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Are The Treatment Expectations of ‘Significant Others’ Psychosocial Obstacles to Work Participation for Those with Persistent Low Back Pain?

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Abstract

Background

Treatment expectations form a fundamental component of the self-regulatory model of health behavior, which defines such cognitions as illness perceptions. Unrealistic and/or unhelpful treatment expectations have been linked to detrimental clinical and work outcomes in those with persistent low back pain. However, research of this nature has rarely focused on the influence of 'significant others' (spouse/partner/close family member).

Objective

To provide an in-depth examination of the treatment expectations of the 'significant others' of individuals who have become unable to work due to persistent low back pain, highlighting how significant others may influence recovery and work participation outcomes for such individuals.

Participants

A convenience sample (n=18) of work disability benefit claimants and their significant others were recruited from two settings in the North of England.

Method

A qualitative research design was employed, and semi-structured interviews based on the chronic pain version of the Illness Perceptions Questionnaire-Revised were conducted with claimants and their significant others. Interview data were analysed using template analysis.

Results

It was found that significant others expected a substantial reduction or complete removal of pain in order for treatment to be considered successful. The pursuit of diagnostic tests was important in validating such expectations, and there was continued scepticism of treatments already undertaken or offered as an alternative.

Like the individuals affected, significant others believed that a correct diagnosis had not yet been received, which led to a continued delay in return to work.

Conclusions

This study demonstrates that significant others have similar unrealistic and/or unhelpful treatment expectations to those widely reported by individuals with persistent low back pain, and could further reinforce such illness perceptions and serve as wider psychosocial obstacles to recovery and continued work participation.

Keywords: back pain; illness perceptions; significant others; work disability

Introduction

Musculoskeletal conditions in the workplace account for 9.5 million days of work absence in the United Kingdom (UK), and persistent low back pain accounts for around 20 per cent of claims for long-term state benefit (1, 2) . As part of the continued effort to prevent work disability due to low back pain, there is an emerging body of evidence indicating that illness perceptions are important influences on clinical and work outcomes for those with low back pain (3-10). Illness perceptions are derived from the self-regulatory model (SRM) of health behavior (11), which proposes that these are an individual's own implicit, common-sense beliefs about illness that are associated with behavioral responses to manage outcomes. Specifically, expectations about treatment efficacy are thought to be particularly important illness perceptions affecting recovery from disabling low back pain.

It has been demonstrated that many individuals with persistent low back pain expect treatment to result in a significant reduction or complete removal of pain in order for it to be considered successful and for them to be able to return to work (12). These expectations often result in a continued pursuit of diagnostic tests in an attempt to

validate the legitimacy of a condition that most often does not have a medical explanation (13-20), further delaying return to work and placing a significant economic burden on the healthcare system (21-25). Whilst this phenomenon is well documented in individuals with persistent low back pain, there has been little focus on the treatment expectations of the 'significant others' (spouse/partner/close family member) of such individuals. This is despite the fact that most theories of health behavior cite the role of significant others as a major influence on illness outcomes.

Significant others are reported to be salient sources of discriminative cues, punishment or reinforcement for pain behaviors (26, 27), and that spousal beliefs about pain, disability, treatment control, and medication have been significantly correlated with their partners' pain severity (28). More specifically, it has been documented that significant others shoulder the burden of care for individuals with persistent low back pain and are key to their recovery and return-to-work (29-32). By examining the treatment expectations of significant others, the aim of the present study was to add to the emerging body of evidence exploring the wider psychosocial obstacles involved in recovery and continued work participation for individuals with persistent low back pain.

Methodology

Qualitative research methods were used to explore the treatment expectations of the significant others of individuals with persistent back pain in relation to their work disability. A semi-structured interview schedule was derived from the chronic pain version of the revised Illness Perceptions Questionnaire (IPQ-R) (33). The IPQ-R provides a quantitative measure of illness perceptions for a number of conditions, but a qualitative methodology was chosen in an attempt to elucidate more in-depth data about the experience of persistent and work disabling low back pain; similar methods

were employed in another study of musculoskeletal pain (34), and other findings from our research in this area have been published elsewhere (35, 36).

