see your files and in the study you will be known only by number. The information you have given about your clinical treatment will be also kept confidential, it will not be linked to your name and will not affect or be linked to your current or future treatment in any way. Your signed consent forms will be stored separately from the responses you provide.

Please circle yes or no:

I understand that the data from my interview will be transcribed and analysed by the researcher.

YES / NO

I understand that the findings from this study may be published and that my name and details identifying me will be kept confidential.

YES/ NO

I understand that the information I have given about my clinical treatment will be kept confidential, it will not be linked to my name and will not affect or be linked to my current or future treatment in any way.

YES / NO

The data will be destroyed upon the completion of the entire research project (in 2016).

YES / NO

Signed-----

Name (please print) -----

Date -----

NB: This Consent form will be stored separately from the responses you provide.

Appendix E: Study 1 – 5 Royal Holloway Ethics Approval

Department of Psychology
Royal Holloway, University of London
Egham, Surrey, TW20 0EX, UK
www.rhul.ac.uk

T +44 (0)1784 46326
F +44 (0)1784 494247
PSY-enquiries@rhul.ac.uk



22 February 2010

To whom it may concern:

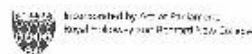
**Researcher: Mrs Danijella Serbic, Supervisor: Dr Tamar Pincus.
Research Study: How does diagnostic labelling relate to acceptance,
guilt and enmeshment of self and pain in chronic back pain patients?
Ethics Reference 2010/008**

This is to confirm that the above study has been approved by RHUL
Psychology Department Ethics Committee, for a period of 60 months
from 1st April 2010.

Yours sincerely,

A handwritten signature in black ink, appearing to be "J. Wann", written over a light blue horizontal line.

Professor John Wann
Chair, Psychology Departmental Ethics Committee



Appendix F: Study 1 Excerpt from an Interview Transcript

ID: R1F36

(Client's notes diagnosis: non-specific mechanical back pain; at the end of the interview I asked the client if she has ever come across this able, she said 'she didn't and she would not like to be told she has something like that, it does not sound nice')

(Bold writing – Researcher)

Ok, I see you put here that you've suffered from back pain for more than 5 years, can you tell me a little bit when your pain started, and when it happened and why it happened?

Ok, It was about 5 and a half years ago, I'll give a bit background am,, I started cheffing in a Hilton hotel since I was sixteen till last year. I did a lot of hours, a lot of say 16 hours 7 day a week a lot, lot of and lifting, heavy lifting so basically what's happened I didn't not look myself properly as in carrying the wrong way, working too many hours, not eating right things and the accumulation of all that everything I did not realise I'd done it, but one morning I got up and barely could get out of bed and I felt as if I died there ammm pooled something or something wrong with the back, went to the hospital and called in sick went to the hospital and they basically did an x ray

Yes

And I can't remember the words there are lots of technical words and it is apparently I've got a curvature of the spine, didn't know that and it's getting worse amm and apparently it's I can't remember, it is I can't remember the word something about; basically the spine is worn there is a word for it beginning with d and I can't remember what it is, but basically that's what they said and it's getting worse as I was working and I can't remember what the word is, so basically he said and then I am with BUPA, so I went to that with the national health and they gave me some tablets and it didn't really make it better and did try and carry on and it got ok and then since then I'd been lifting things and my legs been giving away when I am walking and when I's walking I could not be just walking normallyits 'been years ago and it's been carrying on ever since, it feels like an electric shock in my back and all feeling in my right leg so basically I had to give up work

Completely

last year yeah, I was just I was gonna cause myself and some other peoplewith hotel staff and that's not good so I went to a specialist which is doctor King, amm with BUPA and he gave me some steroids...

Injections

Yes

Steroid injections and they worked for...and painkillers they worked for a short time and then it just came back, so after that he gave me some shock [inaudible] amm I'm not sure something to do with nerve ending he sort of blocked them off, I do not fully understand

Yeas, never mind

And that and then he suggested I come here, that's the progress

So when you went for the first time to see somebody regarding your back pain, what label did they give you or diagnosis, did they give you any diagnosis?

The first, sorry the first doctor at hospital said that, I think he said something about that I'm having sciatica or something else or you just pulled something which is and then I went to a specialist and he'd done an x ray and I went to one of them tubes as well

MRI?

Yeah

I know, it's just too much (both laugh)

Yeah one of them and he showed the word I am looking for again ohh when the spine went down

It degenerates

Yes, degenerated, that's the word, quite lot and he showed me the curvature, I did not know I had, that is just all of that sort of thing

How did you feel about that explanation was it sufficient for you?

The initial one?

Yes

Not very good

Why not?

Because I, there wasn't enough, it was like a nurse type straight doctor and he said that I've got sciatica, I pulled something and it is all, or you might've or you might have done this, so it's like nobody said and that's what it is and they're gonna have that and they're gonna feel better; does that make sense?

Yes

So when I came I rang my mother who is nurse she knows a fair bit, she goes but that doesn't sound like sciatica, or so I am getting all sorts of thing...

