Chronic Pain and Identity

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OVERVIEW

This thesis is presented in three parts. Part One is a literature review that provides an overview of chronic pain research and explores the impact of chronic illness and chronic pain on identity. Part Two presents the empirical paper, describing the quantitative research completed for this thesis. The research explored the construct of identity change in chronic pain and the relationship between identity change and pain, affect and catastrophising. Part Three provides a critical review and reflection of the research.

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PART ONE

LITERATURE REVIEW

THE IMPACT OF CHRONIC PAIN ON IDENTITY

ABSTRACT

This review explores how the experience of chronic pain impacts upon a person's identity. Firstly, drawing on an established body of literature, an outline of chronic pain research is provided. This includes an introduction to theories on cause and treatment, followed by an overview of the physical, psychological and social impact of chronic pain. Secondly, a detailed literature review is conducted on the impact of chronic illness on identity, followed by the impact of chronic pain on identity. Thirdly, factors relating to adjustment in chronic pain are reviewed along with their usefulness in helping us understand what may lead to identity change. Finally, the limitations of studies are discussed along with gaps and directions for future research.

Key Terms: Chronic pain, pain, identity, self, self-concept, adjustment, impact, catastrophising, self-efficacy, helplessness, persistent pain.

INTRODUCTION

Chronic pain is one of the most challenging experiences a person can face. Not only do individuals suffer because of the physical pain, but suffer because the pain can dominate almost every aspect of their life. For example, experiencing chronic pain can make it difficult to work causing financial worries (Niv & Kreitler, 2001). Leisure activities may be reduced and intimate relationships can be affected (Keefe, Rumble, Scipio, Giordano, & Perri, 2004). Literature also suggests that experiencing chronic pain can lead to long term psychological problems such as depression and anxiety (Turk & Monarch, 2002).

In light of the widespread impact of chronic pain it is not surprising individuals report a change in their identity (Clarke & James, 2003). For example, participants describe experiencing an altered sense of self, reporting they hardly recognize who they have become (Williams, 1984). Similarly, Chapman and Gavrin (1999) suggest individuals suffer not just because of the physical pain, but suffer because chronic pain is "a threat to the integrity of the self" (p. 2234).

There is a small yet expanding knowledge base on identity and chronic pain. For example a number of qualitative and empirical studies suggest chronic pain impacts negatively upon identity (Aldrich & Eccleston, 2000; Harris, Morley, & Barton, 2003; Johansson, Hamberg, Westman, & Lindgren, 1999; Miles, Curran, Pearce, & Allan, 2005; Morley, Davies, & Barton, 2005; Osborn & Smith, 1998; Waters, Keefe, & Strauman, 2004). There is also growing empirical evidence of a relationship between identity change in chronic pain and psychological distress (Morley et al., 2005; Waters et al., 2004). In other words, the more a participant's identity changes for the worse compared to before the pain, the higher their level of depression and anxiety. Research has also demonstrated the more depression and anxiety experienced in chronic pain, the more poorly managed and distressing the pain may become (Chapman & Gavrin, 1999). Poorly managed pain could then, in turn, further change a person's identity creating a vicious cycle. In light of this evidence it would be useful to gain a greater understanding of identity change in chronic pain.

Aims of Review

The aim of this review is to explore the impact of chronic pain on identity. The first two sections introduce chronic pain, providing an outline of epidemiology, theories and treatment of chronic pain, followed by an overview of the physical, psychological and social impact of chronic pain. Secondly, literature on chronic illness and identity will be reviewed, followed by a review of research on chronic pain and identity. Thirdly, factors relating to adjustment to chronic pain will be presented followed by a discussion of how they inform understanding of identity change in chronic pain. The final section provides a summary of strengths and limitations of the literature along with directions for future research.

CHRONIC PAIN

Chronic pain has been the subject of research for a number of decades. Over the past thirty years the focus of attention has moved towards investigating psychological and psychosocial factors of chronic pain, and recognising their influence on the pain experience. As a result there is an abundance of research into the experience of chronic pain and the impact it can have on an individual's life. The following section provides an overview of research into chronic pain outlining definition, prevalence, causal theories and evidence based treatment programmes.

Definition

Pain has been defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (International Association for the Study of Pain, 1979). Chronic pain is generally defined as any pain that lasts for longer than three months (International Association for the Study of Pain, Subcommittee on Taxonomy, 1986).

Prevalence

Epidemiological studies conducted in the general population suggest the prevalence of chronic pain ranges from 2% to 40% (VerHaak, Kerssens, Dekker, Sorbi, & Bensing, 1998) and research suggests that in the UK approximately 7% of the population have chronic pain at any one time (Clinical Standards Advisory Group, 2000).

Causal Theories

Patients suffering from chronic pain often show little or no corresponding structural pathology. As a result an individual may continually experience the pain even though the physical abnormality is healed or in some cases never apparent. Thus the chronic pain patient presents medicine with a challenge as orthodox medical treatments rarely help. As described by Turk and Okifuji (1999) the aspects of chronic pain "are incompatible with the assumption of a single one to one correspondence between the report of pain and the presence of underlying disease" (p.1784). As a result patients may not receive causal explanations and that can prove frustrating for all involved (Hallberg & Carlsson, 1998).

Theories of chronic pain have evolved over the last forty years with a shift away from explanations of pain as solely a consequence of corresponding tissue damage. As sensory explanations failed to account for many pain conditions attention was focused on the combined physiological and psychological mechanisms of pain. Melzack and Wall (1965) introduced the Gate-Control Theory of pain that explained pain as a sensory affective interactional model where mood, attention, personality and expectations influence the experience of pain. Since this time behavioural elements have also been noted. For example, Fordyce (1978) described pain as having an accompanying set of behaviours and suggested acute pain becomes chronic due to the effects of operant reinforcement such as avoiding unpleasant tasks. These theories form the basis of multidisciplinary pain management programmes, an evidence based treatment for chronic pain (Flor, Fydrich, & Turk, 1992).

Treatment

Multidisciplinary pain rehabilitation programmes (MPRP) have been demonstrated as an effective treatment for chronic pain. For example, Flor et al. (1992) performed a meta-analytic review of MPRPs and found they were more effective than no treatment, waiting list controls and singular disciplinary treatments. MPRPs help people manage life despite pain by introducing exercise, goals, activity pacing and provide psychoeducation on pain effects, aiming to help patients manage their pain and minimize physical and social disruption. Clinical psychologists work within programmes using Cognitive Behavioural Therapy (CBT: Beck, 1967), an evidence based treatment of pain (Morley, Eccleston, & Williams, 1999) to help patients manage their beliefs, thoughts and behaviours surrounding the pain experience. In many cases the aim of therapy is to work towards adjustment to chronic pain. Adjustment represents reduced psychological distress and subsequently reduced pain and disability (Keefe et al., 2004). In other words rather than working solely to cure the pain, MPRPs focus on helping patients to manage life with the pain.

The following section provides an overview of the physical, psychological and social impact of experiencing persistent pain.

IMPACT OF CHRONIC PAIN

Quality of Life

According to a review by Niv and Kreitler (2001) chronic pain has a significantly adverse impact on quality of life. Quality of life (QOL) is a self reported evaluation of wellbeing and functioning in different life domains and offers a quantifiable measure into how pain affects the person as a whole. For example, Skevington (1998) looked at 250 patients with differing pain diagnoses and found chronic pain affected five out of six domains of QOL, negatively impacting upon physical, social and psychological areas of wellbeing. Research has also revealed that individuals with chronic pain score the lowest on measures of QOL compared to other medical conditions (Ware & Gandek, 1994). This may be because many sufferers experience physical dysfunction, sleep disturbance, social isolation and depression (Rudy, Kerns, & Turk, 1988). Such difficulties have the potential to increase the severity of the pain condition, which in turn may further reduce quality of life.

Physical Impact

Literature focused on the physical impact of chronic pain is sparse and does not consistently link physical factors with any particular aspects of the pain experience. This may be because the physical impact of chronic pain is so diverse among pain patients. For example, a person with persistent back pain will experience physical difficulties very different to someone with facial pain. In addition, it is very difficult to separate physical impact from psychological, as it is hard to disentangle whether people are restricted because of the physical pain, or restricted because of their psychological reaction to the pain. For example, chronic pain may impact upon sexual activity because fear of pain may block arousal, rather than intrusion of the physical pain itself. Putting these issues aside, a small amount of research suggests chronic pain is related to fatigue and lack of motivation (Niv & Kreitler, 2001), poor sleep (Gevirtz, 2005), reduced sexual activity (Maigne & Chatellier, 2001) and reduced general functioning (Niv & Kreitler, 2001).

Psychological Impact

Psychological factors are known to be central to the experience of chronic pain and an abundance of research has considered these variables (for review see Turk & Flor, 1999). Such research utilised questionnaire methods to measure subjective experience of pain and related experience to psychological variables. For the sake of clarity this review will divide psychological factors into affective and cognitive categories following work by Turk and Flor (1999).

The affective components of pain are primarily negative and include many different emotions. As anxiety and depression have received the most attention in literature the following will explore these in more detail.

Anxiety

According to a number of recent reviews anxiety is an important factor in the chronic pain experience (Keefe, et al., 2004; Turk & Flor, 1999; Turk & Okifuji, 2002). For example, persons with chronic pain are four times more likely to have an anxiety disorder than those not affected by pain (Gureje, Von Korff, Simon, & Gater, 1998). This may be because anxiety can be a consequence of pain and can also exacerbate symptoms, disability and reduce adaption to chronic pain (Keefe et al., 2004). Symptoms are exacerbated because pain related anxiety can increase attention to pain as once the threat of intense pain captures a person's attention it can make even low intensity pain less bearable (Turk & Monarch, 2002). Research has also shown pain related anxiety can lower coping capabilities and increase disability as patients are more likely to avoid activities in the home, social, leisure and work arenas (Swinkels-Meewisse, Roelofs, Verbeek, Oostendorp, & Vlaeyen, 2003).

Depression

Numerous studies report a high prevalence of depression in chronic pain (for a review see Keefe et al., 2004). For example, The British Pain Society (2005) conducted a national survey and found 49% of participants with chronic pain also reported themselves to be depressed. Banks and Kerns (1996) described prevalence rates of depression in chronic pain as ranging from 30% to 54%, a rate much higher than 6% in the general population, or in other chronic illness populations. In the majority of cases depression appears to be a consequence of the pain experience. There is little empirical evidence to suggest that depression, for the majority of people, precedes the experience of chronic pain (Turk & Salovey, 1984).

What is in debate is whether depression seen in chronic pain is the same as clinical depression as diagnosed by the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (*DSM-IV: American Psychiatric Association, 1994). There are three parts to this debate. Firstly, the measures used to assess depression in chronic pain are reportedly biased (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997; Pincus & Williams, 1999; Williams, 1998; Wilson, Mikail, D'Eon, & Minns, 2001) as symptoms of chronic pain overlap with the physical symptoms of depression, causing inflated scores. Secondly, differences between 'depression' in chronic pain and clinical depression have been reported. For example, research has found very little self denigration in chronic pain patients labelled 'depressed', a factor central to clinical depression (Morley, Williams, & Black, 2002). Thirdly, research has failed to identify a single affective component in a depressed sample of chronic pain patients, unlike a clinical depressed sample where the central component would be sadness (Morley et al., 2002). So whether or not depression in chronic pain is a manifestation of a diagnosis of clinical depression is still open to debate. What is undeniable however is that chronic pain negatively impacts upon mood.

Social Impact

In a review of quality of life in chronic pain Niv and Kreitler (2001) conclude that pain negatively impacts upon social functioning. This is supported by literature suggesting chronic pain affects employment, leisure activities and relationships (Miles et al., 2005; Skevington, 1998; Smith et al., 2001). However, as with the physical impact, psychological variables play a role. For example, the more individuals fear their pain, the more likely they are to avoid social activities (Swinkels-Meewisse et al., 2003). With this in mind the following explores the social impact of chronic pain.

Reduction in Employment

Reduction in, and loss of employment is a widespread consequence of chronic pain and research has shown that chronic pain significantly interferes with work (e.g. Gureje et al., 1998). Similarly, Smith et al. (2001) carried out a questionnaire survey from the general population in Scotland with 3065 participants and found high rates of employment among participants without chronic pain (81%), falling to 23% among participants with severe chronic pain.

The impact of chronic pain upon employment seems to be a world wide phenomenon. Gureje et al. (1998) conducted a cross cultural study on chronic pain and wellbeing of 5438 patients across Asia, Africa and the Americas. 31% of patients with chronic pain had moderate to severe work interference compared to 13% of patients without chronic pain. Controlling for cultural, pain and psychological variables those with chronic pain showed a two fold increase in work disability.

Reduction in employment can have adverse financial implications on both an individual and national level. On an individual level perceived financial strain has a strong association with psychological distress (Kessler, Turner, & House, 1987). On a national level it was estimated by Rigge (1990) that back pain led to 45 million days lost from work per year in the UK alone (cited in Smith et al., 2001) and the financial cost of lost productivity due to chronic pain (including healthcare) has been estimated at over 70 billion per year (Worsham, 2005).

Reduction in Leisure Activities

According to a number of studies, chronic pain may limit leisure activities such as prohibiting sporting pursuits, reducing social engagements and reducing ability to pursue personal hobbies (Aldrich & Eccleston, 2000; Miles et al., 2005; Risdon, Eccleston, Crombez, & McCracken, 2003; Tewksbury & McGaughey; 1998). With regard to specific QOL measures 'activities of daily living' was rated as one of the most strongly impacted areas (Skevington, 1998).

Gureje et al. (1998) concluded patients with chronic pain were significantly more likely to experience three or more days of activity limitation in the last month, and have a much higher activity limitation that those without pain. In a national survey 72% of people suffering pain had to reduce daily activities (British Pain Society, 2005).

Changes in Relationships

Reduction in social functioning is a widely reported effect of chronic pain (Harris et al., 2003; Niv & Kreitler, 2001; Skevington, 1998; Tewksbury & McGaughey, 1998). Pain has been directly related to interpersonal relations. For example, Rummans et al. (1998) reported that pain negatively affected QOL scores on interpersonal relations, in contrast to non pain physical symptoms that affect scores of functioning. In an interview by

Clarke and James (2003) a female participant stated, "All my relationships with family and everything are different...as far as other relationships with friends and that; they have pretty well all ended" (p. 1391).

Loss of roles is a frequently cited experience of chronic pain sufferers (Harris et al., 2003; Miles et al., 2005; Tewksbury & McGaughey, 1998). For example, due to the limitations imposed by chronic pain, an individual may lose the role of financial provider, manager or tennis partner. Similarly Becker et al. (1997) reported role functioning as one of the most affected domains on QOL measures (as cited in Niv & Kreitler, 2001). In a study of chronic pain patients, Harris et al. (2003) reported mean losses of three to four roles and six to seven attributes since the onset of pain.

Research has shown the more important the roles lost the more negative impact upon psychological wellbeing (Abraido-Lanza, 1997). For example, Miles et al. (2005) reported comments by a 39 year woman who had to give up sport because of pain:

"from being someone that was so active to have to do things and sit down at a desk it is, it is just soul destroying you know because my whole personality revolves around sport, with being physical... I'm not the kind of person who sits behind a desk" (p.436)

Chronic pain has the capacity to impact upon intimate relationships. Flor, Turk and Scholz (1987) explored the effects of chronic pain on marital relationships. Results indicated that pain patients and their partners experienced significant change in marital satisfaction. Chronic pain was also associated with heightened distress and physical symptoms in the partners of pain sufferers.

Summary

The above two sections provided an overview of chronic pain. They outlined the definition, prevalence, causal theories and treatment. In addition, an overview of the physical, social and psychological impact of chronic pain has been presented.

In summary, research suggests that chronic pain cannot be considered simply in terms of physical pathology as experiencing persistent pain can have widespread consequences on many areas of an individual's life. Significant social roles can be lost, anxiety and depression are common and often the diagnosis and prognosis are unclear, resulting in frustration for all involved. With disruption on so many levels it is not surprising pain has been described as a "threat to the integrity of the self" (Chapman & Gavrin, 1999, p. 2234).

As mentioned previously, the aim of this paper is to provide a detailed review of the impact of both chronic illness and chronic pain on identity. However, before this is done the following section provides an overview of what is meant by identity, and outlines details on the literature search process.

IDENTITY

Identity Research

There is a large body of research on identity spanning philosophy (Descartes, see Hatfield, 2003), neuroscience (Damasio, 1998), developmental psychology (Erikson, 1963; Marcia, 1993), social (Rosenberg, 1979), and cognitive psychology (Linville, 1987; Showers, 1992). However it is beyond the scope of this review to consider these large bodies of research in detail, particularly as they are not directly focused on identity in chronic pain. What all these areas have in common is that they view identity as a dynamic, multilayered concept and, most notably, that life events and thoughts about those events have the capacity to impact upon and change one's identity (for review see Bersonsky & Adams, 1999). Furthermore, this research suggests identity has implications for psychological adjustment. The more complex (Linville, 1987) and clearer a person's identity (Marcia, 1993) the more psychologically healthy they would be (Showers, Abramson, & Hogan, 1998).

Definition

Thus, building on this research, this paper uses the definition of identity provided by Marcia (1980): "identity is a self-structure, an internal, self-constructed, dynamic organization of drives, abilities, beliefs and individual story" (p. 159).

