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**Beliefs about illness amongst significant
others and their influence on work
participation outcomes for back pain
patients: a pilot study**

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Final Report

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Executive summary

Background

Although there is now a focus on the positive, health-enhancing aspects of work and activity (Waddell & Burton, 2006), it is also acknowledged that there are a wide range of psychosocial factors that act as obstacles to recovery and work participation which require a more in-depth understanding (Nicholas, 2010). People with persisting low back pain (and other illnesses) who are receiving benefits because they cannot work are now being encouraged and helped to return to employment, in line with the UK government's welfare reform agenda. Individual and social influences involved in the everyday life experiences of beneficiaries with persisting low back pain which may act as obstacles to recovery and work participation. However, there is little understanding of these influences. In this exploratory study, we used qualitative methods to facilitate an in-depth examination of the illness beliefs of those close to back pain patients (their 'significant others'), considering how these might influence both patients' own beliefs about their condition and work participation.

Methods

In-depth interviews were conducted with nine patients reporting non-specific low back pain of more than three months duration and their significant others (closest adult family member) (n = 18). The self-regulatory model (SRM) (Leventhal et al., 1984) was used as a guide to organise the interview schedule and interview transcripts were analysed using template analysis (e.g. King, 2004). Analysis focused on the significant other interview data and we sought to identify themes which demonstrated clear contrasts between dyads in which the patient had or had not remained in employment.

Findings

Three overarching themes are presented and discussed: (1) the extent of impact on patient activity (including employment); (2) treatment expectations; (3) patient identity. Overall, the significant others of patients who were out of work due to their back problem tended to emphasise the extreme consequences of the patient's back pain on every aspect of their lives. They described the back pain as preventing the patient from doing things, even though closer analysis of the detail suggested that in fact the patient was able to undertake everyday activities, albeit at a lower functioning level than prior to symptom onset. Significant others of patients who remained in employment focused instead on what the patient could still do. In terms of treatment expectations, significant others of out of work patients appeared to believe that their relatives needed to be pain-free in order to resume participation in normal life, and equated only complete removal of pain with treatment success. In contrast, significant others in the employed sample tended to talk in terms of 'management' rather than 'cure', and were more accepting of the possibility that options available to manage pain were unlikely to provide complete relief of the patient's pain symptoms. These attitudes were further reflected in participants' beliefs about patient identity: significant others of employed patients described their relative in heroic terms; significant others of out of work patients described the patient as disabled and a blameless victim.

Discussion

Previous 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 & Klaber Moffett, 2005). The present study also suggests that socio-economic status has an important role to play in work participation outcomes. In this study, those who had remained in employment had higher status jobs and were more able to negotiate necessary flexibility and role adaptations to enable them to continue in work despite their pain. The role of good existing relationships, particularly with line managers in this context, was apparent.

In terms of treatment expectations, significant others in the employed sample were more accepting when medical professionals were perceived as unable to provide answers in terms of a full explanation of the problem, or to provide a curative treatment. In contrast, significant others of those patients who were out of work were dissatisfied with treatment and sceptical of healthcare providers because patients were still experiencing pain, ultimately equating their relative's recovery with being 'cured'. Expectations about treatment have been proposed to be one of the major influences on outcome for patients with chronic low back pain, and the results from this study suggest that the treatment expectations held by significant others could further reinforce patient expectations, acting as wider psychosocial obstacles to recovery.

There was a notable difference in the way that the two samples described how the patient's back problem had impacted on both the patient's identity and on their activities. The significant others of working patients tended to emphasise what the patient could do despite their back pain and attributed this to the patient's admirable personal characteristics, describing them as heroic and stoical. In contrast, the significant others of non-working patients emphasised the extent to which the back pain prevented the patient doing things and descriptions of patient identity focused on them as a victim, anticipating and rebuffing potential accusations of personal responsibility and blame.

Undertaken as it was in the context of changes to the welfare system in the United Kingdom, this work has potential implications for understanding how patients and their families may respond to the changes, and how that may impact on work participation outcomes. Our findings suggest that, if left to their own devices, there may be a danger that patients who feel that there are insurmountable obstacles to a return to their previous employment and who believe themselves to face socio-cultural scepticism about their condition, along with widespread ill-feeling towards the unemployed, may become entrenched in a position whereby it becomes all the more important to be seen as completely disabled, thus limiting their activity and their chances of any return to work. We discuss current reports and policy initiatives which recommend a focus on what patients can do, rather than what they cannot and note that our results support these initiatives. In addition, our findings, although

preliminary and exploratory, emphasise the importance of taking social and environmental factors into account and we suggest that significant others may have an important role to play in this context.

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Introduction

Back pain is a leading cause of disability in the United Kingdom, especially in adults of working age (Palmer et al., 2000). The recovery rate after twelve weeks of low back pain is likely to be slow and uncertain – fewer than half those individuals disabled for longer than six months return to work, and after two years absence from work, the return-to-work rate is close to zero (Spitzer, 1987). The National Health Service spends more than £1 billion per year on back pain related costs (Maniadakis & Gray, 2000) but the indirect costs of reduced work capacity due to chronic back pain far outweigh direct medical costs (Phillips et al., 2008) and chronic back pain accounts for around 20 per cent of claims for long-term state benefit (Health and Safety Executive, 2007). Clinical guidelines for the management of back pain emphasise the importance of remaining active (Van Tulder, Becker et al., 2006) and vocational rehabilitation research suggests that remaining in work, or returning to work as soon as possible is better for patients and limits the potential negative social, psychological and physical effects of long-term sickness absence (Waddell & Burton, 2006; Waddell et al., 2008).

