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Navigating employment retention with a chronic health condition: a meta-ethnography of the employment experiences of people with musculoskeletal disorders in the UK.

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Abstract (196 words)

Purpose: Musculoskeletal disorders (MSDs) are associated with high rates of work disability in the UK. This review synthesised qualitative evidence concerning the employment experiences of people with MSDs to explore the factors shaping their employment trajectories post-onset and the resources they draw on to remain in work.

Material and methods: Systematic database searches identified 16 qualitative studies of the employment consequences of having a chronic MSD in the UK. Meta-ethnographic methods were utilised to synthesise this body of evidence. This included a translation of concepts across studies to produce a line of argument synthesis.

Results: The lack of certainty associated with often fluctuating and invisible MSD symptoms leads to employees struggling to maintain a stable work identity. Work retention is aided by having: a clear diagnosis, occupational tasks commensurate with altered abilities, and employers and colleagues who understand the nature of the condition. The ability to negotiate and implement workplace adjustments aids work retention but is dependent upon having good quality employee-employer relationships and the degree of autonomy available to the employee.

Conclusion: Individuals with MSDs must draw on a range of personal, social, organisational and institutional resources to remain in or return to work post-onset.

Key words: musculoskeletal disorders; employment; work retention; return-to-work; workplace adjustments; organisational flexibility; qualitative; meta-ethnography.

Introduction

Increased life expectancy and the corresponding removal of the default retirement age have led to growing numbers of workers with disabilities and chronic health conditions in the UK labour market [1]. Disabled workers face significant employment inequities however: in 2015 only 47% of individuals with disabilities in the UK were employed compared with 80% for those without, an employment differential of 33 percentage points [2]. This disability employment gap is the fourth highest among the European Union nations and is significantly higher than that observed in Finland (19%), Sweden (18%), France (18%) and Italy (12%) [3]. International inequalities in the employment rates of people with disabilities are largely due to variations in healthcare systems and national welfare and employment policies. These international employment rates, however, mask the social inequalities in employment rates that exist within countries among people with disabilities or chronic health conditions. For example, having low education in combination with a disability or chronic health condition can create not just additive, but synergistic effects on employment rates, which can be worse for women, and which vary significantly across different welfare regimes [4,5]. These patterns indicate the presence of underlying structural, institutional and individual factors driving employment inequities. Exploring how these factors shape employment trajectories for people with chronic health conditions and disabilities can help to inform employment and health policy interventions aimed at addressing these inequities. In this paper, we use meta-ethnographic methods to synthesise qualitative literature focussing on the employment experiences of individuals with chronic musculoskeletal disorders in the UK to explore the factors that shape their varied employment trajectories and to identify the resources they draw on to remain in employment.

Musculoskeletal disorders and employment

Musculoskeletal disorders (MSDs) are conditions affecting the nerves, tendons and muscles in the back, upper limbs, neck and lower limbs. Many of the common symptoms of MSDs, such as pain, inflammation, joint stiffness and fatigue, are invisible and can fluctuate. Significantly lower employment rates are observed among people with chronic MSDs compared with the general population [6-8], particularly among those with lower levels of education or working in manual occupations [8,9]. In the UK, musculoskeletal disorders are among the most common causes of disability [10] and receipt of health-related unemployment benefits, such as Employment Support Allowance [11].

Quantitative studies of work disability or return-to-work among people with MSDs have focused on identifying the individual and occupational characteristics that increase the risk of becoming work disabled. The degree of pain, stiffness, reduced function and fatigue experienced by people with MSDs varies between diagnostic groups but several studies have demonstrated that physical symptoms are less strongly associated with being out of work than other factors. Studies of people with rheumatoid arthritis, for example, have shown that being of work is more strongly predicted by socio-demographic and work-related factors than by disease-related determinants [12-14]. Being older or less educated, employed in manual work, having a physically demanding job and having less discretion over the pace and activities of work increase the risk of becoming work disabled [9,12-19]. People with rheumatoid arthritis employed in manual occupations are almost five times more likely to be work disabled five years after onset compared with their peers in sedentary jobs, and job loss also occurs earlier in this group [19]. These quantitative studies indicate that remaining in or returning to work with an MSD may depend less on the nature and severity of the condition than on a worker's

socio-demographic characteristics, the nature and demands of their occupation, and the organisational workplace culture. However, quantitative studies provide limited insights into how these factors shape the employment trajectories of workers in different employment contexts contributing to the inequalities in employment outcomes noted above. Evidence from qualitative studies can reveal more about how these trajectories are produced and how individuals navigate work retention and return-to-work.

Evidence from previous qualitative syntheses

Several reviews synthesising qualitative research exploring the lived experience of chronic MSDs have been conducted [20-25], but few have explored their effects on employment. Synthesising international evidence from 19 papers based on 15 qualitative studies, Toye *et al* [26] argue that workers with chronic and unpredictable MSD pain struggle to retain their credibility as valuable workers whilst simultaneously trying to maintain a work-life balance. To manage this struggle workers can employ various strategies: (a) utilise flexible working practices (which are not always available); (b) conceal their work limitations (which can negatively affect a healthy life-work balance); (c) rely on the support of colleagues (which may threaten their image as a reliable worker); (d) take sick leave (which triggers a battle for legitimacy without necessarily facilitating a return-to-work). What these strategies also reveal is a systemic failure in that healthcare services, benefits agencies and employers do not always collaborate to facilitate a return-to-work, and the battle for legitimacy may make it appear risky to leave benefits, although the degree to which this is the case will vary between countries. However, the focus of the review was limited to the barriers to staying in work with chronic musculoskeletal pain and not the resources or factors that support individuals to remain in employment.

A best evidence synthesis [27] of 57 international studies examining low back pain and work participation also found that a lack of work-focused healthcare, poor access to suitable healthcare and poor communication between the healthcare system and other relevant stakeholders are obstacles to work participation. In addition, lack of support from significant others and their negative beliefs about the patient's low back pain created work participation obstacles.

Gewurtz and Kirsh [28], synthesising seven international qualitative studies, characterise disabled people's experiences of workplace organisational culture and how disabilities affect this culture using the concepts *Disruption*, *Disbelief* and *Resistance*. They found some employers regard workplace accommodations that require adaptations to the social environment, such as flexible working, as creating organisational *Disruption* and contradicting the goal of maximising productivity. Such accommodations have the added risk of exposing the subjective nature of workplace rules. Disabled workers with fluctuating conditions may face *Disbelief* from colleagues and employers, leading them to conceal their disability to maintain their identity as a dependable worker. They must, however, reveal their disability to be eligible for workplace accommodations, once more risking their dependable worker identity. Employers may use *Resistance* strategies, such as denying requests for accommodations, to limit the potential impact on workplace policies and structures, and are able to interpret their responsibilities and mould implementation of legislation to minimise *Disruption*. However, international differences in the presence of effective employment legislation protecting the rights of disabled workers make general conclusions problematic.

Another international review also found that unpredictable symptoms make return-to-work

challenging in the face of doubt from co-workers, and the ability to manage the impacts of symptoms depends on workplace conditions, adaptations, social and economic conditions, individuals' own perceptions of their worker identity, interpersonal communication, levels of family support and emotional resilience [29]. A further mixed-method international review [30] found evidence that low perceived physical disability and low emotional distress were associated with staying at work, and key facilitators to staying in work were a combination of workplace adjustments and personal adjustments to home and social lives. The latter relied on effective communication with and support from supervisors and colleagues.