Participants

A purposive convenience sample of disability benefit claimants, along with their significant others (n=18), were recruited from two clinical settings in the North of England – a Condition Management Program (CMP) (37) and a hospital-based Pain Management Clinic (PMC). To be eligible for inclusion in this study, all participants had to be at point of entry (i.e. attending their first appointment) in either setting; report persistent low back pain as their main work-disabling condition, and able to nominate a 'significant other'. Individuals were referred into these programmes by their General Practitioners (GPs), who are the gatekeepers to the sickness benefit system in the UK because they determine fitness for work (38). Individuals who are deemed unable to work due can stay off work for up to 13 weeks without losing income, and after which, if they are still unable to return to work, they will move on to claim state disability benefits and be classed as unfit for work.

Relevant ethical permissions for the research were obtained from the local National Health Service (NHS) Research Ethics Committee, and claimants were invited to participate in the studies either by their clinician. All participants were given full study information sheets and written informed consent was obtained. Interviews with claimants and their significant others were conducted separately in their own homes, and significant others were instructed to answer all questions with reference to the claimant's condition. Interviews were digitally audio-recorded and transcribed in full.

Data analysis

Interview transcripts were analysed using template analysis - a method which provides a systematic technique for categorizing qualitative data thematically, and which has been used previously in both healthcare (39) and occupational research (40). Template analysis was chosen because it allows a-priori themes (in this case, the subscales of the IPQ-R) to focus the development of an initial version of the coding template around specific topic areas of interest. Those a priori themes that do not prove useful in representing and capturing key messages are redefined or discarded as the template is modified in the process of data analysis. New themes, emerging through analytic engagement with the data, may be defined and added to the template structure. Through the process of analysis we were additionally able to identify and incorporate into our template structure additional themes representing some of the ways in which other factors and beliefs may impact on work outcomes for individuals with persistent low back pain.

The main procedural steps undertaken in our analysis were: (1) reading and re-reading of the interview transcripts in order to thoroughly familiarise ourselves with the data; (2) conducting a preliminary thematic coding of the data based on the themes of the IPQ-R; (3) recording any new themes which emerged from the data and organising them into meaningful clusters in order to define an initial coding template, incorporating the relationships between and within themes; (4) constructing an initial template and modifying it in an iterative process until all authors were satisfied that it provided a comprehensive representation of the interview data. We found that the template successfully mapped onto findings from our earlier work, although it required structural modification at lower thematic levels, with some themes being re-titled and amended to better represent the key messages derived from the current study. Data analysis was

initially undertaken by at least two of the authors who checked the coding and analysis, and the final template was agreed by all authors.

Findings relating to significant others' expectations of treatment efficacy for their relative's condition are presented here, and were represented by the 'personal control over illness' and 'treatment control over illness' subscales of the IPQ-R. Within these constructs, three overarching themes emerged from the data: (1) 'return-to-work is dependent on a cure,' (2) 'we have come to the end of the road,' and (3) 'waiting for the right diagnosis.' Verbatim extracts (using pseudonyms) have been selected from the significant other interview data in order to illustrate these themes further.

Results

Participants

Demographic data collected from participants showed that the mean age of claimant participants (n=9) was 48.1 years (ranging from 29 to 63 years), and the mean age of significant other participants (n=9) was 49.7 years (ranging from 21 to 68 years). Claimants had been unfit for work ranging from six months to 11 years. With one exception, all claimants had previously worked in unskilled/manual occupations, and none had continued their education past high school.

Seven of the significant other participants were also not working, with two claiming disability benefits themselves, two having given up work to care for the claimant, and three taking early retirement due to ill health. With one exception, all significant other participants had previously worked/were working in unskilled/manual occupations, and none had continued their education past high school.

The majority of patient participants were male (five out of nine), and the majority of significant other participants were female (six out of nine). Seven of the nine participant dyads were in spousal relationships, and two were parent/child relationships. All participants described themselves as belonging to the 'White British' ethnic group.

Data themes

1. Return-to-work is dependent on a cure

Significant others were largely pessimistic about their relative's condition, seemingly because a cure was not possible. As a result, significant others often portrayed themselves and healthcare providers ('they') as powerless in their relative's recovery and return-to-work:

"They say that if you don't accept your condition then you can't begin to live with it, which we don't think is true . . . there's nothing they can do, it's not curable." [Jill]

"There's nothing you can do when he's in a lot of pain other than, you know, just make sure he's comfortable and things like that." [Sally]

"I just pray that he is better in a year, that's all you can do but I don't think, you don't ever really get rid of a backache, you know, when you do hurt your back, that's it. From then it's gone for life isn't it . . . he's only young and he wants to work but who's going to hire you with a bad back?" [Paula]

“I hope that everything would return to normal and he continue with an active life and get back to work, 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.” [Lydia]

“All I know is she’d like a cure, she isn’t able to do what she’d like to do without having that constant pain . . . she’d like to be able to get that independence back and get out to work.”

