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The influence of 'significant others' on back pain disability and return to work: a qualitative pilot study of illness perceptions.

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LANCASHIRE CONDITION MANAGEMENT PROGRAMME

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a qualitative pilot study of illness perceptions

Final Report

January 2011

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Executive Summary

This report presents the findings and conclusions from a pilot study exploring the illness perceptions of incapacity benefit (IB), or since 2008, employment support allowance (ESA) claimants and those of their 'significant others' (spouse/partner/close family member). The aims of the study were:

- *to examine the feasibility of conducting a semi-structured interview based on the Illness Perceptions Questionnaire and the Work and Social Adjustment Scale in order to provide an in-depth exploration of the influence of significant others in the recovery of back pain disability and return to work;*

- *to produce a qualitative template in order to inform the design of future research projects exploring the role of significant others in the recovery from back pain disability and return to work.*

Background

The widespread welfare reform measures recently proposed by the UK government mean that large numbers of people who are in receipt of IB/ESA will be expected to take appropriate steps to return to work or face withdrawal of benefits. However, there is little understanding of the individual and social influences involved in the everyday life experiences of those with disabling back pain which may act as obstacles to recovery, and ultimately, a return to work. Illness perceptions have been acknowledged as important influences in the course of, and recovery from, back pain and numerous studies report that others have an influence on outcome in chronic pain populations. This pilot study aims to establish the feasibility of exploring the illness perceptions of IB/ESA claimants and those of their significant others in order to reveal the psychosocial factors involved in recovery from disabling back pain and return to work.

Sample and Method

Claimants attending the Lancashire Condition Management Programme were identified and invited to participate in the study, along with their significant others (n=10). Claimant participants varied in age from 28 to 54 years, and had been claiming IB/ESA between 6 months and 2 years. Four claimant participants were male and 1 was female. Significant other participants varied in age from 21 to 62 years, and all were female. Three significant other participants were the spouse/partner, 1 was the daughter, and 1 was the parent of claimant participants. All participants were asked to complete the chronic pain version of the Revised Illness Perception Questionnaire (IPQ-R)(Moss-Morris et al., 2002) and the Work and Social Adjustment Scale (WSAS) (Mundt et al., 2002). Semi-structured interviews based on these questionnaires were then carried out with claimants and their significant others.

Analysis

Questionnaire scores were calculated for the 9 subscales of the IPQ-R: illness identity; timeline (acute/chronic); timeline (cyclical), consequences of illness; personal control over illness; treatment control; emotional representations, illness coherence and beliefs about causality. A summary score for the WSAS was also calculated.

Interviews were audio-taped and transcribed, and transcripts were analysed using template analysis - a method that provides a systematic technique for categorising qualitative data thematically, and which has been used previously in both healthcare and occupational research (King et al., 2002, King, 2004). In order to examine whether the interview method elicited the relevant questionnaire constructs, and/or uncovered any additional salient aspects, template analysis was based on the a-priori themes of the IPQ-R and the WSAS. However, during analysis of the interview data, it was established that questions derived from the WSAS (relating to work and social impairment) were unnecessary and became repetitive, likely due to the defining features of the study population (i.e. being unable to work because of their back pain condition). The relevant themes were already being elicited by the questions in the schedule derived from the IPQ-R, and therefore it was decided that data from the WSAS would be excluded from further analysis in this study.

Complex statistical analyses were not performed on the questionnaire data, as the small sample size limits the accurate and meaningful interpretation of any such findings. However, published mean score data for the IPQ-R taken from chronic pain samples were available (n=63) for comparison purposes - this enabled certain trends to be examined from an under-researched in an appropriate context. Mean scores and standard deviations (SD) for claimants and significant others were calculated for each IPQ-R subscale, with the exception of those for the 'causes' subscale as the authors recommend a sufficient sample size (n=85 or more) in order to use these data as a scale. Items from the 'causal' subscale were presented as grouping variables, i.e. those who do/do not believe in a specific causal factor for the back pain condition (Weinman et al., 2000).

Because a main aim of this study was to examine the influence of significant others, the template was initially constructed using interview data from significant others, and then claimant data was mapped onto these findings in order to explore similarities and/or discrepancies between the two groups. The template comprised of codes representing themes identified in the data through careful reading and re-reading of the text. Analysis was conducted with at least two members of the research team, and the list of codes was modified and finalised through successive readings of the text by all members of the research team.

The final qualitative template was comprised of 6 IPQ-R constructs, compared with the 9 questionnaire subscales. Responses to the questions derived from the 'illness coherence' subscale (defined as 'emotional representations') were more appropriately coded in the 'illness identity' and 'consequences' themes. It was also found that the questions derived from the 'timeline (acute/chronic)', and 'timeline (cyclical)' did not appear as two separate themes in the interview data, but responses were coded in a more general theme of 'negative expectations about timeline'. Similarly, responses to the separate IPQ-R constructs of 'personal control' and 'treatment control' were coded as a singular overall theme of 'curability, control and

management'. However, the interview method elicited two additional themes which appeared to be specific to the study population, i.e. being a benefit claimant and being a significant other. These additional themes were labelled as: 'claimant as 'genuine'', and 'influence of/impact on significant others'.

Findings

Analysis of the questionnaire data showed that claimant mean scores were similar to those from other chronic pain samples, providing a positive indication of the validity of the results found in the study population. Trends in the data showed that there were disparities between claimants and significant others on all of the IPQ-R components, with the exception of 'beliefs about causality' – here all participants were in agreement attributing work to both the initial cause of the back pain condition, and as a 'trigger' for subsequent episodes. Participants also associated their previous work with inflexibility and unsympathetic employers, and therefore not conducive to return to work with a health condition.

Significant others appeared to have less understanding of the back pain condition, held stronger beliefs about the chronic nature of the condition (i.e. it being permanent), had a more pessimistic outlook over the future course of the condition, held stronger beliefs about the negative consequences of the condition, were less positive about the condition being controlled by treatment, and reported greater emotional impact as a result of the condition, compared with claimants. Findings from the interview data supported the disparities shown by questionnaire results, and were similar to those found in other studies of this nature.

In contrast to findings commonly reported in studies investigating the impact of chronic back pain on family members, claimants perceived little impact on significant others' lives as a result of their condition. Significant others may have exaggerated the extent of the impact in order to emphasise their 'good carer' role, or claimants may have been unwilling to acknowledge the burden of their condition, perhaps due to the fact that all significant others in this study also had chronic health problems themselves. Overall, participants' lives were intertwined and defined by the back pain condition, resulting in a 'conferred expertise' about how best to manage the condition, often translating into self-limiting and fear-avoidance behaviour. Illness perceptions were further reinforced by the healthcare profession, socio-economic circumstances and the difficulties associated with work incapacity and being a disability benefit claimant.

Conclusions

An in-depth examination of illness perceptions conducted with IB/ESA benefit claimants and their significant others revealed interesting information about the psychological *and* social factors that may influence recovery from disabling back pain. Although there are several studies investigating the link between others' responses and outcomes in chronic pain populations, few studies of this nature tend to focus on back pain and return to work specifically. Further support of these findings could meaningfully inform future treatment plans and intervention programmes aimed at restoring work function.

Contents

References

Introduction

Musculoskeletal pain, notably back and joint pain, is the dominant single type of chronic pain in developed and developing countries, and affects around 19 per cent of the European adult population (Elliott et al., 1999, Blyth et al., 2001, Demyttenaere et al., 2007). Recent modelling of health survey data in Europe has identified musculoskeletal conditions as the major and most rapidly accelerating potential cause of disability over the next 30 years (Jagger et al., 2006). Chronic back pain is an increasingly complex syndrome with poor prognosis, and is usually accompanied by a wide range of further pains, unpleasant sensory and emotional experiences and certain cognitions and behaviours which interfere with participation in activities of daily life (Kamaleri et al., 2008, Raspe, 2010). Recent figures show that musculoskeletal conditions in the workplace account for 9.5 million days of work absence in the UK, with an estimated cost of £9090 million in lost productivity, and chronic back pain accounts for around 20 per cent of claims for long-term state benefit in the UK (Maniadakis and Gray, 2000, HSE, 2007). The costs of reduced work capacity due to chronic back pain greatly outweigh its direct medical costs (Phillips et al., 2008), and there is now evidence which suggests that remaining in work, or returning to work as soon as possible is beneficial (Waddell and Burton, 2006, Waddell et al., 2008).