Whilst these reviews provide useful insights into the employment experiences of people with chronic MSDs, most focus on the apparent 'barriers' or 'obstacles' to remaining in work, with less attention paid to the factors that facilitate the process. Moreover, these reviews drew on evidence from a range of different countries. Whilst there may be common issues facing people with MSDs living in different contexts, national welfare systems and employment policies differ considerably in their ability to protect the employment of people with long-term conditions or help them return-to-work and this is reflected in wide international variations in their employment rates [4,31-33]. Our previous comparative studies, for example, revealed significantly lower employment rates for disabled people in the UK than in Sweden, Norway, Denmark and Canada [4,31]. The Nordic countries have stronger employment legislation protecting the employment of disabled and other workers than the UK [4]. In addition, the Nordic countries spend more than the UK on Active Labour Market Policies (ALMPs) supporting unemployed people into employment, and focus more of this spending on improving the accessibility of the working environment for disabled workers, while the UK invests more in skill development of disabled individuals [4]. Moreover, as noted in a recent evidence review on workplace interventions to support work retention of employees with

disabilities and long-term conditions [34], employees in Nordic countries, and the Netherlands, have comprehensive workplace health systems, with mandatory actions for employers and better access to rehabilitation and work-focused healthcare than their UK counterparts. Thus, findings from international studies may have limited applicability to the UK.

In this paper, we report the findings of a systematic review which used meta-ethnographic methods to synthesise qualitative research on the employment experiences of people with MSDs. We restricted our review to qualitative studies conducted in the UK so that they were located within the same employment and welfare policy environment. Our review questions are:

What are the employment experiences of people with chronic musculoskeletal disorders?

What resources do people with chronic musculoskeletal disorders draw on to navigate the process of maintaining employment?

Materials and methods

In choosing a method for synthesising qualitative research we examined a range of approaches (see Dixon-Woods *et al*, [35] for a summary), but selected meta-ethnography as we agreed with Noblit and Hare's [36] contention that '*the synthesis of qualitative research should be as interpretive as any ethnographic account.*' Designed by Noblit and Hare as a means of synthesising ethnographic studies of school desegregation in the United States [36], meta-ethnography has been applied and further developed within health research [37-40], and has previously been used to examine the impacts of health on employment [26,28,29,41]. Meta-ethnography aims to develop new interpretations and insights from existing qualitative literature and does so through the synthesis of key concepts identified in a set of individual

studies into higher-order interpretations. In this review, we combined a standard systematic review approach (a review question, structured searches within inclusion and exclusion criteria, the use of a quality appraisal tool) with meta-ethnographic methods for synthesising qualitative studies, in particular developing a ‘line-of-argument’ [36] synthesis. The stages we undertook developing the synthesis are described below.

Data sources and search strategy

Qualitative studies of the employment consequences of having a chronic musculoskeletal disorder in the UK were sourced using several methods. A database search strategy was developed using the questions noted above to guide the development of search terms and these were refined through a scoping exercise. Electronic searches of four databases (Academic Search Complete, CINAHL, MEDLINE, and PsycInfo) were conducted from inception date to April 2018. Search terms were developed relating to three key terms: employment status and employment outcomes; musculoskeletal pain; and qualitative research (see **table 1**). In addition, the bibliographies of all located studies were hand-searched and information on unpublished studies requested from researchers in the field.

[Table 1 here].

Inclusion and exclusion criteria

The review was limited to qualitative studies conducted in the UK in recognition of the potential differential impacts of national welfare, health and employment systems and policies on the ability of people with long-term health conditions to remain in or return-to-work [4,31-33,42,43]. Studies were included in the review if they: were conducted in the UK; published in English; used qualitative methods of data collection and analysis; included a working age (18-64 years) sample; focused on adult-onset musculoskeletal conditions (congenital or childhood-

onset illnesses were excluded); consisted of primary accounts of living with musculoskeletal pain from the perspective of the individual, and of their significant other if included alongside individuals' accounts; and explored the employment consequences of chronic musculoskeletal pain. Papers that included only the accounts of carers, spouses, health care workers or employers were excluded, as were review papers, editorials and studies exploring the outcomes of a surgical intervention, drug therapy or work rehabilitation scheme.

Selection of studies

Once duplicates had been removed, the two authors performed independent screening of the titles and abstracts and then assessed the full papers to establish whether the studies met the inclusion criteria. Any disagreements were resolved through discussion.

Methodological assessment

The appraising of the methodological quality of qualitative studies is controversial, in part due to the flawed nature of criteria-based tools [44,45], but also due to the fundamentally contested notion of what 'quality' means in assessing qualitative studies [46,47]. Popay *et al* [48] set out criteria for assessing qualitative studies that they argue are more sensitive to the ontological and epistemological concerns of qualitative research. Following Sim *et al* [49], we felt these criteria aligned well with the concerns of qualitative research and were applicable across a wide range of qualitative research designs. Popay *et al*'s [48] criteria were developed into a tool to appraise individual papers (**table 2**). The purpose of this was not to provide scores, quality 'standards' or a cut-off point for 'poor quality' studies, but to enable discussion of the strengths and limitations of individual papers and of the set of papers as a body of evidence underpinning an interpretive synthesis. These are discussed in the Results section and in the Discussion where we reflect on the limitations of our study.

[Table 2 here].

Identification of constructs and determining how the studies are related

Firstly, both authors independently read and re-read the papers, extracted data from each paper and entered this into a grid, including authorship; the research question and background; theoretical orientation; study method; sample and study context (sampling strategy, number/type of participants, recruitment, locality and date of study); data analysis; reflexivity; and the study findings and themes. Additions and corrections to the extracted data tables were made after discussion.

The next stage involved identifying and synthesising the key concepts in each study. Noblit and Hare [36] emphasise that meta-ethnography is a process of ‘constructing interpretations, not analyses’ by identifying ethnographic studies of an area of interest that can be compared and juxtaposed, whose concepts and metaphors can be translated across studies to produce either a ‘reciprocal translation’ (direct comparison), a ‘refutational translation’ (opposing interpretations) or a ‘line of argument’ (holistic synthesis). Building on this work, Britten et al [37] developed a process of identifying first- and second-order concepts within the original studies from which a set of third-order concepts were developed to produce a line-of-argument synthesis. This approach has been replicated in other meta-ethnographies [26,28,38,39,41,50,51], however, as others have noted [52,53] there is no agreed terminology to describe the processes of meta-ethnography, particularly what constitutes first- and second-order constructs. For example, some authors [59] describe first-order constructs as derived from the authors’ original findings using original terms and key concepts from the article; second-order constructs are derived by translating the first-order constructs across articles,

while third-order constructs (overarching concepts) are the synthesis of second-order constructs. Conversely, other authors [38,39,50] describe first-order constructs as the reported data (research participants' experiences), while second-order constructs are the authors' interpretations of these data in the original studies, and third-order constructs are the synthesis of first- and second-order constructs across the studies.

Our method resembled this latter approach: our first-order constructs were 'common and recurring concepts' [37] that we identified within the study participants' primary accounts of working or attempting to return-to-work with a chronic MSD as described in the results section of the studies included in the review. Second-order constructs were the original study authors' interpretations of the participants' accounts as described in the discussion and conclusion of each paper. The first- and second-order constructs were extracted from the papers and entered into a separate table for each research question. The process of translating studies into each other involved the development of new third-order interpretations, or an overarching framework, drawn from the first- and second-order constructs in each study, that transcend those from the individual studies. Interpreting these concepts identified through the process of translation, we developed a 'line-of-argument' synthesis [36] leading to a new, holistic interpretation of the studies' findings.

At the start of the review we set out to explore the employment consequences of having a chronic MSD in the UK, and to identify what factors enabled or prevented people with MSDs remaining in or returning to work. These initial questions guided our data extraction. However, as the review developed our research questions inevitably progressed as we interpreted the

data. As well as identifying the employment experiences of people with chronic MSDs we also sought to establish which resources people with MSDs draw on to navigate employment retention.

