

## Original article

# Work participation and arthritis: a systematic overview of challenges, adaptations and opportunities for interventions

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## Abstract

**Objective.** Understanding the factors that play a role in maintaining people with inflammatory arthritis in the workforce may aid the design of interventions to support work participation. The objective of this systematic overview is to summarize qualitative studies that explore experiences of patients with inflammatory arthritis to remain employed or return to work.

**Methods.** Bibliographic databases including MEDLINE, EMBASE and PsycInfo were searched until December 2011 to identify any qualitative studies that focused on experiences, challenges or adaptations of patients with inflammatory arthritis to remain employed. Thematic analyses were used to identify any first or higher order themes for which all data were entered into MAXQDA software. In addition, methodological quality was assessed using an eight-item checklist.

**Results.** Of 6338 citations, 10 studies were included. RA was the condition in eight studies. Individual interviews (six studies) were used more frequently than group interviews (four studies). Methodological quality varied from 2 to 8 points and had no effect on the number of themes identified. Thematic analyses showed seven key concepts important to patients, including disease symptoms, management of the disease, socioeconomic issues, work conditions and adaptations, emotional challenges, interpersonal issues affecting work and family life and meaning of work.

**Conclusion.** By including studies from different countries and settings, we show a comprehensive overview of themes considered important by patients and strengthen our belief that these factors should be considered in interventions that aim to improve work participation for patients with inflammatory arthritis.

**Key words:** work participation, inflammatory arthritis, systematic review, return to work, management, employment.

## Introduction

It has been estimated that about 20–70% of people employed at the onset of RA will be work disabled after

7–10 years [1]. Not being able to perform work can have negative consequences, including a decrease in social activities and quality of life, isolation, financial hardship and lower self-esteem. Work is important to patients with arthritis and most patients will go to great lengths to remain employed. The decision to stop working depends on many factors, including personal factors such as coping style and external factors such as working conditions or the social insurance system, and also factors related to the disease, including disease severity as depicted in the International Classification of Functioning, Disability and Health [2].

It is not clear whether vocational interventions reported in effectiveness studies, which aim to reduce work

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disability, target all key aspects important to patients with arthritis [3–6]. In addition, prognostic and survey studies have included many factors predicting work disability [7], but whether they cover all aspects important to patients with arthritis remains to be seen. Qualitative research has value answering these sorts of exploratory questions that cannot be answered by experimental research, such as randomized controlled trials or questionnaire studies.

A better understanding of the factors that play a role in maintaining people with inflammatory arthritis in the workforce may aid the design of vocational interventions that support patients to remain at work or return to work. Confirmation of the concepts by several studies in different settings and disease categories strengthens our belief that these concepts should be used when designing new interventions in clinical settings. The objective of this systematic overview is to summarize qualitative studies that explore the experiences of patients with inflammatory arthritis to remain employed or return to work.

## Patients and methods

### Search strategy and selection

We searched the following bibliographic databases from the start of each database until December 2011: MEDLINE (1966), EMBASE (1980), PsycInfo (1967) and Cumulative Index to Nursing and Allied Health Literature (CINAHL, 1989). The terms selected to identify studies were grouped in three categories combined with the Boolean operator AND: (i) arthritis both as a MESH term and as a free text word, (ii) search terms for identifying survey studies and qualitative studies as published by Shaw *et al.* [8] and used in MEDLINE [9], EMBASE [10], CINAHL [11, 12] and PsycInfo [13] and (iii) work-related terms as proposed by others [14, 15]. The search strategy is available upon request from the authors. Citation searches of relevant studies were performed in ISI Web of Science. Reference lists of relevant studies and reviews were examined.

The focus of this systematic overview was on qualitative studies that summarized experiences by arthritis patients in returning to work or remain at work. Titles and abstracts from the searches were screened against the inclusion criteria listed below and final selection was performed independently by a pair of two researchers using full text articles. Any discrepancies were resolved through consensus.

To be included, the studies (i) focused on experiences, challenges, barriers or adaptations of patients in order to return to work or remain employed; (ii) included patients (>50%) with inflammatory rheumatic diseases (major groups: RA, AS, PsA and lupus); (iii) included respondents who were either working or were employed; (iv) used a qualitative design (interviews, individual or groups) and (v) reported some sort of thematic analyses and showed subsequent narratives or themes in the results.

