

**‘Whenever I can I push myself to go to work’: a qualitative study of experiences of
sickness presenteeism among workers with rheumatoid arthritis.**

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Abstract

Purpose: UK government policy emphasises the importance of continuing to work for recovery from poor health, yet sickness presenteeism (going to work whilst ill) is commonly regarded as having negative consequences for organisations and individuals. Our study explores experiences of working after onset of rheumatoid arthritis (RA), a chronic musculoskeletal disorder characterised by high rates of work disability.

Materials and methods: An exploratory qualitative study consisting of in-depth interviews and six-month follow-up with 11 men and women with RA employed at disease onset.

Results: We expand upon previous models of sickness presenteeism by distinguishing between presenteeism that occurs voluntarily (wanting to work despite illness) and involuntarily (feeling pressured to work when ill). RA onset affected participants’ ability to work, yet motivation to remain working remained high. The implementation of workplace adjustments enabled participants to stay working and restore their work capacity. Conversely, managers’ misinterpretation of organisational sickness absence policies could lead to involuntary presenteeism or delayed return to work, conflicting with the notion of work as an aid to recovery.

Conclusion: Workplace adjustments can facilitate voluntary sickness presenteeism. To reduce work disability and sickness absence, organisational policies should be sufficiently flexible to accommodate the needs of workers with fluctuating conditions.

Key words: sickness presenteeism; sickness absence; rheumatoid arthritis; musculoskeletal disorders; workplace adjustments; organisational policy.

Implications for rehabilitation

- Individuals with rheumatoid arthritis (RA) are at high risk of work disability.
- Individuals' motivation to remain in work following onset of RA remains high, yet sickness presenteeism (working while ill) has received largely negative attention.
- It is important to distinguish between voluntary and involuntary forms of sickness presenteeism.
- Workplace adjustments facilitate voluntary sickness presenteeism (wanting to work despite illness) and improve job retention and productivity among workers with RA.
- Involuntary presenteeism (feeling pressured to work while ill) may occur if organisational policies are not sufficiently flexible to accommodate the needs of workers with RA.

Background

Rheumatoid arthritis (RA) is an inflammatory chronic musculoskeletal disorder associated with high rates of job loss and sickness absence [1-2]. Symptoms of RA include painful and swollen joints (particularly upon waking), chronic fatigue and flu-like illness [3-4]. RA is a permanent condition but unpredictable flare-ups of symptoms are common and may require medical consultations for adjustments to medication [3-4]. Reduced physical functioning can impact on the ability to self-care and complete occupational and other activities and this, in combination with the physical symptoms of RA, can lead to depression, anxiety and suicidal ideation [3-4]. Difficulties caused by the symptoms of RA, the unpredictable nature of the condition and the uncertainty this causes for individuals and their employers leads to high rates of work disability, with between 20-70% of individuals with RA becoming work-disabled 7-10 years after onset [1].

Onset of RA peaks between the ages of 40-60, a stage of life where being in employment is the social norm. Previous studies have shown that continuing to work after onset of RA is of considerable importance to most individuals of working age [2], and that doing so reduces pain and increases quality of life [5-6]. Evidence regarding the benefits of good quality work for health and wellbeing [7] underpinned the recent introduction of the *Fit Note* and *Fit for Work* service¹ in the UK. These policy initiatives emphasise that working can aid recovery from poor health, and highlight the roles healthcare professionals and employers have in providing work-focussed healthcare and workplace adjustments to promote job retention and early return to work from sickness absence [8-10]. However, this stance that working while ill should be encouraged is at odds with most academic literature, in which sickness presenteeism (going to work “despite complaints and ill health that should

¹ The Statement of Fitness for Work (‘Fit Note’) allows clinicians to state a patient ‘may be fit for work’ if employers implement appropriate workplace adjustments to working hours, duties or equipment [8]. Employers and general practitioners can refer workers on sick leave to Fit for Work for free occupational health and return to work support [9].

prompt rest and absence from work” [11,p.503]) has been conceptualised as a negative behaviour posing economic costs to organisations and risks to individuals’ future health [12-13]. We argue, however, that the context in which sickness presenteeism occurs is important and distinctions should be made between voluntary sickness presenteeism, where individuals with chronic conditions who wish to work are facilitated to do so through employers’ support, and sickness presenteeism that occurs involuntarily through organisational pressure to work when ill. This paper explores how individuals’ motivation to work and organisational policy and practice can lead to voluntary and involuntary forms of sickness presenteeism following onset of RA.