Although research has demonstrated the positive, health-enhancing aspects of work and activity (Kendall & Burton, 2009), it is also acknowledged that there are a wide range of psychosocial factors that act as obstacles to recovery and work participation (Nicholas, 2010). The list of psychosocial risk factors for long-term disability and incapacity for work as a result of back pain is extensive, and includes: psychological distress, fear-avoidance, catastrophising, 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 et al., 2009). It has been established that early intervention is a vital element in reducing long term incapacity in the context of back pain (Waddell & Burton, 2005) and psychological factors are thought to play an important role in the transition to chronicity in low back pain (Pincus et al., 2002). Biopsychosocial models of pain suggest that somatic, psychological and environmental/ social factors all play a significant role in the experience of chronic pain and its impact on individuals. However, although biopsychosocial models of pain are widely accepted by both researchers and clinicians working with back pain patients, much of the literature addressing psychosocial factors is 'fuzzy' (Blyth et al., 2010), and a comprehensive picture of the role of psychosocial factors in low back pain is presently lacking (Foster et al., 2010). Blyth et al. (2007) suggest that current models may be too broad and require better articulation and conceptual development

One model that has been established as a useful framework through which to explore beliefs about illness (e.g. Heijmans, 1998; Moss-Morris, 2005; Clements et al., 1997) is the self-regulatory model of health and illness (SRM) (Leventhal et al., 1980; Leventhal et al., 1984). The SRM conceptualises individuals as having internal common-sense models about illness and health threats incorporating five core dimensions: (i) illness identity (including symptoms and label); (ii) perceived cause; (iii) expectations about timeline; (iv) consequences of the illness; (v) beliefs about curability and control. There is an emerging body of research indicating that illness perceptions are important influences on

outcome in back pain (Foster et al., 2008; Foster et al., 2010; Nicholas, 2010). These studies have concentrated on the illness perceptions of individual patients, yet little research of this nature has been conducted with the 'significant others' (spouse/partner/close family member) of those with chronic low back pain. Consideration of significant others' may be particularly illuminating in helping to understand the wider psychosocial obstacles to recovery and illness outcomes (McCluskey et al., 2011a; 2011b).

The illness perceptions of significant others have been shown to have an impact on clinical management in a number of health conditions (e.g. Searle et al., 2007). The potential for a mediating influence of significant others in low back pain is supported by the biopsychosocial model, which suggests that pain behaviour demonstrated by an individual at any point in time is a product of their beliefs, and may in turn be influenced by the social environment in which it takes place (Main & Waddell, 1998). It has already been demonstrated that significant others are salient sources of discriminative cues, punishment or reinforcement for pain behaviours (Boothby et al., 2004; Leonard et al., 2006; Stroud et al., 2006), and that spousal pain beliefs about disability, treatment control and medication are significantly correlated with partners' pain severity and other indicators of pain adjustment (Cano et al., 2009). Several studies report the benefit of social support in chronic pain (Waxman et al., 2008). It has been documented that patients have expressed anxiety about how their pain affects other family members (De Souza & Frank, 2011), and that the inclusion of the family in pain treatment may be beneficial to the patient (Keefe et al, 2004; Cano & Leonard, 2006). It has also been reported that significant others shoulder the burden of care for individuals with chronic low back pain and are key to their recovery (Miller & Timson, 2004). Thus, the lived experience of persisting low back pain has ramifications that appear to reach into work and social relationships, and it seems likely that the illness perceptions of significant others may impact on and influence individual pain outcomes, but this remains largely unexplored.

There has recently been a call in the literature for more qualitative research to provide further insight into the belief systems of individuals who experience low back pain in order to better understand psychosocial obstacles to recovery and work participation (Wynn & Money, 2009). Although it is now widely accepted that psychosocial factors are important contributors both to the propensity of, and to the consequences of back pain (e.g. sickness absence and incapacity for work (Waddell & Aylward, 2010; Wynne-Jones & Main, 2010)), to date, research aimed at exploring the influence of these issues has been largely quantitative and lacking an individual view-point. This imbalance has implications for the management of back pain and prevention of disability, as there is evidence to suggest that standardised 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 (e.g. Ong et al., 2006). Discrepancies have also been reported between narrative accounts of patients' pain experiences and scores on standardised pain and disability measures (DeSouza et al., 2007). Qualitative research may offer an especially useful insight into these issues as it 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. The inclusion of a qualitative element to back pain research aimed at extracting hypotheses direct from patients themselves may help to establish where further support and help may be given, under what circumstances and for whom (Carr & Klaber Moffett, 2005).

Identifying the influences on recovery and work participation from significant others along the temporal spectrum of low back pain is a unique and promising area of research. Whilst there is good evidence that active self-management of persisting health conditions can improve clinical outcomes, it is established that self-management requires a whole system approach to be effective (The Health Foundation, 2008). It is also known from other conditions that when patients and their doctors share an explanatory model, patients are more likely to engage with treatment recommendations and to be more satisfied with their treatment (e.g. Chew-Graham et al., 2011). A more in-depth understanding of the social and contextual influences involved in low back pain is clearly important in designing appropriate and acceptable treatment interventions but, as yet, our knowledge of these factors is incomplete. 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 other studies have investigated the link between others' responses and outcomes in chronic pain populations, few studies of this nature tend to focus on return to work specifically.

In 2010, this research team undertook a pilot study exploring the illness perceptions of incapacity benefit/employment support allowance claimants and those of their significant others (McCluskey et al., 2011a; 2011b). The results revealed how others and wider social circumstances might be contributing both to the propensity of persistent back pain and to its consequences. However, this previous study comprised only of those individuals who had become incapacitated for work. In the present study, we collected data from both those who had remained at work *and* those who had become incapacitated due to their back pain to allow for a preliminary comparison between these two groups in order that potentially important variables differentiating them might be identified.

Methods

Sampling

Research ethical approval for the study was sought and obtained from the relevant Health Authority and University Ethics Committees. Participants were a convenience sample (n=9) of patients with persisting low back pain (and their significant others) attending a pain management programme at Huddersfield Royal Infirmary, West Yorkshire. The total participant sample size was thus eighteen.

Patients attending the pain management programme and reporting non-specific low back pain of at least twelve weeks duration were eligible for inclusion. Five patients were still in employment despite their back pain; four were not working and attributed this to their back pain. Recruitment of participants was facilitated by the hospital consultant running the clinic. Patients attending programme were given an information sheet by the consultant informing them that the purpose of the study was to look at how living with a patient with back pain might impact on families and to see in turn what impact the family might have on the patient. If patients were interested in participating and were prepared to nominate their closest adult family member (their 'significant other') to participate with them in the study, they were asked if they were willing to be contacted without any obligation on their part, by the first author. Contact details were passed to the first author, who spoke to both patients and significant others by telephone to ascertain their willingness to be interviewed. All participants gave written informed consent prior to participation. All names have been changed and any identifying information removed from quotes to protect participants' anonymity.