Information?

Yeah, and people at work said, oh my granddad had sciatica; and that's, I just sat there oh I don't feel like this. So that's when mum said why you don't go to your consultant and all of that, it was just quick and easy and they could give me something

And when you saw the first person and they gave you this explanation you said it was a bit confusing, how did it make you feel I mean because you had to go back to your friends and co-workers to explain what happened to you?

Because I had to take a day off sick and I had not taken a day off sick in 18 years and I'd gone in and they said what's wrong with you don't take day sick for nothing you worked here for like 10 years, what's happened it must be something serious; I said I'm not sure really and I said and the man says what's happened; I do not really know, the doctor said at the hospital, said I've got sciatica or I pulled a muscle. I'd rather have one explanation than all this [inaudible]. And I felt the unknown sort of thing I was not very happy with that, if that makes sense.

Did they spend time with you like explaining what it was, the doctors there?

Not really, not really because they said if it's sciatica there is not really a lot you can do with it, and I went ok; and if it's a pulled muscle you need to have a bed rest

And then your subsequent consultations, what was explained to you?

Ohh so much more basically

Was it with a consultant you said?

It was a BUP consultant

BUPA consultant

Dr King and he actually... I went to two specialists that's right, the first one I went was, aarr the second one was the nerve because it felt like it was a nerve...

Neurologist

Neurologist; and the first one was a spinal and he past me over to Dr King, who does the steroids and all that sort of thing and he put me... said to go for an MRI, and he showed me the spine, it went on disc and showed on the computer and flipped it around and he said this is your spine you've got a curvature there, see these ammmm columns

Yeah

That's gone down X 4, that's where you are getting pain, what I want do is to go into each facet, sort of explained it to me, broke it down, draw a picture and didn't use many large words, which is good

Yes

Which is quite good you know and the diagrams and he gave me the copy of the CD and x ray and MRI-s and everything else, and it's just that, at least I knew there was , he could do something rather than going home and have some sleep and have a painkiller, rather than if I could do this rather than the other; that was the initial, and then he said I'll do this nerve ending thing and then he said to come here, so it was like a process of elimination type of thing.

Yeah and with him, I mean did it make you feel better than after the first consultation

Yeah I had some sort of reassurances as to say, this is what you've got, but we can sort it out sort of thing or we can go through procedures rather than....he made me feel better yeah

Appendix G: Study 2 Online Survey Invitation Placed on Back Care Website

An invitation to people with back pain to take part in a research study:

The impact of chronic back pain on patients' feelings and coping

A survey study is being carried out at the Psychology Department, Royal Holloway, University of London, to explore how chronic back pain patients feel and cope with their back pain. This is an online survey and it will take approximately 15 minutes of your time. Your participation will be anonymous and confidential. If you have back pain and would like to find out more about this study and/or take part please follow this link:

Email link

<http://www.pc.rhul.ac.uk/sites/surveys/TakeSurvey.asp?SurveyID=7L16535029m3G>

Web link

The impact of back pain on feelings and coping Survey

Appendix H: Study 2 Online Study Information Sheet

Department of Psychology
Royal Holloway,
University of London,
Egham, Surrey, TW20 0EX

INFORMATION SHEET

The impact of chronic back pain on patients' feelings and coping

My name is Danijela Serbic and I am a PhD student at the Psychology Department, Royal Holloway, University of London. This study is supervised by Professor Tamar Pincus.

We are carrying out a study to explore how patients respond to having chronic low back pain. People who experience pain for long periods of time often have to adjust their life and behaviours because of the pain. Our research has suggested that many patients feel bad, and even guilty about having to make these changes. However, this area is very poorly researched and we would like to understand how prevalent these feelings are and how they impact on patients' coping with back pain. We believe that better understanding and awareness of emotions that back pain patients experience will enable researchers and medical professionals help people with pain more effectively.

If you decide to take part in this study, please complete the attached questionnaire which consists of questions asking you how you understand your diagnosis, about your functioning, mood, engagement in activities and pain related feelings of guilt. It will take approximately 15 minutes to complete the questionnaire and you will be asked to complete it online.

Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason. You can decide not to answer any questions if you prefer not to. Your participation is anonymous and confidential, nobody except myself and my supervisor will be allowed to see your files and in the study you will

be known only by number. We do not require your name or any other personal details which may reveal your identity. Your signed consent form will be stored separately from the responses you provide.

This study has been reviewed and approved by the Psychology Department Ethics Committee at Royal Holloway, University of London, and by the Back Care Charity.

Please retain this information sheet for reference and if you have any queries contact me by email: danijela.serbic@rhul.ac.uk or by phone 01784 443913. A summary of the findings will be available on request.

Thank you for taking the time to read this information.