Sickness presenteeism

The majority of research into sickness presenteeism has focussed on negative health consequences for workers [14], with little exploration of positive benefits. For example, a recent review of prospective studies found presenteeism is associated with a subsequent increased risk of poor self-rated health and future sickness absence [13]. However, most studies on the health consequences of sickness presenteeism have been restricted to general populations of employees, and the relationship between sickness presenteeism and subsequent health and absenteeism in workers with long-term health conditions is less clear. Research which has included workers with long-term conditions has concluded that health conditions such as arthritis are associated with reduced productivity [12]. Thus presenteeism is represented as a ‘problem’ organisations need to address. However, focussing on productivity losses to organisations precludes that supporting individuals to remain working, even if below par, may benefit both employees and organisations by avoiding long-term sick leave and retaining valued staff. As Johns [14,p.521] suggests, “presentees will surely be more productive than absentees”. Further research is needed that explores individuals’ experiences of working after diagnosis of a long-term health condition.

The personal and organisational context of sickness presenteeism

The government's stance that working while ill can be positive for workers when properly supported [15] highlights the importance of the personal and organisational context in which sickness presenteeism occurs. Theoretical models offered by Aronsson and Gustaffson [16] and Johns [14] for researching sickness presenteeism suggest that individuals' decisions to go to work whilst ill or take sick leave are not solely based on the extent of illness or capacity loss but are influenced by attendance demands. These demands can be personal factors, such as financial demands and boundarylessness (difficulty in saying no), and work-related factors including their perceived replaceability, work demands, control over the pace of work [16], organisational absence policies, job security and team work [14]. Other factors influencing the decision to attend work when ill include concerns about passing infectious illness to co-workers, beliefs concerning the acceptability of presenteeism [17], attitudes towards work and taking sick leave [14] and management responses to presenteeism [18-19].

Sickness presenteeism can be conceptualised as occurring voluntarily (wanting to work despite illness) or involuntarily (demanding personal and work-related factors mean that the consequences of absence are too high) [20]. Previous studies have demonstrated that sickness presenteeism may have negative impacts if it occurs involuntarily because of organisational pressure to work when ill, for example, as a result of punitive organisational sickness absence policies [21-23].

In contrast, the concept of voluntary sickness presenteeism, whereby individuals work while ill because they find it to be beneficial, has often been overlooked. However, evidence suggests that when voluntary, and with organisational support, sickness presenteeism can be beneficial for individuals being rehabilitated back into work after long-term sickness [16,24].

The UK Equality Act 2010 obliges employers to make reasonable workplace adjustments² to accommodate the needs of disabled workers [25]. Organisational rehabilitation policies, such as phased return and light or modified duties which are mutually agreed and supportive, can have positive consequences for both organisations and individuals, enabling organisations to retain experienced and trained staff and allowing employees to maintain self-confidence and skills [16,24]. For workers with RA, the adoption of flexible organisational policies and appropriate workplace adjustments has been shown to be efficacious in facilitating job retention, reducing sick leave and aiding return to work [26-29]. Episodes of symptom remission and flare-up can cause workers with RA to cycle between periods of normal productivity, reduced performance and short-term sickness absence [30], but those able to negotiate necessary workplace adjustments are likely to have improved health and work outcomes [31]. However, a systematic review of disability and organisational culture found that physical workplace adjustments are more likely to be implemented by employers than adjustments to working hours, duties and other aspects of the ‘social environment’ which require their sustained support and are disruptive to the daily operating of organisations [30]. Indeed, a study on long-term sickness absence found 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 [32].

Most studies on experiences of sickness presenteeism have excluded the perspectives of workers with long-term health conditions or disabilities, who have to frequently grapple with decisions about whether to work while ill throughout their working life. Previous studies have also been limited by overlooking the perceived benefits of working while ill among workers with long-term conditions and the concept of sickness presenteeism as a voluntary

² Reasonable adjustments include technical accommodations (modified computer keyboards, voice recognition software), adjustments to increase workplace accessibility (ramps, lifts), and social support interventions (adjustments to working hours, tasks and the location of work) [33].

behaviour. This study seeks to address these gaps in knowledge, and to identify ways health professionals and employers can support workers with RA who wish to remain working, by exploring experiences of sickness presenteeism among workers with RA. We draw on the sickness presenteeism models of Aronsson and Gustafsson [16] and Johns [14] to explore individuals' experiences of working following the onset of RA, including how their willingness to remain in work, the availability of workplace adjustments and the nature of organisational sickness absence policies can lead to voluntary and involuntary forms of sickness presenteeism.

Method

Participants and procedure

A qualitative approach was adopted as the study aimed to gain an in-depth understanding of participants' experiences of working following onset of RA and their perceptions of how their condition had affected their work capacity and workplace relationships (findings on workplace relationships are reported elsewhere [34]). The authors are experienced researchers with expertise in health inequalities research and the impact of long-term conditions on employment (first author), and in sickness presenteeism and organisational policy and practice (second author). The study arose from the first author's previous quantitative research which documented the prevalence of worklessness among individuals with musculoskeletal disorders [35] and other long-term conditions [36-37] but raised questions regarding how people with long-term conditions experience employment following onset of illness, and phenomena important to their job retention or job loss. Fewer studies have been conducted on the experiences of workers with long-term conditions than on their employment levels [38].

