Building a self-management program for workers with a chronic somatic disease

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Chapter 4

Preventing work disability among employees with rheumatoid arthritis: what medical professionals can learn from the patients’ perspective

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Abstract

Objective
To compare the perspectives of employees with rheumatoid arthritis (RA) with those of medical professionals regarding what people with RA need in order to prevent work disability.

Methods
Concept mapping was conducted in a group session with 21 employees and by mail with 17 medical professionals. Each group was asked to formulate statements on what enables employees with RA to retain their jobs. Group members scored all statements for importance, and clustered them into themes. Results were statistically aggregated at the group level.

Results
The concept mapping with employees yielded 59 statements, which were clustered into seven themes. The four most important themes were: (1) employer support; (2) understanding and acceptance of illness by employees themselves; (3) suitable working conditions; and (4) support from colleagues, health professionals and the patient’s organization. The concept mapping with medical professionals yielded 63 statements, which were clustered into eight themes. The six most important themes were: (1) well-informed professionals who cooperate effectively; (2) employees’ coping capacities and commitment to work; (3) financial regulations at the workplace; (4) adequate social security provisions, medication, and therapy; (5) a positive attitude on the part of employers and colleagues; and (6) suitable working conditions.

Conclusion
Factors that enable continued employment lie at different levels, including the psychosocial, practical, organizational and social policy levels. Health professionals appear to underestimate factors that are important from the patient’s perspective, especially support from employers. In discussing work with patients, health professionals need to address themes that are important from the patient’s perspective.
4.1 Introduction

Work disability among people with rheumatoid arthritis (RA) often starts soon after diagnosis, and is estimated to occur in 22 to 44% of all cases. Although there appears to be a positive trend in the Netherlands and Germany, the general impression is that work disability is still a serious problem that needs to be addressed. Over the past few decades, social policies have sought to improve employment rates among people with chronic health conditions, such as RA, by offering support to disabled individuals who want to enter or return to the job market. Not until recently has specific attention been devoted to preventing work disability among employees with chronic diseases or disabilities. Some outpatient clinics and vocational rehabilitation services have launched such prevention programs, and occupational health care physicians have become increasingly interested in preventing work disability among people with chronic health conditions.

Health professionals who deal with RA could play an important role in preventing premature job loss among RA patients. They are in a position to identify patients at risk for work disability and to discuss work-related problems and solutions with them. If needed, they can refer patients to occupational health or vocational rehabilitation services. Traditionally, however, medical specialists have focused on the clinical aspects of RA, and rehabilitation physicians have focused on adaptations at home. Occupational physicians, in their turn, have concentrated on occupational diseases, or on monitoring sickness-related absenteeism in the workplace. Consequently, most physicians have little experience in addressing work-related problems among RA patients. To support patients with work-related problems, it is important for professionals to pay attention to the employment situation of patients and have an accurate understanding of the problems patients can experience at work and what they need to resolve those problems.

Although many studies have investigated the employment situation of persons with RA, very few of those studies have focused specifically on the patient’s perspective. The identification of risk factors associated with work disability has been one important theme in review studies. Old age, lower levels of education, physically demanding occupations, low functional capacity, and full-time jobs were related to work disability. In contrast, biomedical factors appeared not to be consistently related to work disability. Due to a lack of high methodological quality, no evidence was found regarding personal factors, such as coping style, and work-related factors, such as work autonomy, support or work adjustments.