It has been estimated that physical work-environment exposures (i.e. working posture, suitability of work stations or occupational injuries caused by heavy lifting and repetitive movements) only account for between 10 and 30 per-cent of long-term sickness absence due to chronic back pain, and that the rest can be attributed to psychosocial risk factors (Wynne-Jones and Main, 2010). The list of psychosocial risk factors for long-term disability and incapacity for work as a result of chronic back pain is extensive, and includes: psychological distress, fear-avoidance, catastrophizing, pain behaviour and beliefs, job dissatisfaction, and social support in the workplace (Shaw et al., 2002, Schultz et al., 2004, Bartys et al., 2005, Griffiths et al., 2006, Niedhammer et al., 2008, Kendall and Burton, 2009). More recently, illness perceptions have been acknowledged to be important influences in the course of, and recovery from back pain, and have been proposed to determine coping style, treatment compliance and emotional impact (Hagger and Orbell, 2003). More specifically, it has been demonstrated that illness perceptions have a significant association with clinical outcomes for back pain over a 6-month period (Foster et al., 2008, Foster et al., 2010), and results from a recent systematic review suggest that illness perceptions may play an important role in mediating between illness and work outcomes (Hoving et al., 2010).

The concept of illness perceptions is derived from the self-regulatory model (SRM) of health behaviour (Leventhal et al., 1984), which provides a framework for understanding the processes by which an individual's own implicit, common-sense beliefs about illness (illness perceptions) are associated with behavioural responses employed to manage outcomes. Whilst the importance of individual illness perceptions is widely acknowledged in health research, there is less understanding of the influence of the illness representations of 'significant others' (spouse/partner/close family member). Behavioural theory applied to chronic pain hypothesizes that others' responses influence pain, illness behaviour, and likewise, pain-related dysfunction (Fordyce, 1976). Numerous studies have demonstrated that spouses or significant others may be particularly salient sources of discriminative cues, punishment or reinforcement for pain behaviours (Leonard et al., 2006, Stroud et al., 2006). More specifically, spousal pain beliefs about disability, emotion, control and medication have been found to be significantly correlated with partners' pain severity and other indicators of pain adjustment (Cano et al., 2009), and care-giving and expressions of sympathy have been found to be associated positively with pain intensity and pain behaviours among persons with chronic pain (Romano and Schmaling, 2001). Several studies report the benefit of social support in chronic pain (Waxman et al., 2008), however, solicitous (e.g. responding to pain expressions with assistance) and negative partner responses can result in decreases in function and increased catastrophizing (Newton-John, 2002, Boothby et al., 2004).

Although it is now widely accepted that psychosocial factors are important contributors both to the propensity of, and to the consequences of chronic back pain (e.g. sickness absence and incapacity for work)(Waddell and Aylward, 2010), research aimed at exploring these influences to date has tended to be largely focused on individual, quantitative risk factors for incapacity, mostly from the point-of-view of the healthcare provider or employer. This imbalance has implications for the management of chronic back pain, and there is evidence to suggest that the standardized patient-report instruments which aim to measure the effect of psychological and social factors on outcome do not align well with individuals' experiences of recovery from back pain or treatment (Ong et al., 2006, Underwood et al., 2006). Discrepancies have also been reported between narrative accounts of patients' pain experiences and scores on standardized pain and disability measures (De Souza and Frank, 2007), and it has been recently proposed that more qualitative research is needed to provide further insight into the belief systems of individuals who become disabled due to back pain to better understand psychosocial obstacles to recovery and return to work (Wynn and Money, 2009).

Qualitative research is concerned with understanding the meanings that people attach to their actions, and attempts to understand the ways in which people make sense of and interpret the world around them. Therefore, a qualitative exploration of the illness perceptions of those experiencing disabling back pain involving 'significant others' may offer an especially useful insight into the issues involved. Whilst many studies have investigated the link between others' responses and outcomes in chronic pain populations, few have focused on return to work specifically. Therefore, this is a promising area of research which has implications for the management of back pain disability and return to work.

Aims

The aims of this study are:

- to examine the feasibility of conducting a semi-structured interview based on the Illness Perceptions Questionnaire and the Work and Social Adjustment Scale in order to provide an in-depth exploration of the influence of significant others in the recovery of back pain disability and return to work;

- to produce a qualitative template in order to inform the design of future research projects exploring the role of significant others in the recovery from back pain disability and return to work.

Method

This study employed a mixed-methods design and relevant permissions for the study were granted by NHS Greater Manchester West Research Ethics Committee (reference no: 10/H1014/19) and NHS Blackburn with Darwen

Sample

A convenience sample of IB/ESA claimants enrolled in the Lancashire Condition Management Programme (CMP), along with their 'significant others' were identified and invited to participate in the study (n=10). CMPs were conceived as part of the national Pathways to Work initiative (Department for Work and Pensions, 2002), and are a joint intervention between Job Centre Plus and the NHS. They support those claimants with mild to moderate mental health, musculoskeletal or cardio-respiratory problems back into work wherever possible. Approximately one-third of referrals to the Lancashire CMP were experiencing musculoskeletal conditions at the time of this study, and only those individuals who reported back pain as their main condition were eligible for inclusion in the study.

Study procedure and instruments

Participant information sheets were sent out to those individuals who agreed to be contacted, and if agreeable, arrangements were then made to conduct face-to-face interviews in participants' homes at a convenient time. Due to time constraints, one set of interviews was conducted over the telephone, with an SAE provided for return of questionnaires. Participants were asked to read and sign a consent form at the time of the interview, or give verbal consent over the telephone. Participants were asked to complete the Illness Perception Questionnaire – Chronic Pain Version (IPQ-R) (Moss-Morris et al., 2002), and The Work and Social Adjustment Scale (WSAS) (Mundt et al., 2002). Significant others were instructed to answer all questions in relation to the claimant's condition.

The IPQ-R is comprised of 9 subscales: illness identity; timeline (acute/chronic); timeline (cyclical), consequences of illness; personal control over illness; treatment control; emotional representations, illness coherence and beliefs about causality. The dimensions have Likert-type response formats which measure negative or positive perceptions of each item or attribute - the

IPQ-R provides a quantitative measure of illness perceptions for a number of conditions and has demonstrated good reliability and validity. The WSAS is also a quantitative generic scale measuring perceptions of disability across five areas of functioning; work, home management, social-leisure, private-leisure and home/family relationships. It is a validated tool, has been previously used in CMP settings, and is deemed appropriate to measure perceived disability for people with physical health problems. Scores can range between 0-40, with a higher score indicating greater problems with adjustment.

Following completion of the questionnaires, semi-structured interviews based on the above questionnaires were conducted separately with claimants and their significant others. Again, significant others were asked to answer questions in relation to the claimant's condition.

Analysis

Questionnaire scores were calculated for the 9 subscales of the IPQ-R, along with a summary score for the WSAS. Interviews were audio-taped and transcribed, and transcripts were analysed using template analysis - a method that provides a systematic technique for categorising qualitative data thematically, and which has been used previously in both healthcare and occupational research (King et al., 2002, King, 2004). In order to examine whether the interview method elicited the relevant questionnaire constructs, and/or uncovered any additional salient aspects, template analysis was based on the a-priori themes of the IPQ-R and the WSAS. However, during analysis of the interview data, it was established that questions derived from the WSAS (relating to work and social impairment) were unnecessary and became repetitive, possibly due to the defining features of the study population (i.e. being unable to work because of their back pain condition), and therefore the relevant themes were already being elicited by the questions in the schedule derived from the IPQ-R. Therefore, it was decided that data from the WSAS would be excluded from further analysis in this study.

Complex statistical analyses were not performed on the questionnaire data, as the small sample size limits the accurate and meaningful interpretation of any such findings. However, published mean score data for the IPQ-R taken from chronic pain samples were available (n=63) for comparison purposes. This allowed certain trends to be examined in an appropriate context. Mean scores and standard deviations (SD) for claimants and significant others were calculated for each IPQ-R subscale, with the exception of those for the 'causes' subscale as the authors recommend a sufficient sample size (n=85 or more) in order to use these data as a scale. Iitems from the 'causal' subscale were presented as grouping variables, i.e. those who do/do not believe in a specific causal factor (Weinman et al., 2000).

Because one of the main aims of this study was to examine the influence of significant others, the template was also constructed using interview data from significant others first, and then mapping claimant interview data onto these findings in order to explore similarities and/or discrepancies between the two groups. The template comprised of codes representing themes identified in the data through careful reading and re-reading of the text. Analysis was conducted with at least two members of the research team, and the list of codes was modified and finalised through successive readings of the text by all members of the research team.

The final qualitative template comprised of 6 IPQ-R constructs, compared with the 9 questionnaire subscales. Responses to the questions derived from the 'illness coherence' subscale were more appropriately coded in the 'illness identity' and 'consequences' themes. It was also found that the questions derived from the 'timeline (acute/chronic)', and 'timeline (cyclical)' did not appear as two separate themes in the interview data, but responses were coded in a more general theme of 'negative expectations about timeline'. Similarly, responses to the separate IPQ-R constructs of 'personal control' and 'treatment control' were coded as a singular overall theme of 'curability, control and management'. However, the interview method elicited two additional themes which appeared to be specific to the study population, i.e. being a benefit claimant and being a significant other. These additional themes were labelled as: 'claimant as 'genuine'', and 'influence of/impact on significant others'.

