



Chapter 1

General introduction

Rheumatoid arthritis

Rheumatoid arthritis (RA) is a chronic, systemic inflammatory disease of the joints (1-4). The disease manifests itself in the synovial membrane (i.e. the membrane which connects two bones in a joint), and the infection may result in structural damage of the joint. Patients with RA experience pain, tender and swollen joints and stiffness of the joints. Many patients with RA furthermore experience fatigue. Complaints due to RA might fluctuate over time and its disease course is unpredictable.

Globally, the prevalence of RA was 0.24% in 2010 (5;6). In a recent study, RA was ranked as the 42nd highest contributor to global disability, when measured in finalized years lived with disability (5). The prevalence of RA in Northern European and North American countries is higher and lies between 0.5 and 1.0% (7;8) and mostly women are affected (9). Specifically in the Netherlands, the prevalence of RA is 0.5 among men and 0.9 among women (10).

Patients with RA are in the Netherlands usually treated by a rheumatologist. When needed, a patient might be referred to other caregivers such as a physical therapist or occupational therapist. The medical treatment of RA has improved tremendously over time, and with the current treatment, it is possible to control disease activity and prevent structural, irreversible damage. Patients are mostly treated with Disease Modifying Anti-Rheumatic Drugs (DMARDs) and biological therapeutics. DMARDs aim to bring chronic inflammations to a halt, and thereby prevent damage of the joint. Biological therapeutics aim to remove proteins involved in the immune reaction that causes inflammation of the joints. The effectiveness of both DMARD therapy and biological therapeutics on decreasing disease activity has been established (11;12). Despite the fact that in general, patients with a chronic disease are less likely to be involved in paid work (13), usual care for patients with RA does not include consultations with occupational health services. This may result in a lack of attention for work-related problems. Patients in the Netherlands visit occupational health services in case of prolonged sick leave, rather than earlier in the process to prevent limitations in work activities (14). Furthermore, communication between occupational health services and treating physicians might be less than optimal (15).

Treatment of patients with RA comes with costs. These costs include both direct and indirect costs. Direct costs refer to costs for detection, treatment, and care, while indirect costs refer to costs due to a loss of work capacity. A review by Lundkvist et al has shown that the mean annual cost per patient was estimated at 13.500 Euros in Europe (16). Medication costs have increased during the last years, especially due to the increase in the use of biological therapeutics, while indirect costs have decreased slightly because of a reduced percentage of patients getting work disabled (17). Nonetheless, Franke et al showed that still 57% of the total costs for RA are due to productivity losses (18).

RA and Work

RA affects participation, and for patients with RA it is especially difficult to maintain work functioning (19). Work disability is the state in which a worker is no longer able to work and stops working permanently; a state which generally develops gradually over time. Work disability rates are high among patients with RA. Although estimates differ, work disability rates lie around 30% after five disease years (20-26). Work disability occurs mostly in the first years after diagnosis (27;28). Absenteeism refers to missed work days for employed patients, and occurs frequently for patients with RA (29;30). In a recent study, it was shown that 19% of a sample of 137 working patients with RA reported absenteeism during the past week due to their health (31).

Instead of calling in sick (absenteeism), patients might also be limited in their functioning while being present at work. Presenteeism refers to being present at the job, but being limited in meeting work demands. Presenteeism was reported by 24% of working RA patients (31), and by 43.8% in another study (32). Presenteeism occurs more structurally, while absenteeism and permanent work disability occur more incidentally, therefore, costs for presenteeism are high. It was estimated that 41% of the total costs for lost productivity are due to presenteeism costs, followed by wage loss from stopping or changing jobs (37%), decreased hours (12%), and finally absenteeism (10%) (33).

Many studies have investigated the magnitude of permanent work disability, and possible predictors for work disability in RA. Although very important, the meaning of work for patients with RA received a lot less attention. It was shown however that RA lowers health-related quality of life (34), and also that having a paid job is an important determinant of physical health-related quality of life (35). A qualitative study conducted in Sweden investigated emotions patients have with regard to their restrictions in employment (36). They reported that patients experience feelings of hopelessness (limited work time), sadness (having difficulties with using tools, and continue working), and feelings of fear (disclose RA at the workplace, losing work capacity, handling work tasks).