A number of studies have focused on work-related problems among employees with RA and potential work adaptations. The study by Lerner et al, which examined a large sample of employees in the United States, found that persons with chronic musculoskeletal conditions can experience difficulties in meeting physical work demands (32.5%), psychosocial work demands (31%), or environmental work demands (17%). Allaire et al conducted a study among persons with arthritis and other rheumatic diseases, who were at risk for work disability. The
subjects experienced difficulties with a mean of 15 out of a list of 99 possible work barriers in work site access, physical activity, working conditions and task-related activity domains. Thirty-eight percent of the subjects used at least one job accommodation. Whereas the abovementioned studies were based on pre-formulated questionnaires, Mancuso et al.\textsuperscript{10} have studied work-related problems among people with RA from the point of view of patients themselves. They conducted open-ended interviews with 22 employees with RA. These employees said they encountered a wide range of challenges at work, such as fatigue, pain, typing, writing, physical requirements, the need to maintain a pleasant disposition, overtime hours, business trips, commuting, the need for punctuality, inability to choose rest periods, and environmental issues. They also mentioned that they had made many adaptations at work to keep their jobs. However, many employees still felt they were at risk of losing their jobs. The study points to many problems experienced by employees with RA, which were not identified in the earlier survey studies. It also shows how these problems can be modified to prevent work disability. This study investigates the perspectives of employees with RA, as well as those of health professionals, regarding what employees with RA may need to retain their jobs. A comparison of these perspectives could reveal whether health professionals are overlooking certain issues relating to job retention that are important to employees with RA. This information could help health professionals in their efforts to prevent early work disability among employees with RA.

4.2 Patients and methods

We used a method known as “concept mapping” to collect information on the perspectives of employees with RA and health professionals regarding factors that might enable job retention. Concept mapping is a commonly used tool to collect, aggregate and analyze the ideas of a group of 20-30 individuals on a certain focus question. It involves a quantitative analysis of qualitative data and results in a pictorial map that displays the interrelationships among ideas expressed by the group members.\textsuperscript{11,12}

Participants

Employees were selected based on the following inclusion criteria: employment in a paid or unpaid job, age range 20-65 years and diagnosed with RA\textsuperscript{13} but not another chronic condition that could affect work ability. The participants were recruited through the Rheumatology Outpatient Clinic of the Academic Medical Center in Amsterdam, as well as by referrals from occupational health services and two patient organizations. An arthritis consultant screened patients to make sure they met the disease inclusion criteria. A researcher (SD) checked whether they satisfied the inclusion criteria for employment and age. Sixty-one patients who met the inclusion criteria were invited to participate in the study by mail and telephone. Of these patients, 21 agreed to participate. Sixteen were patients from the rheumatology outpatient clinic, three were referred by occupational physicians, and two by patient organizations. The fairly high non-response rate may be due to the fact that the group session took place during a weekend in the summer. To be included in the study, health
professionals were required to be a physician or paramedic with specific experience in RA care provision. Participants were recruited through referrals from experts in the departments of rheumatology, general practice and occupational medicine at three university hospitals and from the Dutch Association of General Practitioners. Of the twenty health professionals experienced in rheumatology care that were invited to participate in the study, 17 agreed to participate. This group consisted of six general practitioners, five occupational physicians, one rheumatologist, three rheumatology nurses/consultants, one rehabilitation physician and one psychologist. Two of these professionals did not complete the entire study due to a lack of time.

Data collection
Concept mapping starts with a focal question. In consultation with five employees with RA and two experts on concept mapping, we formulated the following fill-in-the-blank focal question for this study: “What employees with RA need to enable them to continue working is...”.

Separate concept mapping sessions were held for the employees and the professionals. A five-hour collective group session including breaks was organized for the employees. A facilitator chaired the session, which took place at the Academic Medical Center in Amsterdam. A typist was also present. During the first forty minutes of the session, the participants were asked to formulate statements to complete the focal question. Each participant was allowed to submit more than one statement. The facilitator assisted the participants in wording their statements clearly. Statements were not supposed to contain multiple ideas or be restricted to time or place. The facilitator also made sure that similar statements were submitted only once. Each statement was typed out on a computer and then printed on a card. After a break, each participant received a complete stack of cards and was asked to rate how important they regarded each statement using a Likert scale of 1 (lowest priority) to 5 (highest priority). Participants were encouraged to distribute the statements equally among the five priorities. Following this task, the participants were asked to sort the statements logically according to themes or clusters, using at least two but no more than ten themes or clusters. Each participant recorded the results of the rating and the sorting task on a special form. These forms were entered into the computer during a second break of the concept mapping session. Concept mapping for the health professionals took place by mail or by e-mail because it was impossible to arrange a meeting that everyone could attend. The process began by sending letters to all the professionals, asking them to complete the fill-in-the-blank focal question with a maximum of 10 statements. The researcher (SD) consolidated all of the participants’ statements in a list, but deleted similar statements. This list was sent to the participants in a second letter, asking them to prioritize and cluster the statements using the method described above, and to record the results on the special form.