Findings

Table 1 provides details of those who took part in the study. In order to maximise anonymity, participants were given pseudonyms which are used throughout this report.

Table 1. Participant details

Pseudonym	Participant type	Relationship	Age	Time claiming IB/ESA
Alistair	Claimant	Son	29	6 months
Paula	Significant other	Mother	62	N/A
Adrian	Claimant	Partner	28	2 years
Nadia	Significant other	Partner	21	N/A
Helen	Claimant	Civil Partner	46	1 year
Jill	Significant other	Civil Partner	41	N/A
Michael	Claimant	Father	48	6 months
Sally	Significant other	Daughter	22	N/A
Roger	Claimant	Spouse	54	2 years
Lydia	Significant other	Spouse	55	N/A

None of the participants (with the exception of one significant other participant) had received a higher education qualification, and all described themselves as belonging to the 'White British' ethnic group. All significant other participants were female.

Presentation of data

Mean scores and standard deviations (SD) for each of the IPQ-R subscales were calculated for claimants and significant others, and are presented with other published IPQ-R data taken from chronic pain samples (Moss-Morris et al., 2002). Findings from the analysis of the interview data are presented in relation to each of the IPQ-R subscales.

1. Illness identity

This component of the IPQ-R is related to the description of symptoms and labelling of the condition. Table 2 illustrates the mean scores and standard deviations (SD) for claimants and significant others, along with similar published data taken from chronic pain samples. Scores on this scale range between 0 and 14, with higher scores representing strongly held beliefs about the number of symptoms attributed to the illness.

Table 2: Mean scores (SD) for claimants and significant others, along with published mean scores for 'illness identity' in a chronic pain sample.

Group	**Mean (SD) score**
Claimants (n=4)	6.25 (2.87)
Significant others (n=4)	5.75 (3.69)
Chronic Pain Sample (n=63)	6.19 (2.40)

The above data show that claimant mean scores were similar to those in other chronic pain samples, but that significant other mean scores were slightly lower. These scores may indicate a discrepancy between claimants and significant others, with claimants having a clearer understanding of their illness. This discrepancy appears to be supported by the interview data, with claimants often reporting they had a clear understanding of their condition, but this meant they often labelled themselves as disabled. Significant others did not use this term, nor did they appear to have as clear an understanding of the condition:

Significant others
"We just call it a back problem" [Jill] "I don't really know what's wrong with his back [Sally]
Claimants
"I'm an invalid" [Roger] "I can't see myself as a disabled person but also know that I won't get any help unless I do" [Helen]

The use of the term 'disabled' or 'invalid' suggests that claimants perceive they have reached an 'endpoint' to their condition, progressing as far along the continuum of chronicity as is possible. Such beliefs may have been shaped by status as a disability benefit claimant, whereby individuals are defined by their inability to work. This view also suggests that claimants may have adopted the 'sick role', whereby individuals perceive they are exempt from normal social roles and responsibilities, and feel entitled to special care (Glenton, 2003).

Overall, participants defined the condition in terms of pain – symptoms, severity, referring to multiple pain sites. Participants also commonly referred to other co-morbidities. These characteristics have been identified in the literature as the most common and frequently described in relation to chronic pain (Dionne, 2010), and several studies have found a high prevalence of 'co-morbid conditions' with chronic back pain (Hestbaek et al., 2003, Hestbaek et al., 2004, Schneider et al., 2007). These findings suggest that this study population has similar characteristics to other chronic back pain populations.

2. Beliefs about causality

Due to the small sample size, items from the 'causal' subscale of the IPQ-R were calculated as grouping variables, i.e. those who do/do not believe in a specific causal factor. Overall, claimants and significant others reported similar beliefs on the IPQ-R about causality of the back pain condition, largely attributing the cause to overwork or a workplace accident/injury. This was supported by findings from the interview data, with previous work and certain types of work (manual/heavy/repetitive) being cited as the most common initial cause of the condition, and as a 'trigger' for subsequent onsets of back pain:

Significant others

"It's probably something that he carried in work that hurt his back" [Paula]

"He was doing a job which involves lifting a lot of things" [Nadia]

"He had an accident at work, slipped"[Lydia]

Claimants

"I didn't have any problem with it up until going into that job and that's why I've put it down to doing those things....if I'm in a job where I'm sitting down all day or standing or whatever at a machine all day then it's going to go, it's going to continue to go" [Alistair]

"It was my attitude towards work, probably it was the biggest single factor" [Helen]

"Well many moons ago I would say yes I'll take on manual jobs, I've worked on building sites, I've done various jobs in and out of there, but there again carrying slate up on the roof with a bad back isn't an option unfortunately" [Adrian]

"All the time I've found it comes on more the harder work I'm doing....it's the heavy building I think ...and certain jobs" [Michael]

Some participants also indicated that psychological factors had an influence over the cause and exacerbation of their pain:

Significant others

"But I think he has been quite stressed recently so I think that can bring it [pain] on as well....I think it [stress] does make it worse ...he gets a bit tighter, you know?" [Sally]

Claimants

"I had all these problems ...the doctor realised how much stress I were under with the pain....this last two years I've been under an extreme lot of stress with er, work and er, family" [Michael]

Interestingly, the above findings were not reported in the questionnaire, but 'revealed' during the interview. It is common that those experiencing chronic pain often avoid referring to individual psychological factors as a cause of their pain in case their symptoms are viewed as fabricated or as part of malingering (Jones et al., 2010). In this case, the strong attributions towards work being a causal factor for the condition may have been influenced by the need to legitimise their status as a disability benefit claimant and not appear 'fraudulent', but also because it is likely that the cause of claimants' back pain remains medically unexplained, as is the case for 90% of sufferers (Van-Tulder and Koes, 2002). It has been shown that the avoidance of cultural stereotypes associated with unexplained back pain (such as 'malingerer') becomes very important and individuals feel the need to establish their credibility, proving their pain is real (Toye and Barker, 2010).

3. Expectations about timeline

Tables 3a and 3b illustrate the mean scores and standard deviations (SD) for claimants and significant others on the 'timeline (acute/ chronic)', and 'timeline (cyclical) subscales of the IPQ-R, along with similar published data from chronic pain samples. Scores on the 'timeline (acute/ chronic)' subscale range between 6 and 30, and scores on the 'timeline (cyclical)' subscale range between 4 and 20, with higher scores representing more strongly held beliefs about the chronic and cyclical nature of the condition respectively.

Table 3a: Mean scores (SD) for claimants and significant others, along with published mean scores for 'timeline (acute/chronic)' in a chronic pain sample.

Group	**Mean (SD) score**
Claimants (n=4)	26.00 (3.65)
Significant others (n=4)	27.00 (3.46)
Chronic Pain Sample (n=63)	23.12 (4.41)

Table 3b: Mean scores (SD) for claimants and significant others, along with published mean scores for 'timeline (cyclical)' in a chronic pain sample.

Group	**Mean (SD) score**
Claimants (n=4)	12.75 (4.11)
Significant others (n=4)	15.25 (4.03)
Chronic Pain Sample (n=63)	12.87 (3.89)

The above data show that claimant mean scores were similar to those in other chronic pain samples on the 'timeline (cyclical)' subscale, but not as similar on the 'timeline (acute/chronic)' subscale. In addition, significant other mean scores were higher than both groups on both subscales, indicating a disparity. Findings from the interview data show that although both claimants and significant others viewed the back pain condition as permanent, significant others had a more pessimistic outlook, and in particular expressed beliefs about the negative impact of ageing on the condition:

Significant others

"It's the same all the time. Same all the time...it won't get any worse but won't get any better if you know ...what I mean?" [Paula]

"I'd probably say it'll be an ongoing thing ...I think he's had it that long I don't think there's gonna be dramatic changes" [Nadia]

"As you get older you don't bounce back so now when her back goes out she'll be out for weeks rather than days...the older you get the worse your health gets if you've got a problem" [Jill]

"I suppose he feels, you know, as though he's on the scrap heap you know his age goes against him...personally I think he'd get worse, with age if you're not moving about, I think you start to fade a little bit" [Lydia]

Claimants

"It won't get any worse but it won't get any better" [Adrian]

"I'm kind of expecting that it will stay pretty much the same unless there is a medical development and I can't really say fairer than that" [Helen]

"I've gotta learn to live with it" [Michael]

Participants' view that the condition is permanent may have resulted in the IPQ-R constructs of 'timeline (acute/chronic)' and 'timeline (cyclical)' not appearing as distinct and separate themes in the interview data – but rather responses were represented as a more general, overall theme of 'expectations about timeline (chronic)'.

4. Consequences

Table 4 illustrates the mean scores and standard deviations (SD) for claimants and significant others on the 'consequences' subscale of the IPQ-R, along with similar published data taken from chronic pain samples. Scores range between 6 and 30, with higher scores representing strongly held beliefs about the negative consequences of the condition.