The Self

There has been some debate in literature whether the term 'identity' is a separate construct to 'self' (Kralik, Koch, & Eastwood, 2003). One argument is that 'identity' is socially defined, reflecting a label imposed by others whereas 'self' is the internal thinking 'me'. However, as can be noted from the above definition, identity has also been defined as an internal structure. In addition, a review of literature indicated many studies used the terms 'identity' and 'self' interchangeably (Carricaburu & Pierret, 1995; Charmaz, 1983; Kelly & Dickinson, 1997; Strauss & Glaser, 1975). In light of these findings this review will also use the terms 'self' and 'identity' interchangeably.

Literature Search

All literature cited in this review was obtained from a comprehensive literature search. Specifically, a search was performed over a number of months into MEDLINE, BIDS, PSYCHLIT and PUBMED for studies containing the following search terms from 1966 to 2006 (The number of abstracts each search produced is in parenthesis). "Identity" (limited to original articles, review or reports: 799), "Chronic pain and identity" (512), "chronic pain and experience of self" (42), "identity formation" (review, 32), "pain and self" (245), "self concept and pain" (34), "illness and identity" (950), "chronic illness and self" (48), "pain and self" (703). Thus a total of 3,365 abstracts were read and those deemed relevant were read in full.

The following two sections contain an in-depth review of literature on chronic illness and identity, followed by a review of literature on chronic pain and identity.

CHRONIC ILLNESS AND IDENTITY

The scope of this review has been widened to include research on chronic illness and identity. This is because chronic pain and identity is a relatively new area and only a small number of studies have been published.

Chronic illness research suggests three main themes. Firstly, chronic illness changes perceptions of the self. Secondly, identity change is a dynamic process. Thirdly, some individuals experience a positive identity change.

Perceptions of Self

Research on chronic illness and identity began in the early 1980's. Bury (1982) introduced the term "biographical disruption" suggesting that chronic illness causes a "fundamental rethinking of the person's biography and self concept" (p. 169). Following on from this Charmaz (1983) analysed data from fifty seven chronically ill patients and reported that chronic illness causes a loss of self. She highlighted four factors which lead to loss of self in the chronically ill: leading restricted lives, experiencing social isolation, being discredited and burdening others.

Since this time a handful of qualitative studies have explored identity in chronic illness. Different diagnoses were considered such as multiple sclerosis, fibromyalgia, tendonitis, depression, narcolepsy, PTSD and chronic fatigue syndrome (Asbring, 2000; Axtell, 1999; Clarke & James, 2003; Kralik et al., 2003). All studies concluded that chronic illness has the capacity to negatively change the way a person feels about himself or herself. For example, in a study by Asbring (2000) a participant suffering from fibromyalgia reported the following:

> *"This having lived a little over two years with 'me' that is no longer the 'real me', because it is a completely new person. As time passes I can find certain things that I recognize from before but the rest is actually new and it's not me and I don't recognize myself"* (p. 315).

Change as a Process

According to studies in chronic illness, identity change occurs along a continuum. One end represents the person's healthy identity and the other end represents the new identity as an ill individual (Asbring, 2000; Axtell, 1999). For example, Clarke and James (2003) suggested sufferers go through a process from immediate short term loss of self through to construction of a new identity incorporating the illness. Similarly, Tewskbury and McGaughey (1998) suggested that identity change in chronic illness is like a pendulum (Yoshida, 1993). People move back and forth between healthy and ill identities during periods called "critical milestones". A critical milestone is a significant event related to the illness, for example receiving a diagnosis and/ or telling others of the diagnosis. When a person reaches a critical milestone their identity moves like a pendulum from a healthy identity to an illness identity. Once the event had passed they move back to a healthy identity. Thus identity change is a fluid, dynamic bi-directional process.

Research suggests an individual may not move completely from one side of the continuum to the other. For example, Asbring (2000) found that identity may be partially transformed depending upon illness severity. This is because the development of a new identity is comprised of finding activities that can be continued and those that need to be given up. The more activities given up because of the illness, the more an individual may move towards the illness identity.

Positive Change

Evidence suggests there are both positive and negative aspects to being at the far end of the continuum and holding an illness identity (Axtell, 1999). Negative aspects are reported as not being happy with whom they have become, missing their old selves, not feeling like who they should be (Asbring, 2000). Positive aspects were feeling their new identities were more valued and better than the old, being able to value relationships more than before, being more compassionate to others and being less troubled by trivial matters (Clarke & James, 2003). For example, when questioned on how chronic fatigue syndrome changed her, a female participant replied:

"I think possibly more positive because I think I've begun to think....have learned to think also about the bigger picture, what things are really important in life, and what things are really not. And even though my body's aching and not functioning well, that is not the most important thing in my life" (p. 1392).

Research Limitations

The body of research on chronic illness and identity has a number of limitations. Firstly, one of the main drawbacks is the lack of empirical evidence to support the hypothesis that chronic illness relates to identity change. As all studies in this area utilise qualitative methodology the relationship between chronic illness and identity change is only speculative.

Secondly, several authors neglect to state their perspective at the outset and appear to use the data to support a previously held hypothesis (Bury, 1982; Charmaz, 1983; Tewksbury & McGaughey, 1998). Such an approach has the potential to bias data collection and direction of the analysis. Furthermore, the language used to report findings was sometimes absolute and final, when data suggested the results could only be interpreted speculatively. For example Charmaz (1983) has been criticized for her absolutist use of language such as "chronically ill experience a crumbling away of their former self images" (p. 11) when her data is based on a small, restricted sample size (Cuthbert, 1999).

Thirdly, generalisability of findings was limited. For example, hypotheses about identity change in chronic illness were supported by comments from only one or two participants (Asbring, 2000; Clarke & James, 2003). Furthermore the samples were often drawn from populations with severe symptoms who volunteered for the research (Kralik et al., 2003). Further research into participants with reduced symptoms would be beneficial to see if identity change also occurs in this population.

CHRONIC PAIN AND IDENTIY

An in-depth literature review was conducted to explore the impact of chronic pain on identity. However searches revealed only a small number of studies focussed on the self in chronic pain. The majority of these were qualitative. Only three empirical studies were found. As a body of literature two main themes emerged: pain negatively impacts upon identity and identity change is related to psychological distress. Each of these themes will be explored then limitations to the literature will be discussed.

Pain Negatively Impacts on Identity

Many studies reported that pain negatively impacts upon identity (Harris et al., 2003; Johansson et al., 1999; Miles et al., 2005; Morley et al., 2005; Waters et al., 2004). For example, in a study by Aldrich and Eccleston (2000) participants endorsed statements such as "pain makes you prisoner, you are no longer able to do what you want when you want" and reported pain to be "all consuming… it takes you over completely" (p.1637). In light of their findings the authors conceptualized pain as representing a fundamental challenge to identity, suggesting "a defining feature of pain it its intrinsic ability to change the self" (p. 1640).

Similarly, Johansson et al. (1999) interviewed twenty female participants with chronic pain and found change in self perception was one of four main symptoms identified. More specifically, participants felt their self perceptions were suffering because they had no clear diagnosis and the pain could not be seen by other people. Thus the validity of their condition was questioned. The authors suggested doubt and mistrust might damage a person's sense of self, as people see themselves partly in the mirror of others' judgments and form their own self concept accordingly (Strauss, 1997).

Miles et al. (2005) also demonstrated the negative impact of chronic pain on identity and explored factors leading to identity change. They interviewed twenty nine chronic pain patients attending an outpatient clinic. Using grounded theory they suggested three categories of constraint because of the pain. One of these categories was 'challenge to identity'. According to the study, different situations could lead to pain being a challenge to identity. These included actions and judgments of other people, an individual's ability to do things and physical changes. Furthermore Miles et al. (2005) found that different ways of coping with the pain impacted differently upon identity. Four methods of coping with the pain were presented: assimilation, accommodation, subversion and confrontation. Assimilation and accommodation referred to coping where normal life was maintained or redefined. In contrary, coping through confrontation meant constraints were severe but pre-pain activities were engaged with. The coping style most likely to impact upon identity was subversion. Subversion refers to a coping style where activities were curtailed to a significant degree in an effort to maintain a 'normal' identity. Restriction in activity was about an individual feeling stigmatized rather than the pain constraining the activity itself.

Three empirical studies (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004) also demonstrated a relationship between chronic pain and identity change, despite using different measurement tools. For example, Harris et al. (2003) conceptualised identity change as role loss and reported a mean loss of three roles and six attributes since the onset of pain. Similarly, Morley et al. (2005) and Waters et al. (2004) found a reduction in roles and attributes since the onset of pain. These studies will be described in more detail in the following section.

Limitations of Research

The qualitative studies have a number of limitations. Firstly, the small sample sizes characteristic of qualitative research limits the generalisability of findings. Secondly, some studies used highly specific populations. For example Johansson et al. (1999) interviewed chronic pain patients who received unsuccessful treatment. They were described as being in a stalemate position. It is possible their identity would reflect more of a change than a patient who was about to embark on a hopeful treatment plan. Thirdly, the authors did not clearly state their perspective and its possible influence on data analysis that, according to Elliott, Fischer and Rennie (1999) is one of the guidelines for qualitative studies enabling readers to evaluate their interpretation of data.

The quantitative studies also have a number of limitations. These will be discussed in the next section following a more detailed presentation of the studies themselves.

Identity Change Relates to Psychological Distress

Three empirical studies demonstrated a relationship between identity change and psychological distress (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). Each paper considered the impact of chronic pain on identity from a different theoretical stance: role loss and Self Concept Differentiation (Harris et al., 2003), Self Discrepancy Theory (Waters et al., 2004) and Enmeshment Theory (Morley et al., 2005). As a result each study measured identity change in a different way. However despite these differences all studies found identity change related to distress. As there were so few studies the following will explore each paper in more detail.

Harris et al. (2003) conceptualized identity change as role loss and discovered that role loss was related to depression. More specifically, the authors measured identity change by measuring the number of roles (e.g. manager, husband) and attributes (e.g. supportive, leader) the person had before the pain and compared this to with the pain.

Harris et al. (2003) also explored whether different structures of the self were related to depression, drawing on the theory of Self Concept Differentiation (Donahue, Robins, Roberts, & John, 1993; Linville, 1987; Showers, 1992). Self concept differentiation refers to the extent to which a person's self representations are different for different roles (Diehl, Hastings, & Stanton, 2001). Someone with identical attributes over different social roles is said to have low self concept differentiation. The lower the self concept differentiation, the more roles are affected when an attribute is lost. For example, a person who is a sports teacher, tennis coach and swimmer will have low self concept differentiation as all roles involve the same attributes of being energetic, sporty and motivated. If chronic pain meant the person was no longer energetic, all three roles would be affected. In contrast, the higher differentiated an individual is, the less roles are affected when an attribute is lost. Thus the authors hypothesized that higher self concept differentiation before the onset of pain would relate to less psychological distress.

The authors interviewed eighty patients with a diagnosis of a painful condition. Role and attributes were measured using the Role Attribute Test (RAT). The RAT required participants to generate four roles and two attributes per role within four social domains (friendship, occupation, leisure and family) for prior onset of pain and presently with the pain. Harris et al. (2003) discovered greater role and attribute loss in friendship, occupation and leisure domains compared to the family domain. Furthermore they found that role and attribute loss predicted depression scores. However, there was no evidence to suggest self concept differentiation related to depression.

Waters et al. (2004) conceptualized the self according to Self Discrepancy Theory (Higgins, 1987) and found change in self in chronic pain relates to depression. Self Discrepancy theory conceptualizes the self as the summation of a list of attributes. Furthermore, previous research on a non chronic pain population showed discrepancies between attributes in people's actual selves, ideal selves and ought selves predicted depression scores (Strauman & Higgins, 1988). The theory also maintains that discrepancies between the way individuals think others want them to be (ideal other) or how they think others believe they should be (ought other) can also have an impact on distress. The authors measured self discrepancies by using an interview version of the Selves Questionnaire (Strauman, 1990). The Selves Questionnaire required patients to generate lists of up to ten traits for each self domain: actual self, ideal self, ought self, ideal-other self and ought other self. The authors then scored associations between attributes. A self discrepancy score was obtained by subtracting the number of matches from the number of mismatches. Data analysis revealed that patients who had large ideal-self discrepancies reported higher levels of depression and psychological distress. For example, those with large differences between attributes for the actual self, compared to the ideal self were more likely to be depressed. In other words, patients with chronic pain who described their actual self as different to how they would like to be had more psychological distress.

However the study was limited as it did not consider changes in the self in relationship to the presence of pain. For example, measuring differences between actual and ideal self does not mean one is measuring the impact of pain per se, just that participants are not as they would like to be.

The third empirical study to find a relationship between identity change and distress was by Morley et al. (2005). The authors understood the self in the context of Enmeshment Theory (Pincus & Morley, 2001). Enmeshment Theory conceptualized the self as a schema containing different attributes (e.g. caring, fun, moody). The more the self schema overlaps with the pain schema the more distress is experienced. For example, the more a person sees him or herself as a pain sufferer and little else, the higher level of distress (Pincus & Morley, 2001).

Morley et al. (2005) interviewed eighty nine chronic pain patients. They measured enmeshment of pain and self schemas through the Possible Selves Task where participants were required to generate ten attributes for three aspects of their self: actual self, hoped for self and feared for self. Participants were then asked to rate the degree to which the hoped for self and feared for self were conditional on the absence and presence of pain. Multiple regression revealed that patients who saw their hoped for self as unobtainable if the pain continued, had higher scores on a measure of depression. For example, an individual's hoped for self may be to own their own business. However if this happening was conditional on the pain being ameliorated, they would be more likely to score higher on a measure of depression, than those whose hoped for self is not conditional on the pain. Morley et al. (2005) described such individuals as having an enmeshed pain and self schema. This is because attributes belonging to the self schema such as being a business owner, were directly reliant upon and thus enmeshed with the presence or absence of the pain. The more pain and self were enmeshed, the higher levels of psychological distress.

In summary, even though the above three chronic pain studies draw from different theoretical perspectives and measure identity change in a different way, all studies demonstrate a relationship between identity change and psychological distress.

Limitations of Research

The above studies have a number of limitations regarding diverse theoretical foundations, measurements of identity change, confounding variables and validity of depression measure.

Firstly, each study approached the topic from a different theoretical standpoint which means there is no singular, clear theoretical foundation to understanding identity in chronic pain. For example, Harris et al. (2003) investigated from two perspectives: the impact of role and attribute loss on chronic pain and the impact of self concept differentiation. Waters et al. (2004) drew on the Self Discrepancy Theory to explore the relationship between actual, ought and ideal selves. Morley et al. (2005) tested the Enmeshment Theory maintaining the self and pain schemas become enmeshed. Whilst diversity in theoretical approach is a welcome aspect of research, there are drawbacks as it is difficult to directly compare studies when their methodology is not the same, as for example, differences in results could be due to differences in measures used. Furthermore the theories do not lend themselves easily to clinical application. For example, even if one was to assume a patient had an enmeshed self and pain schema, conceptualizing their difficulties in this way does not clearly indicate what form of treatment would be beneficial. It may be useful for further research to develop a more clinically applicable model of identity change whilst building on the theoretical perspectives already offered.

The second limitation concerned the measurement of identity change. Contrary to qualitative literature that reports identity as a singular central construct, empirical studies measured identity as a list of attributes (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). For example, Harris et al. (2003) concluded that change in role and attributes meant a change in identity. However, in qualitative research patients refer to identity as a core structure, a construct in its own right, not a representation of role loss. For example, a participant in the study by Clarke and James reported, "you know you feel like you've lost yourself, your identity" (p. 1390). It is possible that conceptualizing identity just on the basis of roles and attributes neglects to directly ask participants what they think about their identity. It may be useful for future research to explore identity change using a measure directly accessing how the patient feels about themselves, in order to be sure what is being measured is an individual's evaluation of their identity.

The third limitation concerned potential confounding variables in the measurement of identity change. All three studies measured identity change by comparing lists of participant generated attributes for different identities (Harriet et al., 2003; Morley et al., 2005; Waters et al., 2004). However the ability to generate attributes may have been influenced by two confounding variables: abstract verbal fluency and depression. For example, with regard to verbal fluency, it is possible that generating attributes for the present self in the study by Waters et al. (2004) would be easier than generating attributes for the ideal self and ought self, as these require more abstract future orientated verbal fluency. Thus differences in attributes between actual self and ideal self may be attributable to differences in a participant's abstract verbal fluency. In addition, depression may have influenced the generation of attributes for past and present identity. For example, depressed participants in Harries et al. (2003) may have looked on the past in a more favourable light as it was before the depression took hold. As a result they may have generated more attributes for before the onset of pain, and subsequently before the depression, than for present attributes. The reduced attributes would then be a result of the depression rather than the pain condition per se. It could be beneficial for future research to measure identity change in a way that does not require generation of attributes, or in the least provide a control for abstract verbal fluency and mood.

The fourth limitation concerned the validity of using the Beck Depression Inventory (BDI: Beck, Ward, & Mendelson, 1961) as a measure of depression in a chronic pain population. All three empirical studies employed the BDI to measure the relationship between identity change and depression (Harriet et al., 2003; Morley et al., 2005; Waters et al., 2004). However, as previously mentioned, the BDI has been criticized in recent years for its invalidity in chronic pain populations (Fishbain et al., 1997; Pincus & Williams, 1999; Williams, 1998; Wilson, et al., 2001) as chronic pain overlaps with the physical symptoms of depression, causing an inflated score on the BDI. It could be useful for further research to explore the relationship between identity change and depression using a depression measure applicable to the chronic pain population.