### Quality assessment

One researcher with the help of another appraised the methodological quality using a checklist developed by Mills *et al.* [16] that was based on the Critical Appraisal Skills Program (CASP) checklist for qualitative studies, resolving any disagreement through consensus. Quality assessment of the included studies was also used to describe the quality of the study in relation to the number and type of themes identified in the studies.

### Data extraction and data synthesis

Characteristics of the studies that were extracted included the type of qualitative methodology used, the setting, the analysis methods used, the type and duration of arthritis, sex, age and work and education characteristics of the study populations. Studies were read by two investigators and the outcomes of interest, i.e. experiences, adaptations, barriers and suggestions for interventions, were identified. Subsequently the major themes were identified in the original studies using thematic synthesis using MAXQDA 2007 (Udo Kuckartz, Berlin, Germany). This created a framework in which the different major themes were structured and discussed by the researchers. Then the summary information from the individual studies was listed and compared with the major themes in our framework and further organized using major headings and subheadings. By comparing and relating the themes in each study with the others, we investigated how the different studies explained and interpreted the themes using thematic analyses [17].

## Results

### Search results and characteristics of studies

The search strategy from six sources identified 6338 citations for possible inclusion, which were reduced to 68 potential studies using only title and abstract. After applying all inclusion and exclusion criteria, using full-text publications, 10 qualitative studies were selected by the two reviewers [18–27]. The 10 studies included between 3 and 47 patients, and the diagnosis of RA was most prevalent (8 studies). The interviews were conducted either in groups (four studies) or individually (six studies). Most patients had sedentary jobs and/or a higher educational level (Table 1). Two studies used the same patient sample but analysed these in two separate studies and were included separately in this review [17, 19].

The quality of the individual studies varied considerably but was not related to the number of themes identified by the individual studies (Table 2). The studies by Barlow *et al.* [20] and Lacaille *et al.* [21] showed similar themes to the rest of the studies (Table 3), representing, respectively, the lowest (score 2) and highest quality score (score 8 = maximum). Quality items scored less frequently included information indicating the researchers obtained data saturation (in three studies) or performed a member check (in five studies).

TABLE 1 Characteristics of studies

Author (year), location	Method of study	Sampling method	Setting	Analyses	Type of arthritis, duration	Number and sex	Age, years	Education and work characteristics
Barlow <i>et al.</i> [20] (2001), UK	Semi-structured telephone interviews	Subset of larger cross-sectional survey (two larger samples of $n = 39$ , $n = 94$ )	First: consecutive patients rheumatology outpatient clinic, second: random sample member of national AS society	Middle order approach	AS, duration in sample 25–30 years	6 persons (men in sample: +/-72–73%)	(sample mean age 44.7–51.1)	—
Detaille <i>et al.</i> [18] (2003), The Netherlands	Concept mapping, in 4 h sessions with maximum 25 employees, led by facilitator	Purposeful sampling	Rheumatology outpatient, academic medical centre, occupational physicians and Dutch association for RA	Patients with help of facilitator sorted statements from patients and prioritized these. Using multidimensional scaling techniques, the statements were clustered	RA, 73% had diagnosis <5 years	8 men, 13 women	Mean age 50, range 23–65	Education: 85% had middle or high level of education Profession: 71% performed light or heavy mental work
Gilworth <i>et al.</i> [26] (2001), UK	Semi-structured in-depth interviews, mostly at people's homes	Purposeful sampling, ensuring range of occupations, some subjects on sick leave	Rheumatology database, pre-senting within 1 year with RA	Content analyses by Straus and Corbin	RA, mean duration 2.3 years, range 2 months to 6 years	18 males, 29 females	Mean age 40, range 26–55	Profession: sedentary work ( $n = 20$ ), light physical work ( $n = 21$ ), heavy physical work ( $n = 6$ )
Howden <i>et al.</i> [27] (2003), UK	Semi-structured interviews at people's homes. Part study on pain experiences	Selected for further analyses as they illustrated three distinct employment histories	Through advertisement at three hospital outpatient waiting areas	Cases were analysed individually, identifying and describing experiences. Discussions between researchers on emerging themes	RA, for at least 1 year	2 males, 1 female	52, 57 and 70	Profession: self-employed painter and decorator, manual work/maintenance/store man, painter
Lacaille <i>et al.</i> [21] (2007), Canada	Five focus groups	—	Outpatient arthritis treatment programme, rheumatologist practices, advertisement, waiting areas, mailed invitations	Script design using brainstorming techniques, root cause analysis to capture in-depth information about underlying causes of problems. Descriptive qualitative analyses	IA, mean duration 11.4 years	5 males, 31 females	Between 18 and +60, 72% older than 40	Education: 75% had community college level or higher Profession: office, clerical, and administrative 10 (28%); management 5 (14%); professional and technical 12 (33%); retail/customer service 3 (8%); manual labour 1 (3%); arts 2 (6%); other 3 (8%)
Mancuso <i>et al.</i> [23] (2000), USA	Home interviews using questionnaire with open-ended and structured-response format questions	Selection using random order generated list	Hospital for Special Surgery, Rheumatoid Arthritis Registry, medical research database from participating rheumatologists	Standard qualitative research methodology in three steps, transcribing, grouping, identifying concepts, reassessment using iterative processes	RA, mean duration 15 years	2 males, 23 females	Mean age 50	Education: 84% college graduate or higher, 76% full-time employed, 95% had either a sedentary or light physical strength requirements Profession: mostly higher professional jobs