Procedure and interview

The first and second authors (JB and SM) interviewed most participants separately in their own homes. One significant other was interviewed in a private room at the University of Huddersfield as this was more convenient for him and one participant was interviewed by the third author (NK). No information obtained in the interviews was shared with the other party in the dyad. Leventhal's self-regulatory model (SRM) (Leventhal et al., 1980; Leventhal et al., 1984) was used as a guide to construct semi-structured interview schedules. The following areas were covered in each interview: (1) history of the illness ('perceived causality' dimension of the SRM); (2) perceptions of identity of the illness and current status of the illness, including symptoms ('illness identity' dimension); (3) illness management ('beliefs about curability and control' dimension); (4) timeline of the illness ('expectations about timeline' dimension); (5) impact of the illness on the lives of both patient and spouse ('consequences of the illness' dimension). The interview schedule was flexible and allowed participants to raise topics as they wished, assisting in the establishment and maintenance of rapport. Questions were open-ended and non-directive, and were modified to be posed to the patient or their spouse as appropriate. Interviews lasted for between forty-five and eighty minutes. They were taped with the permission of participants and transcribed verbatim.

Analysis

All interviews were analysed using the template analysis style of thematic analysis (King, 2004, 2012). In this, themes are organised in hierarchical clusters, with the broader in scope encompassing the more specific. An advantage of template analysis as compared to many other methods of qualitative data analysis in applied research settings is that template analysis allows themes (known as 'a priori themes') to be provisionally identified from the onset of coding, usually because the research project has started with the assumption that certain aspects of the phenomena under investigation should be focused on. In this project, given our focus from the outset on the SRM to conceptualise beliefs about the back pain condition under investigation, we used dimensions from the SRM to organise our template in the first instance. In addition to these themes, two additional main themes emerged through analysis of the data as important: 'patient identity' and 'impact on and of significant others'. The final template is presented in Appendix A.

Findings

Given the focus of our research, we will concentrate on those areas in which there are clear differences between those dyads in which patients have remain employed, and those dyads in which the patient is no longer in work due to their back pain. Additionally, we will focus in this report on the interviews from the significant others rather than using data from the patient interviews. The volume and richness of the data we collected mean that the findings presented must of necessity be selective. Our analysis of the patient interview data suggested that the narratives provided by patient and significant other were similar across the dyads and there is existing work which focuses on the beliefs of patients in this respect. The focus on significant others provides a novel angle and it is therefore this which is reported on more fully here. In the various outputs planned from this work, we will use data from across the full sample set to demonstrate how dyads construct a joint narrative around chronic illness. However, for the purposes of this report, we wish to specifically consider the beliefs and potential impact of significant others in this context.

Details of our participant sample, including the present employment status and past employment details of both patients and significant others, are presented in table 1. We recruited eight participants in the non-working sample: four patients and four significant others. Three of the significant others were male, one was female and all were married to the patient. The mean age of the patients in this sample was 57 years; the mean age of the significant others was 61.5 years.

We recruited ten participants in our working sample: five patients and five significant others. Two of the significant others were female and three were male. Three of the patients were female and two were male. Three of the significant others were married to the patient and two were the patient's adult child. The mean age of the patients in this sample was 49.2 years; the mean age of the significant others was 36.6 years. All participants and their significant others were of White British ethnic origin.

Three overarching themes are presented and discussed, two of which stem from original SRM dimensions and two of which emerged through the process of data analysis:

1. From 'Consequences' dimension: Extent of impact on patient activity [including employment]
2. From 'Cure/ Control' and 'Illness Coherence': Treatment expectations
3. Patient identity

Table 1: Participant Details

Name of significant other (Pseudonym)	Relationship to patient	Patient employment status	Years in education (patient)	Years in education (significant other)	Significant other occupation	Duration of patient back pain
Harry	Spouse	Out of work (previously supermarket checkout assistant)	Left at 16	Left at 16	Engineer	11 years
Belinda	Spouse	Out of work (previously bus driver)	Left at 16	Left at 16	Unemployed (stopped work to care for patient)	18 months
Frank	Spouse	Out of work (previously school cleaner)	Left at 16	Left at 16	Retired	3 years
Gary	Spouse	Out of work (previously clerical worker)	Left at 16	Left at 16	Council worker (manual)	5 years
Tess	Spouse	Employed (Manager)	Degree	Doctoral	Doctor	11 years
Vikki	Spouse	Employed (Manager)	Degree	Professional qualification	Management consultant	10 years
Will	Son	Employed (volunteer service)	Left at 16	Left at 16	Property developer	26 years
David	Spouse	Employed (Training consultant)	Degree	Degree and professional qualification	Teacher	3 years
Brian	Son	Employed (Social worker)	Professional qualification	NVQ	Plumber	3 years

1. Extent of impact on patient activity

The two samples differed significantly in the extent to which they reported the back pain had impacted on the patient's everyday life and activities. For dyads in which the patient was out of work due to their back problem, participants reported that the back pain had impacted on the minutiae of everyday life. Work was not necessarily a priority concern for participants in this group any longer. Participants had seemingly resigned themselves to the fact that the patient would not be able to take up employment again and seemed more concerned to emphasise the current impact of the back pain on domestic and family activities. Examples of such activities included shopping, bathing and household chores such as cleaning.