[Terry]

2. ‘We have come to the end of the road’

Significant others all described a ‘journey’ claimants had taken through the healthcare system, commenting on the various treatment options they had been offered. This journey usually began with the prescription of pain medication, and all significant others reported that claimants were reliant on long-term, heavy pain medication. They appeared to describe this as testament to the severity of the claimant’s pain and how it contributed to their incapacity:

“It’s weeks of massive pain relief that she has to dose, then she can’t do anything but sleep.

Nothing has really given her any long-term relief” [Jill]

“They put him on all these tablets, and he couldn’t even manage to get out of bed if he didn’t have any tablets at all, let alone go to work.” [Nadia]

“He copes well when he’s taking his painkillers, but he’s drugged up....they keep putting him on pain relief and saying it’s just an age thing” [Lydia]

Significant others seemed to view medication as largely ineffective because it failed to ‘remove’ the claimant’s pain:

“They haven’t made any difference . . . there’s been no improvement whatsoever. She can take as many tablets as she wants and it’s still there is the pain. [sic]” [Colin]

“He got the morphine but it was still as bad . . . it didn’t work I mean he’s been given two lot of tablets, some painkillers and a night tablet and it’s not working.” [Harriet]

“The tablets aren’t going to take the pain away are they?” [Paula]

On the next step of this ‘journey’, all significant others reported that claimants had been referred to a physiotherapist, but again viewed this as an ineffective treatment. Some significant others perceived physiotherapy as ‘invalid’ because it did not involve medical examination or testing:

“He just has to keep trying . . . with the physio and see what happens. But I don’t think it’s gonna help him.” [Paula]

“He had a mild form of physiotherapy, that didn’t work either.” [Lydia]

“He did go last year for a few sessions but they just gave him a sheet of paper with some pictures on.” [Harriet]

“It wasn’t treatment . . . it was talking, showed you how to do an exercise, but no treatment, so you don’t get an ultra-sound or you don’t get heat, nothing like that. So it’s a bit wishy-washy.”

[Colin]

All claimants had also been offered surgery, with some having undergone a procedure to address the pain. Although significant others did not appear to fully understand the nature of the procedure, they perceived it to be risky, having potentially negative physiological outcomes, and were doubtful of its efficacy:

“An operation on your back’s risky she could end up worse you know....they did say you know the chances you know you could end up in a wheelchair for the rest of your life. So it’s a big risk to take. do you live with what you’ve got and keep mobile like she is now and in pain or do you take the risk and be a bit more mobile but probably still in pain you know and risk being stuck completely in a wheelchair.” [Terry]

“This operation, I think it’s a bit hit and miss...I can’t tell.... but I can only see if we go on it will just deteriorate a little bit, you know, it’s not going to get better.” [Colin]

"I don't like the thought of him going, you know, under the knife. Especially on your back."

[Paula]

"And she won't have the disc out because it's only a temporary answer . . . she doesn't want to take that risk." [Jill]

Significant others described the culmination of this 'journey' through the healthcare system as being at 'the end of the road,' having exhausted all treatment options and perceiving they had been 'abandoned' because none of the treatments had been effective in removing the claimant's pain, 'curing' them, or restoring their work function:

"We've seen lots of specialists, they always sign you off and nothing has really given her long term relief . . . she's kind of reached the end of her road for her back in the last year and they've said to her that there's nothing more that they can do...I've run out of ideas." [Jill]

"She went for various treatments and we're at a dead end really . . . we've tried various ways to ease things, but it just seems there's nothing, at the moment, we just don't know which road to go down now, you know." [Colin]

3. *Waiting for an answer*

Perhaps because of the long-term nature of their condition and their 'failed' journey through the healthcare system, most significant others appeared to believe that the reason for the claimants' non-recovery was because they had not been given a timely diagnosis, and that they were waiting for this in order to receive the most effective treatment which would then allow them to return to work:

"The doctors, they didn't diagnose it straight away; it took quite a while to find out what the problem was." [Lydia]

"I'm not happy that he's not been able to really get to see anybody and he's been waiting for so long and I don't think that's very good at all really." [Sally]

"We're still waiting but that was months ago and we're still waiting, and I can see that that's probably what's not helping him now." [Nadia]

"I didn't expect it to go on as long as it did . . . you have faith in hospitals and doctors to sort it out but it just hasn't happened I think a little bit more treatment straightaway and a bit more care and she wouldn't have ended up as bad as she was." [Terry]

Significant others described feelings of anger and disappointment, and some were suspicious of the overall motives of the healthcare profession:

“He was mortified, horrified. There weren’t words to describe it you know, it had gone on that long without anything being done about it, just putting him on pain relief and saying that it was an age thing and being fobbed off basically for quite a long time . . . what a letdown.”