Table 4: Mean scores (SD) for claimants and significant others, along with published mean scores for 'consequences' in a chronic pain sample.

Group	**Mean (SD) score**
Claimants (n=4)	23.25 (3.30)
Significant others (n=4)	24.50 (1.73)
Chronic Pain Sample (n=63)	23.45 (3.89)

The above data show that claimant mean scores were similar to those in other chronic pain samples, but that significant other scores were slightly higher, perhaps indicating more negative beliefs about the consequences of the condition. Findings from the interview data show that participants reported a high degree of exclusion from participation in 'normal' life citing isolation, lack of mobility, and impact on social life/activities:

Significant others

"He can't be doing what he wants to be doing and more so the fact that he's on his own here...he's just on his own......on a daily basis he's sometimes just like couch-bound ... in here...... he used to be really fit, used to run marathons and stuff ..." [Sally]

"He's just in the house all the time now.....I know he played football and that and he enjoyed it, and he's just in the house all the time now" [Paula]

"If you'd been indoors for the best part of two years and you don't see anybody, you know, what's he got to talk about?" [Lydia]

"she's had long periods where she's had to lie flat...it's weeks in bed and it's weeks trying to get her to the toilet, trying to get her to the bath because she can't ...... when she goes her legs kind of go so she can't walk properly" [Jill]

Claimants

"I've always been able to interact with people and not being able to interact has crippled me mentally" [Adrian]

"I don't want to talk to people, I just don't wanna do anything" [Michael]

"I've cut myself off, I just wish the walls round me house were a bit bigger" [Roger]

"I can't stand for very long lengths of time either, so I tend to potter a lot....every few weeks I get a flare up which confines me to bed" [Helen]

"But what it's shown me is if I continue to do stuff, sit down for too long or anything then it's going to keep going more often so I've stopped playing football altogether because I can't be bothered with it going again......I don't socialize" [Alistair]

"I used to do mountaineering, football, orienteering, I was in the cadets, the scouts, I was in all of that and because of my back I've just had to stop it" [Adrian]

These findings indicate that participants were becoming self-limiting and fearful of activity. Interestingly, these fears are also shared by significant others. However, what generated the most discussion in this section was the impact of the condition on the ability to work, with participants citing a need for flexibility in their work. Significant others appeared to be more sceptical about the availability of flexible work and sympathy from employers compared with claimants, but all participants felt that the type of work claimants did (i.e. manual/repetitive/heavy) was not conducive to a successful return to work:

Significant others

"He can't work 'cos he's got so much back pain....I think he would be open to doing something else, but by trade that's [building] the only thing he could do really" [Sally]

"And, as I say to him, who's going to hire you? With a backache, you know......how can he get a job with, you know, his back the way it is, when he can't sit down too long, he can't walk too long, he has to lie down. And who's gonna let him lie down when he's working in the factory, no-one are they?" [Paula]

"I know that there's jobs he wants to do out there but he can't because of his back" [Nadia]

"If he does go back to work what's he even going to be able to do because he's always been physical?" [Lydia]

"If she's got the freedom to stand up and work or sit down for 10 minutes, if she can jiggle herself around then she can work" [Jill]

Claimants

"If I didn't have a back problem I'd be working....what's important for us is I'm not sat down or stood still or something like day after day because it'll stop me from walking, which will stop me from working" [Alistair]

"I can't imagine me going back to work...I don't ever think that I'll be able to do anything in the building trade" [Roger]

"I'll come back on the jobseekers, try and find a job, but then if it starts again, I've to go on the sick".... "I'll look well trying to get a job when I've got a problem with a trapped nerve in my back" [Michael]

"If I could actually get up and walk around in my own time......." [Adrian]

"I would be looking for an employer that would not mind if I didn't turn up for several weeks at a time with a flare up which I was suffering with last year for 24 weeks out of the year...it's bringing my brain to work but not necessarily my body" [Helen]

5. Control, management and treatment

As a result of missing data from two claimant participants on the 'personal control' subscale of the IPQ-R, it was not meaningful to calculate mean scores for this group. Therefore, in order to provide some illustration of similarities/differences between the two groups, Table 5a shows individual scores for claimants and their significant others on the 'personal control' subscale. Table 5b illustrates the mean scores and standard deviations (SD) for claimants and significant others on the 'treatment control' subscale of the IPQ-R, along with similar published data from chronic pain samples. Scores on the 'personal control' subscale range between 6 and 30, and scores on the 'treatment control' subscale range between 5 and 25, with higher scores on each representing more positive beliefs about the controllability of the condition.

Table 5a: Individual 'personal control' scores for claimants and their significant others

Psuedonym	**Score**
Alistair	23
Paula*	24
Adrian	*missing*
Nadia*	26
Helen	28
Jill*	15
Michael	*missing*
Sally*	18

** Significant Others*

Table 5b: Mean scores (SD) for claimants and significant others, along with published mean scores for 'treatment control' in a chronic pain sample.

Group	**Mean (SD) score**
Claimants (n=4)	14.75 (5.06)
Significant others (n=4)	12.25 (4.72)
Chronic Pain Sample (n=63)	14.22 (3.36)

Where data exists, Table 5a shows there was some disparity between claimants and significant others in relation to their beliefs about the personal control over the condition. This finding was also replicated in Table 5b with respect to beliefs about the treatment control over the condition. Again, claimant scores were similar to published IPQ-R scores taken from chronic pain populations. These data suggest that significant others may have less positive beliefs about the controllability of the condition, particularly in relation to treatment.

This disparity was also reflected in findings from the interview data whereby most claimants reported that they managed the condition themselves, but significant others often reported the need for outside help in managing the condition. Both claimants and significant others reported the need for heavy medication, but significant others appeared to view this as necessary, effective treatment whereas claimants expressed their dissatisfaction with this treatment, citing ineffectiveness and unwanted side-effects:

Significant others

"It's weeks of massive pain relief that she has to dose" [Jill]

"He couldn't manage it if he didn't have any tablets at all" [Nadia]

"He's coping well when he's drugged up, taking his painkillers" [Lydia]

"He can't control it himself, without taking the tablets or seeing anybody for it" [Sally]

Claimants

"I have to put myself out on pain killers and then I can't think, all I have to do is sleep.....I was out of it for 10 days...it's the sleepiness that really worries me. Because it might be a fantastic pain killer but if I can't think..... it would make really, really happy not to take tablets at all" [Helen]

"There will always be time when the pain relief is at the top of its effectiveness and times when it's at the bottom of its effectiveness and there's nothing that you can do about that" [Helen]

"After two years of popping pills like they were sweeties, I just couldn't take feeding my body like that anymore......I've had a lot of concentration problems since I started taking the tablets" [Adrian]

"I've taken pain killers but they've done nothing so I stopped it" [Alistair]

"To be honest, I don't wanna be on [painkillers] for the rest of my life" [Michael]

In terms of treatment, all claimants had been offered physiotherapy, and participants reported mixed results with regard to effectiveness, with good results being attributed to the 'right' physiotherapist. In addition, most claimants had been offered and accepted surgery and again, significant others reported this as an effective treatment whereas claimants tended to view its effectiveness as limited:

Significant others

"He's a lot better than what it was, he's able to move you know, a bit more" [Nadia]

"It's a lot better since he had the operation, it's now much easier to walk whereas before he couldn't walk properly at all" [Lydia]

Claimants

"I went into hospital and had the operation and obviously now it's not sorted but it won't get any worse but it won't get any better, so it's basically kept the condition as it was but it won't deteriorate" [Adrian]

"They've operated on it and quite honestly I haven't got a clue what they've done but it's not really helped" [Roger]

All participants expressed dissatisfaction and anger with healthcare provision for significant delays in diagnosis, a lack of effective treatments, and towards their GP for only prescribing medication and administering long-term sickness certification:

Significant others

"The doctors, they didn't diagnose it straightaway, it took quite a while to find out what the problem was ... just putting him on pain relief and saying that, umm, it was an age thing and fobbed off basically for quite a long time" [Lydia]

"He's been waiting for so long and ...and I don't think that's very good at all really" [Sally]

"They always sign you off....they just say that there is nothing further that they can do" [Jill]

"Well he's still waiting to hear about going to physio but that was months ago and we're still waiting on it and I can see that that's probably what's not helping him now, because he didn't wanna do any exercise himself because he's scared of wrecking himself" [Nadia]

Claimants

"To be honest with you my doctor doesn't give me much information....I believe they could have done a bit more in the long space of time that they've had. Two years is a long time especially when you're only 28 years of age" [Adrian]

"So I've probably been misdiagnosed for all of this time" [Helen]

"Every time I went in for sick note he wrote the same thing, pain in lower back area, I didn't get an X-ray I didn't get an MRI scan, I didn't get bugger all for 12 months, the NHS stinks" [Roger]

