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A synthesis of qualitative research exploring the barriers to staying in work with chronic musculoskeletal pain

Abstract

Purpose - Qualitative research can help to advance our understanding, management, and prevention of work disability. Our aim was to integrate qualitative research findings in order to increase our understanding of barriers to staying in work with chronic pain.

Methods - We searched five electronic bibliographic databases until September 2012, supplemented by citation tracking and hand-searching. We used meta-ethnography to synthesis our findings. Central to meta-ethnography is identifying 'concepts' and developing a conceptual model. Concepts were compared and organised into categories.

Results – The following categories can have an impact on the decision to remain in work: struggling to affirm myself as a good worker; balancing life and work in the face of unpredictable symptoms; my work colleagues don't believe me; the system does not facilitate return to work; the battle for legitimacy.

Conclusions - Our innovation is to present an internationally relevant model based on a conceptual synthesis. This model highlights the adversarial work experience of people with chronic. The papers span fifteen years of qualitative research. A significant finding is that these themes continue to pervade the current work environment for those in pain, and this has clear implications for education, social care and policy.

Introduction

Around 25% of adults suffer with moderate or severe pain [1-5], and for 6–14 % of these the pain is severe and disabling [6, 7]. People in chronic pain are seven times more likely to give up their jobs, are more likely to report poor general health and have mean mental health wellbeing scores which are comparable with the lowest 10% in a pain free population [8]. Musculoskeletal (MSK) pain (notably back and joint pain) is one of the most predominant types of chronic pain, and is increasing [7, 9]. We know that chronic illness has a significant impact on a sense of self and biography [10-13]. Chronic pain affects a person's ability to continue working. More than 3 million days are lost per year in the UK due to MSK disorders, notably back pain [14]. Most people get back to work in a short time but up to 44% will be off work again because of their pain within one year [15].

Qualitative research can help to advance our understanding, management, and prevention of work disability. Our aim was to integrate qualitative research findings in order to increase our understanding of patients' experiences of chronic musculoskeletal pain at work and explore barriers to staying in work with pain. This article uses the methods of meta-ethnography to further understand the complex process involved with remaining at work with pain. Importantly, although there is good evidence that work facilitates recovery [16, 17], there is an is an inherent tension between the benefits of a timely return to work and the barriers. In a recent qualitative synthesis of patients' perceptions of MSK pain funded by the National Institute of Health Research, UK [18], the authors found that the struggle to negotiate work exemplified the overriding adversarial struggle for people with chronic MSK. This paper reports for the first time, conceptual categories related to work and MSK pain, drawn from 19 of the 77 qualitative reports included in the synthesis. We present a conceptual model that helps us to understand the barriers to return to work in those with MSK pain despite evidence that returning to work is good for you.

Method

We included reports of qualitative studies that explored adults' own experience of chronic non-malignant MSK pain. Chronic was defined as three months or more. Exclusion criteria were: cancer; neurological; phantom; facial; head, dental/mouth; abdominal/visceral; menstrual/gynaecological; pelvic; not explicitly chronic pain; other chronic pain conditions; auto-ethnography; individual case studies. We searched six electronic bibliographic databases up until February 2012 (Medline, Embase, Cinahl, Psychinfo, Amed and HMIC). We limited the search to English language. We used a combination of free text terms and thesaurus or subject headings. Full details of the searches uses have been published elsewhere [18].

We hand-searched the contents list of specific journals for 2001-2011: Journal of Advanced Nursing, Social Science and Medicine, Qualitative Heath Research, Sociology of Health and Illness, Arthritis Care and Research, Disability and Rehabilitation, Scandinavian Journal of Caring Sciences and BMC Musculoskeletal Disorders. We searched reference lists for further potential studies. We screened titles, abstracts or full texts to exclude articles that did not meet the inclusion criteria. We used three appraisal tools as a focus for discussion, rather than as an inclusion cut-off; (1) Critical Appraisal Skills Programme (CASP) for appraising qualitative research [19], (2) Qualitative Assessment and Review Instrument (JBI-QARI) [20] and finally, (3) we categorised papers as either, 'key paper' ('conceptually rich and could potentially make an important contribution to the synthesis'), satisfactory paper, irrelevant paper or fatally flawed paper [21]. Two team members appraised all papers, and if they did not reach an agreement sent the paper to two other team members for a decision. We used the methods of meta-ethnography [22] to synthesise the data [23-25]. Central to meta-ethnography is identifying key ideas or 'concepts' and comparing these concepts across studies[22]. Meta-ethnography aims to organise the original author's ideas into a conceptual model that is 'more than the sum of its parts'[22]. We made the decision not to use the original participants' narrative as primary data, but rather to identify and describe the concepts within the primary papers. Three members of the team read each paper to identify and describe the concepts. If the concept was not clear we did not include it. We then collaboratively organised concepts into categories with

shared meaning through constant comparison[26], and developed a conceptual model [22]. This paper reports the conceptual categories related to work and proposes a line of argument that makes sense of these categories.