Statistical analysis
The results were aggregated at the group level using the computer program Ariadne. First, arithmetic mean scores per statement and SDs were calculated to indicate the priority of statements at the group level. Second, a multi-dimensional scaling technique and cluster
analysis were used to calculate how often statements were grouped into the same cluster. This resulted in a two-dimensional cluster map in which statements which are more often placed in the same cluster are located closer to each other. Based on this map, a number of clusters or themes can be distinguished. The average scores of these themes were also calculated. In the group session for employees with RA, this procedure was conducted during the second break. The results in the form of the cluster map were discussed after the break, and the group was asked to suggest the most appropriate names for the themes. The researchers (SD and JH) proposed names for the themes produced by the professionals, who were then asked to comments on these names by mail. To identify similarities and differences between the perspectives of the employees and the professionals, we compared the themes and ratings produced by both groups. Data were collected in 2001 and 2002. This research was part of a larger project that also focused on the needs of employees suffering from diabetes mellitus and hearing loss. The Medical Ethics Committee of the Academic Medical Center in Amsterdam approved the study.

Table 1. Personal characteristics of patient participants (n=21).

| Characteristic                  | % * |
|--------------------------------|-----|
| Sex                            |     |
| male                           | 38  |
| female                         | 62  |
| Mean age (range)               | 50  |
|                                | (23-65) |
| Level of education             |     |
| low                            | 5   |
| middle                         | 62  |
| higher                         | 29  |
| no further information         | 5   |
| Type of work                   |     |
| volunteer work                 | 14  |
| light mental demands           | 33  |
| heavy mental demands           | 24  |
| physical demands (light and heavy) | 29   |
| Years since diagnosis          |     |
| 0-2 years                      | 43  |
| 2-5 years                      | 30  |
| 5-10 years                     | 17  |
| >10 years                      | 10  |
Views of employees with rheumatoid arthritis and health professionals

| Medication for RA** |   |
|---------------------|---|
| no medication       | 10|
| yes, NSAIDs or analgesics | 57|
| yes, DMARDS         | 81|
| yes, prednisone     | 14|
| yes, biologicals    | 5 |
| yes, experimental therapy | 10|
| yes, no further information | 5 |

| Employment situation after diagnosis |   |
|--------------------------------------|---|
| no changes                           | 45|
| reduced working hours                | 25|
| other job with same employer         | 20|
| acquired work accommodations         | 10|

* Values are percentages unless otherwise indicated.

** Percentages add up to > 100% because more than one medication may be used.

4.3 Results

Patients

The personal characteristics of the 21 employees with RA who participated in the concept mapping session are presented in Table 1. The mean age was 50, and almost two-thirds were women. Most participants were well educated (having completed middle or higher educational levels) and most had no physically demanding jobs. Almost three-quarters of the participants had been diagnosed with RA less than five years before this study. Almost all participants were taking RA medication: the majority were taking disease-modifying antirheumatic drugs and more than half were taking nonsteroidal anti-inflammatory drugs or analgesics. A slight majority had made changes in their working conditions after the diagnosis: they had cut back working hours, obtained a different job with the same employer, or acquired work accommodations.