Participants had strong beliefs of what they could expect from their healthcare provider. These findings were similar to those found in a systematic review of patient expectations of treatment for back pain, where it was reported that patients want a clear diagnosis of the cause of their pain, resulting from physical examinations, diagnostic tests, and referrals to therapy or specialists. It was concluded that patients want their healthcare provider to confirm their pain is real, and that they have been understood, respected and included in decision-making (Verbeek et al., 2004). Findings in the current study show it was clear that such expectations (whether realistic or not) had not been met, resulting in an overall dissatisfaction with their treatment. Interestingly, significant others appeared to be more distressed about this compared with claimants:

Significant others

"he was gutted, he was mortified, horrified. There weren't words to describe it, umm....you know the NHS what a letdown" [Lydia]

"There's nothing they can do, it's not curable" [Jill]

"Just pray that he is [better in a year]. That's all you can do..."I don't think you ever really get rid of a backache, you know, when you do hurt your back, that's it. From then it's gone then for life isn't it?" [Paula]

"I hope that everything would return to normal and he's active but when you've had something like this, or living with someone like this for two years, you're hoping and praying it'll get better but I don't know…..there's nothing you can do, there's absolutely nothing you can do except just deal with it and deal with it best way you can" [Lydia]

Claimants

"I don't think that at the present time there is anything that can be done and I've been told several times in no uncertain terms there is nothing more that can be done" [Helen]

"He [the GP] just said it won't get better, you'll get it worse in the middle of your back and your neck, he says, and you've gotta learn to put up with it….In my own mind I know it'll never go away 'cos I've had it that long so I've always had to accept that I've got back trouble" [Michael]

"It's something that I have to live with for the rest of my life, I've just got to accept it" [Adrian]

Perhaps as a result of dissatisfaction with healthcare provision, claimants ultimately came to hold strong beliefs about how best to manage their condition. However, this often resulted in self-limiting or fear-avoidance behaviour:

Claimants

"I think I can manage it completely but it will mean just not doing anything at all….I can stop the pain altogether by lying down all day….what it's shown me is if I continue to do stuff, sit down for too long or anything then it's going to keep going more often" [Alistair]

"I can control it as long as I don't exert myself….most people would say I'm now more fearful" [Adrian]

"We'll know that I'm going to have to watch myself very, very carefully" [Helen]

"I give a great deal of thought, somebody says, we're going so and so and such and such today and I think, plot it out in me mind" [Roger]

6. Emotional representations

Emotional representations are derived from the 'illness coherence' subscale of the IPQ-R. As a result of missing data from one claimant participant, it was not meaningful to calculate mean scores for this group. Therefore, in order to provide some illustration of similarities/differences between claimants and significant others, Table 6 shows individual scores. Scores range between 6 and 30, with higher scores representing strong emotional representations (positive or negative) in relation to the condition.

It was found that the 'illness coherence' theme within the IPQ-R did not clearly emerge during analysis of the interview data, with responses to the related questions being coded in the 'illness identity', 'consequences', and influence of/impact on significant others' themes. This suggests that all participants defined the emotional impact and understanding of the condition in terms of the symptoms and everyday limitations, and this is supported by previous findings in this study whereby participants largely defined their condition in terms of pain symptoms, and reported a high degree of exclusion from normal life. Where data exist, Table 6 shows that there appears to be some disparity between claimants and significant others in relation to the emotional representations attached to the condition.

Table 6: Individual 'emotional representations' scores for claimants and their significant others

Psuedonym	**Score**
Alistair Paula*	19 22
Adrian Nadia*	19 15
Helen Jill*	*missing* 17
Michael Sally*	17 25

** Significant Others*

Whilst there was broad agreement between claimants and significant others in terms of emotions experienced by claimants (catastrophizing, anger, fear, feeling low/depressed, anxiety/worry/sadness, stress, irritability, shame, shock and frustration), there was a disparity in relation to perceived emotional impact on significant others as a result of the condition. Significant others reported experiencing a similar number of emotions to claimants, whereas claimants perceived relatively little emotional impact on significant others.

7. Claimant as 'genuine'

This theme was identified as separate and distinct from the IPQ-R components, and it became apparent that it was an overarching theme across this study and was as a result of the characteristics of the study population (i.e. disability benefit claimants). The need to validate the genuine nature of the back pain condition can be seen to influence response to other areas of this study, and it was found that in general, significant others were keen remove blame from claimants, emphasising that claimants did not want to be seen as a burden and that they were not their 'real selves'. They often blamed the condition for undesirable behaviours in claimants, such as irritability, and limited function, and reported witnessing the claimants' pain as if to validate it:

Significant others

"But you can see, you can see it in his face, you know, when he's walking....he walks from the hallway, in here, just keeps walking around for about ten, twenty minutes and er, then he has to go back upstairs and lie on his bed" [Paula]

"I can probably tell when he gets up 'cos I can see the way he walks, if he's like sore or not....I could see how much pain he was in ...just for even sitting down for more than half-an-hour" [Nadia]

"I've seen, you know living with somebody who's in a lot of pain" [Lydia]

Significant others also often reported claimants as having admirable attitudes towards the condition, such as defiance and stoicism:

Significant others

"He's quite a strong person, he tries to like, just get through it and carry on, but for as long as I can remember he's always been in pain or just like forced himself to work...he will work even like, you know, if he's in loads of pain" [Sally]

"Because we're not the kind of people to give up, like we might be ill but we're not ready to be old codgers just yet......you don't have to just give up to accept that you've got a condition, you can accept it and still have determination and spirit" [Jill]

"He's the kind of person, even though he's got pain he'll just persevere and push through it" [Nadia]

"He came home in an awful lot of pain and you know he tried to disregard it and carried on working" [Lydia]

Interview data from claimants mapped well onto this theme, with claimants presenting themselves in a similar way (e.g. stoical, and as 'a fighter'). However, the removal of blame and insistence about the genuine nature of the condition sometimes led to claimants becoming angry as they perceived that others viewed their condition with suspicion:

Claimants

"Some people don't think there's any problem at all. That's made me very angry. They've said I've just a mild problem. How can they say it's a mild problem when it's going to stop me walking? That makes me very angry" [Alistair]

"It's not effecting me mentally if that's what you think....I'm at the point where everybody'd see that I'm not a raving lunatic.....I'm not depressed. Trust me I'm not....there's nothing up with me head and me brain, it's me physical body" [Roger]

8. *Influence of/impact on 'significant other'*

Another theme identified as separate from the IPQ-R was related to both the influence of, and impact on, significant others. Participants' lives were intertwined, and in some cases, defined by the back pain condition. This may have been as a result of the familiarity between claimants and significant others, and also the chronic nature of the condition (i.e. experienced for a long period of time). An important finding within this theme was that significant others also had long-term health conditions (with some being IB/ESA benefit claimants themselves). This may have further enhanced significant others' influence/impact through a shared understanding about chronic illness:

Significant others

"Maybe we're an odd household because we're both ill that that makes us more understanding of each other" [Jill]

"I think if I didn't get this [back pain] I'd be more, get up, you know, stop whingeing and just carry on and, but no, recently he's not been able to, to carry on, and I sympathise with him a lot" [Sally]

"I think we sort of get sympathy pains for each other" [Nadia]

On the whole, significant others saw themselves as the claimant's 'only carer', and reported high levels of routine dependency by the claimant. However, this inter-dependency was rarely presented in a negative light, but rather as a display of the strength of the relationship and dedication to the claimant:

Significant others

"He doesn't have any family" [Sally]

"I've got to be breadwinner, having to go to work and not being there to actually help him at home....I just do it all, basically" [Lydia]

"I just help him, run up and down stairs, run up and down stairs when he wants" [Paula]

"I cook for him so he doesn't have to stand and cook, if he has problems getting in and out of bed I'll try and help him as much as I can, erm, pretty much anything, like, that he can't do I'll like try and do for....I'm willing to do it" [Nadia]

"She needs a lot of physical support and stuff while it's going on....she can't really do anything for herself when she's that bad she just has to lay in bed and be waited on" [Jill]

As shown previously, claimants often reported that the condition had little impact on significant others' lives, yet significant others reported the far-reaching impact of the claimant's condition on their lives, including the impact on their own working life and the implications this had for their own health condition:

Significant others

"Your social life suffers because he doesn't really want to go out...I daren't [suggest going out] because I don't see him much at all now and if you just mention it, the look on his face is shock horror so I wouldn't" [Lydia]

"Well, yeah, 'cos we can't really go out and do much ...If I were to get a job I could only go part-time because obviously I'm, well caring for him" [Nadia]

"We're quite limited in the fact that if we had to go out we've got to make sure it's optimum times and the rest of it for her" [Jill]

"I daren't go sick, I daren't ever consider going part time" [Lydia]