(continued)

TABLE 1 Continued

Author (year), location	Method of study	Sampling method	Setting	Analyses	Type of arthritis, duration	Number and sex	Age, years	Education and work characteristics
Nilsson <i>et al.</i> [25] (2007), Sweden	Focus groups, three groups, two groups were seen twice	—	Register hospital department of rheumatology	Constant comparative method by Strauss and Corbin	RA, between 1–4 years, working at least 20h	4 men, 6 women	Mean age 51, range 32–59	Professions: assistant to handicapped pupil, builder, preschool teacher, cook, engineer, foreman, insurance agent, student, supervisor and a teacher
Varekamp <i>et al.</i> [19] (2005), The Netherlands	Concept mapping group session of 5h, led by facilitator	—	Rheumatology outpatient, academic medical centre, occupational health services, and two patient organizations	Patients and facilitator sorted and prioritized statements from patients. Using multidimensional scaling techniques, statements were clustered by researchers	RA, 73% had diagnosis <5 years	8 men, 13 women	Mean age 50, range 23–65	Profession: 71% performed light or heavy mental work, 85% had middle or high level of education
Codd <i>et al.</i> [24] (2010), Ireland	In-depth semi-structured interviews	Retrospective chart review of patients attending early arthritis clinic	Early arthritis clinic	Descriptive approach using interpretative phenomenological analyses to study the transcripts	RA, <2 years duration (range 9–23 months)	3 men, 7 women	Mean age 38, range 25–60	Profession: porter supervisor, office clerk, sales representative, accounts payable manager, retail manager, self-employed mechanic, health professional, dry cleaning business, bank clerk, bank official
van der Meer <i>et al.</i> [22] (2011), The Netherlands	Semi-structured interviews, worker role interview; follow-up 6 months	Purposeful sampling	Rheumatology outpatient clinic of academic medical centre. All patients treated with anti-TNF	Inductive analysis was carried out, using open axial and selective coding	RA, on TNF therapy, mean duration 7.7 years	2 men, 12 women	Mean age 47	Profession: teacher 2, counsellor 2, office or administrative worker 7, caterer 1, driver 1, volunteer 1

RD: other rheumatic disease; IA: inflammatory arthritis (RA, PsA, AS, SpA or SLE with significant arthritis).