Summary

The above two sections present the results of the literature review on the impact of chronic illness and chronic pain on identity. Findings suggest that both chronic illness and chronic pain have the capacity to negatively impact upon identity, and that negative identity change relates to psychological distress. In addition identity change can be viewed as a process and there is the potential for identity to change positively. However, there were a number of limitations to this research. For example, only three empirical studies were found indicating a lack of substantial empirical evidence. Furthermore, of the empirical evidence found, there were questions around the validity of measures used and a lack of consistent theoretical approach.

In summary, research on identity in chronic pain is at an early stage. Few links have been made between the main knowledge base in chronic pain and research into chronic pain and identity. For example, there is an abundance of literature on adjustment to chronic pain considering the importance of physical, psychological and social variables. However, the relationship between variables of adjustment and identity in chronic pain has not yet been explored. It would be beneficial to investigate whether factors related to adjustment also impact upon identity change in chronic pain. To this end the following section outlines research into adjustment introducing, alongside physical variables, important psychosocial factors such as self efficacy, catastrophising, helplessness and social support. This paper will then explore whether factors of adjustment could relate to identity change in chronic pain.

ADJUSTMENT TO CHRONIC PAIN

Adjustment to chronic pain has been described as reduction in pain, distress and disability (Keefe et al., 2004) or correspondingly an increase in scores on a Quality of Life scale (Niv & Kreitler, 2001). In other words, if an individual was adjusting to the pain experience they would show a reduction in negative emotions surrounding the pain experience, exhibit more adaptive behaviours and show reduced disability.

The following section provides an overview of factors related to adjustment, with an aim to directing future identity research. For example, having an understanding of what makes things better or worse in chronic pain may provide insight into what could increase or decrease negative identity change. Firstly, physical factors will be introduced (pain duration, intensity, extent and diagnosis) followed by psychological factors (catastrophising, self efficacy and control/ helplessness) and then social factors (social support). The eight factors presented are not an exhaustive list of mediating factors but are considered to be most central to adjustment in chronic pain.

Physical Factors

Pain Duration and Intensity

According to a review by Niv and Kreitler (2001) pain duration and intensity relate to quality of life scores. For example, they cited a study by Skevington (1998) who compared QOL scores for patients suffering from acute pain, patients who suffered pain two months to one year and those whose pain lasted for more than twelve months. The longer the duration of pain the worse scores on a measure of QOL. However, the clinical significance of self-reported pain intensity has been criticised by Mayer et al. (1987) as many studies have failed to replicate a relationship between pain duration and intensity with adjustment (as cited in Tait, 1999, p. 459).

The extent of a person's pain has also been related to quality of life (Niv & Kreitler, 2001). For example, Croft, Rigby, Boswell, Schollum and Silman (1993) explored the prevalence of chronic pain in the general population and conducted a survey of 2,034 adults in England. Out of the 11.2% with chronic pain, the more widespread the pain, the lower a person's quality of life, a finding also replicated by Latham and Davis (1994).

Diagnosis

The presence or absence of a diagnosis for pain has been related to adjustment (Jackson, 1992). Many patients are unable to obtain a clear diagnosis (Kroenke, 1992). For example, epidemiological studies have found 55% of common pain symptoms are usually not associated with observable tissue damage, rendering a clear diagnosis difficult to make (Marple, Kroenke, Lucey, Wilder, & Lucas, 1997). Eccleston, Williams and Rogers (1997) reported that when a diagnosis is 'lost', the patient "reappears to own that loss; the patient becomes the lost cause" (p.700). As a result difficulties may arise in encounters with medical professionals due to frustrations of both the clinician and the patient (Daykin & Richardson, 2004). Sufferers may experience mistrust and stigmatization from both the medical profession and in their personal lives. As described by Miles et al. (2005), "without an identifiable cause, the claims of the sufferer that they are in pain are undermined, and questions are raised about the extent to which the sufferer is responsible for their pain" (p. 432).

On the other hand, research found patients who obtain a diagnosis of their chronic pain increased in measures of adjustment. For example, White, Neilson, Harth, Ostbye and Speechley (2002) interviewed seventy two newly diagnosed cases of fibromyalgia (FM) at initial diagnosis, twelve months and thirty six months later. Although physical functioning decreased there were significant improvements with satisfaction in health and fewer symptoms at follow up. The authors argued that the FM label allowed for more appropriate medical management, including more pacing of activities accounting for the positive changes. It is unknown whether the diagnosis per se or changes in illness management brought about adjustment. However, irrespective of the mechanism of influence, it appeared that obtaining a diagnosis put into action a series of events which increased adjustment to the pain experience.

Psychological factors

Catastrophising

Numerous studies suggest catastrophising has an important role in adjustment to chronic pain (for review see Sullivan et al., 2001). Catastrophising can be broadly defined as the tendency to focus on pain and have a negative evaluation of one's ability to deal with the pain, resulting in negative rumination and worry (Sullivan & Neish, 1998; Sullivan, et al., 2001). For instance, as suggested by Spanos et al. (1979) individuals who are unable to divert attention away from the pain and report worry and fear about the pain such as "I can't stand this any longer", would be classified as catastrophizers (cited in Sullivan et al., 2001).

Catastrophising has emerged as one of the most significant predictors of pain accounting for up to 31% of the variance in pain ratings (Sullivan et al., 2001). Catastrophising has also been related to increased pain intensity, disability and distress even when controlling for physical impairment (Severeijns, Vlaeyen, Van Den Hout, & Weber, 2001; Sullivan & Neish, 1998). In a review of the psychosocial factors related to pain Zaza and Baine (2002) found that three of the four studies examined demonstrated an association between increased catastrophising and increased pain intensity.

There are a number of strengths in the research on pain catastrophising. Firstly, there is an availability of valid and reliable measures of catastrophising (Sullivan, Bishop, & Pivik, 1995). Secondly, research has been conducted in a diverse array of community and clinical samples (Keefe et al., 2004) and thirdly, evidence suggests that catastrophising is amenable to intervention. For example, catastrophising is one of the cognitive biases identified in work by Beck (1967) and is amenable to Cognitive Behavioural Therapy.

Self Efficacy

Self efficacy has been related to adjustment in chronic pain (e.g. Parker, Callahan, & Smarr, 1993). Self efficacy has been defined as "a personal conviction that one can successfully execute a course of action (i.e. perform required behaviours) to produce a desired outcome in a given situation" (Turk & Monarch, 2002, p. 15). Self efficacy was originally conceptualized by Bandura (1977) who suggested a person's self efficacy beliefs determines whether or not the behaviour will be initiated, how much effort will be put into it and how long the effort will be sustained if obstacles should arise. Those with low self efficacy were said to be less likely to persevere in the face of obstacles (Turk & Okifuji, 2002).

Chronic pain research demonstrates that patients with higher levels of self efficacy report lower levels of pain, psychological distress and negative medical outcomes (Keefe et al., 2004). Lorig, Chastain, Ung, Shoor and Holman (1989) demonstrated that disability, depression, impairment and treatment outcome all related to self efficacy (as cited in Tait, 1999, p. 462). Furthermore, there is evidence to suggest that improvements in self efficacy are related to positive outcomes in educational self help interventions (Lorig, Mazonson, & Holman, 1993).

Marhold, Linton and Melin (2002) demonstrated that self efficacy predicted whether pain patients returning to work stayed in lasting employment. One hundred and fifty four participants completed the Obstacles to Return to Work Questionnaire (Marhold et al., 2002). The results of the questionnaire were tested against sick leave nine months after assessment. Findings indicated that perceived prognosis regarding return to work could significantly predict sick leave. In other words the extent an individual believed they would hold down employment predicted whether their employment would last.

The factor of self efficacy has two main strengths. Firstly, the concept draws attention to an individual's strengths and what they can master, rather than pathologising what they cannot do (Keefe et al., 2004). Secondly, self efficacy is amenable to intervention through using techniques such as social reinforcement and mastery experiences, a component of Cognitive Behavioural Therapy (Beck, 1967).

Control and Helplessness

Research has shown that perceived lack of control relates to poor adjustment (Turk & Flor, 1999). As described by Turk and Rudy (1988) a large proportion of chronic pain sufferers perceive a lack of control over their pain, most likely as a result of their inability to influence the pain experience. A continued lack of perceived control has been conceptualized as a form of learned helplessness (Abramson, Seligman, & Teasdale, 1978) and used to explain why some individuals cease attempts to control their pain following previously unsuccessful experiences (Nicassio, Wallston, Callahan, Herbert, & Pincus, 1985).

Flor and Turk (1988) found controllability and helplessness were related to levels of pain. They explored the relationship between pain related thoughts, beliefs of personal control, pain severity and disability levels in patients with rheumatoid arthritis and lower back pain. They found that for both samples, beliefs of personal controllability and helplessness were more highly related to disability and pain levels than disease related factors. Similarly, a number of cross sectional studies have shown a relationship between high scores on a helplessness scale and higher levels of pain, depression and disability (Nicassio, Schuman, Radojevic, & Weisman 1999; Smith, Peck, & Ward, 1990). Such individuals also have poorer outcomes in therapy (Smith, Christensen, Peck, & Ward, 1994).

A limitation of control and helplessness research is that even though the research demonstrates the importance of helplessness, there are few clinical interventions aimed directly at increasing perceived control (Flor & Turk, 1988). In addition the majority of studies on helplessness have been limited to rheumatic pain conditions. It would be useful for future studies to include a more diverse chronic pain population. There have also been questions regarding the overlap of helplessness with other concepts such as catastrophising (Keefe et al., 2004). It would be beneficial for future research to test the usefulness of control and helplessness research compared to related constructs in understanding adjustment to chronic pain conditions.

Social Factors

Social Support

According to a review by Dworkin and Banks (2000) studies exploring the relationship between social support and chronic pain have found both beneficial and detrimental effects of social support. The authors suggest that this is because issues around social support and pain are complex as pre-existing psychological problems may confound with social support. For example, psychologically distressed individuals may be less able to establish supportive relationships (Monroe & Steiner, 1986). Limitations aside, research has demonstrated the importance of social support. For example, Zaza and

Baine (2002) found seven out of the eight studies reviewed showed significant associations between higher levels of pain and decreased social support. More specifically Jamison and Virts (1990) explored the influence of family support in insulating chronic pain patients from maladaptive behaviours. Two hundred and seventy five patients who described their family as unsupportive and disharmonious were compared to two hundred and thirty three patients who described their family as always being supportive. A random sample of one hundred and eighty one patients were interviewed, one year after completing an out-patient pain programme. The authors found patients with non supportive families relied more on medication, had more pain sites, more pain intensity and emotional distress and less activity levels compared to patients with supportive families. Thus there is evidence to suggest social support relates to the impact of chronic pain on adjustment.

Research into social support in chronic pain has a number of strengths. Firstly, empirical literature employed different measurements of social support yet still found a relationship between social support and adjustment. Secondly, different levels of social support have been related to adjustment including intimate social support through to wider social network. However, as highlighted by Cano, Gillis, Heinz, Geisser and Fornan (2004) social support such as marital functioning is viewed as a minor player in existing treatment models of pain. A future goal would be to integrate social support with existing models of treatment for pain and distress.

Relevance for Identity Change

As previously mentioned, factors relating to adjustment in chronic pain may provide a direction for future identity research. For example, focussing primarily on psychosocial variables (as these are directly amenable to psychological intervention), it seems that catastrophising, self efficacy, helplessness and social support are all important factors in the pain experience.

However, as literature on identity and chronic pain is still developing there are no empirical studies on the relevance of psychosocial factors for identity change. Nevertheless qualitative literature on pain and identity made a number of speculations regarding the importance of psychosocial variables. For example, Tewksbury and McGaughey (1998) considered the importance of catastrophising and found those who catastrophised experienced a significant disruption in their identity.

Self efficacy and helplessness were mentioned by Johansson et al. (1999) who found that some patients described their symptoms as unpredictable and out of control and it seemed that these patients also felt they had threatened identities because of the pain. Qualitative studies also suggest social support may reduce negative identity change in chronic illness (Abraido-Lanza, 1997; Charmaz, 1983; Kralik et al., 2002). However as research is so sparse it would be beneficial for future research to explore this area further.

CONCLUSIONS

This paper attempted to provide an in-depth review of literature on chronic illness, chronic pain and identity. This was achieved by firstly introducing chronic pain by outlining the definition, prevalence, causal theories and treatment, followed by the impact of chronic pain on physical, psychological and social aspects of an individual's life. Secondly, this paper provided an outline of what was meant by identity and located the review within the wider body of identity research. Thirdly, findings were presented from an in-depth literature review of chronic illness and identity, followed by a review of literature on chronic pain and identity. Finally, factors contributing to adjustment in chronic pain were explored in order to provide direction for future research in identity and chronic pain.

Taking all literature into account it is possible to conclude that chronic pain has the capacity to impact negatively upon identity (Aldrich & Eccleston, 2000; Chapman & Gavrin, 1999; Clarke & James, 2003; Johansson et al., 1999; Miles et al., 2005; Williams, 1984). Furthermore, empirical studies suggest the more a person's identity changes, the more they experience psychological distress (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004).

A reduction in social, occupational or leisure activities seems to be central to the process of identity change. For example, in qualitative studies loss of relationships, work, social and leisure activities are some of the main reasons cited for identity change (Charmaz, 1983; Clarke & James, 2003; Miles et al., 2005). Role and attribute loss was mirrored in the empirical conceptualisation of identify. For example, Harris et al. (2003), Morley et al. (2005) and Waters et al. (2004) measured identity change by asking participants to generate lists of roles and attributes. The amount of reduction in the number of roles and attributes represented the amount of negative identity change.

Reduction in social activities and social contact could also reduce validation of the worthwhile self through reducing satisfying interactions. In other words, reducing opportunities to be seen in ways other than a dependent, chronic pain sufferer. As argued by Strauss (1997), people partly see themselves in the mirror of others' judgments and form their own self concept accordingly. It could be that receiving affirming reflections communicates that the person is still valued for being the *same person deep down*; this may then be internalized by the individual to bolster their sense of self. As described by Charmaz (1983) a supportive intimate may maintain continuity with the past pre-illness self concept.

Strengths of the Research

Even though research into chronic pain and identity is in a very early stage it has a number of strengths. Firstly, studies are diverse in their methodology, sample and recruitment and all point to the same theme that chronic pain negatively impacts upon identity, thus strengthening the reliability of this finding.

Secondly, qualitative studies provide evidence directly from patients themselves, that chronic pain changes their identity. Such studies provide a grounding for research into the area, demonstrating that from patients' points of view, it is an area of concern and worthy of further exploration.

Thirdly, empirical studies have begun to address important issues such as the relationship between identity change and variables relevant to the pain experience, such as anxiety and depression. They have also provided a methodology for quantifying identity change, providing a framework from which future empirical work can be based.

Limitations of the Research

Research on identity in chronic pain is at a relatively early stage of development. This means the majority of studies are qualitative and can only speculate on the relationship between chronic pain and identity change. As empirical evidence was offered by only three studies the reliability of this finding is limited and requires further replication.

In addition the empirical studies have a number of limitations (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). Firstly, each study approached the topic from a different theoretical standpoint which means there is no singular, clear theoretical foundation to understanding identity in chronic pain. Whilst diversity in theoretical approach is a welcome aspect of research, there are drawbacks as it is difficult to directly compare studies when their methodology is not the same, as for example, differences in results could be due to differences in measures used. Secondly, empirical studies measured identity as a list of attributes yet did not ask participants whether they thought their identity had changed. It is possible that conceptualising identity solely as roles and attributes may not access an important element of the construct: how the person evaluates him or herself.

Thirdly there were a number of shortcomings with regard to measures of distress. For example, the measures used to obtain levels of anxiety and depressions were standardized in non-pain populations and the physical pain could have inflated their scores. In addition, with regard to measures of roles and attributes, authors neglected to control for potentially confounding variables of verbal fluency (Harris et al., 2003; Waters et al., 2004) and depression (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004).

Future Research

In light of the above limitations, there are number of areas where research would be beneficial. Firstly, there is a need for more empirical studies on the relationship between chronic pain and identity change. Secondly, it would be valuable for future research to assess the relationship between identity change and psychological distress using measures standardized in a chronic pain population. Thirdly, it would be useful to ask participants directly about the amount they believe their identity has changed since the onset of the pain. Finally, it would be beneficial to consider what factors lead to identity change in an aim to developing a clinically applicable model. For example, this review has demonstrated that catastrophising, self efficacy and helplessness are related to adjustment in chronic pain. It is possible these factors could also play a role in identity change and understanding what these are may provide direction for interventions.

In conclusion, identity change in people with chronic pain is a growing area of research. A number of both qualitative and quantitative studies have demonstrated the importance of identity change and provided the foundation for exciting, innovative future research.