Ultimately, claimants and significant others were in agreement about their perceived lack of support by others, including family and friends, the benefit system, employers and healthcare professionals. This led to feelings of despair, anger, scepticism, anxiety and hopelessness:

Significant others

"Some quite hurtful, some rude, you know things like ' I know you've got a bad back but what happened to your sense of humour?' and you feel like saying, well, if you'd been indoors for best part of two years and you don't see anybody, you know, what's he got to talk about?" [Lydia]

"All he wants is someone to help him to get back into work....he thinks that he can just go to someone and they'll help him to find a job that he can do" [Paula]

"If you tell loads of lies you get everything. Tell the truth you get nothing" [Paula]

Claimants

"There is an amount of disbelief and scepticism and I think that's painful and hurtful and it adds to the anxiety of my problem.....other people, I think, have been reluctant to come near us. There's this kind of feeling that if you're ill you've just become a whinger" [Helen]

"I think my ex-wife got fed up of it, so, that's why she went" [Michael]

"It's worrying me that I can't get the help that I need....the reason why I've gone on to this [condition management programme] is because I've got told I'd get help finding suitable positions....I got told they'd help me find work and stuff because I struggled all last year to find suitable positions......it's not the actual back that's worrying me it's the fact that I'm not going to get the help I need" [Alistair]

"I don't feel like I get much help from anybody to be honest....I just need a bit of guidance...nobody's advised me on what sort of education or tried to put me on any sort of course, so yet again, this is another part of the boxes on my sheet and I've got to put a big cross in it and that's another failure from bloody Government" [Roger]

"I feel angry at the way that the people who employed me at the time of me accident when it was an industrial accident threatened me by sacking me, then they had the audacity to say that we weren't aware of him having an accident – I can't believe that" [Roger]

Discussion

For individuals who have been on prolonged sickness absence for 23 months, there is a 90% chance that they will not return to any form of work in the foreseeable future (Waddell et al., 2002). It is only a small number of individuals who report significant work disability due to chronic back pain, but it is this minority which incur the majority of cost in terms of benefit payments and associated healthcare costs (Black, 2008). There is clearly a need to identify those factors which impede recovery from chronic back pain in order to avoid the adverse physical, mental and social effects associated with long-term worklessness and incapacity (Waddell and Burton, 2006). A great deal of research has been conducted on spousal/partner beliefs about chronic pain, yet few studies of this nature focus on back pain and return to work specifically. Findings from this pilot study highlight some of the psychological *and* social factors that may contribute to chronic back pain, and which also may influence recovery and return to work.

The data showed there were disparities between the illness representations of claimants and their significant others. Significant others appeared to have less understanding of the back pain condition, held stronger beliefs about the chronic nature of the condition (i.e. it being permanent), had a more pessimistic outlook over the future course of the condition, held stronger beliefs about the negative consequences of the condition, were less positive about the condition being controlled by treatment, and reported greater emotional impact as a result of the condition. It was not possible within the remit of this pilot study to establish whether the illness perceptions of significant others had an association with claimant's pain and work outcomes, but the disparities found are in line with those reported in numerous other studies investigating the association between partner response and chronic pain behaviour and dysfunction (Raichle et al., 2011). Furthermore, claimant mean scores on the IPQ-R were similar to those taken from other chronic pain samples, providing a positive indication of the validity of the results found in this pain population.

Overall, significant others appeared to want to portray themselves as 'good carers', acting as a 'witness' to the claimant's pain and validating pain severity. Very rarely did significant others express frustration or negativity towards the claimants' high levels of routine dependency as a result of the condition, but reported that they largely accepted the restrictions placed on them, partly as dedication to the claimant and as testament to the strength of their relationship. These findings are unusual when compared with other similar studies which consistently show that the spouse/partner is profoundly affected by the limitations placed on them (De Souza and Frank, 2011). However, other studies investigating the role of pain-related empathy may help to further understand the findings of the current study, as it has been reported that this could be seen by many partners as an essential ingredient of relationship quality, and that it is viewed by many as an important requisite for meeting the patient's support needs (Gauthier et al., 2008). However, many studies have linked such solicitous responding to poorer functional outcomes, greater pain behaviours and reports of greater pain intensity in patients with chronic pain (Romano et al., 1995, Romano et al., 2000, Flor et al., 1987). It appears that role expectations of significant others may be worthy of further investigation, including the influence of gender (for example, all significant others in this study were female) and the nature of the relationship (i.e. whether the significant other is the partner/spouse, or the parent/child).

Whilst significant others reported a far-reaching impact of the claimant's condition on most aspects of their lives, claimants on the other hand perceived little impact on significant others. This finding is in contrast to others from studies of this nature whereby individuals experiencing chronic back pain tend to express a high degree of anxiety about how their pain affects other family members (De Souza and Frank, 2011). It could have been that significant others exaggerated the impact of the condition in order to fulfil their 'good carer' role (as discussed above), or claimants may have been unwilling to acknowledge the burden placed on significant others by their condition, perhaps due to the fact that all significant others in this study also had chronic health problems themselves.

The fact that significant others also had chronic health problems (with some also being IB/ESA claimants) has strong implications for illness beliefs, which may be reinforced by a shared understanding of chronic illness. The influence of significant others on claimant illness perceptions may be strengthened by the level of familiarity between each other, and more time spent together as a result of both not working. Overall, participants' lives were intertwined and defined by the back pain condition, resulting in a 'conferred expertise' about how best to manage the condition, which often translated into self-limiting and fear-avoidance behaviour. This 'conferred expertise' could also have arisen as a result of participants' largely negative experiences of the healthcare system. Participants reported significant experience of 'failed' treatments offered by the healthcare profession, and a lack of clear information and communication - it was often reported that the only option appeared to be 'prescribed sick leave' (Glenton, 2003). This may have led participants to believe that the condition was largely 'incurable', further reinforcing strong inevitability beliefs which are difficult to overcome. It has been suggested that new strategies need to be developed in order to better meet patient expectations, and that facilitating adjustment to chronic pain may be more helpful than inferring the potential for a life free of pain as a result of therapeutic endeavours (De Souza and Frank, 2007).

The area where participants were in agreement was related to beliefs about causality – here all participants attributed work both to the initial cause of, and a 'trigger' for, subsequent episodes of back pain. Here, work was viewed in largely negative terms, with participants discussing the inability to maintain work function whilst experiencing chronic pain. It has been reported that pain symptoms are generally more common in blue collar workers, and that the risk of pain in these groups remains even after taking into account the influence of individual psychosocial factors (Papageorgiou et al., 1997). For men, long-term sickness absence associated with working in mainly a standing or squatting position and lifting or carrying loads is estimated to be 23% and 28% respectively (Bang et al., 2007). However, what these figures demonstrate is that the majority of individuals doing this kind of work do not take long-term sickness absence. Findings from this study show that perhaps more importantly, participants associated this type of work with inflexibility and unsympathetic employers, and was therefore not perceived to be conducive to return to work with a health condition.

There is some evidence which suggests that individuals who are fit for the job are more likely to be employed than those who are not (Osmotherly and Attia, 2006) – unfortunately the pressures of succeeding in an economic downturn mean that this may currently be a necessity for some. Whilst individuals must accept a certain degree of responsibility in their recovery and return to work, these findings suggest that it is also important that employers provide the supportive environment and accommodating job design which help promote successful work retention. In addition to a perceived lack of flexibility available in their current occupation, claimants also felt that their lack of qualifications, and/or relevant training in more suitable occupations further limited their future work options. The ability to re-train or obtain further educational qualifications was often out of reach due to claimants' financial constraints, existing educational level, and limitations posed by their ill-health. These findings highlight the difficulties in maintaining work function faced by certain groups in the population, and appear to add weight to the small body of research which has directed attention to how sickness absence is mediated by other social factors (Barnes et al., 2008).

Similarly, it should be acknowledged that the context of the study population (i.e. being a benefit claimant) probably had an overarching influence on response, especially in relation to work. Disability benefit claimants are defined in terms of their incapacity, and there is an explicit link between ill health and work. Indeed, it has previously been suggested that welfare systems may promote the problem of disability by rewarding sickness absence (Waddell and Aylward, 2005). This was somewhat apparent when a clear theme emerged from the interview data, labelled as 'claimant as genuine' whereby participants were keen to remove any attributions of self- blame for fear of appearing 'fraudulent'. Claimants often became angry as they recalled others viewing their condition with suspicion, and the new government proposals around welfare reform led to some claimants in particular becoming highly anxious as they perceived that they wouldn't be 'believed' and their benefits would be withdrawn, leaving them with nothing to live on and with little hope of finding suitable work. The desire to be seen as genuine may also have resulted in claimants becoming increasingly self-limiting in order to fulfil their 'disabled role'. Taken from this viewpoint, the adoption of this role is not just an individual reaction to illness, but is also influenced by socio-cultural factors.