Results

We screened 24,992 titles, 676 abstracts and 321 full texts of potentially relevant studies. We excluded 228 of 321 potential studies that did not meet the study aims. We appraised 93 papers; 16 studies were excluded following quality appraisal, leaving 77 papers reporting 60 studies[18]. A conceptual analysis of these 77 papers is reported in full elsewhere [18]. Of these 77 papers, 19 (reporting 15 qualitative studies) included concepts related to experience at work [14, 15, 27-43]. This study reports a conceptual analysis of papers related to experience of work with chronic MSK pain. Table 1 describes the characteristics of these studies.

Struggling to negotiate work - Conceptual Categories

The following section describes conceptual categories related to work. Central to these concepts is the struggle to negotiate the workplace and maintain a positive sense of self with chronic MSK pain. We developed the following conceptual categories from our analysis of primary studies: (1) Struggling to affirm my credibility as a good worker; (2) My work colleagues don't believe that I am in pain; (3) Balancing life and work in the face of unpredictable symptoms; (4) The system does not facilitate return to work; (5) the battle for legitimacy. Each conceptual category is illustrated by a concept chosen from a primary study. Team memos describe our interpretation of these primary concepts. Although we recognised that participants' own words can be powerful, we do not to use their words as exemplars in order to emphasise that the data of meta-ethnography are the *concepts* not narrative.

Struggle to affirm my credibility as a 'good worker'

This describes the losses to self that accompany changes in work role. Work is described as adding value to self. Work can be a place where a person feels respected and valued; giving a sense that work makes us what we are.

> DE VRIES 2011[29]: WORK AS VALUE
> TEAM MEMOS: Work gave recognition, approval, self-realisation and self-respect. Work gives status and offers opportunity to be valued by peers. Work provides a mission to life. Work gave link to society and value to life. Work is the 'normal' thing to do.

Employees therefore struggled to maintain a positive image, and were particularly concerned not to be seen as 'bad workers' or as letting the side down.

> PATEL 2007 [38]: FEAR OF LETTING EMPLOYER DOWN
> TEAM MEMOS: Letting people down was expressed in terms of a threat to the patient's own self image as a worker: Some left work voluntarily for fear of letting employers down or not being seen as a good worker.

To avoid this negative image they used various strategies: struggling on at work and relying on colleagues in spite of pain; taking annual leave rather than taking time of 'off sick' or finally leaving work. A small minority described possible benefits of flexible working arrangements, although these might not be available. Chronic pain threatened their sense of being integral to the work place and some felt easily dispensable or feared that employers saw them as too risky to keep on. Some now felt as if they were being 'treated like a number', which lead to a sense of betrayal if their employer failed to support them in continued work.

> WALKER 2006 [43]: LOSS – EMPLOYMENT
> TEAM MEMOS: Sense of loss related to work exacerbated by lack of understanding from employers, particularly if employment had been longstanding. Felt a sense of betrayal by employer as pressure felt to leave work. Feel like they are treated 'just like a number' even when work had been valued prior to pain. Patients went to great lengths to find employment and often hid back pain from their employers (e.g. by taking holiday instead of sick leave). Felt guilt and resentment at losing/not finding suitable employment.

Balancing life and work in the face of unpredictable symptoms

The unpredictability and relentlessness of symptoms, along with fear of symptom progression made people feel that they could not continue at work.

> COOLE 2010B: DIFFICULTY COPING WITH FLARE UPS [28]

> TEAM MEMOS: Uncertainty at the unpredictable nature of their pain which made them unable to work at times. Effect on consistency of ability to work. Loss of confidence. Concerned that employers would not tolerate this unpredictability.

The struggle to affirm myself as a good worker and maintain work commitments took its toll on the life outside work. Workers struggled to balance work commitments with other essential roles, leisure and social activities. Some were forced out of work because they found it impossible to find this balance.

> DE VRIES 2011 [29]: CONSEQUENCES OF STAYING AT WORK
> TEAM MEMOS: Patients generally felt staying in work had many benefits. Dis-benefits included reduced opportunities for a social life and to pursue hobbies. Diminished capacity for leisure and pleasurable activities; increased pain and fatigue.