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PART TWO

EMPIRICAL PAPER

IDENTITY CHANGE IN CHRONIC PAIN: RELATION TO PAIN, AFFECT AND CATASTROPHISING

ABSTRACT

The purpose of this study was to explore the relationship between chronic pain and identity in greater detail than previous research. This was achieved in two ways: firstly, identity change was measured in five different domains: globally (*Overall* identity change) and specifically (*Friendship, Family, Leisure* and *Work)* and their interrelationships explored. Secondly, the relationship between identity change and pain, affect and catastrophising was investigated. Sixty four chronic pain patients completed measures of pain, disability (Pain Disability Index), affect (Sentence Completion Test for Depression / Depression, Anxiety and Positive Outlook Scale) and catastrophising (Subscale of the Coping Strategies Questionnaire). On average negative identity change occurred in both global and specific domains. Principal component analysis identified two factors underlying the specific measures of identity: *Public* and *Private* identity. Multiple regression analysis revealed that after controlling for pain and affect, *Catastrophising* predicted *Overall* identity change and *Positive Outlook* predicted *Private* identity change. These findings are discussed in relation to the wider literature with recommendations for future research.

Key Terms: Identity, self concept, chronic pain, catastrophising, negative affect, pain, depression, anxiety, identity change

INTRODUCTION

The nature of chronic pain causes suffering that extends far beyond physical realms. Whilst the physiological discomfort is immense, the social, occupational and emotional price of suffering persistent pain is great (for review see Keefe, Rumble, Scipio, Giordano, & Perri, 2004). For example, loss of employment is widespread and financial difficulties can often arise (Niv & Kreitler, 2001). Leisure and social activities are often reduced (Keefe et al., 2004). Intimate relationships may be impacted, with individuals losing valued relationships and roles (Skevington, 1998).

With disruption on so many levels it is not surprising pain has been considered as a threat to identity (e.g. Aldrich & Eccleston, 2000). Identity can be defined as an internal structure with drives, abilities and beliefs (Marcia, 1980). Literature holds many examples of pain sufferers reporting a negative change in identity because of the pain (Aldrich & Eccleston, 2000; Clarke & James, 2003; Harris, Morley, & Barton, 2003; Johansson, Hamberg, Westman, & Lindgren, 1999; Miles, Curran, Pearce, & Allan, 2005; Williams, 1984). For example, pain has been conceptualized as representing a fundamental challenge to identity with the capacity to completely disassemble the self (Aldrich & Eccleston, 2000). Similarly, Chapman and Gavrin (1999) conclude that individuals suffer not just because of the physical pain, but suffer because chronic pain is a "threat to the integrity of the self" (p. 2234).

Chronic illness research also has examples of negative identity change. For example, Bury (1982) describes chronic illness as a biographical disruption, as it causes a "fundamental rethinking of the person's biography and self concept" (p. 169). Similarly qualitative research holds examples of the negative impact of chronic illness on identity (Asbring, 2000; Axtell, 1999; Charmaz, 1983; Kralik, Koch, & Eastwood, 2003).

Research Background

Although there is a large body of psychological research on identity (for review see Bersonsky & Adams, 1999), literature specifically on the relationship between identity and chronic pain is sparse. Identity in chronic pain appears to be a relatively new area of exploration and searches revealed just a handful of qualitative and quantitative studies. The following will explore these in more detail.

Qualitative Studies

Six qualitative studies were identified (Aldrich & Eccleston, 2000; Clarke & James, 2003; Hellstrom, 2001; Johansson et al., 1999; Miles et al., 2005; Williams, 1984) and although they were diverse in their sample and recruitment, each supported the theory that pain negatively impacts upon identity. The qualitative studies were useful in that they provided evidence directly from patients themselves, provided the groundwork for future research and demonstrated that from patients' points of view, identity in chronic pain is an area of concern and thus worthy of further exploration.

Quantitative Studies

Only three empirical studies were identified (Harris et al., 2003; Morley, Davies, & Barton, 2005; Waters, Keefe, & Strauman, 2004). Each study found that chronic pain negatively affects identity and identity change relates to psychological distress. There were a number of similarities and differences between the empirical studies. They differed in their theoretical approach and measurement of identity change. They were similar in their conceptualization of identity, dependent measures and findings. The following explores the similarities and differences in more detail.

Theoretical Approach

The empirical studies were different in their theoretical approach to identity change. For example, Harris et al. (2003) drew on Self Concept Differentiation (Linville, 1987); Waters et al. (2004) drew on Self Discrepancy Theory (Higgins, 1987) and Morley et al. (2005) drew on Enmeshment Theory (Pincus & Morley, 2001). The following will consider each theoretical approach in more detail.

Self Concept Differentiation is defined as "the extent to which a person's self representations are different for different roles" (Diehl, Hastings, & Stanton, 2001, p. 644). For example, an individual with the same attributes across social roles (e.g. teacher) would have much lower Self Concept Differentiation than someone with diverse attributes across social roles (e.g. student, teacher, helper, brother). Harris et al. (2003) hypothesized that higher Self Concept Differentiation before the onset of pain would relate to less psychological distress, as the higher differentiated an individual is the less roles are affected when an attribute is lost because of the pain.

The second empirical paper, by Waters et al. (2004), drew on Self Discrepancy Theory (Higgins, 1987). Self Discrepancy Theory suggests that discrepancies between actual self, ideal self and ought self predict depression scores (Strauman & Higgins, 1988). In other words, the more a person is different from how they ideally would like to be and how they feel they should be, the more they are likely to suffer psychological distress.

Morley et al. (2005) explored the self in the context of Enmeshment Theory (Pincus & Morley, 2001). Enmeshment Theory conceptualizes the self as a schema containing different attributes (e.g. caring, fun, moody) and the more attributes lost because of the pain, the more self/pain enmeshment is experienced. The authors hypothesized that the greater enmeshment between self and pain, the greater the amount of psychological distress.

Measurement of Identity Change

Although diverse in theoretical underpinnings, each empirical study measured identity change as changes in self characteristics (traits, attributes & roles) between two points in time. For example, Harris et al. (2003) used the Role Attribution Test (RAT), which required participants to generate roles and attributes within four social domains (friendship, family, work and leisure) prior to and since the onset of pain.

Morley et al. (2005) used the Possible Selves Task which required participants to generate characteristics (including attributes and roles) to describe their current self, hoped for self and ideal self, and make judgments about the degree to which their future selves (hoped for or feared for) were dependent upon the presence or absence of pain.

Waters et al. (2004) used a questionnaire called the Selves Questionnaire that required patients to generate lists of up to ten traits for each self domain: actual self, ideal self, ought self, ideal-other self and ought-other self. The authors then scored associations between attributes. A score of discrepancy between the different selves was obtained by subtracting the number of matches from the number of mismatches.

Dependent Measures

All studies employed the Beck Depression Inventory (BDI: Beck, Ward & Mendelson, 1961) as a dependent measure of psychological distress. The BDI is a 21 item self report inventory which assesses the degree of cognitive, affective and physiological symptomology of depression. All three studies used the BDI as the dependent variable in the regression, with pain variables and identity change as predictors. Harris et al. (2003) also employed the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) and Waters et al. (2004) used the Global Symptoms Checklist (GSI: Derogatis, 1994) a ninety item rating scale of nine psychiatric disorders ranging from anxiety through to psychoticism.

Findings

Harris et al. (2003) found there was no evidence of a relationship between Self Concept Differentiation and depression scores on the BDI. However, they did find that after controlling for clinical and demographic differences, the amount of role and attribute loss predicted scores on the BDI and HADS. In other words they found a relationship between the amount of identity change and psychological distress.

Waters et al. (2004) found discrepancies between actual and ideal self predicted scores on the BDI. In other words, patients with chronic pain who described their actual self as different to how they would like to be had more psychological distress. However it is difficult to conclude whether changes in the self were related to pain. This is because measuring differences between actual and ideal self does not mean one is measuring the impact of pain per se, just that participants were not as they would like to have been.

Morley et al. (2005) found that the more enmeshed a person's pain and self schema the higher their score on the BDI. In others words, the more a person has lost their identity to the pain (as they are unable to be who they want to be because of the pain), the more psychologically distressed they are likely to be. Thus Morley et al. (2005) also found a relationship between the amount of identity change and psychological distress.

Gaps in Research

There are a number of empirical and theoretical gaps in the research into chronic pain and identity. Firstly, there is only a small amount of empirical evidence of the negative impact of chronic pain on identity, rendering the reliability of this finding limited and requiring further empirical replication.

Secondly, the empirical studies approached the topic from different theoretical standpoints that mean there was no singular, clear theoretical foundation to understanding identity in chronic pain. In order to develop this understanding it would be beneficial for research to build on work already published whilst exploring the relationship of identity with other significant variables in pain literature, such as catastrophising (Sullivan, Bishop, & Pivik, 1995).

The third gap in research is concerned with the measurement of identity change. To date empirical research has measured identity through lists of roles and attributes (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004) but has not asked participants whether they thought their identity had changed. It is possible that conceptualising identity solely as roles and attributes may neglect to access an important element of the construct, namely how the person evaluates his or herself. It would be valuable for research to ask participants directly about the amount they believe their identity has changed since the onset of the pain.

Fourthly, all three empirical studies utilized the BDI as a dependent measure of psychological distress. However the BDI has been criticized in recent years for its invalidity in chronic pain populations (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997; Pincus & Williams, 1999; Williams, 1998; Wilson, Mikail, D'Eon, & Minns, 2001).

Research has argued that symptoms of chronic pain overlap with the physical symptoms of depression, causing an inflated score on the BDI. For example, patients can acquire a high score by endorsing items concerned with sleep problems, fatigue, reduced appetite, motivation etc. and are thus labelled as having severely depressed mood, when in fact the symptoms may be due to pain not mood. As a result studies linking identity change to depression may be inadvertently relating identity change to a high level of somatic symptoms. It would be useful for research to replicate the relationship between identity change and psychological distress using a measure suitable for use in the chronic pain population.

Study Aims

This study aims to address the gaps in research in three ways. Firstly by measuring identity change in more detail than previously attempted. Secondly by employing measures of psychological distress suitable to the chronic pain population and thirdly, by exploring the relationship between identity change and pain, affect and catastrophising.

Measurement of Identity Change

Building on previous research this study introduced two new approaches to measuring identity change. Firstly, identity change was measured by asking participants to rate the extent they believed their identity had changed since the onset of the pain, according to a scale ranging from -5 to +5. A minus change represented a negative change in identity and a positive represented a positive change in identity.

Secondly, identity change was measured on five domains: *Overall* identity change (global) and specific measures of identity change: *Family, Friendship, Leisure* and *Work*. The specific domains were taken from the study by Harris et al. (2003). The interrelationships between the five measures were explored.

Measurement of Distress

This study employed measures of psychological distress suitable to the chronic pain population in order to avoid the contamination by somatic items. The measures chosen were the Depression Anxiety and Positive Outlook Scale (DAPOS: Pincus, Williams, Vogel, & Field, 2004) and the Sentence Completion test for Depression (SCD: Barton & Morley, 1999). Literature searches suggested the DAPOS to be one of the only measures of depressed mood without somatic items whilst measuring negative view of the self, which is considered to be a core feature of depression (Beck, 1967). Questions refer to guilt, feelings of failure, disappointment in self, self blame and self harm. Furthermore, all DAPOS questions were extracted using factor analysis from established standardised measures: Hospital Anxiety Depression Scale (HADS: Zigmund & Snaith, 1983) and the Beck Depression Inventory (BDI: Beck et al., 1961). The DAPOS had an added advantage in that it also provided a measure of anxiety and positive outlook.

The SCD was an open ended measure of negative mood and subsequently free from somatic contamination. Specifically the SCD provided beginnings of sentences such as "I think..." and participants ended the sentences in any way they desired. The beginnings of sentences were provided for five domains: Self, Others, World, Future and

Past (e.g. The past is....). The answers were coded according to a manual (Barton & Morley, 1999) into negative, positive or neutral. Scoring was achieved by summing the number of total negative responses, providing an indication of the amount of negative affect.

Relation to Pain, Affect and Catastrophising

Thirdly, the study explored the relationship between identity change and important variables in the pain experience. Specifically, the study explored the relationship between identity change and pain, affect and catastrophising.

Catastrophising has been defined as a negative cognitive process of exaggerated negative rumination and worry (Sullivan & Neish, 1998). Catastrophising was chosen for this study as it is significantly relates to pain, distress and adjustment. For example, catastrophising accounts for up to 31% of the variance in pain ratings and has also been related to measures of psychological distress and adjustment when controlling for pain levels and depression (Sullivan et al., 2001). Catastrophising also has reliable and valid measures (Sullivan, Bishop, & Pivik, 1995) and is amenable to psychosocial intervention with changes related to long term improvements in psychological functioning, physical disability and pain (Keefe et al., 2004). Surprisingly, catastrophising has not been included in any studies on identity and chronic pain. For this reason it was considered an important variable to include and was measured using the catastrophising subscale of the Coping Strategies Questionnaire (Rosenstiel & Keefe, 1983).

Questions and Hypotheses

In summary this study attempted to answer the following questions:

Question One:

What is the relationship between global and specific measures of identity change?

Question Two: What is the relationship between identity change and pain, affect and catastrophising?

The general hypothesis was that the greater amount of pain, negative affect and catastrophising, the more negative identity change would occur. Furthermore, the greater an individual's positive outlook, the less negative identity change would occur.

METHOD

Design

This study took the form of a cohort single group observational study utilizing hierarchical multiple regression models to test relationships between identity change and pain, affect and catastrophising. As the design was correlational in nature the relationships did not ascribe causality. The study received full ethical approval before the research began.

Participants

Drawing on data provided by Cohen (1992) and a large effect size found by Harris et al. (2003) it was decided that the study required a minimum of sixty participants. Sixty four patients were recruited from an urban pain clinic in the South East of England. The inclusion criteria were as follows: attendance at the pain clinic with a diagnosis of a chronically painful condition (pain duration of at least six months), fluency in written and spoken English and over eighteen years of age. The exclusion criteria were a diagnosis of a progressive life shortening disease or evidence of psychosis or organic brain injury impeding their ability to complete the measures. The exclusion criteria were determined by discussion with medical personnel and examination of patients' files.

Recruitment

Potential participants were identified from patient lists at the pain clinic and information in their files, and checked against inclusion/ exclusion criteria. Individuals suitable for the study were contacted via letter two weeks before their appointment, inviting them to take part on the day of their appointment. On arrival the identified participants were given the information sheet and asked by the consultant or nurse during their appointment whether or not they wanted to take part. Patients providing initial verbal consent were invited to a private room where the study was explained and written consent was obtained.

Measures

Personal and Medical Information

Each participant was asked to record his or her *Gender, Age, Pain Duration* ('How long have you had chronic pain?') and *Pain Location* ('What is the location/locations of your pain?'). *Pain Intensity* was measured on an 11 point scale: 'How intense is your pain' (0 = pain is hardly noticeable/ 10 = pain worst ever felt). *Pain Frequency* was measured using an 11 point scale for 'How often do you feel your pain' (0 = Hardly ever/ 10 = All the time).

Pain Disability Index (PDI)

The PDI is a brief self report measure on which participants rated the extent of disability attributable to pain on seven 11 point scales (0= no disability, 10= total disability) (Pollard, 1984). There are seven items corresponding to seven areas of life; family, recreation, social activities, occupation, sexual behaviour, self care and life support activities. The scale was selected for its brevity and because it has been used in previous research on chronic pain and identity (Harris et al., 2003; Morley et al., 2005).

According to Strong, Ashton and Large (1994) the PDI has good internal consistency within the chronic pain population (Cronbach's $\alpha = 0.76$) and good concurrent validity with other measures of pain, such as the Oswestry Disability Index (Fairbank, Couper, Davies, & O'Brien, 1980) ($r = 0.63$). The total was called *Disability*.

Depression Anxiety and Positive Outlook Scale (DAPOS).

The DAPOS (Pincus et al., 2004) is an eleven item self report measure of depression, anxiety and positive mood. The depression subscale of the DAPOS has high concurrent validity with other measures of emotional distress including the BDI ($r = 0.75$) and the SF-36 emotional and mental health subscales (Ware & Sherbourne, 1992) ($r = -0.43$). The scale has good face validity and internal consistency within the pain population (Pincus et al., 2004). The DAPOS has three subscales: five items for *Depression,* three items for *Anxiety* and three items for *Positive Affect.* All items provide response options ranging from 'almost never' to 'almost all the time'.

Sentence Completion Test for Depression (SCD)

The Sentence Completion test for Depression measures negative affect (SCD: Barton & Morley, 1999). According to Barton, Morley, Bloxham, Kitson and Platts (2005) the SCD has shown good internal consistency (Cronbach's $\alpha = 0.89$), sensitivity, specificity and construct validity within the clinically depressed population, with high concurrent validity with the BDI (Beck et al., 1961) ($r = 0.57$).

Participants completed sentence stems in five domains: Self, Others, World, Future and Past (e.g. 'The future is.....'). Participants were asked to complete the sentences using their own words and to express how they had been feeling over the previous week. The original SCD was a 48 item questionnaire scored according to the five domains with items referred to the individual responding (agency as self) and items concerned with what others might think (agency as other). Barton and Morley (1999) analysed data separately for agency as self and agency as other. In this study the agency as other questions were excluded reducing the SCD to 28 items. As with the original SCD, the agency as self items were composed of 4 positive verbs (love/ care/ trust/ enjoy), 4 negative verbs (fear/ worry/ regret/ hate), 4 neutral verbs (have/ think/ feel/ wonder), 4 neutral verbs with a negative qualification (could not/ did not/ would not/ should not), 4 neutral nouns (world/ things in general/ society/ country), 4 future nouns (future/ next year/ five years/ next week) and four past nouns (the past/ five years ago/ last year/ last week). Answers were coded using a manual (Barton & Morley, 1999) into positive, negative and neutral. Negative completions were concerned with unpleasant emotions, inharmonious relationships with the self or others and pessimism about goals or plans. Positive thoughts were about satisfaction, pleasurable emotions, harmonious relationships and optimism. Neutral statements were about factual information with no negative or positive content, or inclusion of both (Barton et al., 2005).