Therefore, what may be important in understanding why only some people experience chronic pain and the resulting long-term sickness absence is how an individual's wider social circumstances become important contributors both to the propensity of pain to become chronic and to the consequences of pain for sickness absence and incapacity (Wynne-Jones and Main, 2010). Several studies have shown that the impact of musculoskeletal pain and disability is greatest among socially disadvantaged populations, and among those with low education levels, and that low income and low educational attainment are the socioeconomic variables most consistently found to be associated with higher prevalence and severity of musculoskeletal problems (Carr and Klaber Moffett, 2005). Findings from the current study suggest that socioeconomic status may be an important influence on back pain disability, but further research in groups where there are high levels of social disadvantage is required. Such research may provide a better understanding of those factors that improve work retention and vocational rehabilitation in different population groups.

Study limitations

The small sample size in this study means that caution should be applied to the interpretation of results. However, many findings were supported by evidence documented in other studies of chronic back pain. Also, given the focus of the study on the in-depth, everyday life experiences of participants, the main findings presented in this study were qualitative, and a relatively small sample size is usually appropriate (Murphy et al., 1998). However, the study sample were self-selecting, recruited from a program aiming to facilitate return to work and therefore participants may have been work-ready - individuals who are not work-ready may have provided different responses. But it could be argued that using information obtained from individuals who are work-ready may be more helpful, as this would enable interventions to be targeted at those factors that have been identified as obstacles to return to work, providing the most appropriate help and support.

Self-reported narratives retrospectively covering a long period have been questioned, and risks of poor quality caused by distorted memory may need to be assumed (Hansson et al., 2001). A particular strength of this study, however, was its mixed-methods design which allowed data from both questionnaires and interviews to be compared and interpreted in a wider context, and the inclusion of significant others also facilitated a method of triangulation and cross-verification of findings (Bogadan and Biklen, 2006). The use of the IPQ-R alone would have provided an individual psychological model of illness only - the methods employed helped to highlight the less-researched social components of disabling back pain.

Lastly, although the authors of the IPQ have always encouraged researchers to adapt the scale to a particular illness and setting, and have specifically requested that the scale be used in conjunction with other less structured assessment techniques, it is acknowledged that such modifications applied in a larger study of this nature may mean further psychometric testing is required. Further research exploring the role of illness perceptions in relation to occupational outcomes may also benefit from investigating whether combinations of illness perceptions show stronger relationships with work disability when compared with single dimensions. In addition, the use and interpretation of absolute illness perception scores could be improved if cut-off values were proposed and normative data would help distinguish ‘helpful’ from ‘unhelpful’ illness perceptions in different diseases and settings (Hoving et al., 2010).

Summary and recommendations for future research

There is good evidence to support the targeting of illness perceptions in interventions focused on work participation, and it has been shown that reducing unhelpful perceptions can improve coping skills and improve work and health outcomes (Petrie et al., 2002). Preventative action in the workplace could include offering more positive views about working with back pain, providing a supportive and accommodating environment, encouraging communication with supervisors or line-managers and training in problem-focused coping at work. It also seems sensible to target interventions by health professionals to patterns of maladaptive illness representations.

Although it is generally accepted that work is beneficial for health and wellbeing, it is also acknowledged that work varies widely in its nature and quality and that further research is required to establish what kinds of work are beneficial, when, and for whom (Waddell and Burton, 2006). The social context of disabling back pain has received little attention to date, and this study has provided an interesting insight into the psychological *and* social circumstances and difficulties associated with work incapacity due to chronic back pain. Wider support of these findings could meaningfully inform future treatment plans and intervention programmes aimed at restoring work function.

References

BANG, C. K., LUND, T., LABRIOLA, M., VILLADSEN, E. & BULTMANN, U. (2007) The fraction of long-term sickness absence attributable to work environmental factors: prospective results from the Danish Work Environment Cohort Study. *Occup Environ Med,* 64**,** 487-9.

BARNES, M. C., BUCK, R., WILLIAMS, G., WEBB, K. & AYLWARD, M. (2008) Beliefs about common health problems and work: A qualitative study. *Social Science & Medicine,* 67**,** 657-665.

BARTYS, S., BURTON, A. K. & MAIN, C. (2005) A prospective study of psychosocial risk factors and absence due to musculoskeletal disorders - implications for occupational screening. *Occupational Medicine,* 55**,** 375-9.

BLACK, C. (2008) *Working for a healthier tomorrow: review of the Health of Britain's working age population,* London, TSO.

BLYTH, F., MARCH, L., BRNABIC, A., JORM, L., WILLIAMSON, M. & COUSINS, M. (2001) Chronic pain in Australia: a prevalence study. *Pain,* **89,** 127-134.

BOGADAN, R. C. & BIKLEN, S. K. (2006) *Qualitative research in (validation) and qualitative (inquiry) studies,* Allyn & Bacon.

BOOTHBY, J. L., THORN, B. E., OVERDUIN, L. Y. & CHARLES WARD, L. (2004) Catastrophizing and perceived partner responses to pain. *Pain,* **109,** 500-506.

CANO, A., MILLER, L. R. & LOREE, A. (2009) Spouse Beliefs About Partner Chronic Pain. *The Journal of Pain,* **10,** 486-492.

CARR, J. L. & KLABER MOFFETT, J. A. (2005) Review Paper: The impact of social deprivation on chronic back pain outcomes. *Chronic Illness,* **1,** 121-129.

DE SOUZA, L. & FRANK, A. O. (2007) Experiences of living with chronic back pain: the physical disabilities. *Disability and Rehabilitation,* **29,** 587-596.

DE SOUZA, L. & FRANK, A. O. (2011) Patients' experiences of the impact of chronic back pain on family life and work. *Disability and Rehabilitation,* **33,** 310-318.

DEMYTTENAERE, K., R., B. & LEE, S. E. A. (2007) Mental disorders among persons with chronic back or neck pain: results from the world mental health surveys. *Pain,* **129,** 332-342.

DIONNE, C. E. (2010) Measuring chronic pain in populations. IN CROFT, P., BLYTH, F. & VAN DER WINDT, D. (Eds.) *Chronic Pain Epidemiology.* Oxford, Oxford University Press.

ELLIOTT, A., SMITH, B., PENNY, J., SMITH, W. & CHAMBERS, W. (1999) The epidemiology of chronic pain in the community. *Lancet,* **354,** 1248-1252.

FLOR, H., KERNS, R. D. & TURK, D. C. (1987) The role of spouse reinforcement, perceived pain, and activity levels of chronic pain patients. *J Psychosom Res,* **31,** 251-9.

FORDYCE, W. E. (1976) *Behavioural methods for chronic pain and illness,* St Louis, The C.V. Mosby Company.

FOSTER, N. E., BISHOP, A., THOMAS, E., MAIN, C., HORNE, R., WEINMAN, J. & HAY, E. (2008) Illness perceptions of low back pain patients in primary care: what are they, do they change and are they associated with outcome? *Pain,* **136,** 177-187.

FOSTER, N. E., THOMAS, E., BISHOP, A., DUNN, K. M. & MAIN, C. J. (2010) Distinctiveness of psychological obstacles to recovery in low back pain patients in primary care. *Pain,* **148,** 398-406.

GAUTHIER, N., THIBAULT, P. & SULLIVAN, M. J. L. (2008) Individual and relational correlates of pain-related empathic accuracy in spouses of chronic pain patients. *Clin J Pain,* **24,** 669-677.

GLENTON, C. (2003) Chronic back pain sufferers - striving for the sick role. *Social Science & Medicine,* 57, 2243-52.

GRIFFITHS, A., COX, T., KARANIKA, M., KHAN, S. & TOMAS, J. (2006) Work design and management in the manufacturing sector: development and validation of the Work Organisation Assessment Questionnaire. *Occup Environ Med,* 63, 669-75.

HAGGER, M. S. & ORBELL, S. (2003) A meta-analytic review of the common-sense model of illness representations. *Psychology & Health,* 18, 141-184.

HANSSON, M., BOSTROM, C. & HARMS-RINGDAHL, K. (2001) Living with spine-related pain in a changing society - a qualitative study. *Disability and Rehabilitation,* 23, 286-295.

HESTBAEK, L., LEBOEUF-YDE, C. & MANNICHE, C. (2003) Is low back pain part of a general health pattern or is it a separate and distinctive entity? A critical literature review of cormorbidity with low back pain. *J Manipulative Physiological Therap,* 26, 243-252.

HESTBAEK, L., LEBOEUF-YDE, C. & OHM KYVIK, K. E. A. (2004) Comorbidity with low back pain. *Spine,* 29, 1483-1491.

HOVING, J., VAN DER MEER, M., VOLKOVA, A. & FRINGS-DRESEN, M. (2010) Illness perceptions and work participation: a systematic review. *Int Arch Occup Environ Health,* 83, 595-605.

HSE (2007) Self-reported work-related illness and workplace injuries in 2005/6: Results from the Labour Force Survey. *National Statistics.* UK, Health and Safety Executive.