To retain this information sheet for reference please select **‘Print’**

If you would like to take part in the study please select **‘Continue’**

6. Do you have any of the following conditions? Please indicate by ticking either YES or NO.

Cardiovascular disease YES NO

Inflammatory disorder such as YES NO

Rheumatoid Arthritis or Lupus

Ankylosing Spondylitis YES NO

Cancer YES NO

Chronic obstructive pulmonary YES NO

disease (COPD)

Other condition; if YES please specify YES NO

in the box provided

None YES NO

7. We are interested in what you think about your **diagnosis for BACK PAIN**. Please select either YES or NO answer.

a) I have been given a clear label/diagnosis for my back pain YES NO

If YES: Generally speaking, I agree with this label/diagnosis YES NO

b) I have been given a clear explanation about why I have back pain YES NO

If YES: Generally speaking, I agree with this explanation YES NO

c) I think there is something else happening with my back which the doctors have not found out about yet YES NO

Section 2: This section is about back pain related feelings of guilt

People who experience pain for long periods of time often have to adjust their life and behaviours because of the pain. Our research has suggested that many patients feel bad, and even guilty about having to make these changes. However this area is very poorly researched and we would like to understand how prevalent these feelings are and how they impact on patients' coping with back pain.

Please rate each statement on a scale 1 (Never) to 5 (Always).

Never	Seldom	Sometimes	Often	Always
1	2	3	4	5

Because of my back pain I have experienced feelings of guilt:

- | | | | | | |
|---|---|---|---|---|---|
| 1. About not being able to go out more often | 1 | 2 | 3 | 4 | 5 |
| 2. About not being able to attend important events | 1 | 2 | 3 | 4 | 5 |
| 3. About not being able to visit my family and friends | 1 | 2 | 3 | 4 | 5 |
| 4. About not being able to help people close to me when they need me | 1 | 2 | 3 | 4 | 5 |
| 5. When I have been unable to do things <u>with</u> my family and friends | 1 | 2 | 3 | 4 | 5 |
| 6. About not meeting people's expectations | 1 | 2 | 3 | 4 | 5 |

- | | | | | | |
|--|---|---|---|---|---|
| 7. When others make allowances | 1 | 2 | 3 | 4 | 5 |
| 8. About not being able to do my daily tasks | 1 | 2 | 3 | 4 | 5 |
| 9. About being impatient or frustrated with people around me | 1 | 2 | 3 | 4 | 5 |

Please rate each statement on a scale 1 (Never) to 5 (Always).

Never	Seldom	Sometimes	Often	Always
1	2	3	4	5

I have experienced feelings of guilt:

- | | | | | | |
|---|---|---|---|---|---|
| 10. About being unable to cope better with my back pain | 1 | 2 | 3 | 4 | 5 |
| 11. When my therapist is not able to relieve the pain | 1 | 2 | 3 | 4 | 5 |
| 12. About seeing a number of different practitioners in search of help | 1 | 2 | 3 | 4 | 5 |
| 13. About being unable to give a specific reason for what is causing my back pain | 1 | 2 | 3 | 4 | 5 |
| 14. About being unable to provide visible/physical evidence for my back pain | 1 | 2 | 3 | 4 | 5 |

- | | | | | | |
|--|---|---|---|---|---|
| 15. When the pain does not seem to improve | 1 | 2 | 3 | 4 | 5 |
| 16. When I cannot stop worrying about my back problem | 1 | 2 | 3 | 4 | 5 |
| 17. About being unable to produce a clear diagnosis when asked | 1 | 2 | 3 | 4 | 5 |
| 18. About being unable to control the illness and pain | 1 | 2 | 3 | 4 | 5 |
| 19. When my symptoms are not believed by other people | 1 | 2 | 3 | 4 | 5 |

Please rate the following statements on a scale 1 (Never) to 5 (Always)

- | | Never | Seldom | Sometimes | Often | Always |
|--|--------------|---------------|------------------|--------------|---------------|
| | 1 | 2 | 3 | 4 | 5 |
| 20. I apologise a lot <u>for the things I cannot do</u> because of my back pain | 1 | 2 | 3 | 4 | 5 |
| 21. I apologise a lot <u>for the things I do and say</u> because of my back pain | 1 | 2 | 3 | 4 | 5 |
| 22. I do things (e.g. go to work) to feel less guilty in spite of being in pain | 1 | 2 | 3 | 4 | 5 |
| 23. I feel like I am letting people down when I am in pain | 1 | 2 | 3 | 4 | 5 |

If you do not work skip the next question:

1 2 3 4 5

24. I have experienced feelings of guilt when my back
pain has caused colleagues to do extra work

Section 3: This section is about your mood

Please read each item and tick the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or "wound up"

- | | |
|---------------------------------|--------------------------|
| Most of the time | <input type="checkbox"/> |
| A lot of the time | <input type="checkbox"/> |
| From time to time, occasionally | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

2. I still enjoy the things I used to enjoy

- | | |
|--------------------|--------------------------|
| Definitely as much | <input type="checkbox"/> |
| Not quite as much | <input type="checkbox"/> |
| Only a little | <input type="checkbox"/> |
| Hardly at all | <input type="checkbox"/> |