Results

Results of the searches

The database searches identified 3,886 potentially relevant papers, and 16 further references were located through other searches (**figure 1**). After removal of duplicate articles, the titles and abstracts of 2,691 papers were scanned for relevance using the inclusion and exclusion criteria and 2,629 papers were excluded, leaving 62 papers. Inspection of full copies of these papers resulted in 46 being excluded because they were not primary accounts of the impact of having a chronic musculoskeletal disorder on employment, were not solely UK evidence, were not empirical, were an abstract only or were not relevant to the aims of the review. Included in our review were 16 papers, published between 1995 and 2018, based on 13 UK qualitative studies (**table 2**). The primary focus of most of the papers was employment following onset of a chronic MSD; in a minority of papers employment was just one of several outcomes explored. Of the 16 papers included in the review, nine focussed on low back pain [54-62], five on rheumatoid arthritis [63-67] and two on chronic musculoskeletal pain [68,69]. All studies used narrative, semi-structured interviews or focus groups as methods of data collection.

[Figure 1 here].

Results of the quality assessment

Only four of the papers [58,65-67] were assessed as having met all the methodological criteria sufficiently (**table 2**), though publishing requirements may have limited the ability of some

papers to meet the criteria to a sufficient level. Taken as a body of evidence, the main areas of weakness are in evidence of responsiveness to the social context, evidence of adequate description, and the potential for assessing typicality. One aspect of the first of these is that whilst most studies were based on semi-structured or narrative interviews, few papers reported exploring unanticipated questions within the interviews or further developing interview schedules or topic guides as the research progressed. Three papers [54,59,60] developed open questions from the Illness Perception Questionnaire [70]. This gives a relatively narrow focus on the perceived nature, causes and curability of the condition which may have limited the ability of the participants to express their perceptions and experiences of the impacts of their health conditions on employment. Closely linked to this is the lack of adequate or ‘thick description’ [71] in half of the papers. In these papers [54-56,59-61,63,69], analysis relies on the relatively ‘thin description’ provided by selected anonymised quotes linked to researcher-defined themes. In contrast, the papers by Pinder [65,66] in particular, but also Howden *et al* [64], Ryan *et al* [61] and Walker *et al* [62], provide the level of thick description of participants' employment situations, working and social relationships and health conditions that makes ‘thick interpretation’ possible [48]. The limitations of responsiveness to the social context and the lack of adequate description in turn limit the ability to make judgements about the typicality of the findings of some of these papers. We argue, however, that synthesising the findings of this set of papers, even given the noted limitations, enables us to provide an interpretive synthesis of the papers’ findings as a body of evidence. This, we argue, allows us to develop a ‘line of argument’ interpretive synthesis [36] that goes beyond the individual studies to allow us to develop a theoretical understanding of the employment trajectories of people who develop a chronic MSD.

Findings

In the process of synthesising these studies, we identified a series of key concepts based on our readings of the original authors' first- and second-order constructs (**table 3**). Across the 16 papers, a range of employment trajectories were reported, which we juxtaposed under the construct: employment consequences of having a chronic MSD. All 16 papers provide evidence on how a range of factors conditioned these varied employment trajectories following the onset of a chronic MSD. We grouped this range of evidence under the following constructs: fluctuating symptoms and uncertainty; encounters with healthcare professionals; negotiating flexibility; relationships at work; and individuals' attitudes towards work.

[Table 3 here].

Employment consequences of having a chronic MSD

The 16 papers reported a range of impacts on employment from having a chronic MSD. Eleven papers reported job loss [54,58-60,62,64-69], with most study participants being unable to return to the labour market. For many this meant becoming financially dependent on significant others or the benefits system or, for a few, taking early retirement. However, 14 of the papers also reported participants retaining or returning to employment [54-58,60-67,69]. Other effects on participants' employment status included: making informal or (less often) formal work and/or domestic adaptations to help maintain employment [54,56,61,63-67,69], and using sick leave [54-57,61,64-67] or changing employer or employment type [63,64,66] or becoming self-employed [56,67] as strategies for coping with the condition. Across the papers, some participants experienced a range of these consequences. For example, some participants reported losing one job and moving onto another with a more understanding employer who was willing to make adaptations, or to work they felt would be more suited to their changed abilities [58,63,64,66]. Others left the labour market after attempting to maintain employment

through adapting or changing work [54,58,59,62,65,67,69], or after failing to attain what they perceived to be an effective diagnosis and/or treatment, leaving them, in their view, unable to work [58-60,69].

Fluctuating symptoms and uncertainty

Understanding the impact of pain on participants' employment or employability was a central concern of all the papers. To varying degrees, all the papers discussed participants' reports of how pain affected their ability to work or to return-to-work, with two studies focussing specifically on how beliefs about pain shaped participants' employment-related decisions and actions [54,59,60,69]. Other symptoms reported as impacting on work included fatigue [61,63-65,67-69], physical limitations or reduced function [61,64,65,67,69]. One significant theme from participants' accounts across the studies is the degree to which these symptoms posed a threat to their ability to maintain a stable identity as a dependable and reliable worker. Central to this were the difficulties of dealing with the uncertainties and disruptions deriving from symptoms that were subject to fluctuations, 'flare-ups' and unpredictability [55,59,61,65-69]. In some cases this produced 'bodily doubt' [72] - anxiety and uncertainty about the body and the self. Participants discussed how the development of an MSD led them to lose self-confidence [58,62,65,66,69] and become uncertain of their physical ability to continue working or return to work [55,58,59,62,63,66,68,69]. This bodily doubt was for some accompanied by doubts about how employers, managers and colleagues would react to the disruptions stemming from their health condition [55,57,61,62,66-69].

The invisibility of most MSD symptoms also contributes to this uncertainty, and could make it harder for others to understand the condition and its associated limitations. Doubt or disbelief about the condition and its limitations were reported across studies

[55,57,58,61,62,65,66,68,69] including hostility from employers or colleagues [58,61,65,66]. These doubts on the parts of others could have significant and serious consequences, such as for a participant in Walker *et al's* study [62] who was wrongly reported by neighbours for falsely claiming state benefits, or the manager's doubts that contributed to a participant's 'redundancy' in Pinder's study [66]. However, participants who had not experienced such direct consequences feared that others would perceive their condition negatively or doubt the authenticity of their pain and limitations and were concerned about being perceived as a fraud [55,57,61,62,65,68]. Such fears led participants feeling guilty about being off sick [57,61], not leaving the house when off sick [62] or feeling a fraud when having a 'good' day [65]. One participant in Ryan *et al's* study [61] suggested colleagues would be more believing of a visible condition such as a broken arm or leg than an invisible MSD. Indeed, a participant in Holloway *et al's* study [66] reported that she received more sympathy from colleagues after breaking her arm than she did with her 'invisible' chronic back pain.

Pinder suggests fluctuating symptoms cause uncertainty about the ability to work, leading to people becoming 'engaged in a complex process of balancing the demands of [their] body with the need to maintain a respectable flow of work' [65]. Accounts of such balancing acts appear across the studies with participants mobilising a range of strategies to cope with the uncertainty associated with chronic MSDs and accompanying perceived loss of control. One strategy could be characterised as a form of denial of the effects of symptoms, described or interpreted as 'stoicism' [54], presenteeism (working when ill) [57,61,67] or 'maladaptive coping styles' [69]. Another strategy employed was that of concealing their condition from employers and colleagues where they felt it might endanger their employment [55,62,63]. Employees also disguised sickness absence by using annual leave or time off *in lieu* [55,62]. Others reported coping with fatigue, and saving sufficient energy to remain working, by curtailing their domestic roles and leisure activities at some personal and emotional cost [62].