The SCD provided seven scores. Firstly, as with the original SCD, a score called *Negative Affect* was derived by summing up the total number of negative sentence completions. Secondly, this study used the SCD in a novel way: to derive a total for the number of negative sentence completions concerning pain (*Pain Neg.*). This score was divided along the median to form two groups. Thirdly, the SCD provided five scores of the proportion of negative statements in each domain (*Self Neg., Other Neg., World Neg., Future Neg., Past Neg.*) These were also divided at the median point.

Catastrophising Subscale of CSQ

The catastrophising subscale is a 6-item subscale of the Coping Strategies Questionnaire (Rosenstiel & Keefe, 1983). According to Stewart, Harvey and Evans (2001) the catastrophising subscale has demonstrated good retest reliability ($r = 0.77$) and high internal consistency (Cronbach's $\alpha = 0.81$) in the chronic pain population.

Identity Change

In total there were five measures of identity change: global identity change (*Overall)* and specific identity change (*Friendship, Family, Work* and *Leisure).* All were single item measures of positive and negative identity change on an 11 point scale (-5 to 5+). The questionnaire was introduced to participants with the following comments:

Some people say having chronic pain changes who they are as a person. They say they don't feel themselves since the pain began, as if having chronic pain changed their identity.

How much do you feel your identity has changed since the pain began?
[A negative number means your identity has changed for the worse. A positive number means your identity has changed for the better.]

Before each of the measures of specific identity change, the following was written *"Please rate how much you feel your identity has changed in the area of friendship/ family/ work/ leisure*".

Procedure

After giving consent participants were invited individually into a separate room where they were given the measures to complete. To minimise order effects the measures were presented in the following order: Personal and medical information, SCD, PDI, identity change measures, CSQ subscale and DAPOS. The measures took around twenty minutes to complete.

Data Analysis

Firstly, the data were examined to check for distributions and potential outliers. Secondly, summary statistics were computed for the chronic pain sample in terms of demographics, pain characteristics, affect, catastrophising and identity change for global and specific domains. Thirdly, the associations between global and specific measures of identity change were explored in three steps: using Pearson correlations, inspecting scatter plots for curvilinear relationships and by conducting two principal component analyses (PCA) with oblique factor rotation (chosen because variables were inter-related). Finally, using *Overall* identity change and the factors derived from the factor rotation as dependent variables, three hierarchical multiple regression models were developed to test the relationship between identity change and pain, affect and catastrophising.

RESULTS

Data Preparation

All variables were checked for normality of distribution using skewness and kurtosis scores. Square root transformations were performed on the following variables: *Pain Intensity, Pain Frequency, Location of Pain* 'more than one location', *Pain Duration, Overall* identity change, *Family* identity change and *Leisure* identity change. *Pain Intensity* and *Pain Frequency* were reflected before undergoing transformations. After performing transformations the skewness and kurtosis scores were recalculated and found to be within acceptable bounds of normality.

Outliers were dealt with by reducing scores to slightly higher than the next participant's score. One outlier was found in each of the following variables: *Pain Duration, Pain Intensity, Pain Frequency* and *Overall* identity change (females only).

Reliability Analysis

Internal consistency (Cronbach's alpha) was calculated for the PDI, DAPOS, SCD and catastrophising subscale of CSQ. All scales were found to have acceptable alpha levels (≥.70; Nunnally, 1978). The results were as follows: PDI (0.85), the DAPOS subscale of depression (0.79), anxiety (0.84), positive outlook (0.80); emotional content in SCD (positive/ negative/ neutral) (0.93), reference group in SCD (self/ world/ future/ other/ past/ present) (0.86) and the catastrophising subscale of the CSQ (0.90).

All scores on the SCD were coded by the researcher and also by an independent rater. Inter rater reliability was found to be substantial for coding of positive/ negative and neutral (kappa = 0.65). Inter rater reliability for coding of reference groups (e.g. self/ other/ future/ past/ world) was only computed for nineteen out of the twenty eight questions and was found to be moderate (kappa = .45). It was not possible to test for kappa on the following questions as the coding was too different to compare: Society/ country/ future/ 5 years time/ next year/ next week/ past/ 5 yrs ago/ last year and last week.

Descriptive Statistics

Personal and Medical Data

Table 1 provides means, standard deviations and ranges for the following variables: *Age, Gender, Pain Location, Pain Duration, Pain Frequency* and *Disability.* A total of 64 participants were recruited from four different consultants with 54 participants recruited from two of the consultants. The sample had 21 males and 43 females and a mean age of 54.7 years (SD = 13.2). 28% of participants described back pain, 47% back and other (limbs/ head/ chest), 8% limbs only and 17% above breast area (head/ face/ mouth/ shoulder).

Table 1: Means and SDs for personal and medical data

Measures (possible range)	Mean	SD	Range
Age	54.7	13.2	29-81
Gender (ratio M:F)	21:43	--	--
Pain Location (1 location, > 1 location)	31:33	--	--
Pain Duration in years	7.6	5.8	0.5-25
Pain Intensity (0-10)	7.6	2.2	2-10
Pain Frequency (0-10)	8.7	1.8	4-10
PDI			
Family (0-10)	6.2	2.6	0-10
Recreation (0-10)	6.8	2.8	0-10
Social activities (0-10)	5.2	3.0	0-10
Occupation (0-10)	5.7	3.3	0-10
Sexual activities (0-10)	4.2	3.8	0-10
Self care (0-10)	3.7	2.6	0-10
Life support (0-10)	4.5	3.2	0-10
Disability Total (0-70)	36.2	15.5	0-65

Psychological Variables

Table 2 provides means, standard deviations and range for scores on the following: DAPOS scores for *Depression, Anxiety* and *Positive Outlook,* SCD score for *Negative Affect* and overall number of negative sentence completions about the pain *(Pain Neg.).* The SCD was also scored according to the proportion of negative answers with respect to all answers in that particular reference group *(Self Neg., Other Neg., World Neg., Future Neg., Past Neg.*). Descriptive statistics for the catastrophising subscale of the CSQ are also included (*Catastrophising*).

Table 2: Means and SDs for affect and catastrophising

Measures (possible range)	Mean	SD	Range
DAPOS			
Depression (5-25)	11.3	4.9	5-22
Anxiety (3-15)	7.1	3.6	3-15
Positive Outlook (3-15)	9.7	3.3	3-15
SCD			
Negative Affect (0-32)	8.0	3.3	0-17
Pain Neg.	1.6	1.7	0-7
Proportion *Self Neg.*	0.33	0.19	0-0.8
Proportion *Other Neg.*	0.21	0.32	0-1
Proportion *World Neg.*	0.32	0.24	0-0.8
Proportion *Future Neg.*	0.17	0.18	0-0.6
Proportion *Past Neg.*	0.16	0.17	0-0.6
CSQ Subscale			
Catastrophising (0-36)	16.6	9.9	0-36

Identity

The extent of identity change was rated on a scale ranging from -5 to +5. Table 3 provides the means and standard deviations for identity change on global and specific scales. All measures of identity change showed a mean change towards the negative. *Overall, Family* and *Friendship* scores showed some positive change, 8%, 13% and 14% of all scores respectively. *Leisure* and W*ork* identity showed the most negative change with no positive change recorded.

Table 3: Means and SDs for global and specific measures of identity

Measures (possible range)	Mean	SD	Range	% Neg.	% Neutral	% Pos.
Global Identity Change						
Overall (-5-+5)	-2.5	2	-5-3	81%	11%	8%
Specific Identity Change						
Family (-5-+5)	-1.3	2.4	-5-5	68%	19%	13%
Friendship (-5-+5)	-1.4	2.5	-5-5	62%	24%	14%
Leisure (-5-+5)	-3.4	1.4	-5-0	94%	6%	---
Work (-5-+5)	-3.4	1.7	-5-0	92%	8%	---

Question One

The first question in this study was: What is the relationship between global and specific measures of identity change? The answer was achieved in three stages. Firstly, linear correlations were explored. Secondly scatter plots were examined for curvilinear relationships. Thirdly, two principal component analyses with oblique rotation were conducted.

Stage One

Firstly, linear relationships between global and specific measures of identity were explored by conducting a Pearson product-moment correlation of all five measures (Table 4). In examining these relationships the amount of variance was considered, with anything above a shared variance of 10 % (0.33) deemed important and highlighted in bold. Please note *Overall* identity change was not the sum of the other measures, but a separate score.

Table 4: Two-tailed Pearson product-moment correlations of identity scores

Measures	*Friendship*	*Family*	*Leisure*	*Work*
Overall	**0.37**	0.23	**0.34**	**0.39**
p.	0.003	0.071	0.007	0.002
Friendship		**0.56**	0.26	**0.34**
p.		<0.001	0.038	0.007
Family			0.12	0.21
p.			0.361	0.105
Leisure				**0.39**
p.				0.002

As can be seen in Table 4, *Overall* identity change was moderately correlated with identity change in *Friendship, Leisure* and *Work.* Similarly, *Friendship* and *Family* were significantly correlated as were *Leisure* and *Work.* However there was no significant relationship between *Work* and *Family.*

Stage Two

The second stage of exploration involved examining scatter plots for evidence of curvilinear relationships. According to visual inspection no curvilinear relationships were detected.

Stage 3

The third stage explored whether the five measures of identity change could be adequately described by fewer dimensions. This was achieved by conducting two separate principal component analyses (PCA) followed by oblique factor rotation. As recommended by Field (2005) oblique rotation (direct oblimin) was chosen because the measures of identity change were correlated with one another.

The first PCA produced a solution with two factors, as determined by Kaiser's (1960) criterion of an eigenvalue greater than one. Across all variables, Kaiser's overall measure of sampling adequacy (MSA) was 0.69. Individual sampling adequacies for each variable ranged from a high of -0.89 for the *Family* identity change, to a low of 0.71 for the *Overall* Identity change. Oblique (direct oblimin) rotation was used to obtain the most interpretable factor structure as the variables were correlated. The two factors were found to account for 66% of the total variance. The factor structure, eigenvalues and factor loadings from this analysis are presented in Table 5. The first factor on which measures of *Family* and *Friendship* identity have high loadings was labelled '*Private Identity*'. The second factor was labelled '*Overall & Public Identity*' since the variables measuring *Overall, Work* and *Leisure* identity loaded highly on this factor. As can be noted from Table 5, there were substantial cross loadings for *Friendship, Overall* and *Work*.

Table 5: Principal component analysis using global and specific measures of identity change

	Factor One *Overall & Public Identity*	Factor Two *Private Identity*
Overall identity change	**0.71**	-0.34
Friendship	0.43	**-0.84**
Family	0.16	**-0.89**
Leisure	**0.78**	-0.08
Work	**0.77**	-0.31
Eigenvalue	1.7	1.9

In an attempt to reduce the cross loadings as mentioned above, a second PCA was conducted using only the specific measures of identity change: *Friendship, Family, Leisure* and *Work.*

For the second PCA the overall Kaiser's measure of sample adequacy PCA was 0.60; individual values ranged from 0.89 to 0.80. The same criterion was used to determine the number of factors to retain for rotation. Two factors were retained and obliquely rotated (using direct oblimin). The two factors were found to account for 74% of variance. Rotated factor loadings and eigenvalues for each factor are presented in Table 6. These factors were labelled '*Private Identity*' and '*Public Identity*'.

As can be seen in Table 6 the two factors were somewhat more distinct than in the previous PCA although there was still some cross loading of *Friendship* and of *Work*.

Table 6: Principal component analysis using specific measures of identity change

	Factor One *Private* identity	Factor Two *Public* identity
Friendship	**0.85**	0.39
Family	**0.89**	0.12
Leisure	0.12	**0.86**
Work	0.35	**0.80**
Eigenvalue	1.7	1.5

In summary, it seemed that the best way of representing the complex relationships among global and specific domains of identity was through the use of three variables: *Overall* identity change and the factors obtained in the second PCA: *Private* and *Public* identity change. As previously mentioned, *Overall* identity change was not the sum of the other measures, but a separate question and thus a unique score. As *Overall, Private* and *Public* identity change seemed to be the best solution for describing the underlying dimensions of identity in this instance, each was used as a dependent variable in the following regressions.

Question Two

The second question was: What is the relationship between identity change and pain, affect and catastrophising? The question was answered in three stages. Firstly, t-tests explored the impact of *Gender, Pain Location* and SCD scores on the dependent variables. Secondly, correlations were run to explore the relationships between variables. Thirdly, a series of hierarchical regressions were run to test the extent to which pain, affect and catastrophising accounted for the variance of *Overall, Private* and *Public* identity change.

T-tests

The results of independent sample t-tests found no statistically significant differences between men and women on *Overall* (t = 0.11, p >0.05), *Private* (t = -0.10, p >0.05) and *Public* identity change (t = 0.07, p >0.05). An independent samples t-test also found no significant differences between patients with one location of pain and more than one location of pain for *Overall* (t = -0.78, p >0.05), *Private* (t = 0.13 p >0.05) and *Public* identity change (t = 1.3, p >0.05).

An independent samples t-test also found no significant differences between patients scoring high verses low on the following SCD scores for *Overall* identity change: *Pain Neg.* (t = -2.65, p >0.05), *Self Neg.* (t = -1.71, p >0.05), *Other Neg.* (t = 0.72, p >0.05), *World Neg.* (t = -0.70, p >0.05), *Future Neg.* (t = -0.39, p>0.05) and *Past Neg.* (t = -0.39, p >0.05).

Pearson product-moment correlations

Correlations were run to explore whether assumptions of multicollinearity were breached as well as providing a basis to select variables for analysis which bore a significant relationship to outcome. Table 7 provides correlations of the following variables: *Age, Pain Duration, Pain Intensity, PDI*, *Anxiety*, *Depression* and *Positive Outlook* from the DAPOS, *Negative Affect* from the SCD, *Catastrophising*, *Overall, Private* and *Public* identity change. Correlations above 10 % (0.33) were deemed important and highlighted in bold.

Pain Frequency and all other scores from the SCD were not included in the correlation or later regression as these variables had minimal variance (almost everyone scored the same).

Table 7: Two-tailed Pearson product-moment correlations of *Overall, Public* and *Private* identity change with age, pain variables, affect and catastrophising

	Pain Intens.	*Pain Duration*	*Disability*	*Anx..*	*Depres.*	*Pos outlook*	*Neg. Affect*	*Catast.*	*Overall*	*Private*	*Public*
Age	0.12	0.80	-0.18	-0.32	-0.28	0.26	-0.03	**-0.36**	0.15	0.22	0.17
p.	*0.925*	*0.563*	*0.158*	*0.011*	*0.031*	*0.041*	*0.794*	***0.005***	*0.250*	*0.083*	*0.187*
Pain Intensity		-.070	**-.34**	-0.27	-0.06	0.01	-0.06	**-0.52**	0.19	0.22	**0.33**
p.		*0.579*	***0.013***	*0.036*	*0.641*	*0.979*	*0.630*	***<0.001***	*0.142*	*0.092*	***0.010***
Pain Duration			-.035	0.01	0.07	0.15	0.12	-0.12	0.26	0.09	0.21
p.			*0.790*	*0.950*	*0.626*	*0.277*	*0.383*	*0.373*	*0.050*	*0.491*	*0.110*
Disability				0.26	0.15	-0.29	0.27	0.49	-0.31	**-0.35**	**-0.43**
p.				*0.046*	*0.241*	*0.022*	*0.033*	*<0.01*	*0.015*	***0.005***	***<0.001***
Anxiety					**0.61**	**-0.34**	**0.31**	**0.54**	-0.32	-0.26	**-0.41**
p.					***<0.001***	***0.006***	***0.013***	***<0.001***	*0.012*	*0.044*	***0.001***
Depression						**-0.33**	**0.46**	**0.46**	-0.28	-0.29	-0.20
p.						***0.010***	***<0.001***	***<0.001***	*0.030*	*0.025*	*0.116*
Pos outlook							**-0.51**	**-0.48**	**0.41**	**0.51**	**0.38**
p.							***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***
Negative Affect								**0.40**	**-0.38**	**-0.43**	**-0.33**
p.								***<0.001***	***0.002***	***<0.001***	***0.010***
Catastrophising									**-0.59**	**-0.48**	**-0.55**
p.									***<0.001***	***<0.001***	***<0.001***
Overall identity										0.30	**0.23**
p.										*0.016*	***<0.001***
Private identity											0.26
p.											*0.044*

Personal and Medical Information

According to Table 7, age and pain variables were unrelated to *Overall* identity change. For example, *Age, Pain Intensity, Pain Duration* and *Disability* all shared less than 10% variance with *Overall i*dentity change. In contrast, *Disability* shared significant variance with *Private* and *Public* identity change, 12 % and 18% respectively. Furthermore, *Pain Intensity* significantly accounted for 10% of variance in *Public* identity. *Age* and *Pain Duration* fell below cut off of 0.33 (10% of shared variance) and were omitted from the later analysis in order to increase the power of the regression.