3. I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
- Yes, but not too badly
- A little but it doesn't worry me
- Not at all

4. I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

5. Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

6. I feel cheerful

- Not at all
- Not often
- Sometimes
- Most of the time

7. I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

8. I feel as if I am slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

9. I get a sort of frightened feeling like “butterflies” in the stomach

- Not at all
- Occasionally
- Quite often
- Very often

10. I have lost interest in my appearance

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

11. I feel restless as if I have to be on the move

- Very much indeed
- Quite a lot
- Not very much
- Not at all

12. I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

13. I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

14. I can enjoy a good book or radio or TV programme

- Often
- Sometimes
- Not often
- Very seldom

<p>Section 4: This section is about how back pain impacts on your daily activities</p>

When your back hurts, you may find it difficult to do some of the things you normally do.

*This list contains sentences that people have used to describe themselves when they have back pain. When you read them, you may find that some stand out because they describe you today. As you read the list, think of yourself today. When you read a sentence that describes you today, put a tick against it. If the sentence does not describe you, then leave the space blank and go on to the next one. Remember; **only tick the sentence if you are sure it describes you today.***

- I stay at home most of the time because of my back.
- I change position frequently to try and get my back comfortable.
- I walk more slowly than usual because of my back.
- Because of my back I am not doing any of the jobs that I usually do around the house.
- Because of my back, I use a handrail to get upstairs.
- Because of my back, I lie down to rest more often.
- Because of my back, I have to hold on to something to get out of an easy chair.
- Because of my back, I try to get other people to do things for me.
- I get dressed more slowly than usual because of my back.
- I only stand for short periods of time because of my back.
- Because of my back, I try not to bend or kneel down.
- I find it difficult to get out of a chair because of my back.
- My back is painful almost all the time.
- I find it difficult to turn over in bed because of my back.
- My appetite is not very good because of my back pain.

- I have trouble putting on my socks (or stockings) because of the pain in my back.
- I only walk short distances because of my back.
- I sleep less well because of my back.
- Because of my back pain, I get dressed with help from someone else.
- I sit down for most of the day because of my back.
- I avoid heavy jobs around the house because of my back.
- Because of my back pain, I am more irritable and bad tempered with people than usual.
- Because of my back, I go upstairs more slowly than usual.
- I stay in bed most of the time because of my back.

Appendix J: Study 3 Information Sheet and Consent Form

Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

INFORMATION ABOUT THE STUDY

The impact of chronic back pain on patients' feelings and coping

My name is Danijela Serbic and I am a PhD student at the Psychology Department, Royal Holloway, University of London. This study is supervised by Professor Tamar Pincus.

We are carrying out a study to explore how patients respond to having chronic low back pain. People who experience pain for long periods of time often have to adjust their life and behaviours because of the pain. Our research has suggested that many patients feel bad, and even guilty about having to make these changes. However this area is very poorly researched and we would like to understand how prevalent these feelings are and how they impact on patients' coping with back pain.

We believe that better understanding and awareness of emotions that back pain patients experience will enable researchers and medical professionals help people with pain more effectively.

If you decide to take part in this study, please complete the attached questionnaire which consists of questions asking you how you understand your diagnosis, about your functioning, engagement in activities, mood and pain related feelings of guilt. It will take approximately 15 minutes to complete the questionnaire. Please leave the completed questionnaire in the sealed response box at the BCOM clinic or post it back to the researcher by using the envelope provided.

Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason. You can decide not to answer any questions if you prefer not to. Your participation is anonymous and confidential, nobody except

myself and my supervisor will be allowed to see your files and in the study you will be known only by number. We do not require your name or any other personal details which may reveal your identity.

This study has been reviewed and approved by the Psychology Department ethics committee at Royal Holloway, University of London and by the BCOM.

Please retain this information sheet for reference and if you have any queries contact me by email: daniijela.serbic@rhul.ac.uk or by phone 01784 443913. A summary of the findings will be available on request.

Thank you for taking the time to read this information.

CONSENT FORM**The impact of chronic back pain on patients' feelings and coping**

Researcher: Danijela Serbic

You have been asked to participate in a study which aim is to explore how patients respond to having chronic low back pain.

Please circle YES or NO:

I have read the information sheet about this study YES/NO

I understand that I am free to withdraw from YES/NO
the study at any time, without giving a reason

I agree to participate in this study YES/NO

The consent form will be stored separately from the responses you provide.

Appendix K: The First Page of Study 4 and 5 NHS Ethics Approval Letter



Health Research Authority

NRES Committee East of England - Cambridge South
 Victoria House
 Capital Park
 Fulbourn
 Cambridge
 CB21 3XB

Telephone: 01223 697750
 Facsimile: 01223 697645

06 December 2011

Mrs Danijeta Serbic
 PhD student
 Royal Holloway, University of London, Department of Psychology
 Egham
 Surrey
 UK
 TW20 0EX

Dear Mrs Serbic

Study title: The impact of chronic back pain on patients' feelings, identity and coping with back pain
REC reference: 11/EE/0479

Thank you for your letter of 25/11/2011 responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.ruforum.nhs.uk>.