For some individuals with MSDs the complexities involved in maintaining this balancing act became too difficult and resulted in their changing [62,67] or losing their job [54,59,60,67,69]. Two papers noted how participants felt this uncertainty about their ability to work reinforced their perceptions that they would be less employable than ‘healthy’ individuals, suggesting their self-image as a reliable worker had been undermined [68,69]. Building on this, some papers described how individual perceptions of their own disability resulting from their MSD may affect this balancing act. A study exploring the employment effects of the illness perceptions of people with MSDs and their significant others described how both parties were at pains to point out that the level of suffering and limitations posed by the MSD were wholly incompatible with a return-to-work [54,59]. This was interpreted as an effort to maintain a legitimate image as a ‘disabled’ worker in a stigmatising climate of narratives about ‘benefit cheats’ and ‘malingering’. Similarly, in a study of university workers with back pain who had returned to work from long-term sick leave, significant others defended the individual from perceived pressure to return-to-work by confirming ‘the perceived limits of the participant’s condition’ [61]. A study exploring cognitive representations of chronic musculoskeletal pain and employment contrasts participants who ‘perceived their condition as a “long term disability”’ to be a significant barrier to return to work, with those ‘determined to “reinvent” themselves in order to re-enter the workforce’ [69].

Encounters with healthcare professionals

Eleven papers reported participants’ experiences of dealing with healthcare professionals, including with medical officers/professionals conducting work-related assessments

[57,58,66,68,69], with healthcare professionals for therapeutic purposes [60,68,69], and with General Practitioners and occupational health in negotiating sickness absence or return-to-work [55-58,60-62,64,66,68]. These were rarely single encounters, but repeated contacts with healthcare and rehabilitation professionals, often over long periods [55,60,64,66,68,69], due to the chronic nature of the MSDs reported in these studies.

There was an underpinning, often unstated, assumption of the authors of the studies that the encounters with healthcare professionals should result in positive rehabilitation experiences for the participant; however, the participants' experiences suggest this was not often the case. As Patel *et al* comment '[h]ealthcare was not a rehabilitation experience for [...] people but actually delayed rehabilitation' [68]. Many papers reported poor or ineffective diagnosis and a lack of effective support from healthcare professionals [55-58,60,62,64,66,68,69]. Despite multiple consultations often over long periods of time, some participants reported unsatisfactory diagnostic and treatment outcomes [55,59,64,66,68,69]. Stressful and stigmatising encounters with healthcare professionals were also described [58,60,64,68], leaving some participants feeling their symptoms were doubted and they were being perceived as malingerers or moral failures [58]. Papers noted participants had become disillusioned with or lost trust in the healthcare system, resulting in them having little expectation of gaining anything from consultations with General Practitioners other than sickness certification and/or analgesic medication [55,57,60,68,69]. Only one paper reported participants engaging with occupational health (OH) [56], noting how participants were left to be the conduit between OH, employers and other health professionals. Immediate line managers tended to be the gatekeeper for OH and decision-maker regarding OH recommendations, which could be problematic given the often contradictory requirements of health advice and the demands of the job [56].

This active and long-term pursuit of a clear diagnosis and treatment plan may reflect a desire of individuals with MSDs to bring legitimacy to their 'sick role' and clarify the uncertainty – in their own and other peoples' eyes – surrounding their condition [58,60,61,64,66,68]. McCluskey *et al* [60] described significant others' narratives of their loved ones' lengthy and disheartening journeys through the healthcare system, arguing that these narratives are used as a means of legitimising their being out of the labour market in times when this is very heavily disapproved of both culturally and politically.

As a number of studies discuss, this desire for diagnostic certainty contradicts the normality of fluctuating symptoms that characterise chronic MSDs [55,56,60,66,68]. This can be interpreted, as some studies do, as a failure of healthcare professionals to comprehend and communicate that whilst MSD symptoms may fluctuate, the effects of these can be managed through self-care, workplace adjustments and flexibility on the part of employers and employees [55-57,68]. Alternatively, Pinder interprets this search for credibility as participants being 'brought face-to-face with the differing imperatives of the medical profession, with its stress on mind-body dualism, and the labour market, which emphasises productivity and performance' [66] with the explanations of the former being inadequate to the latter.

Negotiating flexibility

Across all the papers concepts of flexibility and workplace adaptability were seen as significant factors (even 'vital' [54,63] or 'crucial' [67]) in shaping the ability of people with MSDs to retain employment or to be more productive at work [57]. Gilworth *et al's* [63] study

highlighted the importance of flexibility of employers (in terms of giving the employee time off work for hospital appointments, offering flexi-time to work around 'bad' days and providing alternative tasks) and of employees (in terms of 'adjusting their attitude or action' by, for example, adapting or changing their jobs) in accommodating the unpredictability of fluctuating symptoms. Other studies noted how employees conserved energy for work by restricting their social lives and reducing their domestic duties [57,62,63,68].

In the majority of studies [54-57,61,63-68], participants reported negotiating adjustments to duties, working hours, or equipment on an informal basis with colleagues and/or line managers without reference to formal organisational processes or the involvement of occupational health (where available). These informal adjustments relied on sympathetic and cooperative colleagues, but some participants also described feelings of 'being a burden' and insecurity about colleagues' or managers' attitudes towards them changing [56,61,64,67]. Such informal adjustments also relied on the degree to which participants had the autonomy to negotiate and implement them within their workplace. For participants in low-skilled, low paid work, access to flexible working was limited [54,68], whereas those in higher status roles (and some self-employed participants) had greater ability to negotiate flexible working and workplace adjustments [54,57,61,64,67]. The ability to negotiate formal or informal adjustments also relied on the nature and quality of relationships within work, which we discuss further below.

Whilst flexibility was widely perceived to be essential for maintaining employment with a chronic MSD, the perceived limits of flexibility were noted across the studies. The fluctuating and unpredictable nature of MSDs meant the ability of participants to access workplace adaptations and maintain the required flexibility varied significantly. Participants in some

studies reported being advised to move around regularly to ease their condition, but felt that the nature of their work or organisational demands prohibited this [56,57]. A participant in one study reported being unable to change posture due to being pressured to stay at his desk by his employer [56]. Another perceived limit to flexibility was the degree of employees' workplace autonomy, with self-employed workers reporting being more able to manage their own time and work schedules than employees [57,64,67]. However, higher status roles were also perceived to have limits to flexibility, thus one participant, a personal assistant to a company executive, felt that her condition limited her ability to meet her boss' needs and she had relatively little autonomy to allow her flexibility when required [65].

Relationships at work

Most studies explored how having a chronic MSD affected existing workplace relationships and gave examples of both supportive and unsupportive responses from employers and co-workers. For many participants, the quality of their existing relationships with others at work determined how open they were about their health problem at work. Fear of being labelled a 'fraud' or perceived as unreliable by employers or colleagues led some to conceal their condition at work or in order to obtain work [55,62,63,67]. Where participants did not conceal their condition, studies noted that the invisibility of symptoms led participants to worry that colleagues and managers would doubt the genuineness of their condition, or that they would be hostile towards them [55,57,58,61,62,65-69]. These doubts and tensions often arose from managers and co-workers lacking knowledge and understanding about the fluctuating nature of MSD conditions [58,62,64,65]. Participants whose managers doubted the validity or seriousness of their condition had difficulties in negotiating flexible working or workplace adjustments [54-57,67,69]. In turn, the unwillingness of employers to implement reasonable adjustments could lead to conflict between the individual requiring the adjustment and their

employer [54,56,65,66[67]].

A number of studies commented on how line managers' support to employees with MSDs could be contingent upon their already having a good relationship with them [54,63,65,66], the value placed on the particular employee [63,65] or the level of understanding of their health condition [57,65-67]. This is illustrated well by Pinder's [65] in-depth study of the experiences of two office workers with rheumatoid arthritis; the study contrasts the experience of 'Sally', whose manager also had rheumatoid arthritis and whose personal knowledge meant she could offer Sally advice and support on how to manage at work, with that of 'Elaine' whose manager did not understand and could not accept her illness, leading him to dismiss her whilst she was on sick leave, despite their previously close working relationship.