Affect

With regard to affect, *Positive Outlook* and *Negative Affect* appeared to be the most important as they accounted for significant variance in all three dependent variables. *Anxiety* only accounted for significant variance in *Public* identity (18%). As can be seen in Table 7, *Depression*, measured by the DAPOS, fell below the cut off of 0.33. It also overlapped somewhat with the SCD measure of negative mood (*Negative Affect*), so in order to increase the power of the regression it was decided that *Depression* should be omitted from the final analysis.

Catastrophising

Catastrophising seemed to be an important variable, overlapping with all three dependent measures of identity change.

In light of these findings the following variables were entered into the regression: *Pain Intensity, Disability, Anxiety, Positive Outlook, Negative Affect* and *Catastrophising.*

Hierarchical Regressions

The third stage of the analysis involved conducting a series of hierarchical regressions to test the extent to which *Pain Intensity, Disability, Anxiety, Positive Outlook, Negative Affect* and *Catastrophising* accounted for the variance in *Overall, Private and Public identity change.*

Three regressions were run using the three dependent variables of identity change: *Overall* identity change, *Private* and *Public* identity change. Hierarchical regression was chosen so blocks of variables could be entered to control for other influences. Thus in an attempt to gain an understanding into the unique variance of affect and catastrophising, measures of *Pain Intensity* and *Disability* were entered first, followed by measures of affect (*Positive Outlook, Anxiety, Negative Affect*), then *Catastrophising.* For all three regressions the significance level was reduced to 0.01 to reduce the likelihood of a type 1 error.

Overall Identity Change

Table 8 shows results of the first model in which *Overall* Identity Change was the dependent variable. The first two columns report the semi-partial correlations and standardized beta values for the final model where all the blocks have been entered. The other columns report the adjusted multiple correlations for the model including consecutive blocks along with the significance of variance accounted for with the inclusion of each block. The regression was tested for assumptions of validity as recommended by Field (2005) and all assumptions were found to be true.

Model Fit

As recommended by Field (2005) the accuracy of the regression model was tested using a casewise diagnostics analysis. This suggested only 5% (3) cases had residuals between -3 and +3, suggesting a good fit of line. Standardized residuals were subject to tests of skewness and kurtosis and found to be within a normal distribution. In addition, a test of Cook's distance demonstrated there were no overly influential cases on the regression. Therefore it can be concluded the model can be accurately generalized to the population of interest, only accounting for 7% less variance in *Overall* identity change than in this sample, with a 95% confidence interval of -0.07 to -0.2, suggesting a high level of accuracy.

Table 8: Summary of hierarchical multiple regression for *Overall* identity change

Model Steps	Variables	Beta	Sr	R^2	Adj R^2	R^2 change	F change	p for F change
Blocks								
1. Pain	*Pain Intensity*	-0.07	0.12	0.09	0.06	0.09	2.9	0.062
	Disability	0.00	0.01					
2. Affect	*Anxiety*	0.01	0.03	0.27	0.20	0.18	4.3	**0.009**
	Positive Outlook	0.03	0.04					
	Negative Affect	-0.01	0.03					
3. Catastrophising	*Catastrophising*	**-0.04**	0.01	0.38	0.31	0.11	9.4	**0.003**

In this model blocks two and three contributed significant explanatory variance to the equation. Furthermore, the entire model accounted for 38% of variance in *Overall* Identity Change. Affect (*Anxiety, Positive Outlook* and *Negative Affect*) accounted for 18% of variance when pain was controlled. When pain and affect were controlled, *Catastrophising* accounted for 11% of variance. *Catastrophising* was the only single variable that contributed unique variance (R squared change = 0.11). Thus, as hypothesised, it was found that the greater amount of *Catastrophising* the more negative *Overall* identity change occurred (β= -0.55, p = 0.003).

Private Identity Change

A second hierarchical regression was run using *Private* identity change as the dependent variable. *Private* identity change was obtained from the second PCA and represented a combination of the measures of *Family* and *Friendship* identity. Table 9 shows the results of this regression. This model was also found to meet all assumptions of validity as recommended by Field (2005).

Table 9: Summary of hierarchical multiple regression for *Private* identity change

Model Steps	Variables entered	Beta	Sr	R 2	Adj R	R2 change	F change	p for. F change
Blocks								
1. Pain	*Pain intensity*	0.26	0.16	0.13	0.10	0.13	4.1	0.022
	Disability	-0.00	0.01					
2. Affect	*Anxiety*	0.02	0.04	0.41	0.36	0.28	8.5	**<0.001**
	Positive Outlook	0.17	0.05					**0.002**
	Negative Affect	-0.035	0.04					
3. Catastrophising	*Catastrophising*	-0.00	0.02	0.41	0.34	<0.01	0.5	0.83

In this model only the affect block shared significant explanatory variance with *Private* identity change. Thus, contrary to expectations, adding *Catastrophising* to the regression did not increase the explained variance in *Private* identity change. Affect produced a 28% improvement in explained variance when added to the regression indicating a highly significant change ($p<0.001$). After controlling for *Pain Intensity, Disability, Anxiety, Negative Affect* and *Catastrophising, Positive Outlook* accounted for a significant amount of variance in *Private* identity change ($\beta= 0.17$, $p = 0.002$). Thus in this instance, the greater an individual's *Positive Outlook*, the more positive the change in their *Private* identity.

Model Fit

As done previously, the accuracy of the regression model was tested and analysis suggested only 4% of cases had residuals between –3 and +3. Skewness and kurtosis were also found to be within normal distribution and Cook's distance demonstrated there were no overly influential cases on the regression. The model accounted for only 5% less variance in the population for *Private* identity change, than in this sample, with a 95% confidence interval of 0.04 to 0.03. This data suggests the regression was a good fit of line with a good level of accuracy.

Public Identity Change

A third hierarchical regression was run using *Public* identity change as the dependent variable. Table 10 shows the results of this regression. This model was also found to meet all assumptions of validity as recommended by Field (2005).

Table 10: Summary of hierarchical multiple regression for *Public* identity change

Model Steps	Variables entered	Beta	Sr	R 2	Adj R	R2 change	F change	Sig. F change
Blocks								
1. Pain	*Pain intensity*	0.10	0.17	0.21	0.18	0.21	7.3	**0.002**
	Disability	-0.01	0.01					
2. Affect	*Anxiety*	-0.04	0.04	0.36	0.30	0.15	4.2	**0.010**
	Positive Outlook	0.03	0.05					
	Negative Affect	-0.05	0.04					
3. Catastrophising	*Catastrophising*	-0.02	0.02	0.37	0.30	0.01	1.0	0.316

In this model the first two blocks contributed significant explanatory variance to the equation: pain and affect. Block one (*Pain Intensity* and *Disability*) significantly contributed 21% of variance in *Public* identity change, and block two (*Anxiety, Positive Outlook* and *Negative Affect*) significantly contributed 15% of variance. However, *Catastrophising* in the third block did not account for significant variance in *Public* identity change. No single measure contributed unique variance to the overall model.

Model Fit

As done previously, the accuracy of the regression model was tested. Only 3% of cases had residuals between –3 and +3 with the rest within normal distribution. The model accounted for only 6% less variance in the population for *Private* identity change, than in this sample, with a 95% confidence interval of 0.06 to 0.02. This data suggests the regression was a good fit of line with a good level of accuracy.

DISCUSSION

The purpose of this research was to explore the relationship between chronic pain and identity in greater detail than previous research. This was achieved in two ways: firstly identity change was measured in five different domains: globally (*Overall* identity change) and specifically (*Friendship, Family, Leisure* and *Work*) and their interrelationships explored. Secondly the relationship between identity change and pain, affect and catastrophising was investigated.

Summary of Findings

Identity

The interrelationships between all five measures of identity change were explored (*Overall, Friendship, Family, Leisure* and *Work*). Two primary factors were found to define the specific measures of identity change (*Friendship, Family, Leisure* and *Work)*, accounting for 74% of variance. These were labelled '*Private*' and '*Public'* identity. *Friends* and *Family* mainly loaded onto *Private* identity (48% of variance). *Work* and *Leisure* loaded mainly onto *Public* identity (26% of variance).

Relationship to Pain, Affect and Catastrophising

In the light of the above findings the relationship between identity change and pain, affect and catastrophising was explored for three domains of identity: *Overall, Private* and *Public* identity.

On average, scores on *Overall* identity change were negative with 20% falling within no change or a positive change. Pain and affect were not related to *Overall* identity change whereas catastrophising accounted for a moderate amount of variance (11%), after the influences of pain and affect had been removed. Thus participants who showed a negative bias on pain appraisal tended to negatively appraise the amount their *Overall* identity had changed.

Private identity change represented *Friendship* and *Family* which were scored, on average, as negative. However, over a third of scores in *Friendship* and *Family* fell within the neutral/ positive range. *Pain Intensity, Disability, Anxiety, Positive Outlook* and *Negative Affect* accounted for 41% of variance in *Public* identity. However, only *Positive Outlook* contributed unique variance after controlling for *Pain Intensity, Disability, Anxiety* and *Negative Affect. Catastrophising* made no additional contribution. Thus participants who showed a higher score on *Positive Outlook* tended to rate their *Private* identity change as less negative.

Public identity change represented *Leisure* and *Work* which were scored, compared to other identity measures, as having the greatest amount of negative change. Furthermore neither *Leisure* nor *Work* received any positive scores. A combination of *Pain Intensity, Disability, Anxiety, Positive Outlook* and *Negative Affect* accounted for 35% of variance in *Public* identity change, yet no variables made a unique contribution. Adding *Catastrophising* to the model made no additional contribution.

Wider Literature

Identity

To date identity change in chronic pain has been a concept without an agreed definition. It has been measured as a single construct, calculated by differences in roles and attributes without directly accessing participants' beliefs about the amount their identity had changed (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). In an attempt to address this gap, this research asked participants to evaluate the amount their identity had changed in five different domains: *Overall, Friendship, Family, Leisure* and *Work.* On exploration of shared variance these latter four were reduced to two dimensions labelled '*Private' (Friendship* and *Family*) and '*Public' (Leisure* and *Work)* identity. Interestingly, a number of participants rated their identity change as positive. This was strongest for *Private* identity and supports findings from chronic illness qualitative literature (Axtell, 1999; Clarke & James, 2003). *Public* identity change received the most negative ratings with no positive change recorded. This supported findings by Harris et al. (2003) who found greater role and attribute loss in leisure and work than family domain.

The present study brought chronic pain research in line with identity research in social psychology. For example, Cheek, Smith and Tropp (2002) factor analysed lists of characteristics and produced four domains of identity: Social (e.g. popularity, other reactions, appearance), Personal (e.g. morals, values, dreams), Collective (e.g. religion, race, ethnicity) and Relational identity (close friends, partners, commitments) (Cheek & Briggs, 1982; Cheek, Smith, & Tropp, 2002). Interestingly, there seemed to be some similarity between the findings of Cheek et al. (2002) and the present study. For example, *Private* identity included *Family* and *Friendship* and seemed to overlap with Relational identity. *Public* identity included *Leisure* and *Work* and seemed to overlap with Social identity.

Research has shown that people rated different areas of their identity with differing levels of importance. For example, Penner and Wymer (1983) found that some individuals rated their social identity as more important than other areas of identity, and high social identity correlated with public self consciousness. Similarly, Schlenker and Weigold (1990) found those who put greater importance on social identity had a greater fear of negative evaluation and a stronger need for conformity, than those who rated social identity as less important.

In light of the wider literature it would be useful for future research to broaden the number of identity domains participants are asked about. For example, research could consider the impact of chronic pain on Personal identity (Cheek et al., 2002) and distress. Secondly, it would be beneficial for research to explore the relative importance of different self domains, ideally over two points in time to see whether domain importance and identity change varies as a function of pain levels.

Pain

This study did not find a relationship between identity change and *Pain Intensity, Pain Duration* and *Disability.* This is contrary to previous findings. For example, Harris et al. (2005) found a significant relationship between pain duration, disability and identity change. The difference in findings may be because different measures of identity change were used, accessing different constructs. For example, Harris et al. (2005) measured identity change from a behavioural perspective; calculating the difference between roles and attributes for before the pain, compared to with the pain. In contrast, this study measured identity change as an evaluation and as a result, the measure may have been influenced more by psychological variables such as catastrophising and positive outlook, than by behavioural factors such as disability.

Affect

Contrary to previous findings (Harris, et al., 2003; Morley, et al., 2005; Waters, et al., 2004), this study did not find a unique relationship between negative affect and identity change. However catastrophising, a negative thinking bias, accounted for a moderate amount of variance in *Overall* identity change.

This difference may be accounted for by the use of different measures of negative affect and identity change. For example, previous studies used the BDI to measure negative affect (Beck et al., 1961) which has been criticized for providing inflated scores in pain populations, due to symptoms of pain (Fishbain et al., 1997; Pincus & Williams, 1999; Williams, 1998; Wilson et al., 2001). It may be that, in previous studies, the relationship between the BDI and identity change represented an underlying relationship between the physical symptoms of pain in the BDI, and the behavioural measurement of role loss. This theory is supported by findings by Harris et al. (2005) who reported a significant relationship between pain, role and attribute loss.

The present study lends support for the argument that when measuring negative affect in the pain population measures containing somatic items should not be used. This is because such measures may inflate depression scores providing an unrealistic picture of the pain population. For example, the mean score on the DAPOS used in the present study was below the 50% mark, indicated minimum depression. In contrast, previous studies using the BDI found mean scores indicated moderate depression (Harris, et al., 2003; Morley, et al., 2005). Either the present sample had a surprising lack of negative mood, or the non somatic measures provided a more realistic picture of the amount of depression in chronic pain. It would be interesting to see whether regular inclusion of non somatic measures in pain research could reduce the high estimates of depression in chronic pain (Banks & Kerns, 1996).

Interestingly *Positive Outlook* was found to account for a substantial amount of variance in *Private* identity change. Positive outlook is a rarely measured construct in chronic pain as the majority of studies measure depression with response options ranging from neutral to deeply depressed, without a positive pole. However, as argued by Pincus et al. (2004), positive outlook may be related to coping and adjustment (Isen, 1999) and, rather than the opposite of negative affect, is more usefully conceptualized as a separate dimension (Macleod & Byrne, 1996).

The importance of positive outlook might be related to the work by Seligman (2002) and others who argue for recognition of and research into happiness, described as Positive Psychology. Positive Psychology focuses on factors that lead to pleasure, satisfaction and personal growth across emotions and activities (Seligman, 2002). In support of this movement the present study suggests those who score high on *Positive Outlook* tend to have less negative identity change in the face of chronic pain.

Positive Outlook may relate to *Private* identity change in a number of ways. Firstly, people with greater positive outlook may be more optimistic they will succeed, and consequently try challenging things such as applying for jobs or taking a holiday, despite the presence of the pain. This, if successful, could increase their tendency to try other difficult activities. Furthermore, if successful, the activities themselves may increase positive social reinforcement, providing the individual with an opportunity to experience being related to as a whole person, rather than just a dependent pain sufferer. These factors could potentially decrease negative identity change.

Secondly, it may be that pain sufferers who have greater positive outlook are less preoccupied with the pain and its impact. Instead they focus on the positive aspect of their lives. This may make them more pleasant to be around which could increase the quality of their relationships, increasing positive social reinforcement and decreasing negative identity change. This hypothesis ties in with earlier work by Barton and Morley (1999) who proposed the Enmeshment Theory. Self-pain enmeshment occurs when the self schema overlaps with the pain schema, limiting, because of the pain, a person's sense of who they are and what they might become (Morley et al., 2004). It may be that those who are enmeshed with the pain are less able to see outside the pain experience and, as a result, less able to feel cheerful', 'laugh and see the funny side or 'look forward to things', which are all questions on the *Positive Outlook* scale. Thus lack of positive outlook could make a person less agreeable and subsequently change the way others react towards them. This may in turn negatively impact upon a sufferer's sense of identity, as people see themselves partly through others' judgments (Strauss, 1997).

Catastrophising

Catastrophising seemed to be an important variable in *Overall* identity change. This was not a surprising finding as previous research consistently found that catastrophising is a central factor in the chronic pain experience, associated with greater pain intensity and distress (for review see Sullivan, 2001). One explanation for the role of catastrophising in *Overall* identity change could be its influence on activity reduction. One study has shown that those who show greater catastrophising are less likely to return to work, irrespective of their level of pain (Adams & Williams, 2003). Furthermore, catastrophising has been associated with greater disability, even when controlling for anxiety, depression, neuroticism, pain severity and disease severity (Sullivan et al., 2001). It is possible that individuals who score highly on a measure of catastrophising are less likely to take risks such as looking for supportive employment and/or attempting to continue with leisure activities. As a consequence, activities are reduced to a greater extent than by those who have less of a tendency to catastrophise, which means a greater number of roles and attributes lost. As demonstrated by Harris et al. (2003), the more roles and attributes lost, the more identity change occurs.

Thus *Overall* identity change seems to be linked to catastrophising. As catastrophising overlaps with depression and anxiety (Steward & Adams, 2001) identity change may be a risk factor for negative affect. Alternatively, it could be that negative affect precedes identity change and the measures of identity change are influenced by negative mood. It would be useful for future research to consider the direction of the relationship between negative affect and identity change.