Appendix L: Study 4 NHS Information Sheet and Consent Form

Participant Information Sheet

We invite you to take part in a research study called:

The impact of chronic back pain on patients' feelings, identity and coping with back pain

- We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.
- We think you might be suitable to take part in the study, and would be very grateful if you could read this information sheet and fill in the enclosed questionnaire.
- You do not have to take part in the study. It is up to you whether or not you take part.
- Your participation or refusal to participate will not be linked or affect your care in any way.
- Ask us if anything is unclear, or if you would like more information.

Contents:

- 1 What is this study about?
- 2 Why are we doing the study?
- 3 What would we like you to do now?
- 4 What is going to happen in the study if you decide to take part?
- 5 More information about taking part

How to contact us:

If you have any questions about this study, please contact:

Researcher: Danijela Serbic

Address: Department of Psychology,
Royal Holloway, University of
London, Egham, Surrey, TW20 0EX
Telephone: 01784443913

Email: danijela.serbic@rhul.ac.uk

1 What is this study about?

- This research study explores how patients respond to having chronic low back pain, how they feel about their back pain and how they cope with it.
- It consists of a questionnaire only; if you decide to participate your participation will be anonymous and you will be given a questionnaire to complete.

2 Why are we doing the study?

- People who experience pain for long periods of time often have to adjust their life and behaviour because of the pain. Our research has suggested that many patients experience difficulties, and sometimes feel guilty about having to make these changes. However this area is poorly researched.
- We believe that better understanding and awareness of coping strategies and emotions that back pain patients experience will enable researchers and medical professionals help people with back pain more effectively.

3 What would we like you to do now?

- We are asking you to read the information about the study and complete the enclosed questionnaire. Once you completed the questionnaire, please send it back using the self-addressed stamped envelope we provided, or leaving it in the response box in the clinic.
- You do not have to complete the questionnaire. Although your practitioner or the researcher will invite you to take part in the study, your personal details will not be recorded, hence your participation will be anonymous.

4 What is going to happen in the study if you decide to take part?

- The researcher or your practitioner will hand out the information sheet and the questionnaire to you because you have back pain. They will explain to you what the study is all about and what you are expected to do. This will also give you a chance to ask any questions you may have about the study. If you are still interested in participating after talking to them you can then take the questionnaire home to consider whether you want to take part or not in the study.

5 More information about taking part in the study

Do I have to take part?

- Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason.
- You can decide not to answer any questions if you prefer not to.
- Your participation or refusal to participate will not be recorded anywhere, linked or affect your care in any way.
- Please read this information sheet carefully, and discuss it with friends/relatives if you like in order to decide whether or not you wish to take part.

Will my taking part be kept confidential?

- All your personal details and answers to questions will be kept confidential as required by the Data Protection Act 1998 and in line with the consent you have given.
- Your participation is anonymous. In the study you will be known only by number.
- You will be asked to complete a consent form but you do not need to include your personal details or sign it.
- Your data will be stored securely at the researcher's office at Royal Holloway University of London and only the researcher and her supervisor will have access to it.
- This study is part of a PhD project and participants' files will be destroyed when the PhD is completed.
- If you are interested in taking part in the study and fill in the enclosed questionnaire, it will be completely confidential.
- It is possible that the information collected for this study may be shared with other researchers in the future or that the study gets published in a scientific journal. If this happens only group results (across all participants who took part in the study) would be made available and your data would not be identifiable from it.
- Your healthcare records will be only looked at by your practitioner. The researcher may wish to confirm details with practitioner who initially assessed you to confirm your eligibility to take part in the study before you are asked to participate, but your name and personal details will not be recorded anywhere and your participation from this point on will be anonymous.

What will happen if I do not want to carry on with the study, or if I'm found not to be eligible after I've consented to take part?

- If you are found not to be eligible for the study, we will not record your details.

What if something goes wrong?

- All tasks in the study are known to be safe and we do not expect there to be any risks in taking part. If you have a concern about any aspect of this study, you should speak with the researcher who will do her best to answer your questions. If you remain unhappy you may wish to consult with your treating practitioner or you may wish to contact your local Patient Advice and Liaison Service (PALS); Charing Cross's PALS telephone number is: 020 33130088 or 020 33133322). If you wish to complain formally you can do this through the NHS Complaints Procedure.

Involvement of your practitioner:

- Once you have been identified by the practitioner that you suffer from back pain, you will be invited to take part in the study and given the study pack, but from this point onwards your participation in the study will be anonymous, so we will not inform your practitioner that you decided to take part in this study.

Who is organising, funding and reviewing the research?