The employees with RA produced 59 statements in response to the question ‘What employees with RA need to enable them to continue working is...’ Participants sorted these statements into seven themes, or clusters, with arithmetic mean scores ranging from 2.4 to 3.5. Table 2 presents the seven themes, the mean scores, the total number of statements referring to each theme, and the statements with a mean score of 3 or higher. The first theme, consisting of 12 statements, emphasizes that employees with RA need acceptance and support from their employer in order to retain their job. The second theme concerns the capacities and responsibilities of the employees themselves. They must, for instance, make sure they have the right medication, become adequately informed about their disease and know their own capacities. The third theme, consisting of 21 items, concerns the importance of working conditions and work accommodations. Physical work accommodations, such as a comfortable chair and an accessible working area are mentioned along with organizational
accommodations, such as autonomy at work and flexible working hours. A large number of statements were grouped under this theme, several of which had low scores. Therefore, its average priority is not high, though many individual statements did show high scores. The fourth theme contains a variety of statements about relationships. These statements indicate the importance of having colleagues and employers that are well informed and aware, and the importance of having access to an arbitration body when conflicts and work-related problems arise. Some of the statements grouped under this theme appear to be paradoxical: colleagues should acknowledge that employees with RA cannot perform all activities, but they should also treat them as healthy individuals. Themes five, six and seven are residual clusters, consisting of only one or two statements. Theme six, entitled “reinforced position in society”, contains one high scoring item: the availability of social disability pensions that enable employees to work part-time and to be classified as partially work disabled.

Sub-analyses were performed for subgroups of employees in different types of occupations, i.e. mentally demanding versus physically demanding. For both subgroups, support from employers continued to be the most important theme. The second most important theme for the individuals performing physical work was support from colleagues and others. For those with mentally demanding jobs, working conditions were the second most important theme (data not shown).

Table 2. What employees with RA need to enable them to continue working: themes and statements scoring 3 or higher with mean scores. Patients’ perspectives (n=21)*.

| Theme 1. Support on the part of employers for their careers (3.5). | Mean | Statements (12 in total) |
|---------------------------------------------------------------|------|--------------------------|
| 4.3 | An employer who accepts the sick employee. |
| 3.9 | An employer who shows understanding for situations that bother the employee. |
| 3.7 | An employer who has an active career management policy. |
| 3.7 | An employer who cooperates with the employee in seeking alternative places to work. |
| 3.5 | A clear understanding on the part of the employer and the employee regarding the extent of their remaining work capacity. |
| 3.5 | An employer who tries to place himself/herself in the position of the employee with RA. |
| 3.5 | An employer who knows the consequences of RA for the job and the company. |
| 3.4 | Opportunities to receive training for a more suitable job. |
| 3.4 | A good social plan when working is no longer possible. |
| 3.1 | An employer who does not discriminate or make it impossible for the employee to continue his/her career. |
| 3.0 | Opportunities for extra training for jobs that require less manual activity. |

| Theme 2. Understanding and acceptance of the disease, responsibility and coping ability (3.0) | Mean | Statements (8 in total) |
|-------------------------------------------|------|--------------------------|
| 3.6 | Optimal medication that reduces fatigue at work. |
| 3.6 | Very thorough knowledge of their own syndrome. |
| 3.3 | A clear understanding of what they can or cannot do on the job. |
| 3.0 | Assertiveness. |
| 3.0 | Opportunities to exercise as well as work. |
Table 3. What employees with RA need to enable them to continue working: themes and statements scoring 3 or higher with mean scores. Professional perspectives (n=17).*

| Theme 1. Well-informed professionals who cooperate effectively (3.3) | Mean | Statements (10 in total) |
|---------------------------------------------------------------|------|-------------------------|
| 4.3 Clear agreements between the patient, occupational physician and employer and follow up to check whether adaptations are needed. |      |                         |
| 3.9 An occupational physician who is an expert in RA care for patients in their particular line of work. |      |                         |
| 3.8 Physicians who think beyond pain management and focus on reducing dysfunctioning. |      |                         |
| 3.6 A good patient-doctor relationship with their occupational physician. |      |                         |
| 3.6 Physicians who cooperate well, and will work in an interdisciplinary context if necessary. |      |                         |
| 3.4 A physician who has a solid base of knowledge for assessing the positive or negative influences of work-related activities on the prognosis of the disease. |      |                         |
| 3.4 Professionals who realize that a chronic disease does not necessarily lead to work disability. |      |                         |
| 3.3 An occupational physician who is knowledgeable about RA. |      |                         |
| 3.1 More structured consultation between their occupational physicians and rheumatologists. |      |                         |

Lengthy sentence structures have been rephrased.