**TABLE 2** Results of quality assessment

Categories reported by authors	Barlow <i>et al.</i> [20]	Detaille <i>et al.</i> [18]	Gilworth <i>et al.</i> [26]	Howden <i>et al.</i> [27]	Lacaille <i>et al.</i> [21]	Mancuso <i>et al.</i> [23]	Nilsson <i>et al.</i> [25]	Varekamp <i>et al.</i> [19]	Codd <i>et al.</i> [24]	van der Meer <i>et al.</i> [22]
Data transcribed verbatim	-	+	+	+	+	+	+	+	+	+
Questions predefined or training facilitator	-	+	+	-	+	+	+	+	+	+
Saturation mentioned	-	-	-	-	+	-	+	-	-	+
Description of how the research themes were identified	+	+	+	-	+	+	+	+	+	+
Research findings analysed by > 1 assessor	-	+	+	+	+	+	+	+	+	+
Answer clarification (member check)	-	+	-	-	+	-	-	+	+	+
Sequences original data presented	+	-	+	+	+	-	+	-	+	+
Ethics review	-	+	-	+	+	+	+	+	+	+
Total number of items fulfilling criterion	2	6	5	4	8	5	7	6	7	8

**TABLE 3** Main themes of qualitative studies

Themes	Barlow <i>et al.</i> [20]	Detaille <i>et al.</i> [18]	Gilworth <i>et al.</i> [26]	Howden <i>et al.</i> [27]	Lacaille <i>et al.</i> [21]	Mancuso <i>et al.</i> [23]	Nilsson <i>et al.</i> [25]	Varekamp <i>et al.</i> [19]	Codd <i>et al.</i> [24]	van der Meer <i>et al.</i> [22]
Symptoms of disease	x	x	x	x	x	x	x	x	x	x
Management of disease		x			x			x	x	
Social/economic issues		x			x	x	x	x	x	
Work conditions	x	x	x	x	x	x	x	x	x	x
Emotional challenges	x		x		x	x	x	x		x
Interpersonal issues		x	x	x	x	x	x	x		x
Meaning of work	x			x	x	x	x		x	x

**TABLE 4** Overview of themes, challenges and adaptations reported in 10 qualitative studies

Main category	Subcategories
Symptoms and disease and effects on work	Fatigue and energy Pain and stiffness Physical limitations Unpredictability and invisibility activity arthritis and flares Concentration
Managing arthritis and consequences	Help, information, access and treatment of arthritis from health care Optimal medical care and importance of healthy lifestyle Importance of disease activity Coping, understanding, adapting and managing disease Awareness of limitations and abilities, balancing work and leisure activities Importance of assertiveness, importance of planning Desire of contact or information from others with disease
Social/economic factors	Job insecurity and financial concerns Support from society, regulations and aid for persons with arthritis Opportunities for part-time work or disability benefits
Work conditions and adaptations	Support or help from employer and/or supervisor: such as active help with looking for solutions, providing adequate work conditions, work accommodation Employer help/advocacy/policies regarding career planning, (re)training, accommodation Psychological help: understanding, acceptance, considering needs of the patient Providing flexibility regarding work arrangements, and working time schedules, medical appointments and taking of time Ergonomic assessment and ergonomic adjustments to workplace
Emotional challenges	Setting boundaries, self-confidence Dealing with feeling like a burden, dealing with reactions colleagues Managing fear and anxiety, guilt, sadness, stress Feelings of dependency or helplessness Impact on personal fulfilment
Interpersonal issues and choices affecting work and family life	Role of understanding and social support from all actors such as colleagues, supervisors, health care professionals and patient organizations Difficulty with/lack of communication, mistrust and acceptance Relationship with colleagues Dealing with negative comments at work, asking for help, dealing with unsolicited help Reluctance to disclose (consequences of having) arthritis and being honest to colleagues Family and work life balance: challenges and negative effects that occur as a result of maintaining work for family life and in communicating with family
Meaning of work	Perceptions and meaning of work Desire, value and motivation to work Importance of worker role and identity Work important to well-being Value of work in social environment/friends Diverting attention away from disease Work as rehabilitative factor

### Challenges and adaptations reported by patients

Seven key concepts were identified in the 10 selected studies, some described only briefly and others extensively (Tables 3 and 4). No higher-level concepts were identified. The summaries of the findings are not exhaustive but intend to present findings deemed by the authors as most relevant to the review. Some of the individual studies present extensive subcategories of some of the themes listed below; we particularly refer to studies by Lacaille *et al.* [21], van der Meer *et al.* [22] and Varekamp *et al.* [19].