In some studies participants reported that co-workers could provide practical support with work tasks that the individual struggled with, making it easier for them to remain in work [57,61,64]. However, there were also instances where the individual felt a burden to colleagues when work tasks they were unable to complete were passed to others [57,63,64]. In addition, one study noted how workplace adjustments were withdrawn following apparent 'jealousy' on the part of other workers [67].

Individuals' attitudes to work

A number of studies explored individuals' attitudes towards work and how these are affected by the onset of MSDs [54,59,60,64,67,69]. Participants discussed how work provided meaning, social support and financial benefits all of which were motivating factors to remain in or return to work [54,64,67,69]. In addition, participants in three papers saw a further motivation as work distracted them from the negative effects of their condition [54,67,69]. Participants also

described being '*devastated*' by job loss [62,64], suffering depression whilst being off work [67] and undertaking significant personal battles to maintain employment [54,61,62,67,69].

Studies that explored how participants' cognitive representations of their conditions shaped their employment trajectories identified contrasting beliefs about MSD symptoms and their impacts on the ability to work [54,59,60,69]. Kalsi *et al* [69] emphasised how individuals who accepted 'pain as a permanent part of life' and developed 'positive coping representations' were better at considering alternative employment or being prepared to make changes to maintain employment. McCluskey *et al* [59] referred to the 'self-limiting behaviour' of unemployed individuals and their significant others who perceived manual work as the cause of their back pain and were fearful and pessimistic about the likelihood of returning to work [59]. In a similar vein, Brooks *et al* [54] referred to accounts of 'helplessness' from unemployed individuals with back pain who emphasised that their condition prevented them doing things, drawing a contrast with employed participants in the sample who focussed more positively on what they could do. This study, however, points to the importance of work context: the unemployed study participants were previously employed in manual occupations, which generally have less scope for workplace adaptations [43], while the working participants were employed in higher status roles in which they reported they had flexible working conditions and the autonomy to negotiate or implement adjustments. These social class contextual differences are likely to have shaped participants' contrasting attitudes to work.

Third-order interpretations and line of argument

Drawing on the key concepts identified across the studies, we identified four third-order interpretations which we incorporate here into our 'line of argument'.

Diagnosis of uncertainty

People with chronic MSDs experience pain, stiffness and fatigue which can negatively affect their physical capacity to fulfil their work duties and the concentration required to execute them well. These symptoms fluctuate, flare-up and are unpredictable in terms of their frequency and intensity. This creates uncertainty and doubt for individuals – and their work colleagues and employers – regarding their ability to fulfil their work duties.

For many people with chronic MSDs, the diagnosis, treatment and management of their condition necessitates repeated and ongoing encounters with health professionals. Where symptoms are conferred a clear clinical diagnosis, this reduces some of the uncertainty that the onset of a chronic MSD brings and can form the basis of a legitimate request for workplace adjustments. However, the perceived or actual failure of the healthcare system to fulfil its functional role in legitimating sickness through diagnosis can undermine the desired return to ‘normality’ or adjustment to this new ‘bodily doubt’ [72]. On the other hand, the absence of a clear diagnosis (and therefore appropriate treatment) may also be perceived as conferring legitimacy to individuals who are not able to return-to-work.

Struggle to maintain stable work identity

The uncertain and fluctuating nature of chronic MSDs can cause individuals to doubt their ability to fulfil their normal and expected employment tasks and responsibilities. The invisibility of the condition may also lead to others’ doubt about the condition’s authenticity, the limitations it poses, and the individuals’ reliability as a worker. For the individual, this leads to a struggle to maintain their identity as a stable and reliable worker and colleague. To manage

this instability individuals mobilise different strategies, including seeking medical legitimacy and ‘cure’; denying or concealing their condition at work; working when ill (presenteeism); negotiating work adjustments with their employer; and changing occupation and/or employer. Where these strategies fail, individuals risk moving into long-term sick leave, leaving work and claiming unemployment or health-related benefits, or retiring early on medical grounds. Individuals may experience several of these employment outcomes during their working lives. The differing employment trajectories following onset of a chronic MSD - work retention, job change, job loss, and early retirement - are determined by the degree of organisational flexibility and autonomy available to the individual, as discussed below.

Flexibility

Workplace flexibility is regarded by many individuals with fluctuating MSD symptoms as the key factor helping them retain employment. In the absence of an occupational health system within many workplaces, the implementation and continuation of appropriate workplace adjustments and flexible working often rests on informal agreements reached through negotiations between the individual and their line manager or employer. Decisions to implement temporal flexibility (reduced hours, time off to attend medical appointments, flexi-time to work around flare-ups) or task flexibility (altered duties) to support work retention are then highly conditioned by the following: the quality of the employee/employer relationship; the perceived value of the employee to the organisation; the employee’s knowledge of their employment rights; their ability to draw on colleagues’ informal support and agreement for adjustments, or on outside support, for example from health professionals; and employers’ and colleagues’ understanding of the nature of the condition and a willingness to accommodate its fluctuations. However, managers may resist requests for workplace flexibility if they doubt the legitimacy of the condition or if flexibility conflicts with organisational demands or processes.

Flexibility outside of the workplace may also be needed to support work retention; people with chronic MSDs may reduce their domestic and social activities to save sufficient energy to maintain their employment, which requires understanding and support from significant others.

Autonomy

The ability to maintain an identity as a dependable and reliable worker, despite having a fluctuating and chronic MSD, and to negotiate workplace flexibility to achieve that identity, is conditioned by the degree of autonomy available to the employee. The desire to remain in work requires individuals to act flexibly themselves by changing their occupations or employer, or restricting their social and domestic lives to save energy for work. Where they have the autonomy to do so, they may adapt their own work tasks or working hours to accommodate their symptoms or request these adjustments from their employer. The level of autonomy individuals are able to exercise in the workplace is itself determined by the nature and conditions of their employment; professionals and self-employed workers have greater ability to negotiate workplace adjustments or manage their own time and work schedules than manual workers and employees.

Discussion

This review used meta-ethnographic methods to explore the employment consequences of having a chronic MSD in the UK, to identify the factors that shape employment trajectories following onset of an MSD, and to identify the resources individuals with MSDs draw on to remain in or return to employment. The papers included in the synthesis identified several adverse employment outcomes of having a chronic MSD, including long-term sick leave, job loss, early retirement and the presence of institutional, organisational, social and personal factors that pose barriers to returning to work. Remaining in work was aided by having a clear

diagnosis, having occupational tasks commensurate with altered abilities, and having employers and co-workers who understood the nature of the condition and provided practical support. In addition, participants adopted various strategies to remain in work that required the ability to act autonomously within or outside of the workplace, such as reducing working hours or becoming self-employed; using sick leave to cope with flare-ups; organising or adapting work tasks around pain and other symptoms; requesting workplace adjustments; changing occupations; and curtailing social and domestic activities.

Autonomously adopting strategies to support work retention is consistent with the ethos of UK health policy that encourages individuals to self-manage their long-term condition. However, in our review study participants unable to exercise autonomy at work were less likely to remain in work or anticipate a return-to-work. This is an important finding given that in the UK over the last 15 years levels of work autonomy have declined, both in terms of when and how work is completed and job content, and particularly so for low-skilled clerical workers [73]. In contrast, in Nordic countries, where job quality and trade union membership are higher, work autonomy remains above the EU average [73]. That working conditions vary by welfare regime illustrates the importance of focussing our review on the UK context; the inclusion of evidence from Nordic countries may have masked the negative impacts of MSDs on employment and the importance of autonomy for work retention. Declining levels of work autonomy in the UK are also of concern because low work autonomy, in combination with high work intensity, is associated with high risks of musculoskeletal disorders, cardiovascular disease and depression [74,75]. Thus, low autonomy provides both a mechanism for increasing the prevalence of MSDs and for worsening employment outcomes post-onset.