Table 3. What employees with RA need to enable them to continue working: themes and statements scoring 3 or higher with mean scores. Professional perspectives (n=17).*

| Theme 2. Suitable working conditions (3.0) | Mean | Statements (21 in total) |
|-------------------------------------------|------|-------------------------|
| 3.8 An employer who provides adequate work accommodations, such as a split computer board, or a comfortable chair. |      |                         |
| 3.7 The freedom to determine their own working pace. |      |                         |
| 3.7 The option of working fewer hours per day. |      |                         |
| 3.6 Freedom in planning work, due to variations in the severity of symptoms. |      |                         |
| 3.6 Flexible working hours. |      |                         |
| 3.4 Freedom to decide on the proportion of the day/week they work. |      |                         |
| 3.3 An accessible working area and facilities. |      |                         |
| 3.2 The chance to change postures during work. |      |                         |
| 3.2 The option of telecommuting or working at home, if the job allows it. |      |                         |
| 3.2 Freedom from having to carry things (books, laptop) to work. |      |                         |
| 3.1 The freedom to draw up their own working schedule. |      |                         |

| Theme 3. Support from colleagues, health professionals and patients’ organization (2.8) | Mean | Statements (12 in total) |
|--------------------------------------------------------------------------------------|------|-------------------------|
| 3.6 Access to a supportive organization when conflicts arise with official agencies or the employer. |      |                         |
| 3.3 Colleagues who know that they have RA and understand what they can and cannot do. |      |                         |
| 3.2 Colleagues who treat them as healthy people. |      |                         |

| Theme 5. Regulations that take account of persons with chronic disorders, and the opportunity to learn from the experiences of other employees with RA (2.4) | Mean | Statements (2 in total) |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|-------------------------|
| 3.6 The option of working part-time and receiving part-time disability benefits (3.6). |      |                         |

| Theme 6. Reinforcement of societal position (2.4) | Mean | Statements (2 in total) |
|--------------------------------------------------|------|-------------------------|
| 3.6 The option of working part-time and receiving part-time disability benefits (3.6). |      |                         |

| Theme 7. A social climate at work (2.4) | Mean | Statements (1 in total) |
|----------------------------------------|------|-------------------------|
| 3.6 The option of working part-time and receiving part-time disability benefits (3.6). |      |                         |

Lengthy sentence structures have been rephrased.
Chapter 4

Theme 2. Coping capacities and commitment (3.3)

Mean Statements (11 in total)

3.6 Insight into their own capabilities.
3.6 To give timely notification of what they can and cannot do.
3.6 To learn to cope with the ups and downs of their illness on the job.
3.6 An ability to cope with RA.
3.5 Willingness to invest in job training or accommodations.
3.4 To maintain a sense of responsibility for continuity (at work), despite their RA.
3.4 To avoid slipping into the role of a victim.
3.1 Knowledge of legislation and rules concerning employment.

Theme 3. Financial regulations at the workplace (3.2)

Mean Statements (3 in total)

3.3 Financial provisions for ergonomic work accommodations.
3.2 Financial compensation for the employer in case of higher absenteeism and periods of lower productivity.
3.1 Solution of problems before the employee has to apply for sick leave.

Theme 4. Adequate social security provisions, medication, and therapy (3.1)

Mean Statements (6 in total)

3.7 A decision on the part of the government not to pass new legislation abolishing the current financial compensation provisions for partially disabled employees.
3.3 More or less effective management of pain and functional limitations.
3.3 Adequate RA treatment with medication and physical or exercise therapy.
3.1 A society that wants to help people with chronic diseases continue participating in its job market.
3.0 Sufficient suppression of disease activity by medication.