- This study is part of a PhD project and is supervised by Professor Tamar Pincus, Royal Holloway University of London
- The main sponsor is Royal Holloway University of London. It is partly funded by Pain Relief Foundation
- This study has been reviewed and approved by the NHS Cambridge South Research Ethics Committee, Imperial College Healthcare NHS Trust and by Royal Holloway University of London.
- A summary of the findings will be available on the researcher's webpage, which is part of Royal Holloway University of London Research webpage. This is the web address <http://www.rhul.ac.uk/research/home.aspx>. Please enter the researcher's name (Danijela Serbic) in 'Search for researcher' field.

Thank you for taking time to read this information leaflet

PARTICIPANT CONSENT FORM**The impact of chronic back pain on patients' feelings, identity and coping with back pain**

You have been asked to participate in a study which aim is to explore how chronic back pain patients respond to having low back pain.

**Please initial
box**

1. I have read and understood this information sheet and have been able to ask questions.
2. I understand that I may not be eligible to take part even though I am giving my consent. If I am not eligible the researcher will tell me. I understand that this will not affect the care or the type of treatment I receive.
3. I understand that my taking part in the study is voluntary and that I am free to drop out at any time without my medical care or legal rights being affected.
4. I understand that my healthcare records will be looked at only by my practitioner. The researcher may wish to confirm details with my practitioner to confirm my eligibility to take part in the study.
5. I agree to allow any information or results arising from this study to be used for further research and scientific publications on the understanding that my identity will remain anonymous.
6. I agree to take part in the study.

Date.....

How would you rate your back pain over the past week on a scale of 0 - 10, where 0 is 'no pain' and 10 is 'pain as bad as could be'? (please tick one)

No												Pain
												as
Pain												bad as
												can be
0	1	2	3	4	5	6	7	8	9	10		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Do you have any of the following conditions? Please indicate by ticking either YES or NO.

Rheumatoid Arthritis YES NO

Ankylosing Spondylitis YES NO

Osteoporosis YES NO

Cancer YES NO

Pregnancy YES NO

Other condition; if YES please specify

in the box provided YES NO

We are interested in what you think about your **DIAGNOSIS for BACK PAIN**.
Please select either YES or NO answer.

I have been given a clear label/diagnosis for my back pain YES NO

If YES:

What diagnosis have you been
given? _____

Generally speaking, I agree with this label/diagnosis YES NO

Was this diagnosis obtained from (select all that apply to you):

- Your GP
 - A physiotherapist
 - An osteopath
 - A chiropractor
 - A rheumatologist
 - An orthopaedic surgeon
 - Other (please specify)
-

Was the consultation in which you were provided the diagnosis
within an NHS setting? YES NO

I have been given a clear explanation about why I have back pain
YES NO

If YES: Generally speaking, I agree with this explanation YES NO

Section 2: This section is about back pain related feelings of guilt

Directions: The following scale measures pain-related guilt. It includes a list of 12 statements and there are no right or wrong answers. Please rate the extent to which each statement relates to you over the past few weeks by circling a number. Use the following rating scale to make your choices.

Never	Seldom	Sometimes	Often	Always
1	2	3	4	5

Because of my back pain I have experienced feelings of guilt:

13. About not being able to go out more often	1	2	3	4	5
14. About being unable to control the illness and pain	1	2	3	4	5
15. About being unable to give a specific reason for what is causing my back pain	1	2	3	4	5
16. When I have been unable to do things with my family and friends	1	2	3	4	5
17. When the pain does not seem to improve	1	2	3	4	5
18. About being unable to provide visible/physical evidence for my back pain	1	2	3	4	5
19. About not being able to attend important events	1	2	3	4	5
20. When I cannot stop worrying about my back problem	1	2	3	4	5
21. About being unable to produce a clear diagnosis when asked	1	2	3	4	5
22. When my therapist is not able to relieve the pain	1	2	3	4	5
23. About not being able to help people close to me when they need me	1	2	3	4	5
24. About seeing a number of different practitioners in search of help	1	2	3	4	5

Section 3: This section is about how back pain impacts on your daily activities

When your back hurts, you may find it difficult to do some of the things you normally do.

*This list contains sentences that people have used to describe themselves when they have back pain. When you read them, you may find that some stand out because they describe you today. As you read the list, think of yourself today. When you read a sentence that describes you today, put a tick against it. If the sentence does not describe you, then leave the space blank and go on to the next one. Remember; **only tick the sentence if you are sure it describes you today.***

- I stay at home most of the time because of my back.
- I change position frequently to try and get my back comfortable.
- I walk more slowly than usual because of my back.
- Because of my back I am not doing any of the jobs that I usually do around the house.
- Because of my back, I use a handrail to get upstairs.
- Because of my back, I lie down to rest more often.
- Because of my back, I have to hold on to something to get out of an easy chair.
- Because of my back, I try to get other people to do things for me.
- I get dressed more slowly than usual because of my back.
- I only stand for short periods of time because of my back.
- Because of my back, I try not to bend or kneel down.
- I find it difficult to get out of a chair because of my back.