The study was approved by Lancaster University's Research Ethics Committee and advertised on the website of the National Rheumatoid Arthritis Society (NRAS). Individuals interested in participating were invited to contact the first author by email or telephone for a participant information sheet and consent form. Questions about the purpose of the study and the nature of the interview were answered by email or telephone according to the wishes of the individual. Participants were selected using purposive sampling and were recruited if they were of working age, diagnosed with RA and had been employed at first onset. Recruitment was limited to the North West of England due to the exploratory nature of the study. By completing their consent form participants consented to their anonymised accounts being included in publications. The sample of 11 participants was interviewed by the first author in their homes (n=10) or by telephone (n=1). In-depth semi-structured interviews were used to explore the employment experiences of participants since RA onset. The interviews followed a standard interview schedule of pre-defined open-ended questions but with sufficient flexibility to allow participants to raise issues they perceived as important. Key topic areas included the impact of RA on the ability to work and on work relationships; the implementation and efficacy of workplace adjustments; and factors perceived as important in maintaining employment. Interviews lasted around one hour and were digitally audio-recorded. Additional notes were made during and immediately after interview. Participants were contacted again by email six months later for an update on their work situation and their written updates were included in the data analysis.

Data analysis

In accordance with the epistemological stance adopted in this study we viewed the narrative accounts of participants as being socially constructed, in that respondents have given meaning to incidents, situations and their context and have acted accordingly. Interviews were transcribed verbatim. Transcripts were analysed using thematic analysis, a

method for identifying, organising and analysing textual data into patterns or themes [39]. The first author coded the printed transcripts manually using highlighters and assembled the codes into basic themes. Basic themes similar in content and meaning were classified into sub-themes. Data extracts relating to each sub-theme were collated into individual word-processing documents, enabling the identification of overarching or global themes. Global themes were identified if they captured important aspects of participants' employment experiences or if an issue was raised by several participants [39]. Data coding and the content of the final themes and sub-themes were reviewed and validated through discussion with the second author. Data analysis revealed several global themes: four relating to presenteeism are presented here, while themes relating to the impact of RA on workplace relationships and experiences of conflict and support with employers and colleagues are reported in a separate paper [34]. The coding tree, with themes and sub-themes, is presented in figure 1. All participants have been assigned pseudonyms.

[Figure 1 about here.]

Study participants

Eleven participants (nine women, two men) were interviewed; all were white British, born in the UK and aged between 32-58 years (table 1). Median time since diagnosis was 3 years (range 1-15 years). Two participants had left employment since diagnosis; one was a home-maker caring for her children, and one had retired early from a nursing career in the National Health Service (NHS) at age 46. Nine participants were still employed at interview (four working full-time, five working part-time), three of whom were on sick leave at interview. Following diagnosis, one full-time worker had left their job and become self-employed; at 6-month follow-up another full-time worker reported having become self-employed since interview. Participants worked in professional/administrative and semi-skilled occupations across the private and public sectors. Six of the 11 participants reported

having had a period of long-term sick leave since RA onset (defined as four weeks or longer [40]). Spells of long-term sick leave ranged from six weeks to nine months; three participants reported sick leave of six months or longer, from RA onset until a suitable medication regimen had been established.

[Table 1 about here.]

Results

Data analysis revealed four key themes relating to presenteeism: 1) The perceived importance of work; 2) Seeking normality after first onset; 3) Keeping productive, and employed, through workplace adjustments; 4) Sickness absence policies causing pressure to work.

The perceived importance of work.

All participants still employed at interview expressed the importance of their remaining in work, many attributing their determination as a major factor in doing so:

There is a statistic somewhere that says within 5 years of diagnosis most people have given up work, and I, when I was reading up on the disease, looked at that statistic and thought ‘well that’s not going to happen to me’ because I was 41 at the time and I thought I can’t see myself at 46 not working. Lisa, age 44, sales co-ordinator.

Being of working age and at a period of life where employment is largely the norm, work was highly valued and the “need” to work commonly expressed: the need to work to be productive; to earn; to keep physically and mentally active; to gain social stimulation; and to provide distraction from pain and fatigue. Participants who were currently working (albeit

with some or considerable difficulty) appreciated their ability to do so and wished to remain working as long as they could.

The importance of working was particularly emphasised in the accounts of individuals who had experienced long-term sick leave. Sickness absence was common after first onset of symptoms and some participants reflected that not working had negatively affected their mental health. Loss of routine, social isolation and boredom led to reduced wellbeing, although it also seemed to heighten the resolve to stay working. Sarah declined her rheumatologist's offer of declaring her permanently unfit for work:

I became quite depressed, not just because of how ill I was, but because of being stuck in...when you go to work you see different people and it's a break...Even if I've only made it in work for two hours I feel better in myself for doing it so that's why I've fought to try and stay on...I'm only 33 there's no way I want to give up work now and be stuck at home for the rest of my life. Sarah, age 33, production planner.