Theme 5. A positive attitude on the part of employers and colleagues (3.1)

Mean Statements (11 in total)

3.6 Understanding of the work capacity of the RA-patient.
3.6 A work climate of tolerance and respect.
3.3 A hospital and employer who devote attention to conditions at work in the early stages of RA.
3.2 An employer and colleagues who understand the limitations that can result from RA.
3.1 Colleagues who are able to see the employee with RA first and foremost as a fellow colleague employee, and then as a patient.
3.1 An employer and colleagues who know about the variation that can occur in the severity of symptoms.
3.0 An employer who is knowledgeable about RA.

Theme 6. Suitable working conditions (3.0)

Mean Statements (22 in total)

4.0 Adjustment of working pace to the current physical condition.
3.9 Flexible working hours and breaks, as required due to unpredictable bouts of fatigue.
3.6 Consideration for the variable course RA can take in assessing patients for jobs.
3.5 Adequate financial provisions for counseling in the company and for work accommodations.
3.4 An ergonomically balanced workplace.
3.3 Well-balanced working hours and breaks.
3.3 An employer who is willing to provide ergonomic work accommodations.
3.2 An employer who makes every effort to adapt their work to their limitations.
3.2 Good provisions for commuting and good parking facilities.
3.2 Provisions that allow them to avoid standing or walking for longer periods (for patients with painful knees or ankles).
3.1 Provisions that allow them to avoid work that requires physical strength, especially in the hands, (for patients suffering from reduced joint function and fatigue).
3.1 Sufficient financial resources to cope with the impairments and limitations due to RA.
3.1 Opportunities for job retraining, if necessary.

Theme 7. Arrangements at home (1.9)

(one statement)

Theme 8. Alternative doctors (1.6)

(one statement)

* Lengthy sentence structures have been rephrase
Health professionals
The 17 health professionals who participated in concept mapping by mail produced 65 statements in response to the focal question. These statements were clustered into eight themes, with mean scores ranging from 1.6 to 3.3. The eight themes, the mean scores, the total number of statements grouped under each theme and the statements with a mean score of 3 or higher are presented in Table 3. The first theme reveals the importance that medical professionals assign to their own role in enabling employees with RA to continue working. The health professionals mentioned the need for cooperation between clinical professionals and occupational health services. They also stressed how important it is for occupational physicians to acquire sufficient knowledge of RA and for doctors to realize that a chronic disease will not necessarily result in work disability. The second theme shows that professionals also assign an important role to the employees themselves in continuing to work. For instance, the employee needs insight into his/her work capabilities, coping capacity, and knowledge of legal regulations. Theme three concerns financial regulations in the workplace. Theme four is a collection of six statements regarding the importance of government financial regulations that allow people with RA to keep part-time jobs, and adequate RA treatment aimed at maintaining work ability. Theme five stresses the importance of an understanding and accepting attitude on the part of employers and colleagues. Theme six, consisting of 22 statements, concerns working conditions and work accommodations. Variations in the severity of symptoms were cited as a reason for organizational work accommodations, such as flexible working hours and adjustments in working pace. Notwithstanding the low average score for this theme, many individual statements had high priority. Themes seven and eight are residual categories. By and large, the themes showed little difference in terms of their mean priority scores, with the exception of the last two themes.

Comparison between the two groups
The employees and health professionals had several themes in common, including ability to accept and cope with RA (theme 2 in both groups), suitable working conditions (theme 3 employees, theme 6 professionals), a positive attitude or support on the part of employer, colleagues or health professionals (themes 1 and 4 in the employee group, themes 1 and 5 in the professionals group), and adequate social security provisions or other regulations for persons with RA (themes 5 and 6 in the employee group, themes 3 and 4 in the professionals group). With one exception, the two groups differ with respect to the importance they attributed to these themes. Both groups feel that employees themselves play an important part in staying at work. However, the employees rank their employer’s attitude and the active support of people with chronic conditions as the most important conditions to stay at work. In contrast, the health professionals ranked well-informed health professionals who cooperate effectively with the patient, employer, and other health professionals as the most important condition, and they put less emphasis on the attitude of employers.
4.4 Discussion