### *Disease symptoms and effects on work*

Challenges to continued employment, including fatigue and energy loss, pain and stiffness or physical limitations, were mentioned most frequently. Interestingly, some described disease-related fatigue as more dominant than pain [20, 23]. In addition, pain, stiffness and fatigue were mentioned as being related to symptoms such as decreased concentration and decreased problem-solving ability that all decreased the patient's ability to work and also spilled over into patients' personal lives. Fatigue was mentioned as less accepted by co-workers and patients themselves, which was aggravated by the invisibility of



arthritis. Physical limitations included working with the hands, prolonged standing or repetitive movements. The fluctuating nature of arthritis was mentioned as a barrier that made it difficult to plan.

#### *Managing arthritis and its consequences*

The role of the stage of the disease and adjusting to the diagnosis were considered important. Patients differ in their ability to accept their disease [18, 21, 24], have a sense of control [19, 21, 24] and effectively change work practices [24]. So-called self-preserving strategies to cope with pain and fatigue were also mentioned to limit satisfaction on a work and personal level [21]. External factors such as work load and also time and support of the work environment are described as constantly changing factors that require different modes of adaptation over time [22]. This also requires being aware of one's capacities and limitations. Adaptations to both work and leisure activities were mentioned to have been partly subconscious [25]. The difficulty in judging one's own abilities was mentioned as a constant limiting factor for some [18], even in the case of better medication [22]. Early medical treatment was considered important in reducing the disease symptoms and having more energy [18, 19, 25]. Early rehabilitation was thought to be essential, and preferably this also included information about the disease or the opportunity to meet others [25]. Managing the disease proved problematic sometimes, as patients did not take care of their disease as well as they could because of lack of energy, time limitations, lack of access to information or lack of services to help deal with arthritis on a daily basis [21].

#### *Societal and economic factors*

The effects of external factors at a societal and economic level were described in terms of both barriers and adaptations or opportunities [18, 19, 21, 23]. Not only were the financial consequences of not being able to work or losing benefits mentioned [21], but also its consequences for paying for arthritis treatment [21] and its emotional effects such as stress, fear, guilt and uncertainty about the ability to work in the future. More distally, financial concerns affect job choices and career prospects. Opportunities described were the ability to receive part-time disability benefits and regulations for persons with chronic disorders to keep working [18, 19]. The studies reporting societal and economic factors originated from North America [21, 23] and the Netherlands [18, 19], reflecting substantial differences in the availability and level of disability benefits. The meaning of this theme should therefore be seen in light of the broader societal and economic context.

#### *Work conditions and adaptations*

Work conditions and the working environment were described extensively in terms of adaptations and challenges [18–27]. Many adaptations could be made by employers or management to improve work conditions, including ergonomic improvements and arrangements for flexible working hours or work routines. Transportation challenges and solutions were mentioned

as important to patients [21, 23, 26]. Employers could provide training, education and help with career planning. Though these are clear actions, less visible aspects were mentioned, such as acceptance by the employer, a supportive employer who shows understanding and an employer who discusses solutions in a collaborative way. Thus the work environment could aid the patient in both practical and more interactive ways. By providing flexibility and autonomy in work routines and working time, utilizing recovery opportunities, patients are more likely to remain at work.

#### *Emotional challenges*

Emotional challenges were mentioned in five studies causing stress in daily life [20, 21, 22, 23, 26]. Emotions included fear and anxiety due to the uncertain impact of the disease on future work ability, sadness about limitations posed by the arthritis, feelings of dependency on others or helplessness or feeling guilty when taking time off work. Patients frequently feel uneasy asking for help and feel like a burden to the organization. Also described was loss of personal fulfilment, risk-taking aversion and difficulties setting boundaries. Frustration and other negative emotions also made it more difficult to deal with colleagues and maintain a pleasant disposition at work.

#### *Interpersonal issues and choices affecting work and family life*

Patients show variable experiences in managing relationships in their work environment, in the health care sector and at home, all affecting working life [18, 19, 21–23, 25–27]. An important prerequisite mentioned for functioning well was understanding and disclosure, which if absent led to misconceptions and difficult interactions at work with colleagues, especially in teams. Communication played a vital role, not only in getting understanding, but also in getting help and giving others insight into what they could or could not do. Reluctance in disclosing arthritis (flares) [21, 23, 26] at work also meant some patients not getting any practical or emotional support. The importance of addressing work challenges and support with health care professionals and patient organizations was also highlighted. Family and work life was often difficult to manage leading to frustration in interactions with family members. This was highlighted by the observation that adaptations were often made to keep working at the cost of personal life fulfilment, and not the other way around.