I wouldn't want to sit at home all day because it is soul destroying and I find it really hard being at home, I miss the stimulation of work and the company of other people. Jackie, age 46, pharmacy technician.

This determination to stay working was a thread running throughout participants' accounts and appeared to drive voluntary sickness presenteeism (see '*Seeking normality after first onset*'). Determination to remain working, along with recognition that assistance was needed to achieve it, also appeared instrumental in the initiation of requests for workplace adjustments (see '*Keeping productive*').

Seeking normality after first onset.

Participants' accounts suggested that continuing to work after the first onset of RA was important in maintaining a sense of normality in the face of illness. Some spoke of being in denial of their early symptoms and forcing themselves to carry on working in the same capacity as usual, until it became clear to themselves or others that help was needed. Dawn was employed as an NHS Direct telephone health advisor when her symptoms started. Her pain "*got gradually worse and I kind of put it to the back of my mind*" until it got so severe she had to inform her supervisor: "*I said 'I just can't, I can't carry on', I couldn't hold the mouse, I couldn't write, I couldn't type, I said 'I'm in agony'*". Dawn took several months' sick leave then resumed work on a phased return. However, she reported "*it was like I'd done too much too soon*" and pain and fatigue resulted in further sick leave.

Charlotte, an NHS nurse, also ignored her early pain: "*I was in denial really that I had this problem*", and carried on working despite her hand being badly deformed, even when her finger tendon ruptured: "*this finger was just hanging down like a rag...Anyway I still went to work; put my splint on and drove to work*". Her nursing colleagues intervened and arranged an appointment for her at the rheumatology clinic where she was advised to have wrist surgery. Following surgery Charlotte commenced a phased return to work: "*I was told...no heavy lifting ever again but I thought well surely I can carry on working without any heavy lifting*". However, she struggled with most physical tasks, often asking the husbands of her female patients to snap the top off the glass ampoules when giving injections. This appeared to affect her self-efficacy ("*I used to feel a bit of an idiot.*")

Other participants also referred to the dangers of 'overdoing' it early after onset before workplace adjustments had been put in place. Sarah's wish to carry on working meant that:

Whenever I can I do push myself to go in work...My doctor actually wrote me a note 'do no more than four hours until I had got some better treatment' because what I was doing at first was trying to do more hours and knacker myself up and only ending up doing a couple of days a week. Sarah, age 33, production planner.

Clive, a postal worker, also reported that before he was given alternative duties, continuing to post letters worsened his wrist pain and had resulted in sick leave.

The fluctuating nature of RA, particularly soon after onset, made maintaining a sense of normality difficult; flare-ups caused several participants uncertainty about their ability to continue working. Frequent spells of absenteeism in a six-month period made Rachael depressed and suicidal:

I sat looking at all my tablets and I kept thinking it would just be so easy now just to take all these...I kept thinking I don't want to be in any pain...I had to snap myself out of it but I was just so depressed and miserable and I didn't want to give up work, I didn't want to give up living really but I just couldn't see a way out of it. Rachael, age 46, nursery cook.

To avoid 'overdoing it' and needing time off work, participants referred to learning to pace themselves and saving enough energy for work by resting on their days off, taking naps or restricting their social life. However, they reported that the implementation of workplace adjustments was most crucial in enabling them to return from sick leave, improve their productivity and remain working.

Keeping productive, and employed, through workplace adjustments.

All participants reported that RA affected their capacity to work in some way, due to pain, stiffness, fatigue or impaired concentration. Limited physical dexterity affected manual

and non-manual workers alike: office workers reported difficulties typing and sitting still for long periods; the postal worker struggled to walk and post letters on his 3.5 hour round; the nursery cook could not open jars, lift heavy saucepans or chop vegetables; the pharmacist's painful hands made dispensing tablets difficult; the former nurse had struggled giving injections, taking blood pressure and lifting patients.

A minority of participants had sufficient autonomy to arrange their work around their symptoms. During flare-ups, Martin, an NHS medical instructor, chose teaching sessions requiring two instructors so his colleague could perform the demonstrations: "*I plan my own work...I haven't done any less as a result of it, but I have had to modify how it's done.*" The majority of participants, however, requested workplace adjustments from their employers or (in larger companies) their organisation's occupational health services. The employers of all participants appeared willing to implement at least some workplace adjustments, although most often to working hours or equipment rather than duties. On the whole, participants reported that their adjustments were successful and facilitated their return to work, helped improve their productivity and aided job retention. In some instances, workplace adjustments proved to be short-lived and were withdrawn by the organisation.