For some workers, there remained the possibility of maintaining work-life balance with some flexibility in working arrangements. However, this flexibility was not generally forthcoming and there was a sense that they needed to limit the support that they could expect from colleagues, particularly in a harsh financial climate where jobs were not secure.

> DE VRIES 2011[29]: ADJUSTMENT LATITUDE
> TEAM MEMOS: involves a range of crucial adaptation strategies around prioritising work, being flexible in execution of tasks (e.g. using a mobile phone that allowed one to not be confined to a desk), adapting ways of working with colleagues (delegation of tasks and accepting assistance) and working in partnership with families (i.e. accepting support as may be necessary). Not everyone at work experiences this latitude at work.

My work colleagues don't believe that I am in pain

For those who managed to stay in work, relationships with colleagues could become hostile. They did not feel understood by others and worried about gaining a reputation for being 'work shy'. This feeling was exacerbated by a culture of scepticism and mistrust regarding chronic pain that was seen to be promoted by media stereotypes and benefits agencies.

> SLADE 2009C[40]: STIGMA - WORKPLACE
> Many felt responsible for back injuries despite poor workplace policies. This guilt compounded by judgements by colleagues. Culture of judgement exacerbated by compensable bodies. Reputation for being 'work shy' despite attempts to stay in work.

The system does not facilitate return to work

This describes the negative impact of organisational systems on return to work. Those with chronic pain were forced to access healthcare to seek the legitimisation of a diagnosis in order to validate

time off work. Legitimising sick leave in this way was described as a double edged sword. For example, it may affect access to future employment or alienate you from work colleagues who thought that they would now have to shoulder your work load. Some workers chose to take holiday rather than be certified sick. Compensation claims could also alienate workers from their colleagues in this way.

> COOLE 2010B [28]: CONCERN ABOUT SICKNESS RECORD
> TEAM MEMOS: Concerns that sick leave perceived negatively and had an impact on employment record and job security. Use holiday leave rather than sick leave. Paradox - only seen as legitimate if they have a sick note, not self-certified - damned if I do and damned if I don't! I.e. need sick record to be legitimate but don't want a sick record.

This also describes the lack of dialogue between employers, occupational health and health services that inhibits return to work. Doctors were described as issuing sick notes rather than being involved in facilitating a gradual and sensible return to work in collaboration with the employer, employee and occupational health department.

> COOLE 2010A [14]: NO EMPLOYMENT HELP FROM GP - GPS WRITE SICK NOTES
> TEAM MEMOS: GPs wrote sick notes rather than suggesting modifications to work duties. Most of the advice about returning to work did not follow the occupational guidelines and many either did not return to work or had to request additional information on their certificates to permit them adjusted work duties. Some patients felt they simply had to comply with what the GP said. Others signed off work while awaiting tests and results.

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Contact with health care professionals did not facilitate a graded return to work. Patients were told to 'take care' or avoid certain tasks. Others were issued sick notes whilst they waited for test results and became trapped in the system of medical consultations.

> PATEL 2007 [38]: HEALTHCARE BARRIERS
> TEAM MEMOS: Trapped in a cycle of repeated consultations that stopped return to work. Long waits and not being taken seriously by HCPs exacerbated this. Some had been classified unsuitable to work by benefits medical officers. This assessment for work eligibility became a deterrent to taking on rehab to return to work

The battle for legitimacy

This describes the battle to prove that I can no longer work because of my pain and that I need sickness benefit. There was a sense that critical decisions about my life are outside of my control and in the hands of other people that do not necessarily believe me.

> HOLLOWAY 2007 [30]: STIGMATISATION IN HEALTH CARE SYSTEMS
> TEAM MEMOS: Often disbelieved by health professionals and told pain was 'all in the head'. This has an impact on benefits and compensation as patients perceived as malingerers.

Choosing to leave benefits and return to work after a period of absence was thus seen as risky because of the difficulties associated with accessing benefits.

> PATEL 2007 [38]: UNCERTAINTY – BENEFITS
> TEAM MEMOS: Patients not only perceive leaving benefits as risky but also returning back to benefits as time consuming and bureaucratic. Feared leaving benefits but saw employment as making them better off.

Workers were less likely to risk leaving benefits for a job that did not match their capability. There was a sense that benefits officers lacked the skills and understanding to help them get back to the right job, and that because of their pain, they were stuck in a low income job with no opportunity for retraining.