#### *Meaning of work*

Described in variable length was the influence of arthritis over time and its effect on how patients perceive work, showing great differences between patients [20–25, 27]. The worker role was described as important to the patients' self-identity, providing social contact, financial gains, diverting attention away from disease and pain, a sense of independence, intellectual stimulation and psychosocial benefits. On the other hand, some patients gave new meaning to life in general, in which work was viewed as less important [20]. The importance of work was also

**TABLE 5** Suggestions for improving intervention components by included studies

Recommendations made by reviewed studies	References
Improve timing and accessibility of work interventions, information and support along disease trajectory	[21, 22, 24, 25]
Tailoring interventions to perspectives, needs and goals of the patients	[19, 22, 25]
Improve involvement of health professionals in discussing issues related to work, and/or ergonomists, occupational therapists or vocational counsellors	[19, 21–23, 27]
Support and discuss meaning of maintaining work and worker role	[24, 25]
Importance of symptom/fatigue management and early medical treatment	[18, 21, 24–26]
Importance of screening for barriers and adaptations at the medical, psychosocial, practical, organizational or social policy level	[18, 19, 21, 23, 26]

illustrated by the finding that some patients wanted to avoid being obliged to take periods of sick leave [25] and also that sick leave increased their appreciation of work and that work was seen as a rehabilitative factor. Though desire and motivation to work were mentioned as important to patients, pressure to work was also mentioned as a financial necessity [20, 23].

#### Recommendations made by study authors

In addition to summarizing the themes identified in the qualitative studies, we also include a summary of the recommendations put forward by the authors of the studies (by at least two authors) that in our view affirmed the data we observed across the studies (Table 5).

As seen in Table 5, several recommendations are made by the authors, including the timing of interventions to patients, highlighting the episodic nature of arthritis and the need for interventions to address these proactively. In addition, using a screening list was not only recommended to help identify and prioritize patient's goals relating to employment issues, but also in targeting interventions towards the patient's needs.

## Discussion

The challenges posed to patients with inflammatory arthritis illustrate that patients deal with a variety of daily problems impacting their work, but these are quite different between patients. These challenges put a strain on the coping abilities of patients and require problem solving by patients. Success in dealing with these challenges is determined by a mix of personal factors, environmental factors and disease-related factors.

#### Reviewing the themes

##### *Fluctuating unpredictable disease activity*

More specific for inflammatory arthritis, in contrast to other chronic diseases, is its unpredictable and fluctuating disease activity, where episodes of limited functioning put a strain on patients' coping resources [28]. This also means that patients' need for support or job accommodations fluctuates over time, which, given the invisibility of arthritis, can remain unresolved unless the patient is able to communicate and act on these at work, at home or

at the medical office. Consequently patients need to variably manage these different phases and resulting loss of functioning by using strategies at work or at home or by seeking professional help. It also means that the availability of support for patients with arthritis regarding work participation issues needs to be well coordinated over time, as each new phase demands readjustment [29].

##### *Role of emotions*

Emotional challenges have received little attention in descriptions of interventions [30]. Patients not only have to deal with physical symptoms or cognitions at work, but also need to manage emotions deemed important in rebuilding self-confidence at work. Although emotional support is available to some patients at work, this requires open communication and trust. Acknowledgement of changed capabilities has been shown to be an important requirement for the successful self-management of symptoms and use of supportive resources [31].

##### *Role of the meaning of work*

The meaning of work is an important theme not only in patients with arthritis [20–25, 27], but also for patients with other chronic diseases including cancer [31] or even traumatic brain injury [32]. The importance of the role of work in forming an individual's sense of identity is not addressed in descriptions of vocational intervention studies on arthritis [4–6, 33]. Aside from the financial necessity to work, participants in the included studies indicated they wanted to work. However, a few indicated that work was less important, a finding that would likely impact treatment choices or treatment adherence. In addition, it is clear that the meaning of work can be influenced by the perceptions that patients have regarding their arthritis or its consequences on work and vice versa. These so-called illness perceptions can be targeted by interventions in the work context, with potential beneficial effects on work participation [34].