So we know now that patients with RA experience difficulties with maintaining work functioning. To investigate what exactly these difficulties are for patients with RA, several qualitative studies were conducted to address this issue. In order to develop interventions to support patients with RA to maintain work functioning, it is essential to have more insight in barriers for work functioning for patients with RA. Varekamp et al performed a qualitative study in which they conducted group sessions with patients with RA, in which the groups were asked to formulate statements on what enables workers with RA to continue working (37). The most important theme was support and acceptance from the employer. For example an employer who shows understanding and cooperates in situations which limit the employee. This was followed by understanding and acceptance of the disease, suitable working conditions, and support from colleagues and health professionals. From these

results, it emerges that besides working conditions suitable for a patient with RA, support at the workplace is very important. Furthermore, workers with RA struggle with fatigue at work, no job control, and not being understood/ supported by the supervisor and colleagues (38). A systematic review of qualitative studies also investigated concepts which are important for patients with RA to continue working (39). They showed that management of the disease and disease symptoms, suitable working conditions and adaptations, social/economic factors, emotional challenges, interpersonal issues such as support, and meaning of work all play a role. In short, for patients with RA to continue working, it is vital that their work is adapted to their needs, they get support from their supervisor and colleagues, and the disease is managed and under control.

In summary, patients with RA are limited in their work functioning, and occupational care is not a component of curative care. To maintain work functioning, interventions for patients with RA should involve support at the workplace, a workplace adapted to their needs, and more integration of curative and occupational care. Below, I will describe interventions focused on work participation already evaluated in practice.

Efforts to improve work participation

In the past, several studies reported the effect of pharmacological interventions on work participation (40;41) with mixed results. As described before, patients with RA do not generally visit the occupational health service, and work is not a topic during consultations with the treating physician. Therefore, to support RA patients with work limitations, multidisciplinary integrated care in which the rheumatologist and occupational health care cooperate is necessary.

In this thesis, I focus on work-related interventions to support workers with RA. A recent systematic review on non-pharmacological interventions to prevent job loss in patients with RA, included only three randomized controlled trials (RCT) (42). I will describe these three here to present the effects of these interventions. Allaire et al evaluated an intervention consisting of job accommodation (changes to the work environment), vocational counseling, and education (43). The intervention group was significantly delayed and reduced in incidence of job loss. De Buck et al evaluated an intervention with the aim to guide patients and adapt an intervention to the specific needs of a patient. On job retention, no differences were found between the intervention and control group. Finally, Macedo et al evaluated an intervention consisting of an assessment of medical history, a work assessment, functional assessment, and psychosocial assessment, resulting in an individualized treatment plan (44). The treatment plan might involve, amongst others, an ergonomic review, and consultations with the employer regarding job accommodations. The intervention was effective on work instability, work performance, and work satisfaction. Based on these three studies, it was concluded in

the systematic review that work-related interventions have the potential to support workers with RA to continue working, but that results up until now are uncertain (42).

Care for Work

“There is a need to shift away from the concept of work loss, to look instead at ability/disability while at work”(45).

RA is a severe condition with a large impact on work participation. Interventions should specifically focus on supporting patients who are still working instead of on patients on sick leave to prevent job loss. How to support patients with RA to continue working is yet to be established. There is a need to develop an intervention that focuses on patients still working, and incorporating the most important difficulties for proper work functioning. This includes that interventions should focus on integrating medical and occupational health care, improve support at the workplace, and adapt a workplace to the needs of a patient. All this led to the following objectives of this thesis:

Objectives

1. To review the literature concerning the effectiveness of workplace interventions to prevent work disability;
2. To investigate factors associated with at-work productivity loss, and the association between at-work productivity loss and quality of life for workers with RA;
3. To develop and evaluate an intervention at the workplace with the aim to improve and maintain work productivity for workers with RA;

Outline of this thesis

In chapter 2, a systematic literature review is described on the effectiveness of workplace interventions on work disability. In chapter 3, factors associated with at-work productivity loss are reported, as well as the association between at-work productivity loss and quality of life. Chapter 4 describes the development of the Care for Work project; the design of an intervention program with the aim to maintain and improve work productivity for workers with RA, including the design of the evaluation of the (cost) effectiveness and implementation. In chapter 5, the implementation of the intervention program is evaluated. Chapter 6 describes the effectiveness on supervisor support, work instability and at-work productivity loss after 6 months of follow-up, while chapter 7 describes the effectiveness on at-work productivity

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loss, work instability, pain, fatigue and quality of life after 12 months of follow-up. Chapter 8 describes the cost-effectiveness evaluation of the Care for Work project. This thesis closes with a general discussion of the main findings, in chapter 9.

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