> PATEL 2007 [38]: PERSONAL OBSTACLES - QUALIFICATIONS AND EXPERIENCE
> TEAM MEMOS: High level skills could be a barrier for return to work as applicants did not want to be trapped in a job that was not commensurate with their level of training. Those with low level skills thought lack of training was also a barrier to return to work.

Line of Argument

Meta-ethnography aims to develop a conceptual model from the categories of analysis. Figure 1 illustrates our line of argument developed from the conceptual categories from nineteen international studies. Central to this line of argument is the struggle to hold onto a sense of being a valued worker - 'I am not the sort to let the side down'. Our model suggest that for some, the need to make a valuable contribution at work is central to a sense of self and this is threatened by chronic pain: Firstly, my work colleagues do not believe that I have pain; secondly, I am struggling to affirm my

credibility as valuable member of the workforce; thirdly, I am trying to maintain my work and life balance in spite of unpredictable pain. In the struggle to affirm my sense of self as a good worker, there are several strategies available to me: (a) I can utilise more flexible working practises that allow me to stay at work. However, although this has distinct advantages, it is not a strategy that is always available. (b) I can hide my inability to be work at full capacity by taking annual leave instead of sick leave. This strategy is difficult to sustain and can have adverse effects on maintaining a healthy life-work balance. (c) I can persevere as normal and rely on the support of colleagues at work. This incorporates the negative consequence of being seen as an unreliable or 'work-shy' and therefore threatens my self-identity (d) I can go to the doctor in order to be 'diagnosed' as sick and thus gain legitimate sick leave, or sickness benefits. This process of taking sick leave triggers a battle for legitimacy that does not necessarily facilitate a return to work, thus highlighting the need for changes at a system level. Rather than being part of a joined up system incorporating employee, employer, occupational health and the benefits agencies with a joint aim of returning workers to work, the health care service is described as primarily validating illness and issuing sick notes. Similarly the benefits agencies are described as lacking skills to facilitate an optimum return to work. Finally, the battle to negotiate legitimacy makes it too risky to give up benefits and return to work, and thus can become integral to continued unemployment. People described feeling trapped by the system; in short, healthcare, benefits, and employers did not talk to each other in order to facilitate a person's return to work.

Discussion

Qualitative research can help to advance our understanding, management, and prevention of work disability. Our aim was to integrate qualitative research findings in order to increase our understanding of patients' experiences of chronic musculoskeletal pain at work and explore barriers to staying in work with pain. Our innovation is to present for the first time, an internationally relevant model based on a large conceptual synthesis of qualitative research. The papers included in this systematic review span fifteen years of qualitative research exploring the experience of chronic

musculoskeletal pain. A significant finding is that these themes continue to pervade the current work environment for those in pain, and this has clear implications for education, social care and policy internationally.

This model highlights the adversarial work experience of people with chronic MSK pain and demonstrates the complexity of social factors and the systems in place to benefit those impaired by chronic pain can impair return to work. Conceptual categories included: (1) Struggling to affirm my credibility as a good worker; (2) My work colleagues don't believe that I am in pain; (3) Balancing life and work in the face of unpredictable symptoms; (4) The system does not facilitate return to work; (5) the battle for legitimacy. Our model highlights strategies that people with chronic MSK pain use to negotiate their struggle to affirm their credibility and self-concept. Strategies to negotiate work can have negative consequences for those with chronic MSK pain. Our model suggests hiding pain or struggling on at work despite work can involve over- reliance on colleagues. Studies describe concern about gaining the reputation for being 'work shy' which can have an adverse and important effect on a person's positive sense of self. This is exacerbated by the struggle to balance work and life commitments, which can affect quality of life for the worker and their families. Bergstrom and colleagues also suggest that remaining at work whilst sick, 'presenteeism', may have adverse effects on health, performance at work [44]. Our model supports this finding that struggling on as normal or taking leave to hide pain from others is a strategy that can be difficult to maintain. However, taking sick leave is not described as a strategy that is taken lightly. Not only does it have an impact on self-concept but also potential impact on future employment. Our model highlights the struggle to retain personal credibility in the face of scepticism and mistrust. The role of the health care system in relation to work is described as validating pain and issuing sick notes, rather than contributing to a joined up strategy to get people back to work. Despite this, in the UK, primary care practitioners are seen as the main source of advice on sick certification and return to work [14]. This may be because occupational health provision is substantially less than that found in other countries. For example, the Netherlands, France, Belgium, and Finland, achieve 90% coverage, compared to 34% in the UK[45]. There is agreement that work facilitates health and well-being and that you do not need to be entirely

fit in order to return to work[46, 47]. Primary care practitioners face the difficulty of balancing guidelines recommending return to work with patients' expectations for sick certification, and at the same time retaining a positive relationship with patients.