Catastrophising did not account for significant variance in *Private* or *Public* identity change, suggesting a difference in processes between the different domains. Alternatively, this difference may be an artefact of the way the *Overall* question was asked, triggering a negative overgeneralization bias (Teasdale, 1983), whereas the specificity of the other measures prevented this bias.

Limitations and Future Research

Measurement of Identity Change

Firstly, because of the cross sectional design of this study, it is unknown whether identity change is stable over time. It could be that identity change fluctuates on a daily basis and such temporal instability could draw into question the reliability of the conclusions drawn. It would be useful for future research to use the measure within the same sample at different points in time to examine the constructs consistency.

Secondly, it is unknown whether participants understood ‘identity’ to mean the same as its definition in this research. For example, one participant may have understood identity to mean a collective term for their family, reading the question as ‘how much do you feel part of your family identity’. Research has shown that the understanding of identity differs between cultural groups (Collinge et al., 2001) and future research needs to include a definition of identity before the measure is presented, as well as exploring what the participant understands by the term ‘identity’ before the research begins.

Thirdly, the criterion validity of the identity measure is unknown. For example, the degree to which it correlates with previous measures of identity change has not been established, drawing into question the usefulness of the measure in capturing change in identity. It would be beneficial for future research to correlate the Role Attribution Test (RAT: Harris et al., 2003) with the present measure to gain an understanding of its criterion validity. However the measures capture different representations of identity change which may impact upon the criterion validity score. Specifically, RAT captures behavioural elements of identity change and the present measure captures evaluations of identity change. Despite these differences it is important to establish the usefulness of the present measure before firm conclusions can be drawn.

Measures of Affect

There are limitations in the content validity of the Depression, Anxiety and Positive Outlook Scale (DAPOS: Pincus et al., 2004) as the measure only captures cognitive, rather than affective aspects of depression. This may be one reason why the depression subscale of the DAPOS had a low correlation with identity change, when previous studies found a significant relationship (Harris et al., 2003; Morley et al., 2005). Similarly there were also limitations with the Sentence Completion Test for Depression (SCD: Barton & Morley, 1999). The measure was time consuming for participants and many struggled to understand how to complete questions without a prescribed context. Coding was laborious and even though both raters followed the manual, reference group coding was so different for nine of the twenty eight questions inter rater reliability could not be obtained. These problems may have impacted upon the observed relationship between identity change and negative affect. Future research needs to include a measure standardised in the pain population which includes specific affective components in an understandable format, such as the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983).

Clinical Implications

This research suggests that the degree to which a person experiences negative identity change is not directly based on their physical pain experience. This supports previous research on the importance of appraisal in the pain experience and the need for effective psychological treatments such as Cognitive Behavioural Therapy (CBT: Beck, 1967).

This study also suggests positive outlook is related to private identity change. It is possible that therapy to build positive outlook could help reduce negative identity change. However, CBT generally focuses on challenging negative bias rather than promoting positive outlook. It may be that the answer lies with an inclusion of positive psychology (Seligman, 2002) into therapeutic intervention for chronic pain. Integration of such methods could enable therapy to encourage positive outlook and potentially reduce the negative impact of chronic pain on *Private* identity.

Conclusion

This research adds further knowledge to the growing body of literature on identity in chronic pain. The construct of identity has been explored and the relationships between identity change and important clinical variables have been investigated. In conclusion the area would benefit from further empirical research, particularly with regard to the reliability and validity of the identity change measure and how the relationships between identity change, pain, affect and catastrophising change over time.

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PART THREE

CRITICAL APPRAISAL

CRITICAL APPRAISAL

This paper provides a critical review and reflection of the empirical research titled Identity change in chronic pain: Relation to pain, affect and catastrophising. The following are considered: the construct of identity, limitations and strengths of the research and personal reflections on the research process. Recommendations for future research are included at the end of each section.

CONSTRUCT OF IDENTITY

The self has been a focus of research over a number of years and different theories have been proposed. These theories have been divided into two approaches to the self: structural and functional (Harris et al., 2003). Structural approaches are concerned with how the organisation of the self protects against distress. Functional approaches are concerned with how role and attribute loss relate to distress. In order to effectively position the present study within the wider research these two approaches will be outlined in more detail.

Structural Approaches

There seem to be three streams of focus within the structural approach. Firstly, the complexity and inter relatedness of self aspects (Linville, 1985). Secondly, the organisation of positive and negative self aspects (Showers, 1992) and thirdly, the importance assigned to different self aspects.

Self Complexity

Linville (1985) explored the complexity and inter relatedness of different self aspects (e.g. helper/ teacher) and proposed the theory of Self Complexity. Linville (1985) argued that greater self complexity was a protective factor for individuals experiencing stress. This was because someone with high self complexity would have many unrelated self aspects and when faced with stress in one domain (e.g. sports person) the negativity would not spill over and colour thoughts and feelings about other self aspects.

Compartmentalization

Secondly, Showers (1992) proposed Compartmentalization Theory which suggests individuals put positive and negative aspects in separate compartments to protect against distress. When positive self aspects are most frequently accessed it results in more general positive self evaluation. This is because when positive information is accessed it activates all other positive information about the self. However, when negative self aspects are more frequently accessed, it results in more general negative evaluation.

Differential Importance

The third focus within structural approaches is on the importance of self aspects. For example, Pelham and Swann (1989) proposed Differential Importance and suggested that individuals resilient to depression change the amount of importance assigned to a particular self aspect when that aspect is under threat from a negative event. For example, such an individual may reconstruct their belief about the importance of being academic, when faced with poor exam results.

Functional Approaches

Functional approaches are concerned with discrepancies in the amount of roles and attributes between different selves, and how these discrepancies relate to distress. Two areas are Self Discrepancy Theory (Strauman & Higgins, 1988) and Possible Selves (Markus & Nurius, 1986).

Self Discrepancy

Strauman and Higgins (1988) proposed Self Discrepancy Theory. The theory explored discrepancies in roles and attributes between people's actual selves, ideal selves and ought selves. It also explored discrepancies between the way participants thought others wanted them to be (ideal other) or how they thought others believed they should be (ought other). Data analysis revealed that participants who had large ideal-self discrepancies reported higher levels of depression and psychological distress

Possible Selves

Markus and Nurius (1986) suggested the theory of Possible Selves. Possible selves contain hopes, fears, goals and threats about how a person could be in the future. Research has shown that the more detailed and well defined a person's idea of their possible self, the more motivated the individual becomes (Markus & Nurius, 1986).

Chronic Pain Research

To date chronic pain research has measured the self from a functional perspective (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004), calculating differences in the amount of roles and attributes for different selves. From this calculation the authors inferred the amount of identity change. For example, Waters et al. (2004) used a questionnaire called the Selves Questionnaire that required patients to generate lists of up to ten traits for each self domain: actual self, ideal self, ought self, ideal-other self and ought other self. The authors then scored associations between attributes. A score of discrepancy between the different selves was obtained by subtracting the number of matches from the number of mismatches. They found participants who described their actual self as different to how they would like to be, had more psychological distress. However they did not ask participants directly about the amount *they* thought their identity had changed.

Present Study

The present study introduced a new approach to measuring identity change in chronic pain. Specifically, participants were asked to *evaluate* the extent they believed their identity had changed in global (*Overall*) and specific identity domains (*Family, Friendship, Leisure* and *Work*) since the onset of the pain. The specific identity domains were found to have two underlying factors: *Private (Family* and *Friendship)* and *Public (Work* and *Leisure)* identity change.

Findings suggested that only variables of appraisal related to identity change. Specifically, C*atastrophising* shared a significant amount of variance with *Overall* identity change and *Positive Outlook* shared a significant amount of variance with *Private* identity change. Neither pain nor negative affect shared significant variance with identity change. Thus the only variables related to identity change were appraisal based.

It could be argued that the present research introduces a new approach to the self in chronic pain, termed ‘appraisal’. Rather than focussing on role loss or structure of the self, appraisal refers to the way an individual evaluates the impact of the pain on their life. For example, this approach suggests *appraisal* of the pain affects identity, rather than the pain per se. So if an individual has more of a tendency to catastrophise then chronic pain may have *more* of a negative impact on the self. If an individual were to have a more positive outlook chronic pain may have *less* negative impact on the self,

The importance of appraisal is by no means a new finding as an abundance of research has considered the importance of evaluation of chronic pain on distress (for review see Keefe et al., 2004). However, the present study does attempt to bring an appraisal element into research on the self in chronic pain, opening up the way for future studies to consider in more detail, the relationship between appraisal, identity and distress in chronic pain.

Positive Identity Change

Interestingly, in the present study positive identity change was noted in *Overall,* and *Friendship* and *Family* identity. This was a surprising finding as research reporting a positive impact of pain is sparse. However research on chronic fatigue syndrome holds some examples of positive identity change. Participants, on occasion said they preferred some aspects of their new self over their old. These were the ability to spend more time with family and appreciate the small things in life (Clark & James, 2003).

It may be that for some the experience of chronic pain encourages a journey of self growth (Aldrich & Eccleston, 2000), providing the chance for self improvement (Charmaz, 1983) fuelled by an attempt to understand and alleviate the pain.

It would be useful for future research to explore what factors promote positive identity change rather than simply focussing on alleviation of negative identity change, a point argued by Positive Psychology (Seligman, 2002). The Positive Psychology movement was born out of an attempt to redress the imbalance of focus in research primarily on the negative. It was argued that the study of health, fulfilment and wellbeing was as important as the study of dysfunction and distress and research into the strengths and virtues related to happiness should be a central topic of psychology (for review see Linley, Joseph, Harrington, & Wood, 2006). Defined as "the scientific study of optimal functioning" (Linley et al., 2006) the notion of Positive Psychology needs to be applied to identity in chronic pain. Thus it is recommended that future research not only considers what leads to negative identity change, but also seeks to understand the factors that facilitate positive identity change in chronic pain.

RESEARCH STRENGTHS

Sample

The sample was heterogeneous in terms of age, pain duration, pain intensity, pain location and disability. Scores of pain, affect and catastrophising were typical of pain clinical samples (Pincus et al., 2004; Stewart, Harvey, & Evans, 2001). In addition the present study had a low refusal rate of 16%. The majority of reasons for refusal were because individuals were feeling too unwell to take part. Other reasons included forgetting reading glasses or not having the time.

Thus it was not possible to identify any obvious barriers to generalisation, apart from the fact that this sample was in secondary care, in contrast to the majority of pain sufferers managed in primary care (Elliot, Smith, Penny, Smith, & Chambers, 1999).

Inclusion of Older Adults

A strength of the present study was the inclusion of older adults because, unlike previous studies on identity in chronic pain, the criteria for selection did not stipulate a cut off age of 65. In fact the average age of participants was 55 years old with a third of participants over 60, which contrasts with the mean age of 45 in previous research (Harris et al., 2003; Morley et al., 2005).

The inclusion of individuals over 65 was considered an important part of the present study because evidence suggests 73-80% of pain complaints arise from the elderly population (Demlo, Liang, & Eaton, 1986; Toman & Roy, 1988). In addition, Sorkin, Rudy, Hanlon, Turk and Stieg (1990) examined physical and psychosocial factors around the chronic pain experience and found no evidence of significant differences between young and old patients.

However, there does seem to be a tendency for literature to neglect the elderly in chronic pain research (Melding, 1991). This may be due to three reasons: comorbidity, lack of employment and societal views. Firstly, older adults may have comorbid health problems and treatment regimes aside from chronic pain. Secondly, research often focuses on loss of employment that would not be so applicable to older adults. Thirdly, the lack of research into older adults may reflect a societal view that chronic pain is an acceptable part of old age (Lansbury, 2000; Ross, Carswell, Man-Son-Hing, Hollingworth, & Dalziel, 2001). For example, in a study exploring barriers to pain management by Davis, Hiemenz and White (2002), patients voiced concerns that their pain was not taken seriously by GPs because of their age. Two elderly participants in the present research study also had this belief. They described being initially "brushed off" by GPs who said their pain was just because they were old.

This research suggested pain impacts negatively on identity irrespective of age. In other words elderly patients suffer interpersonally just as much as those of younger age, experiencing equally the damaging effects of pain on the self. This may be because in older age chronic pain still had the capacity to limit independence and result in an elderly person needing additional support (Lansbury, 2000). This in turn could result in a loss of roles, which seems to be central to identity change in chronic pain (Harris et al., 2003).

There is a need to promote chronic pain as a disorder separate from the experience of ageing, and a need for research to include older populations when studying chronic pain.

Measures of Identity Change

Importance of Appraisal

The present study asked participants to personally evaluate the degree to which their identity had changed. This contrasted with previous research where authors inferred the degree of identity change through difference in roles and attributes between different selves (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). Thus the present study broadened the understanding of identity change in chronic pain and highlighted the importance of appraisal when considering the impact of chronic pain.

Positive and Negative Change

The present study enabled participants to rate the degree of identity change on a scale ranging from negative through to positive, creating a chance to focus on the positive, something psychological research has been criticised for neglecting (Cuthbert, 1999; Seligman, 2002). It could be argued that because of this the findings were more realistic and provided evidence that not every person with chronic pain experiences negative identity change.

Measures of Distress

Previous studies used the Beck Depression Inventory (BDI: Beck, Ward, & Mendelson, 1961) as a measure of distress (Harris et al., 2003; Morley et al., 2005; Waters et al., 2004). However the BDI has been criticized in recent years for its invalidity in chronic pain populations (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997; Pincus & Williams, 1999; Williams, 1998; Wilson, Mikail, D'Eon, & Minns, 2001). Research has argued that symptoms of chronic pain overlap with the physical symptoms of depression, causing an inflated score on the BDI.

In contrast this study used measures of distress suitable for the chronic pain population (DAPOS, SCD), eliminating the risk of inflated depression scores because of the somatic aspects of chronic pain. Furthermore, the SCD was open ended meaning patients could answer in any way they desired. This measure also enabled a score to be obtained regarding the negative references made to pain that surprisingly was found to be consistently low. It would be useful for future research to use measures suitable for the chronic pain population to gain a more accurate gauge of distress and depression in chronic pain.

RESEARCH LIMITATIONS

The present study had a number of limitations in addition to those addressed in the empirical paper. These were concerned with ethnicity, problems with the SCD and limitations of the identity measure.

Ethnicity

The present study did not record ethnicity and, because of financial constraints, the questionnaires were only available in English, limiting the sample only to those who could fluently speak and write in this language. It is unknown whether ethnicity affected the impact of chronic pain on identity. There is evidence for ethnic differences in the meanings of pain and in coping strategies (for review see Jordan, 1999). For example, Hastie, Riley and Fillingim (2005) found that white people tended to engage more in self care behaviours compared to those from Spanish or African decent, who tended to seek more social support in religious communities. Similarly, Bates (1995) reviewed qualitative and quantitative studies on ethnicity and chronic pain and suggested factors "most often associated with successful adjustment to chronic pain are not biomedical but cultural and psychosocial" (p. 6). This is understandable as psychosocial factors are fundamental to the chronic pain experience and are powerfully shaped by ethnicity and cultural beliefs (Keefe et al., 2004).

Research suggests there are cultural differences in identity and identity importance, with diverse visions of the ideal self (Collinge, Rudell, & Bhui, 2002). For example, in western cultures importance is placed upon the self as independent and unique. In contrast, Bengali culture places particular emphasis on successful role fulfilment and relationships with others (Markus & Kitiama, 1991).

It may be that identity importance moderates the relationship between identity change and psychological distress. This hypothesis was explored by Abraido- Lanza (1997) who tested whether distress increased as a function of pain intrusion into culturally valued identities. The author found that for female Latinos who had strong traditional role identities (e.g. homemaker, mother, grandmother), greater distress was experienced if pain interfered with these roles. Thus identity importance may be grounded in cultural beliefs and it would be useful for future research to consider the role of ethnicity in identity change.

Sentence Completion Test for Depression (SCD)

There were concerns regarding the performance of the SCD. For example, participants aged over sixty (36 % of sample) tended to find the open ended nature of the questionnaire confusing and the majority took over 50 % longer to complete the questionnaire than younger participants. Coding and analysis of the SCD was laborious and time consuming. Furthermore, there were significant coding discrepancies. This meant inter rater reliability could not be calculated for nine of the twenty-eight questions with regard to reference group coding. However, according to the manual each rater coded correctly, bringing the validity of the measure into question.

Measurement of Identity Change

Finally, the measurement of identity change was limited in that participants were restricted to rating their identity in just five areas that were all weighted equally in importance. As these categories were imposed on participants there was no opportunity for other areas of identity to be explored. As mentioned previously it would be useful for future research to expand the identity domain categories and also encourage participants to rate the importance of each identity to their wellbeing.

PERSONAL REFLECTIONS

Conducting research on people with chronic pain was a rewarding experience. Participants were extremely willing to take part and were very open and communicative about their experience. As the participants were interviewed for written consent after their appointment, many spoke at length of their experiences and it was unfortunate that the study did not include a qualitative element to capture this information. However after hearing so many pain narratives three themes emerged. These included the under resourced nature of the pain clinic, the lack of available psychological input and the need for psycho-education on chronic pain.

Under Resourced Pain Clinic

Firstly, it was surprising how overcrowded the system seemed to be for treating chronic pain. The majority of participants spoke of waiting over six months between appointments, a period which many described as an insurmountable amount of time because of the pain. On many occasions patients became distraught when told how long they would have to wait, a situation that was nearly a daily occurrence for the two receptionists. Many participants spoke of feeling unsupported between appointments, particularly with regard to a lack of understanding from their GPs.