Adjustments to the physical environment

*Access to Work*³ grants provided specialist equipment such as adjustable chairs and desks, modified computer keyboards, voice recognition software to aid typing and transportation to work. These adjustments were generally efficacious. Sarah's specialist chair supported her shoulders and arms so effectively that "*I have actually found I've done more hours since I've had this...I was staying in work longer.*" On the recommendation of an occupational therapist Lisa received a new chair, a designated parking space and a downstairs

³ The UK's *Access to Work* scheme supports workers with disabilities or chronic health conditions by funding workplace adaptations, personal assistance and travel to work.

office. She perceived that this support had allowed her to return to work before she was fully recovered:

I probably did go back to work when I was maybe 80% better...I needed their support to do it and to be fair I have had that...there were certain things I couldn't do, but there were also things that I could do just as well as I did before and I wasn't asking for special treatment, all I needed was that little bit of help...to make me still be the employee that I was before. Lisa, age 44, sales co-ordinator.

Rachael, a nursery cook, was fortunate to have a manager who had a relative with rheumatoid arthritis so understood the difficulties it imposed. Her manager redesigned the kitchen to accommodate Rachael's needs, installing a downstairs toilet and lift, adjusting the height of worktops and ordering pre-prepared vegetables. Dawn received adaptive equipment through *Access to Work* including a height-adjustable desk allowing her to work standing up if she needed to change position. Like most people with RA, Dawn's symptoms were invisible and ironically it was her specialist equipment that brought her condition to others' attention. Standing at her desk among seated colleagues made her feel different:

When you stand up and your desk is going [makes sound of desk moving] and there is a sea of desks and you are the only one stood up and everyone is like 'oh look at her' you might as well wear a big hat 'look at me - disabled in the corner'. Dawn, age 40, former telephone health advisor, now self-employed company director.

Flexible working

All participants who requested a later start or reduced hours were granted these changes by their employers, at least initially. Dawn's employers arranged her shifts to start later in the day when she was less stiff. Sarah's supervisors allowed her to work around her fluctuating symptoms doing the hours she felt well enough to do:

They have allowed me to work as I can. So some mornings I might not be able to get there until dinner time because of just being in so much pain...it means that I maybe work until only three o'clock. Sometimes I've actually only managed two hours. I've gone in with the full intention of doing as much as I can but two hours has been as much as pain and fatigue has let me do. Sarah, age 33, production planner.

Workplace flexibility could also be demonstrated by offering homeworking. Suzanne worked for a large telecommunications company and requested a laptop so she could work from home when pain prevented her from driving; this allowed her to maintain her 'productivity', a common theme throughout her interview:

I need to be in work. I want to be productive so I made sure I got an appointment with the occupational health people...I said 'if I could have the option of working from home my productive time would be kept up, you won't see a dip in my performance because I don't want my performance to dip, I don't want my sick rates to go up and I don't want my productivity to go down because we are a team and there's no reason why that should happen providing the right things are in place' and she was in full agreement so we got the laptop set up and I can work from home. Suzanne, age 38, administrator.

Suzanne also worked from home on days when she had monthly blood tests "*otherwise you lose 3 or 4 hours from me rather than an hour*". She acknowledged that basing her request for homeworking in economic terms, to maintain her productivity, had appealed to the company: "*it's how you put it to them...I went in with the view that I do not see why it should affect me in any way if the right things are in place...they are getting maximum productivity out of me*" but the arrangement was mutually beneficial. However, it was clear Suzanne had sufficient autonomy to enable her to self-schedule her work tasks and the nature of her job meant homeworking was feasible; she acknowledged there would have been less room for

flexibility had she worked in the call centre section of the company, where time-keeping was closely monitored. Sarah was also initially allowed to work from home when her health prevented her from going into work, enabling her to work flexibly around her symptoms and feel productive:

So 3 o'clock in a morning if I wasn't sleeping and wasn't feeling good I could actually do just a bit of this work. On some days I might have only done half an hour but other days I might have managed to do 8 hours split up into little breaks which was a lot, lot better. If I could [work from home] I'd probably manage to do a lot more hours.

Sarah, age 33, production planner.

Modified duties

Adjustments to work tasks were less frequently arranged than adjustments to working hours or the physical environment. Clive's manager had gout and understood his difficulties; on days Clive was unable to walk his postal delivery round his manager allocated him tasks indoors sorting mail; work he disliked but was manageable when in pain. This availability of alternative tasks had reduced his need to take sick leave when he could not walk his round, and since RA onset he had had only two days' sick leave: "*I could have been off a lot, lot more but I'd rather just go in and get it done, as long as I can drive into work I can go in and do something*". Clive perceived that this flexibility had been pivotal in him retaining his job.

Self-employment

Two participants referred to the importance of self-employment for remaining working. Martin left his job in the NHS and became self-employed because he felt victimised by his line manager's negative attitude towards him (see *Sickness absence policies causing pressure to work*). Dawn became self-employed after leaving her job as an NHS telephone

health advisor over her own concerns that she might not respond to an emergency call quickly enough because her hands were stiff, despite supportive employers who “*did everything that they could have*”. She became depressed after leaving work but six months later became director of her husband’s small business, allowing her to work from home around her symptoms:

From being where I was, I could have, I was losing the will to live, literally, and now I am ‘oh God, I feel really blessed’. Yes I’ve got [RA] but I am dealing with it, I am working, I am actually getting a wage...I am actually company director...so that in itself makes me feel better, I am not unintelligent, I’ve got a brain and it makes me feel good. Dawn, age 40, former telephone health advisor, now self-employed company director.