Several studies in the review identified organisational flexibility as crucial for work retention.

Organisational flexibility is particularly important for accommodating *fluctuating* chronic health conditions, which test the elasticity of organisational culture and working arrangements. Although the Equality Act 2010 requires employers to implement reasonable adjustments to support the recruitment and retention of workers with disabilities, many do not [76]. Non-inclusive workplaces and employment practices lead to high rates of early retirement and unemployment for workers with long-term conditions and disabilities. Reflecting this, in a study of long-term sickness absence employees cited organisational and social factors as the greatest barriers to their returning to work, rather than their medical condition or their ability to manage it [77]. In a recent UK survey, individuals with rheumatoid arthritis cited, in addition to fluctuating symptoms, a lack of others' understanding and unavailability of reasonable adjustments as the main challenges to remaining in work [78].

Employers are more likely to implement physical adjustments than adjustments to working hours, duties and other aspects of the 'social environment', which may be disruptive to the daily operating of the organisation and require their sustained support [27]. In our review this was echoed by Coole *et al* [57]. Another limit to organisational flexibility we identified was that line managers' support to employees with MSDs could be contingent upon their already having a good relationship with them. This has been observed previously [79] and is concerning, firstly because it conflicts with employers' legal responsibilities expounded in the Equality Act, and secondly, because it has negative implications for employees who have difficult relationships with their managers, and for newly recruited employees who lack pre-existing relationships to draw on. We also found the ability to negotiate workplace flexibility was reliant on medical legitimisation of the health condition, education levels, the nature of work (manual versus non-manual) and workplace culture. That most workplace adjustments were self-implemented or negotiated with managers without formal input from occupational health

meant they could be withdrawn, adding to the uncertainty associated with having a chronic MSD. A previous study showed that workplace adjustments can be withdrawn if they cause conflict with colleagues or disrupt workflow [79].

We found that employees' perceived value, both within the organisation and the wider labour market, influences the degree of autonomy and workplace flexibility available to them. Lack of autonomy over the pace or content of work and the unavailability of workplace adjustments negatively affect work retention and employees' perceptions about their ability to return-to-work. Thus, differential access to autonomy and flexibility contribute to the marked disability employment gap in the UK [2] and observed social inequalities in employment rates among people with disabilities and long-term conditions [4,5].

Policy implications

Addressing the marked disability employment gap in the UK is unlikely to be achieved without the combined efforts of the government, clinicians and employers. Government policy has placed more emphasis thus far on return-to-work interventions than measures to promote work retention. However, tackling employment inequity requires a shift in focus and investment to an upstream preventative approach that prevents job loss and premature retirement after the onset of MSDs and other long-term conditions and disabilities. Given the health-damaging effects of unemployment and insecure employment, measures that strengthen work retention will serve to protect the health and wellbeing of individuals with long-term conditions and disabilities.

Measures to protect the employment of individuals with MSDs include the need to embed work retention and return-to-work as clinical outcomes in primary and secondary care, in treatment guidelines and outcome frameworks. Despite calls to do so [80], studies have shown that employment is still not routinely discussed with patients with MSDs and other long-term conditions, especially in secondary care [79,81]. A screening system is needed requiring clinicians to record details of employment status, work difficulties and whether work-related help is needed, such as that developed for clinicians by the Dutch Rheumatology Association [82].

Productivity loss, sick leave, health-related job loss and litigation are costly to businesses. Cost-benefit studies have identified work adjustments that are cost-effective in preventing and managing MSDs [83], while Business in the Community's 2017 'toolkit for employers' [84] on musculoskeletal health has started the process of tailoring the business case for workplace adjustments according to organisational size and sector, but further work is needed. At the organisational level it is also important line managers receive training in the recruitment and management of workers with MSDs and other long-term conditions and disabilities [85]. A recent survey of individuals with rheumatoid arthritis in the UK found the majority of employers do not fully understand the work limitations posed by the disease [78].

Strengths and limitations of the review

Our previous comparative studies revealed marked international variations in employment rates among disabled people due to differences in disability and employment legislation, welfare state provision, and spending on Active Labour Market Policies [4,28,30,51]. In Nordic countries, for example, higher employment rates are observed for people with disabilities than

in the UK because employees have better access to rehabilitation and work-focused healthcare. Thus, we restricted our review to studies conducted in the UK in recognition of this differential ability of welfare states to support and retain workers with disabilities and long-term conditions in the labour market. Whilst our review will have excluded international papers with important insights into the experiences of workers with MSDs and resources they drew on to remain working, such international studies may have limited applicability to the UK context [34]. Previous reviews of the employment experiences of individuals with MSDs have included international literature [26-30] but this makes it difficult to discern the contextual effects of the prevailing welfare regime and national employment legislation from organisational and individual-level factors that influence the ability to remain in employment.

A further strength of our review was its focus on the employment impact of MSDs in isolation, rather than on a range of long-term health conditions. Although some employment experiences may be shared, the causes and consequences of work disability are likely to differ between health conditions. Condition-specific reviews prevent the assumption that the experiences of disabled people are universal and acknowledge ‘the experience of difference-within-difference’ [66]. It is also important to distinguish between static and fluctuating health conditions, and between those that are visible and invisible. As the papers included in this review have shown, the fluctuating and invisible nature of MSDs makes them poorly understood and causes uncertainty for individuals and employers. Condition-specific studies and reviews allow the identification of interventions tailored to the particular needs of people with those health conditions.

Our review explored the employment consequences of having an MSD and the resources

individuals with MSDs draw on to remain in and return to employment. Previous reviews have been limited by focussing on return-to-work rather than work retention, and on barriers to work retention or return-to-work rather than the facilitators or resources that promote them. Identifying factors that enable people to remain in or return to work provides opportunities for policy interventions to strengthen the employment of workers with MSDs.

A limitation of our review is that only a few studies included in it considered how individuals' personal and socioeconomic circumstances influenced their ability to remain in work, preventing an in-depth consideration of how employment consequences of MSDs vary by social position. The limited evidence within the studies revealed that being employed in manual occupations or lacking qualifications made it more difficult to envisage a return-to-work [54,67] or to negotiate work retention with employers [65]. Further studies are needed to explore whether the resources workers with MSDs draw on to remain in or return-to-work differ according to social position.

Musculoskeletal disorders are among the most common causes of disability and health-related worklessness in the UK [10]. The instability and invisibility of MSD symptoms requires individuals with chronic MSDs to draw on a range of personal, social, organisational and institutional resources to navigate work retention or return-to-work post-onset.

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Declaration of interest

The authors report no conflict of interest.

Implications for rehabilitation

- The fluctuating and invisible nature of chronic musculoskeletal disorders (MSDs) creates uncertainty for individuals about their ability to remain working or return-to-work.
- Individuals with MSDs must draw on a range of personal, social, organisational and institutional resources to remain in work following onset.
- Work retention is aided by having: a clear diagnosis; occupational tasks commensurate with altered abilities; and understanding employers and co-workers.
- Organisational flexibility and the ability to act autonomously by changing occupations or self-implementing or requesting work adjustments are particularly important for work retention.

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Figure 1: Flow diagram of search process.