Need for Psychological Input

Secondly, it was surprising how many participants had not received psychological input. Many seemed distressed enough to warrant psychological intervention yet, because of the year long waiting list for individual therapy and group pain management, the doctors had to be extremely selective about making referrals to psychology. On two occasions the present research prompted a referral to clinical psychology. However because of the waiting list it was also recommended that the patients seek psychological therapy through their GP.

Need for Psycho-education

Thirdly, the participants spoke of not knowing how to manage their pain. They often made catastrophising comments and spoke of limiting as many activities as possible in order to reduce the pain. There also seemed to be a belief for some that the doctors had missed the underlying physical abnormality. They believed the pain indicated continuing physical damage and they needed to rest and heal. There appeared to be a need for psycho-education on chronic pain for many of these participants.

Thus despite the introduction of multidisciplinary pain clinics there seemed to be a lack of support for many people with chronic pain. The pain clinic was stretched nearly to its limit with waiting lists still increasing. It may be that because of the high prevalence of chronic pain the NHS will never realistically be able to offer the sort of support some of these individuals need. It is important then that NHS and voluntary services learn to work together to offer this support. For example, the pain clinic could provide an information pack to all patients encouraging them to utilise approved voluntary organisations, with a special focus on those that provide support alongside evidence based management of pain. Furthermore, there needs to be an education in general society on chronic pain and what people can do to manage in order to dilute the reliance on medical services to provide a 'cure'.

Finally, it seems that services in primary need to become more efficient at supporting individuals with chronic pain. This is especially important in the present climate, where the management of chronic illness is moving more towards primary care services. For example, a survey of the UK primary care services by Foster (2004) found only 20% provided primary care chronic pain management. It could be that for primary care services to be more affective in the management of chronic pain, more funding, dedicated services and training is required.

CONCLUSION

This thesis provided an in depth exploration of identity in chronic pain. Part One provided an overview of the literature. Parts Two and Three, the empirical paper and critical appraisal, contributed to the body of knowledge as a whole. Many possible avenues for further research have been recommended. To conclude, it is hoped that research on this topic will continue and, as a result, patients will be helped to rise above the challenge of chronic pain.

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APPENDICES

APPENDIX A

Letter of Ethical Approval

NHS
The National Hospital for Neurology and Neurosurgery
& Institute of Neurology Joint REC
(Research and Development)
1st Floor Maple House
149 Tottenham Court Road
London
W1P 9LL

Our ref:

23 May 2005

Mrs Abigail Pamich
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Mrs Pamich

Full title of study: ***Exploring Identity in Patients with Chronic Pain***
REC reference number:

The Research Ethics Committee reviewed the above application at the meeting held on 19 May 2005.

Documents reviewed

The documents reviewed at the meeting were:

Document Type:	Version:	Dated:	Date Received:
Application	-	21/04/2005	21/04/2005
Investigator CV	-	14/04/2005	21/04/2005
Protocol	1	14/04/2005	21/04/2005
Covering Letter	-	18/04/2005	21/04/2005
Letter from Sponsor	-	07/04/2005	21/04/2005
Peer Review	-	09/02/2005	21/04/2005
Copy of Questionnaire	-		21/04/2005
Participant Information Sheet	1	14/04/2005	21/04/2005
Participant Consent Form	1	21/04/2005	21/04/2005
Letter from Funder	-	21/03/2005	21/04/2005

Contd.

Provisional opinion

The Committee would like to that you for attending the meeting and answering the questions.

This study was granted ethical approval in principle. However, before final approval is given, the Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information on the information sheet set out below:

- The study reference (05/Q0512/40) should appear in the heading.
- In the Invitation paragraph, the '25 minutes' could be deleted. ✓
- The section titled 'The study' needs to detail the aims of the study. As it stands, there is no information for the potential patient. Also, the first sentence would be better worded 'We are interested in finding out more about how *your* pain affects *your* identity'. ✓
- In the section 'Why we are asking you' the words '...thus a sufferer of chronic pain' could be replaced with '...and have chronic pain'.
- Finally, in the section 'What will happen if I take part', the time required to fill in the questionnaires should be changed from twenty minutes to twenty five minutes. ✓

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

When submitting a response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 20 September 2005.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Communication with sponsor and care organisation(s)

This communication is confidential but you may wish to forward copies to your sponsor and/or relevant NHS care organisation(s) for their information.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Please quote this number on all correspondence

contd

I look forward to receiving your amended information sheet after which I hope to give final approval for the study to proceed.

Yours sincerely,

Virginia Hopson
Temporary Committee Co-ordinator

Enclosures	*List of names and professions of members who were present at the meeting and those who submitted written comments*

Enclosure 1

List of names and professions of members who were present at the meeting and those who submitted written comments

Dr Nicholas Hirsch
Consultant Anaesthetist

Ms Katy Judd
Consultant Nurse

Dr Kailash Bhatia
Consultant Neurologist

Ms Trish Dyson
Principal Pharmacist

Mr Laurence Watkins
Consultant Neurosurgeon

Mrs Ann Rosenthal

Mr Francis Curtiss
Accountant

Dr Janice Holton
Senior Lecturer in Neuropathology

Ms Gella Richards
Lay member

Miss Hilary Watt
Statistician

Professor Linda Luxon
Professor of Audiological Medicine

Dr Mark Barrett
GP

NHS
The National Hospital for Neurology and Neurosurgery
& Institute of Neurology Joint REC
Research & Development
1st Floor Maple House
149 Tottenham Court Road
London
W1P 9LL
Tel:

Our ref:

21 June 2005

Mrs Abigail Pamich
UCL Sub department Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Mrs Pamich

Study title: *Exploring identity in patients with Chronic Pain*
REC reference:
Amendment number: *1*
Amendment date:

Thank you for your letter notifying the Committee of the above amendment. The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on Tuesday 21 June 2005.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

1. *Patient Information Sheet Version 3 dated 13 June 2005*
2. *Consent Form Version 2 dated 13 June 2005*
3. *Research Protocol Version 2 dated 13 June 2005*

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed below:

Dr Nicholas Hirsch - Chair
Mrs Katy Judd - Vice-Chair

Management approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects local management approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: **Please quote this number on all correspondence**

Yours sincerely,

Virginia Hopson
Temporary Committee Administrator

APPENDIX B

Information Sheet

University College London Hospitals NHS
NHS Trust

Pain Management Centre
The National Hospital for Neurology and Neurosurgery
Queen Square
London, WC1N 3BG

Fax: [redacted]

Confidential

Dear,

Exploring Identity in Patients with Chronic Pain

Invitation

You are being invited to take part in a short research study on the day of your appointment. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please call on the above number or ask on the day if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

The study

We are interested in learning about how your pain affects your identity. Specifically we are exploring how an individual's change in identity relates to depression, anxiety, pain experience, thinking patterns and coping style. This study will help us learn more about how to offer effective support for individuals with chronic pain. Data is being collected over six months, at the end of which the results will be analysed, distributed to all interested parties and then published.

Why we are asking you

We are asking you to take part simply because you are an attendee of the Pain Management Centre and have chronic pain. The majority of patients attending the pain centre over the next six months will be invited to take part in this study.

It's Your Choice

It is up to you to decide whether or not to take part. Your participation is entirely voluntary. During your appointment the Doctor or nurse will ask if you are willing to fill out some questionnaires. If you agree the researcher, Abigail Pamich, will take you to a separate room and give you the questionnaires. You are free to decline to enter or withdraw from the study at any time without having to give a reason and this will not affect your future medical care. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time

UCL HOSPITALS

The National Hospital for Neurology and Neurosurgery is part of UCL Hospitals NHS Trust which also includes the Eastman Dental Hospital, Elizabeth Garrett Anderson Hospital and Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The Middlesex Hospital and University College Hospital.

without having to give a reason. Your decision whether to take part or not will not affect the standard of your care and management in any way. Participation in this study will in no way affect your legal rights.

What will happen if I take part?

You will be asked to complete a number of questionnaires. They can be completed either while you are waiting for your appointment with the doctor, or just afterwards. The questionnaires will take about twenty minutes to complete. Your answers will be anonymous. In other words, you will be allocated a number and this will be written at the top of your questionnaires. Your name or personal details will not be connected to your answers. The questionnaires will be stored in a locked filing cabinet in a locked office.

Confidentiality

All information collected from the questionnaires will be treated as strictly confidential and secure according to UCL data protection. It will not be publicly available, although it may be looked at by properly authorised persons to check the study has been carried out correctly, but if any information is released this will be done in a coded format so that confidentiality is strictly maintained. Any information that might identify you personally, such as names and addresses, will be stored separately to your answers. Any data removed from the hospital will have all personal information removed so you cannot be recognised from it. Patient identification codes will be kept on paper and retained for 15 years from the end of the study. Dr Anna Mandeville, an employee of UCLH is the principal investigator and is responsible for the safety and security of the data. Your GP will not be informed of your participation in this research.

What will happen to results of study?

You will be asked at the end of the study if you wish to receive information on the findings. In addition, the findings will be published in academic journals.

Problems?

This study does not involve medical treatment or any changes to medication you are already taking. It is designed to find out how you feel about your identity as a sufferer of chronic pain. If the questionnaires raise concerns or distress for you please let the researcher Abigail Pamich know or ask to speak to a member of staff. You can contact Dr Anna Mandeville, a Clinical Psychologist here at the pain clinic if you are distressed by any aspect of the study. Her extension is 3299.

Patient to receive a copy of the information sheet and a signed consent form to keep

Ethics

This proposal has been reviewed by the National Hospital for Neurology and Neurosurgery and the Institute of Neurology Joint Research Ethics Committee. This study is supervised by Dr Anna Mandeville, a Clinical Psychologist in the Pain Management Centre, and she is the person to contact with any comments or queries about the research. Her extension number is 3299. The questionnaires will be given to you by a researcher called Abigail Pamich who is a trainee clinical psychologist at University College London. This research is part of Abigail's Doctoral training in Clinical Psychology. There is no sponsorship or outside funding for this study. Staff will not be paid if you take part.

Thank you for reading this summary.

APPENDIX C

Consent Form

University College London Hospitals **NHS**
NHS Trust

Pain Management Centre
The National Hospital for Neurology and Neurosurgery
Queen Square
London, WC1N 3BG

Fax:

Confidential

CONSENT FORM

Title of project: *Exploring Identity in Patients with Chronic Pain*

Name of Principal Investigator: *Dr Anna Mandeville*

Please initial box

1. I confirm that I have read and understood the information sheet dated 13/5/05 version 3 for the above study and have had the opportunity to ask questions. ☐

2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

4. I understand that sections of any of my medical notes may be looked at by responsible individuals from UCLH or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

5. I agree to take part in the above study. ☐

Continued on next page/

1 form for Patient
1 to be kept as part of the study documentation
1 to be kept with hospital notes

University College London Hospitals NHS
NHS Trust

Confidential

CONSENT FORM

Title of project: *Exploring Identity in Patients with Chronic Pain*

Name of Principal Investigator: *Dr Anna Mandeville*

Name of patient	Date	Signature
Name of Person taking consent	Date	Signature

Dr Anna Mandeville
to be contacted if there are any problems,

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.

1 form for Patient;
1 to be kept as part of the study documentation,
1 to be kept with hospital notes

APPENDIX D

Questionnaires

Demographic information

CODE________________

What is you age?

What is your gender?

Where is your pain located?

How long have you been experiencing chronic pain?

How intense (strong) is your pain? (please circle)

	0	1	2	3	4	5	6	7	8	9	10
Hardly noticeable											Worst ever felt

How often do you feel your pain? (please circle)

	0	1	2	3	4	5	6	7	8	9	10
Hardly ever											All the time

Code____________

SCD

Please finish the incomplete sentences in your own words, according to how you have been feeling in the last week.

I care....____

I love....____

I trust....____

I enjoy...____

I fear....____

I worry....____

I regret....____

I hate....____

I have....____

I think....____

I feel....____

I wonder...____

Please turn over to next page

I should not....____

I did not....____

I would not....____

I could not....____

The world....____

Things in general....____________________________________

Our society....____

The country...._______________________________________

The future....____

In five years time....____________________________________

Next year....____

Next
week....____

The
past....____

Please turn over to next page

Five years ago....____

Last
year....____

Last
week....____

Pain Inventories

______________________________ **Date:** ______________

PAIN DISABILITY INDEX

Instructions: The rating scales below are designed to measure the degree to which several aspects of your life are presently disrupted by chronic pain. In other words, we would like to know how much your pain is preventing you from doing what you would normally do, or from doing it as well as you normally would. Respond to each category by indicating the overall impact of pain on your life, not just when the pain is at its worst.

For each category, please circle the number which describes the levels of disability you typically experience. A score of 0 means no disability at all and a score of 10 means that all the activities in which you would normally be involved have been totally disrupted or prevented by your pain.

1. **Family/home responsibilities.** Activities related to the home or family, including chores and duties performed around the house (e.g., yard work) and errands or favors for other family members (e.g., driving the children to school).

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

2. **Recreation.** Hobbies, sports and similar leisure time activities.

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

3. **Social activity.** Participation with friends and acquaintances other than family members, including parties, theater, concerts, dining out, and other social functions.

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

4. **Occupation.** Activities that are a part of or directly related to one's job, including nonpaying jobs such as that of a homemaker or volunteer work.

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

5. **Sexual activity.** This category refers to the frequency and quality of one's sex life.

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

6. **Self-care.** Activities of daily maintenance and independent daily living (taking a shower, driving, getting dressed, etc.)

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

7. **Life-support activities.** Basic life-support behaviors such as eating, sleeping, and breathing.

   No disability 0 1 2 3 4 5 6 7 8 9 10 Total disability

CODE ____

Some people say chronic pain changes who they are as a person, that having chronic pain *changes their identity.*

Please circle a number to show how much your identity has changed overall, because of the pain:

- A negative number means your identity has changed for the worse
- A positive number means your identity has changed for the better

-5	-4	-3	-2	-1	0	1	2	3	4	5
Changed for the worse										Changed for the better

Please turn over page

CODE ____

Please circle a number to show how much your identity has changed because of the pain, in the area of <u>friendship</u> (a negative number means a change for the worse and a positive number means a change for the better)

-5	-4	-3	-2	-1	0	1	2	3	4	5
Changed for the worse										Changed for the better

Please circle a number to show how much your identity has changed, because of the pain, in the area of <u>family</u> (a negative number means a change for the worse and a positive number means a change for the better)

-5	-4	-3	-2	-1	0	1	2	3	4	5
Changed for the worse										Changed for the better

Please circle a number to show how much your identity has changed, because of the pain, in the area of <u>leisure</u> (negative number means a change for the worse and a positive number means a change for the better)

-5	-4	-3	-2	-1	0	1	2	3	4	5
Changed for the worse										Changed for the better

Please circle a number to show how much your identity has changed, because of the pain, in the area of <u>work</u> (negative number means a change for the worse and a positive number means a change for the better)

-5	-4	-3	-2	-1	0	1	2	3	4	5
Changed for the worse										Changed for the better

Code_________

CSQ

Individuals who experience pain have developed a number of ways to cope, or deal with, their pain. These include saying things to themselves when they experience pain, or engaging in different activities. Below is a list of things that patients have reported doing when they feel pain.

For each activity, I want you to indicate, using the scale below, how much you engage in that activity when you feel pain, a **0** indicates that you never do that when you are experiencing pain, a **3** indicates you sometimes do that when experiencing pain, and a **6** indicates you always do it when you are experiencing pain.

0	**1**	**2**	**3**	**4**	**5**	**6**
Never do that			Sometimes do that			Always do that

When I feel pain..

It is terrible and I feel it is never going to get any better ....

It is awful and I feel that it overwhelms me....................................... ....

I feel my life isn't worth living ....

I worry all the time about whether it will end...................................... ....

I feel I can't stand it any more ....

I feel like I can't go on ....

Please Turn the Page

Based on all the things you do to cope with your pain, on an average day, how much control do you feel you have over it? Please circle the appropriate number. Remember, you can circle any number along the scale.

0	**1**	**2**	**3**	**4**	**5**	**6**
No control			Some control			Complete control

Based on all these things you do to cope or deal with your pain, on an average day, how much are you able to decrease it? Please circle the appropriate number. Remember, you can circle any number along the scale.

0	**1**	**2**	**3**	**4**	**5**	**6**
Can't decrease it at all			Can decrease it somewhat			Can decrease it completely

Code_________

DAPOS

We would like to know how you have been feeling in the last week. Please circle a number for each statement indicating how often you feel that way, where 1 is almost never, and 5 is almost all the time.

	Almost never				Almost all the time
I feel like a failure	1	2	3	4	5
I get a frightened feeling, as if something awful is about to happen	1	2	3	4	5
I feel guilty	1	2	3	4	5
I can laugh and see the funny side of things	1	2	3	4	5
I am disappointed in myself	1	2	3	4	5
I get a frightened feeling, like butterflies in the stomach	1	2	3	4	5
I feel cheerful	1	2	3	4	5
I blame myself constantly	1	2	3	4	5
I get a sudden feeling of panic	1	2	3	4	5
I look forward with enjoyment to things	1	2	3	4	5
I think about harming myself	1	2	3	4	5