Harry: *Going to supermarket, we've got to go together now. Before she'd go on her own, but now we've to go together. Because she's got trolley to hold onto she's alright, but a loaf of bread and one or two other bits in t'bag and that's it. But four pints of milk, you know, she can't pick more than one up, so we've to go together.*

Belinda: *There were one day he did, excuse me for saying, but he smelt a bit, were warm, and I'm thinking 'Well, why aint he had a shower?' This went on for like two week, and he did turn round to me eventually and say 'I'm frightened of having a shower' cos we've got a glass shower screen and sometimes he can't stand up cos of the pain in his leg and he says 'I'm frightened of having a shower' and I says 'Well, why didn't you tell me before?' If you need a shower then tell me, if you're frightened of having a shower while I'm not here, just tell me and I'll stay here with you'*

Gary: *She'll do the garden, you know, when she can, but she pays for it afterwards and you know, she does normal household chores so long as there's no lifting, you know, but then if she's on her feet for any length of time, you know, she pays for that as well.*

However, there were no participants who reported that the patient was actually physically unable to undertake these type of activities due to their back pain. A thorough reading of the data suggests that the few examples where significant others reported that the patient was completely unable to do something did not constitute activities that could be defined as 'essential':

Harry: *Going to the funfair, before she'd go on the rides with them, she can't now*

Frank: *She has to sit out once or twice at line dances*

Analysis of the data suggests rather that the two participant groups (out of work and employed) thought rather differently about the consequences of their back pain on their activities. The out of work sample tended to 'catastrophise' regarding the consequences of the condition. It seemed that for this sample, if pain was experienced when undertaking activities, this was not acceptable and the back pain was therefore deemed to have had a significant impact on this activity. In contrast, for the working sample dyads, there was far more focus on what the patient could do despite the impact of the back pain experienced.

Will: *She just walks with a bit of a dicky limb sort of thing*

Vikki: *He used to go the gym, but he struggles now to go on a treadmill because of his feet, it's constant impact on his feet all the time, so he doesn't go to the gym anymore, but he does cycling instead [...] If he's walking round and he's struggling, he'll just go and sit down somewhere for a bit. He doesn't make a big fuss about it.*

Tess: *In terms of what does it impact on, well it doesn't impact on anything, 'cos he doesn't not do anything because he's got pain. He's definitely not sitting around not doing anything going 'I've got a back problem'. He gets fed up with it, but it's not really stopped him. He thinks it's stopped him doing things 'cos he would probably do much more manual things, but overall I think he's just kind of gone 'Well this is it, just get on with it'*

David: *Like, friends who go out walking, that would certainly be affected, but you find other things to do to be honest, so it's not that much of an issue*

There is a strong evidence base suggesting that work is generally good for physical and mental health and well-being (Waddell & Burton, 2006). Participants described how the patient's employment was therapeutic in a number of ways. There was only one participant in this group who described the patient's continued employment as resulting solely from economic necessity (**Brian:** *She's got no choice*). For the remaining significant others in the employed sample, the patient's work was rather described in terms of its beneficial consequences for their self-identity and as a welcome distraction from their back pain.

Vikki: *He tries to keep himself occupied. He goes to work because he just won't give in to it and because he wants to keep him himself occupied. He says "I'm not an invalid and I'm not going to be, you know, I'm not going to give in to it". He pushes himself all the time, and I think his mental attitude is probably the reason he does everything that he does and he works full time.*

Will: *I think she's been alright at work. I think it's been good 'cos she's been getting out and about.*

All participants from the working sample dyads referred specifically to the ways in which patients had managed to continue in employment despite their back pain. For all, it was not the case that patients had carried on in employment entirely unaffected by their back problem. Their success in maintaining employment was attributed to two factors: the patient's personal determination to continue in employment, and flexibility from employers in allowing the patient to manage their condition. The former was often associated with personal heroic stoicism on the part of the patient (e.g. **Vikki:** *'I've seen him go to work when he's been in real agony... he goes to work because he just won't give into it')* and is described more fully in the theme 'patient identity' (below). Flexibility from employers, primarily in terms of allowing time off to attend medical appointments but also allowing for reduced or flexible working hours in some instances, was vital in facilitating continued employment. Regrettably, this was not always described as being easily forthcoming. Participants reported that the patient had needed to use their own initiative to obtain and maintain any concessions and that, often, it was personal relationships with managers/ colleagues that facilitated these arrangements.

Vikki: *I think there has been a fear for him in that it would cause problems for him at work. Earlier this year actually the HR department, because of all the cuts in the Public Sector, were starting to ask questions around his back injections and said that because he gets sick notes for it to cover himself, they were saying that it was not something covered under the disability at work, well it's the equality act now. I do cover HR as part of what I do, and I basically said 'Get back to work and tell them to get lost and we'll take a claim against them if they try this one because the only reason you can go to work is because you're pain is managed for you and you've worked for them for bloody donkey's years'. They knew he's been having back injections for years so they can't be playing that one. So anyway, touch wood it hasn't been mentioned for a while but they were and obviously that's worrying for him. The trouble is it's not necessarily the people you're working with, it's someone over there who doesn't know you from Adam, who's making decisions about you who doesn't know the full picture. I think he was just very disappointed and quite upset about it coz like you know 'I do my utmost to come into work every day when I'm like this' and then they do bring something like that up and it's like there's people there that are not going to work when they should be going to work and it just makes a farce of the whole thing. Excuse my French, I think he was really pissed off to be honest with you, but he wasn't alone, so was I but I think, unfortunately, it's a sign of the times. I don't think it would even have reared its head if it hadn't have been that all the Public Sector organisations are looking at the purse strings at the moment. I don't think it would even have come into it to be honest.*

David: Her work have been generally supportive of the time that she's taken for going for treatments and going in and out of hospital for appointments... (but) it can be the little things that can seem trivial, like work if they have her out on the train at rush hour and you're standing up for the whole journey, it's not good for her. They don't seem to get that.

Tess: At that time he had a line manager who's not his current line manager who was very sympathetic. I don't think anybody's been allowed to do it since or before then. But I wrote his application form, maybe that helped (laughs). Work are just a bit 'Oh well, you've got a bad back' but because he doesn't whitter about it and because he never seems to have a problem, I'm not sure how much they believe it.

Interviewer: Are her employers aware, do they know she's got a back problem?

Brian: Oh yeah, me mum will have made them know, yeah. I know she got a special chair, like chair for her in the office, a high back one, I know she got like a special chair. Oh yeah, me mum's definitely someone that'll point it out. She's with Unison and all that, so she's one of them. It's like, if there's a wire on the floor and its not taped down then 'Right, health and safety', you know what I mean. She's one of them, me mum, and if she isn't happy about it, she'll say. Oh, she'll definitely say.

Interviewer: Right, ok, so she's well able to sort of defend her corner around her rights at work with her back.

Brian: Oh yeah, you're telling me.

Flexibility from employers could not always guarantee that patients were able to remain in employment however if the nature of their work meant it was impossible to find tasks which they could undertake without exacerbating their symptoms.