Our findings highlight the need for changes in the systems that govern working lives and the need for a 'cultural transformation in the way clinicians and the public view pain' [48] (page 47). Studies included described the opportunity to modify work as a successful, though not generally available, strategy. This finding is of significance in view of the recommendation to stay at work with pain by taking measures to modify the workplace, or to take minimal sick leave and return to work as soon as possible[49]. There is evidence that making temporary modifications, such as alterations to equipment or environment[50] can keep people in work [51], and inability to modify or adjust work has been identified as a 'black flag' contributing to work disability[52]. Our model supports findings that modifications to work are a strategy that allow workers to successfully negotiate work with chronic MSK pain. These strategies were not routinely available at the time and relied on manager's discretion. In addition, advice from health care workers about modifying work was described as vague and thus difficult to interpret and action. There is strong evidence that an employer's role is fundamental to successful and timely return to work, and can make the return to work twice as fast [53]. Research demonstrates that agreeing goals for a planned return to work with the employer, accommodating the workplace, and communicating with healthcare professionals facilitate return to work. Evidence also support our finding that employers actions including 'doubting the legitimacy of the injury' may impair return to work [53].

More research exploring the impact of the change to 'fit to work' would be useful. The patient narratives that inform the primary studies of this synthesis predate the introduction of the 'Statement of Fitness for Work' or 'fit note' which replaced the 'sick note'. The fit note aims to encourage communication between health services and employers and allow doctors to provide additional information and advice on an individual's fitness for work, thus facilitating a timely return to work.

The rationale of this is supported by this qualitative synthesis. Wainwright and colleagues have identified several barriers to using the fit note in primary care [17], including, the need to preserve a good doctor–patient relationship and inconsistent engagement from employers. They also question whether a new form can achieve such a cultural shift. Research to explore the impact of the 'fit note' on the experience of those with chronic MSK pain would be useful.

Finally, although the recommendation is to return to normal work as soon as possible, this is not always an option in all cases. The benefits system is in place for those who need it, for example, those with persistent and severely disabling chronic MSK pain. Our model demonstrates that in these cases, the person finds themselves battling for legitimacy in an attempt to access benefits. This battle takes place in a cultural arena of mistrust and scepticism which can increase the suffering of those with chronic pain. Having battled to access benefits, those with chronic MSK perceive it too risky to give up their claim and return to work. The system thus becomes integral to sustaining long-term, even permanent unemployment. This issue has far reaching policy implications related to availability of benefits for those with chronic MSK which often remains undiagnosed. In a synthesis of qualitative research, MacEachen and colleagues found that 'goodwill' and trust among parties at work and the important role of work supervisors was influential in return to work. 'Goodwill' involved multiple factors including notions of injury attribution and trust [54]. This supports our finding that social factors at work can have an important impact on successful return to work. MacEachen and colleagues also demonstrate that difficulties negotiating the 'system' and the 'disconnect between employers and physicians' could have an important impact return to work[54].

Our model is based on a rigorous collaborative process that took place over two years. We specifically focused on the experience of chronic MSK pain, which might mean that we excluded some insightful papers. However, meta-ethnography does not aim to summarise the entire body of available knowledge, or make statistical inference. Meta-ethnography focuses on conceptual insight, and some argue that including too many studies might make conceptual analysis 'unwieldy' or make

it difficult to maintain insight or 'sufficient familiarity' [23, 55]. The findings of qualitative research are an *interpretation* of data, and meta-ethnography presents an interpretation of interpretations. Some would therefore argue that qualitative synthesis takes us too far away from the idiographic experience of participants. However, the centrality of interpretation is the strength of qualitative research methodologies, such as meta-ethnography, that aims to challenge and develop ideas. Qualitative research helps us to understand the complex social issues involved in successfully continuing employment. Our model suggests that making a valuable contribution at work is central to a sense of self and that a culture of suspicion does not facilitate a healthy return to work. Strategies such as hiding pain, relying on colleagues, taking sick leave can have a negative impact on credibility and self-worth. Collaborative work modifications and an environment of trust can facilitate healthy return to work. Our findings support the finding that there are challenges in educating patients, the public, and providers that can have an effect on the working lives of people with chronic pain[48]. Our conceptual model provides an interpretation that can help us to understand the barriers to continuing at work with chronic MSK pain.

Conflict of Interest

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