Withdrawal of adjustments

In some instances previously agreed flexible working arrangements were withdrawn by line managers. In her follow-up email six months after interview, Sarah reported that her homeworking arrangement had been withdrawn due to her co-workers’ jealousy, although her GP recommended that: “*if they want better hours out of me [homeworking] is the way forward.*” Sarah’s manager was also pressuring her to increase her working hours and her desk had been moved to an area of the office inaccessible for her wheelchair, which she construed as signs her employers wanted her to resign. The resulting stress led to Sarah taking a period of extended sick leave.

Charlotte’s managers also pressured her to increase her hours after she had reduced them following wrist surgery. Despite struggling with lifting she was not offered lighter nursing duties and her employers “*weren’t keen*” on the trade union’s recommendation that a colleague could cover her heavy tasks. Like Sarah, Charlotte concluded her employers

wanted her to leave: she was told to use her sick leave “*as thinking time*” to reflect on her future. With no other options available to her she took early retirement at age 46.

Sickness absence policies causing pressure to work.

Several participants’ commented that their sickness absence rates were comparable or better than those of their colleagues, but some also indicated there were occasions when working while ill occurred involuntarily. Lisa tried hard to avoid taking sick leave due to concerns about others’ perceptions of her: “*You don’t want to give anybody any excuse...to say ‘you’re always off sick’. I will probably go the opposite way.*” Other participants described difficulties caused by their organisation’s sickness absence policy or their line managers’ interpretation of it. Fluctuating symptoms caused anxiety about the need for sick leave: *It’s the not knowing...you’ll be absolutely fine one day, you can do anything, then the next day it’s just come*”; “*One day you’re fine, you do a 3, 4 mile walk and the next day you literally can’t get out of bed*”.

Sickness absence caused fear of being disciplined. Clive was concerned he may receive a warning for taking single days’ absence when his wrist pain flared so he consulted his Trade Union for advice. Mandy was concerned her record of multiple absences was being used to terminate her employment; in response she had initiated tribunal proceedings against her employer’s application of the sickness absence policy:

[They were] saying ‘oh right you’ve only got so much sick leave left’ and, it was very stressful...two weeks after I’d returned to work [I had] another absence review meeting and I was advised that my reviews had to go to the head of service for him to make a decision on whether I’d be dismissed...and I’d not even had my adjustments put in place and had not even finished my phased return...but it actually states in their sickness policy that avenues need to be tried and worked out before that’s even

considered, so they were thinking of doing it anyway, they were trying to push me out, trying to get rid of me. Mandy, age 34, call-centre administrator.

Mandy perceived this situation had made her health worse and at interview she was on sick leave for “*work-related stress and rheumatoid arthritis*”.

Fear of being disciplined by punitive sickness absence policies led to some respondents changing their work behaviour in two ways. Firstly, the unpredictability of their RA could cause delay returning to work from sick leave. Jackie, a hospital pharmacist, had been absent from work for four weeks at interview and expressed her fears of returning to work too soon in case she “*failed*” to cope and needed further sick leave, a concern exacerbated by recent redundancies:

The bad news is the way things are at work if I go back and fail, make myself off again, they regard it as worse than if I stay off that bit longer. Jackie, age 46, pharmacy technician.

Secondly, fear of sick leave policies, or their line manager’s interpretation of them, led to some respondents continuing to work when they did not feel able to. This involuntary presenteeism could cause stress. Martin, an NHS medical instructor, had raised two grievances against his line manager whom he described as bullying in her interpretation of the NHS Trust’s sickness absence policy. She had refused to acknowledge he had a disability, had disciplined him for taking two weeks’ sick leave, and requested he take sick leave for hospital appointments. Martin feared losing his job:

Rather than being applauded for getting in there, when some days quite frankly I could have stayed in bed, I got the opposite reaction and it was as if I was seen as a sort of weak link...Yes on the one hand the Trust policy does reflect a very sympathetic attitude towards people with disabilities; individual interpretation is quite another matter. My thoughts are that if I have any length of time off sick because

of RA my current manager would pursue the sickness policy vigorously and I'll find myself out of work. When I hear her saying to me 'oh if you can't get in just work from home' I'm very suspicious that will be reflected in any decisions that are made in future so I make every effort to get in every day on time and do 110%...sometimes it creates quite a stressful situation for me because I don't feel at my best when I have a flare-up but I still drive myself to do what I need to do because I'm fearful that I won't have a job in another 3 or 4 years' time and I have a good job that's well paid, that I love doing but the threat's not from the illness itself it's more from attitude and that's my biggest fear. Martin, age 58, medical instructor.

At six months' follow-up Martin wrote that he had left work and become self-employed due to his manager's treatment of him.