Harry: She can't sit for too long before she's to get up to move around and she can't stand for long before she needs to sit down. What job is there in a supermarket? You know, she can't sit at check out with twisting and one thing or another, at the cigarette kiosk you're stood up and moving around and that, so there weren't really a lot I suppose. They said 'If you can find something what you think you can do and we can accommodate you we will do' so yeah, they were great with her

Interviewer: *So you've said already that you think that the kind of work that she was doing had some role in...*

Frank: *Oh I know for a fact, I know for a fact, cos she complained doing it. We've never claimed for the incapacity and we've never claimed any injury, which ninety percent of people would, you know... they just give her, it's a fob off isn't it, she'd go to the caretaker in charge and say "I'll come in, but my back's bad, I can't do bending today" and they'd say, "Well, fair enough" and put her on some windows and you're stretching that way.*

The above quote also demonstrates how participants from the non-working sample were keen to distinguish the patient from potentially censorious attributions associated with being out of work. These issues are covered more fully in a later theme ('Patient Identity') but this research team have noted in previous work with a sample of long-term benefit claimants, that participants were eager to remove any attributions of self-blame for fear of appearing 'fraudulent' (McCluskey et al., 2011a; 2011b). The significant others from the working sample all (without interviewer prompting) made direct comparisons between patients with back pain who maintained employment and people with back pain who gave up work. Participants making this social comparison were rather disparaging about those who were out of work and presumably claiming social security benefits.

Vikki: *He pushes himself to get to work every single day. He's not collecting benefits, he's not sat at home doing nothing, you know, he's trying to do something to help himself*

Interviewer: *How did he find the pain management course?*

Tess: *I think he found it really frustrating, he said there were just loads of people that were just "yes, but", they were all going "I can't do that", "I haven't tried that", "I'm not doing that" and he said that was really frustrating because there was people as well, people who seemed to have a really chronic difficult illness seemed to be trying hard and people who didn't appear to be that incapacitated were just going "I can't possibly do this". I think he used to come back really frustrated.*

Overall, the significant others of patients who were out of work due to their back problem tended to emphasise the extreme consequences of the patient's back pain on every aspect of their lives and described pain experienced as preventing the patient from doing things, even though closer analysis of the detail suggested that in fact the patient was able to undertake everyday activities, albeit at a lower functioning level than prior to symptom onset. We suggest that the need to justify the patient's incapacity and employment status may require that they emphasise the serious consequences of the

patient's back problem on their activities. The significant others of patients who remained in employment were rather keener to emphasise activities that the patient could undertake, even whilst experiencing pain symptoms and attributed this to some extent to personal characteristics of the patient. We suggest that emphasising what patients can do rather than what they cannot do may be beneficial for patients, but also note the potential importance of other factors including employer flexibility and type of work in this context.

2. Treatment expectations

Significant others from the two samples (working/ not working) had rather different expectations in terms of treatment. As noted in the previous theme, significant others of out of work patients appeared to believe that their relatives needed to be pain-free in order to resume participation in normal life, and equated only complete removal of pain with treatment success.

Harry: *I know the back's one of the worst things to try and get repaired and cured so I don't think it will get any better*

Frank: *We want things to improve and this problem to go*

Significant others of the non-working patients seemed to view medication as an ineffective treatment because it failed to 'remove' their relative's pain:

Gary: *They haven't made any difference, the injections, there's been no improvement whatsoever. And she can take as many tablets as she wants and it's still there is the pain*

Belinda: *He got the morphine but it was still as bad.....it didn't work. I mean, he's been given two lots of tablets, some painkillers and a night tablet and it's not working ... The tablets don't work so nothing works.*

In an extreme example of the extent to which this sample reported the patient experiencing pain as intolerable, Belinda commented that she would prefer her spouse to be wheelchair bound and unable to walk rather than be in pain (*'It really doesn't bother me as long as he's not in pain'*).

In contrast, significant others in the employed sample tended to talk in terms of 'management' rather than 'cure', and were more accepting of the possibility that options available to manage pain were unlikely to provide complete relief of the patient's pain symptoms.

Vikki: *He sees the consultant quite regularly to have his pain injection and it's sort of managed now, accepting that they can't actually do anything more*

Tess: *Periodically he'll take codeine but he won't use it unless he has to because of course that has other side effects that can make you feel not very well. But he takes the tablets when he needs to take the tablets, because there's no point being in agony, it can ease it a bit when he needs it.*

David: *She can have spinal surgery, but the alternative to that is having the pain managed, pain management, which according to the doctor and Debbie (patient) agrees is the preferred option given the risk of spinal surgery and what it could entail*

Will: *The injections are like a battery, they slowly wears down. So with them if she's just sensible, you know, doesn't overdo it, does what she can do, she's fine.*

Brian: *The epidurals, they're every six months, and with them she'll be able to manage it*

A further distinction was noted in the attitudes of the two samples towards healthcare professionals. These seemed to centre on the extent to which participants believed that medical staff understood the condition. Significant others in the employed sample were more accepting when medical professionals were perceived as unable to provide answers in terms of a full explanation of the condition or curative treatment. Their attitude towards medics seemed sometimes sympathetic to the perceived quandary faced by professionals when unable to provide an 'answer'.

Brian: *I don't think the doctor will understand it fully. You never know do you, especially with muscles and bones, you're never too sure.*

David: *You always think you can go to a doctor and it can be cured, but with a condition like this, no-one can know what the end result is going to be.*

Tess: *You go and see consultants and you're pretty clear they've no idea either ... I think all health people are a bit as bad aren't they, they don't like not being able to make things better.*

Significant others from the non-working sample perceived the patient as having been 'abandoned' by the healthcare system because none of the treatments had been effective in removing their relative's pain or 'curing' them. They described feelings of anger and disappointment, which were often related to the chronicity of the condition and the time taken to receive treatment.