- My back is painful almost all the time.
- I find it difficult to turn over in bed because of my back.
- My appetite is not very good because of my back pain.
- I have trouble putting on my socks (or stockings) because of the pain in my back.
- I only walk short distances because of my back.
- I sleep less well because of my back.
- Because of my back pain, I get dressed with help from someone else.
- I sit down for most of the day because of my back.
- I avoid heavy jobs around the house because of my back.
- Because of my back pain, I am more irritable and bad tempered with people than usual.
- Because of my back, I go upstairs more slowly than usual.
- I stay in bed most of the time because of my back.

Section 4: This section is about your mood

Please read each item and tick the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or "wound up"

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy

- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
- Yes, but not too badly
- A little but it doesn't worry me
- Not at all

I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like “butterflies” in the stomach

- Not at all
- Occasionally
- Quite often
- Very often

I have lost interest in my appearance

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme

- Often
- Sometimes
- Not often
- Very seldom

Thank you for completing the questionnaire!

Do you have any of the following conditions? Please indicate by ticking either YES or NO.

Rheumatoid Arthritis YES NO

Ankylosing Spondylitis YES NO

Osteoporosis YES NO

Cancer YES NO

Pregnancy YES NO

Other condition; if YES please specify
in the box provided YES NO

We are interested in what you think about your diagnosis for BACK PAIN. Please select either YES or NO answer.

- a) I have been given a clear label/diagnosis for my back pain
YES NO

If YES:

Generally speaking, I agree with this label/diagnosis
YES NO

- b) I have been given a clear explanation about why I have back pain
YES NO

If YES:

Generally speaking, I agree with this explanation
YES NO

- c) I think there is something else happening with my back which
the doctors have not found out about yet
YES NO

CONSENT TO RESEARCHER CONTACT FORM

Thank you for completing this questionnaire. If you think you would like to take part in the study we will contact you by phone to discuss the study and arrange a meeting at your convenience.

If you would like to take part in this study then please leave your contact details below and the researcher will contact you.

We are very grateful for expressing an interest in the study.

I would like to take part in this study: **YES NO**
(If you answered YES please leave your contact details below)

First name: _____

Surname: _____

Address: _____

Home telephone number: _____

Mobile number: _____

Consent to Researcher contact:

I am happy for the researcher to contact me: **YES NO**

I understand that the researcher may wish to confirm details with clinician who initially assessed me to confirm my eligibility to take part in the study:

YES NO

Your Signature: _____

Appendix O: Study 5 Information Sheet and Consent Form

Participant Information Sheet

We invite you to take part in a research study called:

The impact of chronic back pain on patients' feelings, identity and coping with back pain

- We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.
- We think you might be suitable to take part in the study, and would be very grateful if you could read this information sheet and fill in the enclosed questionnaire.
- Filling in the questionnaire does not mean you have to take part in the study. It is up to you whether or not you take part.
- Your participation or refusal to participate will not be linked or affect your care in any way.
- Ask us if anything is unclear, or if you would like more information.

Contents:

- 1 What is this study about?
- 2 Why are we doing the study?
- 3 What would we like you to do now?
- 4 What is going to happen in the study if you decide to take part?
- 5 More information about taking part

How to contact us:

If you have any questions about this study, please contact:

Researcher: Danijela Serbic

Address: Department of Psychology,
Royal Holloway, University of
London, Egham, Surrey, TW20 0EX
Telephone: 01784443913
Email: [danijela.serbic@rhul.ac.uk](mailto:danjela.serbic@rhul.ac.uk)

1 What is this study about?

- This research study explores how patients respond to having chronic low back pain, how they feel about their back pain and how they cope with it.
- It consists of two parts, we call them Study 1 and Study 2; if you decide to participate you will be asked to participate in only one of them.

2 Why are we doing the study?

- People who experience pain for long periods of time often have to adjust their life and behaviour because of the pain. Our research has suggested that many patients experience difficulties, and sometimes feel guilty about having to make these changes. However this area is poorly researched.
- We believe that better understanding and awareness of coping strategies and emotions that back pain patients experience will enable researchers and medical professionals help people with back pain more effectively.

3 What would we like you to do now?

- We are asking you to read the information about the study and complete the enclosed questionnaire. Once you send back the completed questionnaire the researcher will assess your responses to find out if it may be possible for you to potentially take part.
- If they indicate you are potentially eligible to participate and if you consent to the researcher contact, the researcher will telephone you to discuss the study, answer any questions you may have, and if you are happy to proceed with the study she will arrange a meeting with you to take part in the study. This will be at the time convenient for you, for instance it could be arranged just before or after your next appointment in the clinic.
- During the telephone conversation the researcher will also inform you whether you will be taking part in Study 1 or Study 2 of (these are described below). This decision will be based on your answers in the questionnaire.
- You do not have to complete the questionnaire. If you decide not to complete it, we will not contact you again and no information about you will be passed on to study researcher.
- If you are not eligible to take part we will let you know by a letter, but would not then contact you again.