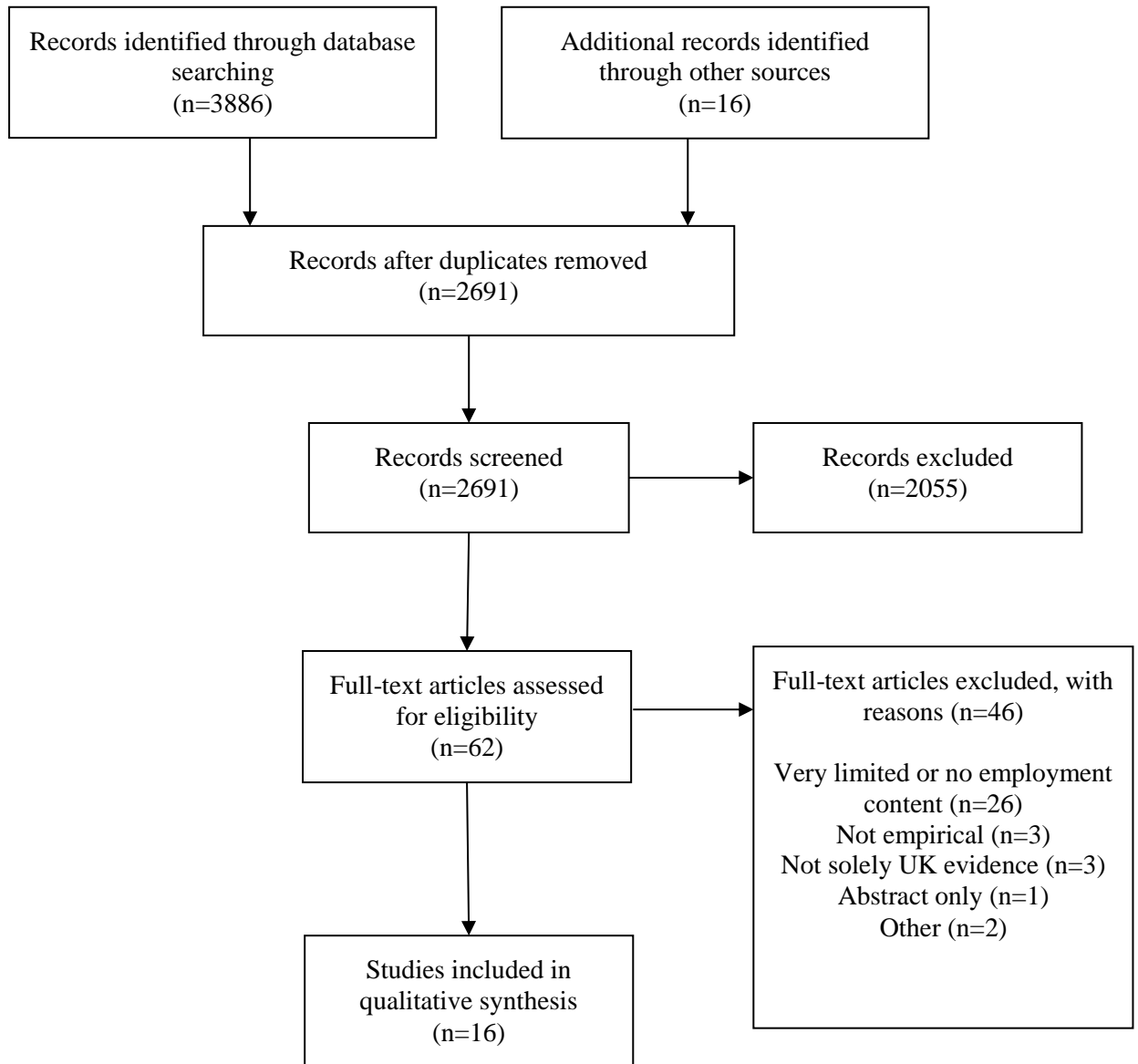


Table 1. Search terms used in the synthesis.

Employment	Musculoskeletal pain	Qualitative methods
"occupational health"	"repetitive strain injury"	ethnograph*
"sick leave"	"Musculoskeletal pain"	"focus group"
"employment"	Tendinopathy	interview
"absenteeism"	Whiplash	(MH "Interviews as Topic")
"occupation"	Fibromyalgia	(MH "Focus Groups")
"work participation"	"Pelvic Pain"	(MH "Qualitative Research+")
"return to work"	"Shoulder Pain"	
"employment status"	"Neck Pain"	
"vocational rehabilitation"	"Back Pain"	
"vocational status"	(MH "Musculoskeletal Pain")	
"occupational ability"	(MH "Musculoskeletal Diseases")	
"stay at work"	(MH "Tendinopathy")	
"job status"	(MH "Whiplash Injuries")	
"presenteeism"	(MH "Fibromyalgia")	
"work capacity"	(MH "Pelvic Pain")	
"employment retention"	(MH "Shoulder Pain")	
"work retention"	(MH "Neck Pain")	
"job retention"	(MH "Back Pain")	
"occupationally active"	(MH "Pain")	
"job performance"	(MH "Chronic Disease")	
"work performance"		
"work attendance"		

"work disability" "work ability" "occupational status" "work status" "sickness absence" (MH "Occupational Health") (MH "Sick Leave") (MH "Absenteeism") (MH "Employment+") (MH "Occupations") (MH "Work")		
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Table 2. Characteristics of studies included in the review.

Author, year	Sample	Method	Setting and recruitment	Aim	Unfulfilled or weak methodological criteria¹
Brooks <i>et al</i> (2013)	9 dyads of patients (6 female; 3 male) with low back pain (in employment (5) or who attributed their unemployment to their back problem (4)), and their significant other (7 spousal relationships, 2 parent-child). All employed patients were in non-manual occupations; unemployed patients had been previously employed in manual occupations.	Individual semi-structured interviews.	A convenience sample of patients reporting non-specific back pain (and significant others) recruited from a hospital pain management clinic in northern England.	To explore whether the illness beliefs of significant others of individuals with back pain differed depending on their relative's working status, and to explore how significant others facilitate or hinder work participation for those with chronic back pain.	2. Evidence of responsiveness 4. Evidence of adequate description
Coole <i>et al</i> (2010a)*	25 patients (13 female; 12 male) with low back pain, all employed, working in the public or private sector in professional, skilled, semi-skilled and unskilled occupations. Most employed in large organisations (>250 employees).	Semi-structured interviews.	A convenience sample of low back pain patients referred to a rehabilitation clinic in northern England.	To explore experiences and perceptions of patients awaiting rehabilitation who were concerned about their ability to work due to chronic lower back pain.	4. Evidence of adequate description
Coole <i>et al</i> (2010b)*	25 patients (13 female; 12 male) with low back pain, all employed, working in the public or private sector in professional, skilled, semi-skilled and unskilled occupations. Most employed in large organisations (>250 employees).	Semi-structured interviews.	A convenience sample of low back pain patients referred to a rehabilitation clinic in northern England.	To explore the experiences of employed people with back pain and their perceptions of how GPs and other clinicians have addressed their work difficulties.	8. Potential for assessing typicality
Coole <i>et al</i> (2010c)*	25 patients (13 female; 12 male) with low back pain, all employed, working in the public or private sector in professional, skilled, semi-skilled and unskilled occupations. Most	Semi-structured interviews.	A convenience sample of low back pain patients referred to a rehabilitation clinic in northern England.	To explore employed patients' experiences and perceptions of work prior to attending a rehabilitation programme.	4. Evidence of adequate description