Belinda: *The doctor didn't examine him or anything, she just asked him questions, give him these tablets and out you go, you know....sometimes it's anger at the doctors more than anything else*

Harry: *I think a little bit more treatment straightaway and a bit more care and that, she wouldn't have ended up as bad as she was ... 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 and stuff like that seems to be bottom of their list*

Amongst significant others of this group, there seemed to be a general belief that their relatives had not yet received a 'correct' diagnosis, that the 'real' problem remained undiscovered and therefore untreated, and that their relatives needed further medical investigations:

Gary: *So she asked the consultant if she could have an MRI scan because she wasn't happy with, you know, she wondered if there's something else underlying that you know, we should be aware of, so that's the next step*

Harry: *She's only been referred to pain management clinic because she pushed her GP again saying, 'You know, I haven't heard anything from them and haven't had any more treatment from them'. Then she got an appointment to the pain clinic and she's seen the consultant who looked at her notes and basically said 'We'll have an MRI scan' which she hasn't had before, it's the first time that she's been offered one. Basically, I thought she should have had one years ago so we'll take it from there.*

3. Patient Identity

Across the two sample types, significant others reported that their closeness to their relative afforded them the opportunity to witness the true impact of the back pain in a way that outsiders could not. Through this, and in their sympathetic descriptions of the patient, significant others took on a role as acting as a 'true witness' to the patient, as being in a position to verify the reality of the condition and its impact.

Frank: *It's usually, she won't tell me, she sits down and watches television all night, she won't say anything, now she might get up and cringe and you know and go back and not tell me. But if we're walking, we'll walk and I'll see her, I'll see her go like that with her hands behind her back and I'll say let's have a sit down and we'll sit down. So yeah, I mean I can't tell how bad the pain is, but I know when it's bad, you know, cos I know. She doesn't cry, she doesn't let on but I know.*

Belinda: *I know what he's going, well I can see what he's going through and I try to help him through it*

Will: *She covers it up so you can't, you know, she does well sort of thing, but it's like, I've told her to do opposite thing instead of putting on a brave face coz everyone thinks you're alright, and then they don't see her when she's knackered*

David: *I see how much it affects you know what she can do and her moods as well*

Vikki: *I think he plays everything down. I think I'm more aware of listening to him and identifying where I see changes in his symptoms or in him mentioning symptoms.*

Tess: *You can judge because he never says when it's bad, but all of us will come and go "His backs bad" because he looks really fed up*

This legitimisation of the patient's illness condition seemed especially important because all participants reported that outsiders were unlikely to comprehend its true nature. Again, there was a clear distinction between the two samples in how they accounted for this lack of outsider understanding. Significant others of patients in employment tended to attribute this to the patient's own reluctance to discuss their condition with outsiders.

Brian: *She always puts a brave face on it ,you know like a brave front on, and until she lets people in she don't like letting them know but she gets to the stage where she puts a front on and then you have to explain why she can't come out and then you have to explain*

Vikki: *He doesn't make a big fuss about it, I think he just won't want to be seen to give in to it*

Tess: *It is a bit invisible. It's not something that comes up in conversation unless somebody happens to know*

This 'invisibility' referred to by Tess took on a far greater importance for the significant others of patients who were not in employment. For these participants, this invisibility could be responsible for the disbelief and scepticism faced by patients about their back pain from some outsiders.

Belinda: *His workmates thought 'Well there's nowt wrong with you, you're sat down, you're walking around', but once he's sat down, he's got pain in the left leg but they can't see that. With him driving, it was taking his mind off the pain, every now and again he would get pain but they didn't see that.*

Later in the interview, Belinda described how in fact she has now provided her husband with some visual evidence of his back pain. However, this has had an impact on his own self-identity.

Belinda: *I thought 'Right, that's it, I'm going to get him a stick'. He said 'I feel like an old man now'. I said 'I don't care'.*

Along with the lack of objective evidence of ill health, the chronicity of the condition was also described as impacting on outsider understanding:

Gary: *Most of her friends are sympathetic but she has lost one of her best friends, I think it's probably down to the problem. She went out for a birthday meal together as they always had done and I don't know whether she had been complaining about, you know, her ailments and her friend just blew up and said, 'You know, I'm sick of hearing about your problems, I think we should call it a day' and they'd been friends for thirty or forty year and they haven't spoken since. That could be down to if she'd been telling her about her problems constantly and she's had zero tolerance. But that were one of her best friends. But all her other friends, they're sympathetic, they'll always ask how she is and that.*

There is a clear difference in how the two samples view the back pain as having impacted on the patient's self-identity. The last quote demonstrates how, for the out of work sample, the back pain could become an important part of the patient's identity. This comes back to our first theme, in which significant others in this sample described the wide-ranging consequences of the condition for patients. For significant others of working patients, not only did both patients and significant others

reject any notion of the patient being disabled by their condition, significant others also described the patient in heroic terms for their management of their back pain. Rather than seeing the patient as a victim or as disabled, participants in this group used the back pain as evidence of the patient's strength of character.

David: *I think she herself manages remarkably. I think she does what she can and I think she's managed it really well.*

Vikki: *He has an amazing pain threshold. I know I couldn't cope with the pain as well as he does, if I was in that much pain coz my pain threshold is rubbish. He can push that pain threshold up to another level and he must do that psychologically because why is he different to anybody else? It can only be a mind over matter thing can't it and how he has this determination where he won't let it, he won't give in to it and he won't let it beat him and he doesn't want to give in. What's the difference between someone who has exactly the same symptoms as him, the same level of pain and one person who's at home and they can't go to work and he's going to work every single day? Well that's got to be something up here that is the difference and I don't see how what else it can be if you've got exactly the same condition and pain level*

Discussion

This pilot study set out to examine the illness beliefs of the significant others of patients with persistent low back pain. There is robust evidence that psychosocial factors play an important role in the management and outcome of back pain but little work has thus far examined the beliefs of those close to the patient in this context and 'psychosocial factors' are known to be a rather heterogeneous group of variables. We sought to explore potential distinctions between the beliefs of significant others whose relative had managed to stay in employment despite their back pain problem, and the beliefs of those whose relative was no longer in employment. We identified three themes where there seemed to be clear differences in the ways in which significant others thought about their relative's condition: beliefs about the consequences of the back pain condition, beliefs with regard to cure and control and beliefs about the patient's self-identity.