Concept mapping is an adequate research method for gathering information about the perspectives of patients and professionals regarding what employees with RA need in order to continue working because it draws directly from the personal experiences and ideas of the immediate stakeholders. The clustering procedure makes it possible to distinguish themes, and the priority rating procedure reveals the relative importance of the different statements and themes. However, only a limited number of participants can be included in a group, which means that results should be generalized with reservation. Also some caution is necessary in interpreting the results of concept mapping. The number of statements in a theme does not necessarily reflect the importance of that theme. Sometimes, statements differ only slightly in meaning. Furthermore, the mean score of themes composed of many statements almost automatically drops, notwithstanding the fact that a number of individual statements may have high scores. The working conditions theme, for example, has a fairly low mean priority score in both groups, but includes a number of high scoring statements. Another aspect for consideration is the clustering procedure, which gives rise to residual categories where statements differing in content and score are placed together. Therefore, separate statements and their scores should always be considered in interpreting themes. A case in point is the high score for a statement on social security benefits for partially work disabled employees, which ended up in residual categories in both groups.

We found that employees with RA and professionals are similar in some aspects and differ in other aspects concerning what they consider important for job retention. Both groups see the employees themselves and suitable working conditions as important or rather important. However, employees ranked the employer’s attitude towards and active support of persons with chronic conditions as being most important. This is in contrast to the perspective of the health professionals, some of whom were working in occupational health care, and others in clinical medicine. They ranked well-informed health professionals who cooperate effectively as the most important enabling factor. This may reflect the focus of professionals on their own professional environment and what they have to offer. This contrast between the perspectives of employees and professionals suggests that both sides stand to learn from the other. Professionals tend to underestimate the impact of psychosocial and organizational features of the workplace which can present obstacles for RA patients. In contrast, professionals may have a broader view of solutions and the cooperation between health professionals that is needed for solutions to work. Health professionals can offer insight that places the problem in a broader perspective than the micro-level view that patients may adopt.

Our study is different from many other studies on factors related to work disability, or impending work disability, in that it focused on modifiable factors. Our study determined the conditions that patients with RA require to continue working. Nevertheless, our findings corroborate the findings of other studies in that they point to problems directly caused by RA, including fatigue and reduced work capacity, as well as problems on a higher level, such
as a lack of support at the workplace or the need for work accommodations. This study adds to what we already know by revealing the need for specific attention to certain problem areas. Examples include the clearly stated importance of support from employers, as well as the importance of insight on the part of RA patients into their own illness and their own capabilities, and the importance of assertiveness. In fact, others have referred to these latter aspects, using slightly different terminology (self-efficacy).9,18

Vocational rehabilitation interventions for patients with rheumatic diseases used to focus on re-entry into the work force.19 Recently, more attention has been devoted to early interventions that support RA patients in their efforts to remain in the workforce.20-24 The rationale for this is that it is much easier to retain a job than to find a new one. Often, the organizational frameworks for these job retention interventions are based in outpatient clinics, and some interventions are multidisciplinary.21-24 Our findings may prove to be particularly important to medical professionals working with employed patients with RA, as well as to professionals who are planning vocational rehabilitation programs for these patients. It is important for professionals in both of these fields to understand the patient’s perspective on work-related problems. Interventions should be patient-centered. In other words, professionals must realize that patients suffering from similar medical conditions may experience different problems at work due to differences in personal attitudes, capacities and work demands, as well as organizational differences at the workplace. Regarding rehabilitation in general, vocational rehabilitation programs must concentrate on the goals that individual patients establish for themselves. Effectiveness studies should be patient centered.25,26 In addition, the statements made by the professionals reveal how important cooperation is between the professionals caring for patients with RA.27

In summary, this concept mapping study among employees with RA and health professionals offers useful insights into what employees need to continue working. The findings reveal that these needs lie at different levels, including the medical, psychosocial, practical, organizational, and social policy levels. This study also demonstrates that health professionals should pay attention to what is important from the patient’s perspective.
Chapter 4

4.5 References

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