[Lydia]

“If you’ve got another condition as well it’s a big no, no. You mix up their figures you see for the funding . . . it’s very much about their targets, their success rate, how it looks on paper as to whether or not they get funding.” [Jill]

“They’re experts and when you think looking back now, they probably didn’t do everything they could have done but we’re stuck . . . I think back pain seems to be bottom of their list.” [Terry]

“The doctor didn’t examine him or anything, she just asked him questions, give him these tablets and out you go, you know . . . sometimes its anger at the doctors more than anything else.” [Harriet]

At the crux of this theme it was revealed that significant others believed that claimants had not yet received a ‘correct’ diagnosis, and that the ‘real’ problem remained undiscovered and therefore untreated, and that this required further medical investigations:

“The scans he had didn’t come up with anything obvious in terms of giving him any answers.... he wanted some different ones and they said they wouldn’t pay for any...they wouldn’t send him for any more scans.” [Sally]

“So we asked the doctor for an MRI scan because we weren’t happy and wondered if there was anything else underlying . . . if there is something, you know, an MRI scan will pick up on it and hopefully they can, you know, prescribe some treatment but I think it’ll be too far, too late now.” [Colin]

“He needs further investigations to see the underlying problems and what’s going to happen in the future.” [Lydia]

Discussion

The results of this novel study demonstrate that the significant others hold similar treatment expectations to those reported by individuals with persistent low back pain, and it is conceivable that such beliefs could further reinforce existing negative beliefs and unrealistic expectations in such individuals, acting as wider psychosocial obstacles to recovery and work participation. Significant others are not formally acknowledged in the treatment for persistent and disabling low back pain, yet they appear to be important influences.

There is some supporting evidence for this. Previous research conducted with family and friends of pain sufferers suggested that greater involvement by significant others steadily reduces the credence of information provided by clinicians (30, 41), and it has

been proposed that operant conditioning contingencies pertaining to the behavior of significant others as they respond to pain behaviors and complaints may partially account for the development of persistent low back pain (42, 43). In the return-to-work process for claimants with musculoskeletal disorders, other research has indicated that important significant others are managers and co-workers (44, 45), and healthcare providers (46). However, the phenomenon of social interaction in persistent low back pain and its influence on outcomes remains complex and is not fully understood.

Unfortunately, it was outside the remit of this exploratory study to shed further light on such complex interactions and explore these factors in-depth. The relatively small sample size meant the proposed influence of significant others can only be inferred. The study design meant it was also not possible to establish whether the treatment expectations of significant others had a direct causal association with worker treatment expectations – a larger study employing quantitative methods is now required. Other possible influences on treatment expectations, such as socio-economic characteristics, perceived role expectations within relationships, significant other illness experience, and the role of health care providers in the return-to-work process could also not be further explored, but are likely to be important (35, 47).

Whilst such limitations are acknowledged, the sample size for this exploratory qualitative study was deemed sufficient (48), and many findings were supported by evidence documented in other studies of persistent low back pain (some including the influence of significant others), all with wider sample heterogeneity. Moreover, this research was conceived in part as a response to a call for more qualitative studies in this area in order to further understand the wider psychosocial obstacles to work participation, particularly illness perceptions (49), and is aligned with the suggestion

that more innovative approaches with a specific focus on maximising the positive impact of treatment expectations, beliefs and attitudes are needed (50-52).

Conclusions

It is now widely accepted that remaining in work, or returning to work as soon as possible is generally beneficial in order to avoid the adverse physical, mental and social effects associated with long-term worklessness (53). The findings from this study shed further light on the less-researched, wider influences on return to work outcomes for those with persistent and disabling low back pain. This research also builds on the existing evidence that suggests significant others may be usefully incorporated into treatment plans for persistent pain (54-56); - and importantly, suggests that rather than focusing solely on individual risk factors for work disability, it may also be important to understand how significant others and wider social circumstances might contribute.

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