While work can be good for health and wellbeing, there is a social gradient in health partly dependent on the nature of work and it has been shown that moving or regaining work can reverse the adverse health effects of being out of work (Waddell & Burton 2006). Previous work from this research team has revealed how those close to patients, as well as the wider social circumstances, may contribute both to the propensity of persistent back pain and to its consequences (McCluskey et al., 2011b). The present work further suggests that socio-economic status has an important role to play in work participation outcomes. In effect, our findings suggest that if you have a higher status job, you are more likely to keep it, or keep working, if you have persistent back pain. This is in part due to the nature of the work (whether or not adaptations can be made to enable employees to continue in post despite their symptoms) and in part due to patients' confidence and ability to negotiate adaptations with their employers (significant others often described themselves as being an important source of support for the patient in this context). These findings highlight the difficulties 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 various social factors (Barnes et al., 2008). 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 & Klaber Moffett, 2005). Whilst the patients in our 'out of work' sample had not necessarily worked in low status or manual jobs, the nature of their previous roles could be perceived as having limited scope for adaptations to accommodate their back problem (e.g. bus driver, school cleaner, supermarket checkout assistant, clerical work). In our 'working' sample, our participants had higher status roles in which the work involved was described as more easily allowing for some balance between sedentary positions and physical movement. These participants had been able to negotiate flexible working hours and adaptations to their role where they felt this necessary. However, even amongst this sample, it did not appear that employers had always been supportive by facilitating accommodation. Often, it was felt to be a personal relationship with line management that had made these concessions possible,

with Human Resource departments often described as less helpful and impersonal. These findings further support the notion that line managers have the key role in this context, which warrants further exploration to ensure that those undertaking this role have the necessary knowledge and support (Black, 2008; Kendall et al., 2009).

Expectations about treatment have been proposed to be one of the major influences on outcome for patients with chronic low back pain (Pransky et al., 2010). In this project, the significant others of those patients who were not employed expected treatment to result in a significant reduction or complete removal of pain in order to consider it successful. Patients are more likely to pursue a diagnostic test if their expectations are not being met - if they feel dissatisfied with treatment or if they perceive they are not believed (Campbell & Guy, 2007; Teh et al., 2009; Vroman et al., 2009; Walker et al., 2006; Walker et al., 1999; Werner & Malterud, 2003). In this way, treatment expectations can act as psychosocial obstacles to recovery, and it is conceivable that treatment expectations held by significant others could also act as obstacles by further reinforcing patient negative beliefs and unrealistic expectations. Significant others are not formally acknowledged in the healthcare process, yet they are frequently peripheral to clinical consultations. Thus, it may be important for treatment providers to engage with their patient's wider experience of chronic low back pain. There is some supportive evidence. Previous research conducted with family and friends of pain patients has suggested that involvement of significant others steadily reduces the weight placed on information provided by clinicians (Kappesser & Williams, 2008; Miller & Timson, 2004) and it has been proposed that operant conditioning contingencies pertaining to the behavioural responses of significant others to pain behaviours and complaints may partially account for the development of chronic low back pain (Turk & Okifuji, 2002; Gatchel & Maddrey, 2004). However, those significant other behaviours which are associated with higher levels of disability in pain patients (such as responsiveness and empathy) have also been shown to predict intimacy and relationship satisfaction in pain couples (Cano & Williams, 2010). It has been suggested that more innovative approaches with a specific focus on maximising the positive impact of patient treatment expectations, beliefs and attitudes may provide the best opportunities for improving outcomes for chronic low back pain and enable healthcare providers to provide more patient-centred care (George & Robinson, 2010; Myers et al., 2008; NICE, 2009; Pransky et al., 2010; Wand & O'Connell, 2008). The findings from this exploratory study shed further light on the less researched, wider influences on outcome and build on the existing evidence which suggests that significant others may be usefully incorporated into the treatment process (Kerns & Otis, 2003; Keefe et al., 2003; Martire et al., 2008) as a novel approach towards tackling psychosocial obstacles to recovery from chronic low back pain.

There was a notable difference in the way that the two samples described how the patient's back condition had impacted on both the patient's identity and on their activities. Briefly summarised, the significant others of working patients tended to emphasise what the patient could do despite their condition and attributed this to the patient's admirable personal characteristics, describing them as heroic and stoical. In contrast, the significant others of non-working patients emphasised the extent to

which the condition prevented the patient doing things and descriptions of patient identity focused on them as a victim, anticipating and rebuffing potential accusations of personal responsibility and blame. The sample as a whole felt the patient's predicament was poorly understood by outsiders due to the invisibility and chronicity of the condition. Outsiders' lack of knowledge about and understanding of the illness was a source of concern for all participants, with the lack of objective evidence a particularly striking theme. Significant others perceived outsiders as lacking in understanding and potentially sceptical about the severity and impact of the condition. For significant others of those patients who are out of work due to their condition, it may be that to justify the patient's inability to continue in employment, it is necessary that the patient be defined in terms of their incapacity and in terms of their being 'disabled'. This means emphasising what patients cannot do rather than what they can do, with potentially detrimental effects on their activity and identity. In the face of stigmatising socio-cultural beliefs about 'benefit cheats' and 'malingering', significant others may feel they cannot allow room for scepticism to develop and it is therefore important that they support patients by emphasising their inactivity and/or disability due to their back condition. There is good reason to believe that this may have negative consequences in terms of participation outcomes because activity avoidance is in direct opposition to the clinical guidelines for best practice management of persisting low back pain, which suggest rather that patients should stay physically active as much as possible (NICE, 2009).

In the United Kingdom, there are a number of important potential implications from this exploratory work. In 2010 the UK Government announced several changes to the British welfare system to make welfare spending more affordable, leading to the Welfare Reform Act which passed into law on 8th March 2012. The government's stated intention behind this legislation is to 'ensure work pays' and to reduce welfare costs, with the underlying rationale of work being good for people's health. Additionally, in April 2010, the Department for Work and Pensions in the UK introduced the Statement of Fitness for Work (the fit note) to replace the previous Medical Statement (the sick note), placing the focus firmly on what people can do despite their health problem, as opposed to emphasising (and certifying) what they cannot do. The findings from this exploratory study would support the suggestion that a 'can do' focus may indeed be associated with better functioning in terms of work participation outcomes. However, our work also suggests that family and social factors (including socio-economic factors and the nature of employment) may have a crucial impact on occupational outcomes in this respect and provides some understanding of the complex beliefs and reasoning, and personal circumstances involved from the viewpoint of close family members.