Discussion

Previous research into sickness presenteeism has concentrated upon working populations, with little consideration of whether employees with chronic health conditions were included in the study sample. Where studies have explored chronic health conditions the emphasis of the research has been on productivity losses for organisations [1,41-42]. Our study contributes to the sickness presenteeism debate by considering the attendance behaviours and working outcomes of employees with RA, a chronic health condition, a neglected population in the sickness presenteeism literature. We expand on previous theoretical models of sickness presenteeism [14,16] by exploring individuals' motivation to work and the organisational context in influencing sickness presenteeism behaviour from the perspective of employees coping with RA. We found that sickness presenteeism is a complex phenomenon and that internal and external pressures can lead to voluntary or involuntary attendance behaviours. These are discussed below.

The role of workplace adjustments in facilitating ‘voluntary sickness presenteeism’

Our participants expressed a strong internal drive to stay working despite the onset of chronic ill-health. The implementation of workplace adjustments was perceived by participants as important in restoring their work capacity and enabling them to continue working. We also found instances where adjustments aided return to work and reduced the need for sick leave, which benefitted both individuals and their organisations.

However, while most participants were granted the specialist equipment or altered working hours they requested, adjustments to duties and responsibilities were less frequently arranged, despite the Equality Act 2010 requiring employers to make ‘reasonable adjustments’ to support workers with disabilities. In addition, we found that agreed arrangements to work flexibly could be withdrawn if they subsequently became inconvenient to the organisation. For example, staffing shortages led to Charlotte being pressured to increase her working hours again and this, in addition to the unavailability of lighter duties, led to her early retirement at age 46. We also found that the reaction of colleagues could influence organisational decisions; Sarah’s homeworking arrangement was withdrawn when it provoked jealousy from peers, resulting in her taking further sick leave. This resonates with studies that have shown employers are less willing to make adjustments that disrupt the daily operating of organisations or require sustained effort from employers [30,43].

Punitive sickness absence policies and ‘involuntary sickness presenteeism’

We found sickness presenteeism also occurred involuntarily due to external pressure to work from the implementation of rigid sickness absence policies, to the extent that some participants were reluctant to take sick leave or delayed their return to work to avoid further spells of absence. Sickness absence policies that discipline workers for exceeding fixed trigger points can unfairly penalise employees with chronic and fluctuating conditions [21-23]. We also found that line managers may interpret organisational sickness absence policy in

different ways, supporting previous research [24,44-45]. However, in our study a key factor in how managers' dealt with employees with RA was their knowledge and understanding of the condition. Managers with personal or familial experience of musculoskeletal conditions appeared to be more flexible in terms of interpreting sickness absence policies. How line managers interpret organisational policies has serious implications for both the organisation and the individual, as the consequences for two of our participants indicate: Martin and Mandy had initiated tribunal and grievance proceedings against their employers, which was followed by an extended period of stress-related sick leave for Mandy, and job exit and self-employment for Martin.

Implications for policy and practice

We demonstrate that in studies of sickness presenteeism it is important to distinguish between voluntary presenteeism (wanting to work despite illness) and involuntary presenteeism (feeling pressured to work when ill). Our findings show that, for individuals with long-term conditions who wish to remain working, the implementation of workplace adjustments can facilitate voluntary presenteeism and work retention. Baker-McClearn *et al* [17] suggest such organisational support is mutually beneficial as employees supported to return to work are less likely to drop out of the labour market, while organisations benefit by retaining valued staff. However, our findings expand on this as we found organisational support could be short-lived, due to the withdrawal of agreed adjustments, and undermined by the implementation of sickness absence policies that did not reflect the realities of working with a fluctuating condition. Thus poorly managed voluntary sickness presenteeism led to involuntary sickness presenteeism. Flexible working arrangements and adjustments are important in improving work retention in workers with RA [27-29]. However they also promote wellbeing [26] and working without appropriate work adjustments can lead to stress and worsening health [21]. Organisations vary in their willingness to adopt flexible policies

and practices to support employees with fluctuating conditions and recent reports suggest employers could do more to improve their job retention by implementing workplace adjustments [46-47].

It has been noted that workplace interventions to reduce sickness absenteeism may lead to increased sickness presenteeism [41]; our findings shed light on this effect to reveal that the rigid application of sickness absence policies may lead to increased *involuntary* sickness presenteeism which may have negative consequences for both employees and organisations. Fear of appearing inequitable may lead organisations to perceive they should “be treating everyone the same” in their sickness absence policies [21,p.1466]. On the contrary, in the interests of equity organisations should devise flexible sickness absence policies to avoid penalising workers with fluctuating chronic conditions [48]; disability in the workplace requires employers to “think specially” rather than adopting a “business as usual” approach [43,p.611].