	employed in large organisations (>250 employees).				
Gilworth <i>et al</i> (2001)	47 employees (29 female; 18 male) with rheumatoid arthritis and 2 employers. Employees were employed in sedentary work (20), light physical work (19) or heavy physical work (4).	Semi-structured interviews.	Yorkshire. A purposive sample of employees with rheumatoid arthritis who had presented to a rheumatologist <1 year after onset.	To explore the employment experiences of people with rheumatoid arthritis and to examine the factors relevant to their remaining in work.	4. Evidence of adequate description 8. Potential for assessing typicality
Holland & Collins (2018)	11 participants (9 female, 2 male) diagnosed with rheumatoid arthritis, 9 employed (4 part-time), 2 left employment after diagnosis. 6 reported period of long-term sick (≥ 4 weeks) leave since diagnosis	Semi-structured interviews	Purposive sample of working age individuals with rheumatoid arthritis recruited through National Rheumatoid Arthritis Society.	To explore individuals' experiences of working following the onset of rheumatoid arthritis, including willingness to remain in work, workplace adjustments and nature of organisational sickness policies that may lead to presenteeism.	
Holloway <i>et al</i> (2007) †	18 people (6 female; 2 male) with chronic back pain recently referred to a pain clinic; only 1 still employed.	Narrative interviews.	A purposive sample of adults assessed as new referrals at a pain clinic in the south of England and diagnosed with chronic benign back pain.	To explore and conceptualise the experiences of people of working age who seek help from pain clinics for chronic back pain.	
Howden <i>et al</i> (2003)	3 case studies (1 female; 2 male) of people with rheumatoid arthritis illustrating 3 distinct employment scenarios.	Semi-structured in-depth interviews.	The sample was drawn from a larger study of pain in people with rheumatoid arthritis.	To explore the work experiences of 3 individuals who have chronic non-cancer pain and to identify factors which may affect their ability to remain in employment.	8. Potential for assessing typicality
Kalsi <i>et al</i> 2016	17 patients (9 female, 8 male) with chronic MSD pain, 8 unemployed >1 year, 4 employed, 5 not stated.	Focus groups	Purposive sample of adult patients attending pain management programme at Royal National Orthopaedic Hospital, UK.	To explore the journey towards stable employment for people with chronic pain.	2.Evidence of responsiveness 4. Evidence of adequate description
McCluskey <i>et al</i> (2011)	5 dyads of work disability benefit claimants (1 female; 4 male) and their significant other (3 spousal relationships, 2 parent-child).	Individual semi-structured interviews.	A convenience sample of work disability benefit claimants (and significant others) on the Lancashire Condition Management Programme	To explore the illness perceptions of individuals with disabling back pain and those of their significant others.	2. Evidence of responsiveness

	Claimants had all been previously employed in manual occupations.		reporting non-specific back pain.		4. Evidence of adequate description 8. Potential for assessing typicality
McCluskey et al (2014)	9 dyads of work disability benefit claimants (4 female; 5 male) and their significant other (7 spousal relationships, 2 parent-child). Eight claimants had previously worked in unskilled manual occupations.	Individual semi-structured interviews.	A convenience sample of work disability benefit claimants (and significant others) recruited from two clinical settings in northern England: a Condition Management Programme, and a hospital-based pain management clinic.	To provide an in-depth examination of the treatment expectations of the significant others of individuals who have become unable to work due to chronic low back pain, highlighting how significant others may influence their recovery and work participation outcomes.	2. Evidence of responsiveness 4. Evidence of adequate description 8. Potential for assessing typicality
Patel et al (2007)	38 unemployed patients (23 female; 15 male) with chronic musculoskeletal pain claiming incapacity benefits.	Semi-structured in-depth interviews.	Recipients of incapacity benefits in Manchester, Bristol, Edinburgh, South Wales who had participated in (18) or had refused to participate in (16) a vocational rehabilitation scheme, and a naive group (4).	To explore the perceived barriers to return to work among unemployed patients with chronic musculoskeletal pain.	2. Evidence of responsiveness 8. Potential for assessing typicality
Pinder (1995)‡	2 case studies of women with rheumatoid arthritis in full-time work at onset.	Ethnography; narrative interviews.	A purposive sample of individuals recruited from a sample of 25 people with different kinds of arthritis in full-time work.	To explore the interface of illness and disability and the public domain of employment. To better understand the experiences of disabled people at work in terms of a dialectic between trust and trouble.	
Pinder (1996)‡	2 case studies of a woman with psoriatic arthritis and a man with rheumatoid arthritis.	Ethnography; narrative interviews.	A purposive sample of individuals recruited from a sample of 25 people with different kinds of arthritis in full-time work.	To explore some of the ambiguities of going sick at work for people disabled with arthritis, and how personal, social and cultural identity is reflected in and shapes disabled people's working lives.	

Ryan <i>et al</i> (2014)	5 female university employees (lecturers or administrative staff) who had returned to work from sickness absence of between 2 weeks to 6 months for lower back pain.	Semi-structured interviews.	A purposive sample of employees recruited from the staff of a UK university.	To explore the experiences of individuals returning to work after an episode of sickness absence due to low back pain.	4. Evidence of adequate description
Walker <i>et al</i> (2006) †	20 (8 female; 12 male) patients with chronic benign back pain. Only 1 patient was employed.	In-depth narrative interviews.	A purposive sample of patients diagnosed with chronic back pain and newly referred to a pain clinic in the south of England.	To elaborate on the lived experience of chronic back pain in those actively seeking help from pain clinics.	8. Potential for assessing typicality

* Reporting on the same study; † Reporting on the same study; ‡ Reporting on the same study

¹ Criteria assigned as follows: 1. Evidence of the privileging of subjective meaning; 2. Evidence of responsiveness to social context; 3. Evidence of purposeful sampling; 4. Evidence of adequate description; 5. Comparing and contrasting different sources of knowledge; 6. Subjective perceptions and experiences treated as knowledge; 7. Evidence of theoretical and conceptual adequacy; 8. Potential for assessing typicality.

Table 3. Key concepts of studies included in the review.

	Pinder 1995 [65]	Pinder 1996 [66]	Gilworth et al 2001 [63]	Howden et al 2003 [64]	Walker et al 2006 [62]	Holloway et al 2007 [58]	Patel et al 2007 [68]	Coole et al 2010a [55]	Coole et al 2010b [56]	Coole et al 2010c [57]	McCluskey et al 2011 [59]	Brooks et al 2013 [54]	McCluskey et al 2014 [60]	Ryan et al 2014 [61]	Kalsi et al 2016 [69]	Holland & Collins 2018 [67]
<i>Employment consequences</i>																
Job loss	X	X		X	X	X	X				X	X	X		X	X
Job retention	X	X	X	X	X	X		X	X	X			X	X	X	X
Workplace adaptations	X	X	X	X					X			X		X		X
Sick leave	X	X		X				X	X	X		X		X	X	X
Change job/employer		X	X	X												X
Leave labour market	X				X	X					X	X	X			X
<i>Fluctuating symptoms and uncertainty</i>																
Impacts of pain/fatigue	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Fluctuations/unpredictability	X	X					X	X			X			X	X	X
Loss of confidence	X	X			X	X										X
Doubts about others' perceptions	X				X		X	X		X				X	X	X
Visibility/invisibility	X	X			X	X	X	X		X	X			X		X

Doubt/negative perceptions	X	X				X	X	X		X					X	
Concealing condition			X		X			X		X				X		X
<i>Encounters with healthcare systems</i>																
Poor/ineffective diagnosis and support		X		X	X	X	X	X	X	X			X		X	
Multiple consultations		X		X			X						X			
Uncertainty/loss of control		X		X		X	X						X			
Control/desire for certainty		X		X	X	X	X	X					X	X		
Limits of sick leave	X		X		X			X						X		
<i>Negotiating flexibility</i>	X	X	X	X			X	X	X	X		X		X		
Vital for work retention			X				X			X		X		X	X	X
Limits of flexibility	X	X	X						X	X		X			X	X
Employee flexibility	X		X		X		X		X	X	X				X	X
Employers'/managers' attitudes	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X
Colleagues' attitudes			X	X		X				X				X	X	X
<i>Relationships at work</i>	X	X	X	X	X	X	X	X	X	X		X		X		X
<i>Individuals' attitudes towards work</i>							X				X	X			X	X