The ongoing changes to the welfare system in the United Kingdom, which are explicitly being implemented to reduce cost to government, raise the possibility risk that initiatives will be interpreted as being linked to and allied with punitive measures perceived as removal of support rather than assistance. Indeed, it has previously been suggested that welfare systems may promote the problem of disability by rewarding sickness absence (Waddell & Aylward, 2005). Our exploratory work suggests that it is possible that, where individuals are faced with more stringent tests to prove the

reality of their symptoms and their condition, this may encourage further efforts by patients and those close to them to demonstrate the (perceived) severity and impact of the illness, thus entrenching attitudes and leading to further patient inactivity. Our study relates to the comments made in a report of an evaluation of the UK Fit For Work Service pilot studies (Hillage et al., 2012):

“Most clients had multiple needs. In addition to health conditions, most clients had other problems or concerns, which together presented significant risks to staying in work. Particularly complex cases involved combinations of multiple health conditions, personal difficulties and problems with their employer. The wide-ranging nature of clients’ needs provides support for the original proposal to use a biopsychosocial case-managed approach to the service.”

Our findings similarly point towards the importance of understanding how an individual’s wider social circumstances might become important contributors both to the propensity of pain to become persistent, and to the consequences in terms of sickness absence and incapacity (Wynne-Jones & Main, 2010). Future research might usefully explore how significant others’ beliefs and their behavioural responses are associated with functional outcomes for patients with back pain conditions. Interventional work might focus on encouraging behavioural and affective responses from significant others that are in accordance with the principles of effective management of the condition. The social context of disabling back pain has received little attention to date. The present study provides an interesting insight into the social circumstances which may impact on work participation outcomes for patients with chronic back pain and could meaningfully inform future treatment plans and intervention programmes aimed at restoring work function.

Study limitations

The small sample size in this study means that caution should be applied to the interpretation of any results. Given the focus of the study on the in-depth, everyday life experiences of participants a relatively small sample size is usually appropriate (Murphy et al., 1998). The present study is limited in that it represents only the experiences of those who participated and results are, as is usual in a qualitative study of this kind, suggestive rather than conclusive. Self-reported narratives retrospectively covering a long period have been questioned (Scott & Alwin, 1998), and risks of poor quality caused by distorted memory may need to be assumed (Hansson et al, 2001). However, many findings were supported by evidence documented in other studies of chronic back pain. The analysis does not address the rhetorical work that participants may be undertaking in interaction with the researcher in order to defend the identities they experience as being under threat due to the condition. This may be particularly relevant in research of this type, in which participants may be especially motivated to persuade an interviewer of their particular individual stance, or more likely to draw on previously established shared perspectives.

The mean age of the patients in our out of work sample (57 years) was higher than that of the patients in our employed sample (49.2 years) and we acknowledge the possibility that proximity to retirement age may have impacted on some participants' decisions about whether or not to remain in employment. However, given our previous work with an out of work sample with a lower mean age (41 years in McCluskey et al., 2011a), we feel able to say we do not think that the themes elicited and reported upon here indicate that age is a factor which can entirely explain away the differences in work participation outcomes for this group. In any case, with retirement ages set to rise in the United Kingdom and people expected to stay in work longer, maintaining work participation amongst this age group is likely to be of ever greater interest and importance.

Appendix A: Final analysis template

1. Illness identity

- 1.1 Specific label attributed to condition
- 1.2 Symptoms
 - 1.2.1 New onset symptoms
 - 1.2.2 Previously experienced symptoms
 - 1.2.3 Pain
 - 1.2.3.1 Constant
 - 1.2.4 Symptoms come and go
- 1.3 Co-morbidities

2. Beliefs about causality

- 2.1 Beliefs about triggers
- 2.2 Cause unknown
- 2.3 Outside sources used to back up causal explanations
- 2.4 Work as causal

3. Expectations about timeline

- 3.1 Chronicity (through experience)
- 3.2 Acute
- 3.3 Cyclical
- 3.4 Degenerative

4. Consequences of illness

- 4.1 Future consequences
 - 4.1.1 Potential future consequences
 - 4.1.2 Expected future consequences
- 4.2 Work
 - 4.2.1 Adjustments/ flexibility at work
- 4.3 Sleep
- 4.4. Things can do
 - 4.4.1 Positive developments skills resulting from condition
- 4.5 Impact on everyday activities

5. Beliefs about curability and management

- 5.1 Pain relief
 - 5.1.1 Medication
 - 5.1.1.1 Dissatisfaction with
 - 5.1.1.1.1 *not a cure*
 - 5.1.1.1.2 *side effects*
 - 5.1.1.2 Would like more
 - 5.1.2 Injections
 - 5.1.2.1 Less effective over time
- 5.2 Surgery
 - 5.2.1 Last resort/ risks
- 5.3 Self management
 - 5.3.1 Just carry on
 - 5.3.1.1 Takes mind off
 - 5.3.2 Keep mobile
 - 5.3.3 Equipment
 - 5.3.4 Weight issues
 - 5.3.4.1 Exercise
- 5.4 Not possible to control/ manage
- 5.5 Treatment expectations
- 5.6 Alternative therapies
- 5.7 Physiotherapy

6. Emotional representations (emotional responses generated by condition)

6.1 SO

6.2 Pat

6.2.1 Antidepressants

7. Patient identity

7.1 Being a fighter

7.2 Removing blame

7.3 Co-morbidities

7.4 SO as 'true witness' to 'real' patient

7.5 Patient as victim

8. Impact on and influence of SO

8.1 Fears of future dependency

8.2 Routine dependency

8.2.1 Normalising dependency

9. Illness coherence

9.1 Understanding of the dyad

9.1.1 Shared understanding

9.1.2 Differing models

9.2 Professional (medical) understanding of condition

9.2.1 Pat or SO as more expert

9.2.2 Time taken for medical treatment

9.3 Outsider understanding

9.3.1 Understanding through personal experience

9.3.2 Unsupportive

9.3.2.1 Due to invisibility

9.4 Social services understanding

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