Our findings resonate with previous research that suggests anti-discrimination legislation fails to adequately protect employees with chronic conditions or disabilities from workplace discrimination. Previous UK studies [49-50] concluded that although organisational policies on sickness absence and workplace adjustments may reflect requirements of anti-discrimination legislation, there often exists a gap between organisational policy and line managers’ practice, indicating that some employees with disabilities or long-term conditions have to rely on the goodwill of individual managers. Our findings also point to the importance of line managers implementing organisational policies accurately and fairly to avoid conflict and legal redress. In *Working for a Healthier Tomorrow*, Dame Carol Black emphasised the role of line managers in protecting the health and wellbeing of workers with long-term conditions by “adjusting or adapting working practices, patterns or job roles where appropriate to do so” [10,p.59]. She also recommends

line managers are trained to implement sickness absence policies appropriately if they are to be effective.

Our findings have implications for clinical practice. The participants in our sample were very concerned about their ability to remain working yet we found discussions about work difficulties were rarely instigated by their general practitioners or rheumatologists, despite the addition of employment retention as a clinical outcome for patients with long-term conditions in the *NHS Outcomes Framework* [51]. This resonates with the findings of a recent clinical audit for RA [52]. It is important that healthcare professionals discuss work issues with their patients. The Fit Note provides a mechanism for recommending to employers appropriate alterations to the workplace, duties or working hours to facilitate job retention.

Strengths and limitations

Our participants provided in-depth and rich accounts of their sickness presenteeism experiences and were drawn from sedentary and manual occupations from the private and public sectors and from organisations varying in size. The sample contained more women than men, reflecting the epidemiology of RA [31]. However, there are limits to the transferability of the findings. We were not able to recruit individuals from ethnic minority groups and manual workers were also under-represented in our sample. Both of the manual workers we interviewed perceived they had remained working because their employers had provided them with alternative duties (Clive) or a modified working environment (Rachael). These experiences are likely to be atypical however, as previous studies have shown higher rates of job loss following RA onset in manual workers [53] and that most recipients of support from *Access to Work* are in professional and non-manual occupations [54]. We sought to ensure the credibility of the data in a variety of ways: we clarified key issues with

participants at interview and follow-up; the second author independently confirmed the themes identified by the first author; and we paid attention to diverging accounts.

Most participants were recruited through the NRAS website which will have excluded individuals with RA not familiar with NRAS' services. However, this was an exploratory study which aimed to investigate participants' experiences of working following onset of RA; a larger follow-up study will explore in greater depth the workplace experiences of manual workers and managers' perspectives.

Conclusion

Sickness presenteeism can be conceptualised as occurring both voluntarily and involuntarily. Flexible organisational policies and practices can facilitate voluntary sickness presenteeism by promoting work retention and reducing sickness absence in employees with fluctuating long-term conditions. Conversely, the withdrawal of workplace adjustments or the rigid application of sickness absence policies can lead to involuntary sickness presenteeism, conflicting with the notion of work as an aid to recovery. Further research is needed focusing on the experiences of manual workers with RA, particularly those in low-skilled occupations with fewer opportunities to negotiate alternative work tasks or move into jobs with lighter duties. Research is also needed on how organisations can develop and implement sickness absence policies appropriate for workers with RA and other chronic fluctuating conditions.

Spataro [55] highlights the importance of workforce diversity, the moral and social obligation of organisations to employ disabled workers, and the positive economic and reputational impact for organisations in doing so. Implementing policies and practices that support disabled and chronically ill employees in the workplace are likely to also promote the productivity, health and wellbeing of the wider workforce.

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Table 1. Participants' details.

Pseudonym	Age	Marital status	Time since diagnosis	AT DIAGNOSIS		AT INTERVIEW	
				Occupation (private/public sector)	Full- or part-time	Employment status	Full- or part-time
Charlotte	53	Married; 2 children at home	15 years	Hospital staff nurse (public sector)	PT	Took ill-health retirement at 46	N/A
Amy	32	Partner; 2 children at home	3½ years	Nursery assistant (private sector)	FT	Looks after family & home	N/A
Sarah	33	Lives with parents	18 months	Production planner (private sector)	FT	Employed in same occupation	PT; on sick leave
Dawn	40	Married; 2 children at home	3½ years	Health advisor (public sector)	PT	Self-employed company director (private sector)	FT
Jackie	46	Single; lives alone	14 months	Pharmacy technician (public sector)	FT	Employed in same occupation	PT; on sick leave
Rachael	46	Married; 1 child at home	3 years	Nursery cook (private sector)	PT	Employed in same occupation	PT
Mandy	34	Single; lives alone	1 year	Call-centre worker (public sector)	FT	Employed in same occupation	PT; on sick leave
Martin	58	Married	3½ years	Medical instructor (public sector)	FT	Employed in same occupation	FT
Suzanne	38	Married	18 months	Administrator (private sector)	FT	Employed in same occupation	FT
Clive	43	Married; 1 child at home	18 months	Postal worker (private sector)	FT	Employed in same occupation	FT
Lisa	44	Married; 2 children at home	3 years	Sales co-ordinator (private sector)	PT	Employed in same occupation	PT

Figure 1. Coding tree.