Professionals may often want to exclude patients who are supposedly not motivated to start a particular vocational rehabilitation programme. In these instances it may be more effective to explore the meaning of work by asking patients what motivates them at work, what they want to achieve regarding work and how they want to deal with their work-related problems [35]. This way patients



set goals important for themselves and engage in problem-solving behaviour required to create work adaptations by asking for support from colleagues or by discussing career options with their employer. Taking into consideration what work means to a patient also aligns well with the patient-centred approach by which an intervention strategy targets only those issues relevant to the individual, in contrast to an intervention to fit all people.

#### *Choices affecting family and work life*

Many decisions or management solutions by patients at work have direct consequences for relationships and communication within families. Studies in this review point at the time and energy that is required for self-care and to accommodate fatigue or other symptoms in order to stay at work, and the finding that little energy remains for other social roles or hobbies, as is the case in many chronic illnesses. Surprisingly, strategies to deal with family and work life issues are not frequently addressed in intervention studies in the field of arthritis [36] but deserve attention.

#### *Realizing adaptations*

Given the variability in the concepts identified, it seems logical to focus the intervention towards what the individual patient needs most, in line with self-management interventions that focus on individual goal setting, problem solving and empowerment [30, 37, 38]. Many improvements can be achieved by patients themselves, as observed in this overview. Although self-management strategies are increasingly advocated, there is a limit to what patients can do for themselves, and the challenge arises in what interventions can be developed that also empower other actors to improve work functioning, not only by employers or supervisors within the work context, but also in the health care context. Engaging patients to be their own problem solvers is not without difficulty for professionals: doctors are typically trained to come up with solutions instead of supporting patients to come up with their own plans and actions.

New interventions may assist patients in addressing work-related problems, including Internet programmes or community programmes for patients with chronic disease. Health professionals may provide patients with e-health interventions involving the work environment, with or without monitoring or counselling by a health care professional [39, 40]. Further, early involvement of a health professional in addressing employment issues can facilitate patients to take necessary steps by seeking help or information. In addition, patients may need to hear from their rheumatologist, whom they trust, concerning what they can or cannot do from a medical point of view. For interventions to be available with flexible timing and delivery, based on patients' goals, these interventions ideally need to be incorporated and available in everyday care so that they are sustainable and not just available to a few in specialized programmes [36]. This may start with patients who take frequent sick leave and are being evaluated by their GP for musculoskeletal symptoms for which early

arthritis is suspected but have not yet received a definitive diagnosis. In this early phase we think patients could benefit from advice and counselling on work challenges and symptom management [40].

On the other hand, addressing work issues and giving advice or information may require good timing to avoid unnecessary worry or hasty (adverse) career decisions.

The systematic review process of summarizing qualitative evidence is emerging as an innovative way for summarizing meaning and explanations lacking in quantitative studies and its methodology is becoming more transparent [41]. We put considerable effort into locating all qualitative studies available, aiming for conceptual saturation as described by Thomas and Harden [41], showing a range of concepts that were in agreement in several studies. Although we cannot exclude the possibility of having missed a study, we think it is unlikely that any other new or higher-level concepts would emerge from the literature at this point. The concordance of themes across several studies in this review and in other studies on chronic diseases supports [31, 32] this viewpoint.

Despite studies reporting favourable results of anti-TNF therapy [22, 42–44] on work participation, work challenges for patients with arthritis remain a persistent problem. The themes that were identified in this review could be used for screening purposes, as recommended by several studies [18, 21, 23, 26], or add to existing ones [45]. By exploring patients' views we hope that professionals develop a greater understanding of what impedes or facilitates work participation and explore these factors with patients to promote job retention in the long term. In addition, we recommend that these factors be considered in the study design of intervention studies that aim to improve work participation in patients with inflammatory arthritis.

#### **Rheumatology key messages**

- Patients with RA have variable work-related problems and needs and ways of managing these.
- Early professional involvement facilitates the prevention of sickness absence and job retention in patients with RA.
- Patients with RA value medical advice about what they can do and discuss work challenges.

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