4 What is going to happen in the study if you decide to take part?

- The study will be conducted by the researcher in your clinic at the time convenient to you.
- The researcher needs to see you only once for approximately 40 minutes.
- The researcher will explain to you what the study is all about and what you are expected to do. This will also give you a chance to ask any questions you may have about the study. If you are still interested in participating after talking to the researcher she will ask you to sign a consent form.
- If you are asked to take part in Study 1, it will involve a brief interview which will include questions about characteristics that describe you and questions about your understanding of word meaning. You will then be asked to complete a questionnaire asking about your diagnosis, your functioning, mood, engagement in activities and pain related feelings of guilt.
- If you are asked to take part in Study 2, you will be presented with a short task. In the task, you will be shown single words on a computer screen and asked to indicate if the words describe you. You will be asked to recall the words you saw. You will then be asked to complete a questionnaire asking about your diagnosis, your functioning, mood, engagement in activities and pain related feelings of guilt.

5 More information about taking part in the study

Do I have to take part?

- Your participation in this study is entirely voluntary and you can withdraw at any time without giving a reason.
- You can decide not to answer any questions if you prefer not to.
- Your participation or refusal to participate will not be linked or affect your care in any way.
- Please read this information sheet carefully, and discuss it with friends/relatives if you like in order to decide whether or not you wish to take part.

Will my taking part be kept confidential?

- All your personal details and answers to questions will be kept confidential as required by the Data Protection Act 1998 and in line with the consent you have given.
- Nobody except myself and my supervisor will be allowed to see your personal details and your responses will be fully anonymised. In the study you will be known only by number.

- Your signed consent form will be stored separately from the responses you provide.
- Your data will be stored securely at the Researcher's Office at Royal Holloway University of London.
- This study is part of a PhD project and participants' files will be destroyed when the PhD is completed.
- If you are interested in taking part in the study and fill in the enclosed questionnaire we will keep it as part of the study, but it will be completely confidential.
- It is possible that the information collected for this study may be shared with other researchers in the future or that the study gets published in a scientific journal. If this happens only group results (across all participants who took part in the study) would be made available and your data would not be identifiable from it.
- Your healthcare records will be only looked at by your practitioner. The researcher may wish to confirm details with practitioner who initially assessed you to confirm your eligibility to take part in the study.

What will happen if I do not want to carry on with the study, or if I'm found not to be eligible after I've consented to take part?

- If you decide to drop out at any stage, or if you are found not to be eligible for the study, the information we have collected from you will be kept at the researcher's office at Royal Holloway University of London but it will not be included in the final study analysis.

What if something goes wrong?

- All tasks in the study are known to be safe and we do not expect there to be any risks in taking part. If you have a concern about any aspect of this study, you should speak with the researcher who will do her best to answer your questions. If you remain unhappy you may wish to consult with your treating practitioner or you may wish to contact your local Patient Advice and Liaison Service (PALS); St Mary's PALS telephone number is: 020 7886 7777). If you wish to complain formally you can do this through the NHS Complaints Procedure.

Involvement of your practitioner:

- We will inform your practitioner that you are taking part in this study.

Who is organising, funding and reviewing the research?

- This study is part of a PhD project and is supervised by Professor Tamar Pincus, Royal Holloway University of London

- The main sponsor is Royal Holloway University of London. It is partly funded by Pain Relief Foundation
- This study has been reviewed and approved by the NHS Cambridge South Research Ethics Committee, St Mary's Hospital-Imperial College Healthcare NHS Trust and by Royal Holloway University of London.
- A summary of the findings will be available on the researcher's webpage, which is part of Royal Holloway University of London Research webpage. This is the web address <http://www.rhul.ac.uk/research/home.aspx>. Please enter the researcher's name (Danijela Serbic) in '*Search for researcher*' field.

Thank you for taking time to read this information leaflet

PARTICIPANT CONSENT FORM**The impact of chronic back pain on patients' feelings, identity and coping with back pain**

You have been asked to participate in a study which aim is to explore how chronic back pain patients respond to having low back pain.

Please initial
box

I have read and understood this information sheet and have been able to ask questions.

I understand that I may not be eligible to take part even though I am giving my consent. If I am not eligible the researcher will tell me. I understand that this will not affect the care or the type of treatment I receive.

I understand that my taking part in the study is voluntary and that I am free to drop out at any time without my medical care or legal rights being affected. I understand that if I drop out, the information collected from me will not be used in the study analysis.

I understand that my healthcare records will be looked at only by my practitioner. The researcher may wish to confirm details with my practitioner to confirm my eligibility to take part in the study.

I agree to allow any information or results arising from this study to be used for further research and scientific publications on the understanding that my identity will remain anonymous.

I agree that my practitioner or any other practitioner treating me at this clinic will be told of my taking part in this study.

I agree to take part in the study.

Participant:

Signature.....

Name (block capitals).....

Date.....

Researcher:

I have explained the study to the above named participant and he/she has indicated his/her willingness to participate.

Signature.....

Name (block capitals).....

Date.....

Appendix P: Study 5 Distractor Task

Butterfly 1



Butterfly 2