JAGGER, C., MATTHEWS, R., SPIERS, N., BRAYNE, C., COMAS-HERRERA, A. & ROBINSON, T. E. A. (2006) Compression or expansion of disability? Forecasting future disability levels under changing patterns of disease. *Wanless Social Care Review Research Report.* Leicester, Leicester Nuffield Research Unit, University of Leicester.

JONES, A. K. P., MCBETH, J. & POWER, A. (2010) The biological response to stress and chronic pain. IN CROFT, P., BLYTH, F. & VAN DER WINDT, D. (Eds.) *Chronic Pain Epidemiology.* Oxford, Oxford University Press.

KAMALERI, Y., NATVIG, B., IHLEBAEK, C. & BRUUSGARD, D. (2008) Localized or widespread musculoskeletal pain: does it matter? *Pain,* 138, 41-46.

KENDALL, N. & BURTON, K. (2009) *Tackling musculoskeletal problems: a guide for clinic and workplace,* Norwich, TSO.

KING, N. (2004) Using templates in the thematic analysis of text. IN CASSELL, C. & SYMON, G. (Eds.) *Essential Guide to Qualitative Methods in Organizational Research.* London, Sage.

KING, N., CARROLL, C., NEWTON, P. & DORNAN, T. (2002) "You can't cure it so you have to endure it": the experience of adaptation to diabetic renal disease. *Qualitative Health Research,* 12, 329-346.

LEONARD, M. T., CANO, A. & JOHANSEN, A. B. (2006) Chronic Pain in a Couples Context: A Review and Integration of Theoretical Models and Empirical Evidence. *The Journal of Pain,* **7,** 377-390.

LEVENTHAL, H., NERENZ, D. & STEELE, D. (1984) Illness representations and coping with health threats. IN BAUM, A., TAYLORE, S. & SINGER, J. (Eds.) *Handbook of Psychology and Health: social psychological aspects of health.* Hillside, NJ, Earlbaum.

MANIADAKIS, N. & GRAY, A. (2000) The economic burden of back pain the UK. *Pain,* **84,** 95-103.

MOSS-MORRIS, R., WEINMAN, J., PETRIE, K., HORNE, R., CAMERON, L. D. & BUICK, D. (2002) The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health,* **17,** 1-16.

MUNDT, J. C., MARKS, I. M., SHEAR, M. K. & GRIEST, J. H. (2002) The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *British Journal of Psychiatry,* **180,** 461-464.

MURPHY, E., DINGWALL, R., GREATBATCH, D., PARKER, S. & WATSON, P. (1998) Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment,* **12,** 16.

NEWTON-JOHN, T. R. O. (2002) Solicitousness and chronic pain: a critical review. *Pain Reviews,* **9,** 7-27.

NIEDHAMMER, I., CHASTANG, J. & DAVID, S. (2008) Importance of psychosocial work factors on general health outcomes in the national French SUMER survey. *Occupational Medicine,* **58,** 15-24.

ONG, B., HOOPER, H., JINKS, C., DUNN, K. M. & CROFT, P. (2006) "I suppose that depends on how I was feeling at the time": perspectives on questionnaires measuring quality of life and musculoskeletal pain. *Journal of Health Services Research Policy,* **11,** 81-88.

OSMOTHERLY, P. & ATTIA, J. (2006) The healthy work survivor effect in a study of neck muscle performance measures in call-centre operators. *Work,* **26,** 399-406.

PAPAGEORGIOU, A. C., MACFARLANE, G. J., THOMAS, E., CROFT, P. R., JAYSON, M. I. & SILMAN, A. J. (1997) Psychosocial factors in the workplace - do they predict new episodes of low back pain? Evidence from the South Manchester Back Pain Study. *Spine,* **22,** 1137-42.

PETRIE, K. J., CAMERON, L. D., ELLIS, C. J., BUICK, D. & WEINMAN, J. (2002) Changing illness perceptions after myocard infarction: an early intervention randomized controlled trial. *Psychosom Med,* **64,** 580-586.

PHILLIPS, C., MAIN, C., BUCK, R., AYLWARD, M., WYNNE-JONES, G. & FARR, A. (2008) Prioritising pain in policy making: The need for a whole systems perspective. *Health Policy,* **88,** 166-175.

RAICHLE, K. A., ROMANO, J. & JENSEN, M. P. (2011) Partner responses to patient pain and well behaviours and their relationship to patient pain behaviour, functioning and depression. *Pain,* 152, 82-88.

RASPE, H. (2010) Measuring the impact of chronic pain on populations: a narrative review. IN CROFT, P., BLYTH, F. & VAN DER WINDT, D. (Eds.) *Chronic Pain Epidemiology: from aetiology to public health.* Oxford, Oxford University Press.

ROMANO, J., JENSEN, M. P., TURNER, J. A., GOOD, A. M. Y. B. & HOPS, H. (2000) Chronic pain patient-partner interactions: further support for a behavioural model of chronic pain. *Behav Ther,* 31, 415-40.

ROMANO, J. & SCHMALING, K. (2001) Assessment of couples and families with chronic pain. IN TURK, D. C. & MELZACK, R. (Eds.) *Handbook of Pain Assessment (2nd edition).* New York, The Guildford Press.

ROMANO, J. M., TURNER, J. A., JENSEN, M. P., FRIEDMAN, L. S., BULCROFT, R. A., HOPS, H. & WRIGHT, S. F. (1995) Chronic pain patient-spouse behavioral interactions predict patient disability. *Pain,* 63, 353-360.

SCHNEIDER, S., MOHNEN, S. M., SCHILTENWOLF, M. & RAU, C. (2007) Comorbidity of low back pain: representative outcomes of a national study in the Federal Republic of Germany. *Eur J Pain,* 11, 387-397.

SCHULTZ, I., CROOK, J. & MELOCHE, G. E. A. (2004) Psychosocial factors predictive of occupational low back disability: towards development of a return-to-work model. *Pain,* 107, 77-85.

SHAW, L., SEGAL, R., POLATAJKO, H. & HARBURN, K. (2002) Understanding return to work behaviours: promoting the importance of individual perceptions in the study of return to work. *Disability and Rehabilitation,* 24, 185-195.

STROUD, M. W., TURNER, J. A., JENSEN, M. P. & CARDENAS, D. D. (2006) Partner responses to pain behaviours are associated with depression and activity interference among persons with chronic pain and spinal cord injury. *The Journal of Pain,* 7, 91-99.

TOYE, F. & BARKER, K. (2010) 'Could I be imagining this?' - the dialectic struggles of people with persistent unexplained back pain. *Disability and Rehabilitation,* 32, 1722-1732.

UNDERWOOD, M., HARDING, G. & KLABER MOFFETT, J. A. (2006) Patient perceptions of physical therapy within a trial for back pain treatments (UK BEAM). *Rheumatology (Oxford),* 45, 751-756.

VAN-TULDER, M. & KOES, B. (2002) Low back pain and sciatica (chronic). *Clin Evid,* 7, 1032-1048.

VERBEEK, J. M. D. P., SENGERS, M.-J. M., RIEMENS, L. & HAAFKENS, J. P. (2004) Patient Expectations of Treatment for Back Pain: A Systematic Review of Qualitative and Quantitative Studies. *Spine,* 29, 2309-2318.

WADDELL, G. & AYLWARD, M. (2005) *The scientific and conceptual basis of incapacity benefits,* London, TSO.

WADDELL, G. & AYLWARD, M. (2010) *Models of sickness and disability: applied to common health problems,* London, The Royal Society of Medicine Press Ltd.

WADDELL, G., AYLWARD, M. & SAWNEY, P. (2002) Back pain, incapacity for work and social security benefits: an international literature review and analysis. Royal Society of Medicine Press Ltd.

WADDELL, G. & BURTON, K. (2006) *Is work good for your health?,* London, TSO.

WADDELL, G., BURTON, K. & KENDALL, N. (2008) *Vocational rehabilitation: what works, for whom, and when?,* London, TSO.

WAXMAN, S. E., TRIPP, D. A. & FLAMENBAUM, R. (2008) The mediating role of depression and negative partner responses in chronic low back pain and relationship satisfaction. *The Journal of Pain,* 9, 434-442.

WEINMAN, J., PETRIE, K., SHARPE, N. & WALKER, S. (2000) Causal attributions in patients and spouses following a heart attack and subsequent lifestyle changes. *British Journal of Health Psychology,* 5, 263-273.

WYNN, P. & MONEY, A. (2009) Qualitative research and Occupational Medicine. *Occupational Medicine,* 59, 138-139.

WYNNE-JONES, G. & MAIN, C. (2010) The potential for prevention: occupation. IN CROFT, P., BLYTH, F. & VAN DER WINDT, D. (Eds.) *Chronic Pain Epidemiology: from aetiology to public health.* Oxford, Oxford University Press.