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Empowerment of employees with a chronic disease

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Contents

Chapter 1

General introduction

Introduction

The main objectives of this thesis are to investigate the barriers experienced by employees with a chronic disease at work and to evaluate whether a vocational rehabilitation programme for these employees makes sense. We implemented a special rehabilitation programme aimed at job retention and well-being at work based on individual empowerment. In this introductory chapter, I will discuss the concepts of chronic disease, work-related problems, vocational rehabilitation, empowerment and self-efficacy. I will then formulate research questions followed by an outline of the thesis.

Chronic diseases, longstanding health problems and social policy

Sixteen percent of European people aged 16-64 years have, by their own judgment, a longstanding health problem or disability [1]. The figures range from 6% for the healthiest nation to 32% for the unhealthiest nation. The Netherlands occupy an intermediate position in this group with 25% unhealthy inhabitants. These figures appear to be slightly alarming. However, we find Romania (6%) to be extremely healthier than Finland (32%). It raises the issue concerning how respondents in different countries perceive questions about their health, as the authors of the above mentioned report note. I begin with these figures in order to focus on the meaning of the concepts of health, chronic disease and longstanding health problems.

The concept of health has many meanings; it may be defined as the absence of disease or symptoms, as being in balance or as the ability to perform certain activities [2]. When study participants are asked whether they have a longstanding health problem, cultural differences in meaning may contribute to varied responses. The concept of chronic disease may present similar definition problems. In 1991, the Dutch government created the National Committee on Chronic Diseases. The task of this committee was to demand attention for the chronically ill, by determining the common interests of various groups of chronically ill populations and to stimulate policy to improve their care and position in society [3]. Originally, chronic disease was a health care term used to denote irreversible diseases such as diabetes, rheumatoid arthritis, Crohn's disease, multiple sclerosis and renal failure. As such, the group of people with a chronic disease to a certain extent shows overlap with the group of the disabled for whom social policy measures already had been taken. Chronic diseases do not go away. As long as medical breakthroughs in treatment are absent, these patients experience either stability, or instability in terms of relapses and recoveries, or downright deterioration of health. Common characteristics of chronic disease include, apart from irreversibility, an unpredictable course, day-to-day variability of symptoms, and in many cases invisibility, all of which may lead to a lack of understanding from others in the workplace such as colleagues or supervisors [4].

In the 1980s and 1990s, governments, employers, HRM managers and occupational health services became highly interested in the issue of employees with long-term sickness absence, with one of the underlying motives being to lower costs for companies and to decrease rates of permanent work disability. Long-term sickness absences are often experienced by employees with longstanding but reversible conditions, which may be work-related (e.g., non-specific low back pain, complaints of arm, neck and/or shoulder, or burnout). Medical treatment aimed at cures and the removal of contributing factors from the workplace are ways to deal with these health problems. The treatment of maintaining factors, like disabling illness perceptions or a mediocre physical condition, is an additional treatment option. Sometimes temporary or permanent work adaptations are necessary.

Concerning work disability policy, workers with a chronic disease and workers with a reversible medical condition with long-term sick leave are often combined as one target group for Disability Management. Disability Management is a government-stimulated HRM approach aimed at increasing the employability of people with health problems [5]. In the Netherlands, this policy has been evaluated with the yearly Monitor of Work Disabled [6]. Although the group of people with a chronic disease does overlap with those on long-term sickness leave, there are essential differences between these two populations that should be realised. Otherwise, supervisors at work and HRM personnel are missing the point and employees will feel misunderstood. The main differences between these workers are that chronic diseases do not vanish and work accommodations may need to be made permanent. Waddel et al. [7] recently made a similar distinction. They speak of 'common health problems' like mild and moderate musculoskeletal, mental and cardio-respiratory conditions and 'severe medical conditions' such as neurological conditions or blindness. The first group accounts for two-thirds of sickness absence and long-term incapacity cases in the UK. However, these authors argue that these conditions are 'characterised more by responses to symptoms than by objective impairment', and restoration of function should be possible. The second group has specialised rehabilitation needs. This thesis is concerned with irreversible chronic diseases and not with longstanding but reversible conditions, although we do not always make this clear distinction.

Employees with chronic diseases, work-related problems and work disability

Many employees with a disease are only slightly limited or not limited at all in daily functioning and can manage their work quite well. Others are severely hampered.

Health complaints like pain or fatigue, physical, sensory or cognitive limitations and medical requirements may impair work performance. Lerner et al. [8] studied a large sample of employees in the USA with a variety of chronic conditions. Depending upon the condition, they found that 22% to 49% of the employees experienced difficulties in meeting physical demands and 27% to 58% in meeting psychosocial work demands. These difficulties may become so serious that employees must stop working. Persons with neurological disorders, such as Parkinson's disease or multiple sclerosis, or dialysis patients more often than not are without a job [9-12]. For rheumatoid diseases, haemophilia, inflammatory bowel disease and COPD, employment figures are lower, but not dramatically lower, than those for healthy persons [13-19].

Whether one experiences difficulties or becomes work-disabled depends on more than disease severity or subsequent limitations of body functions and structures. The International Classification of Functioning, Disability and Health (ICF) of the WHO [20] offers a heuristic model to interpret disability or participation problems as functions of medical, psychological and social factors (Figure 1). The discussion preceding this classification, especially the contribution of Jette and Verbrugge, quoted more than 800 times in the scientific literature, is worth mentioning [21]

Two major points should be noted. First, although disease may affect functioning, which in its turn may lead to disability, this statement does not imply that disability is an inherent personal feature. Disability can be regarded as an aspect of the relationship

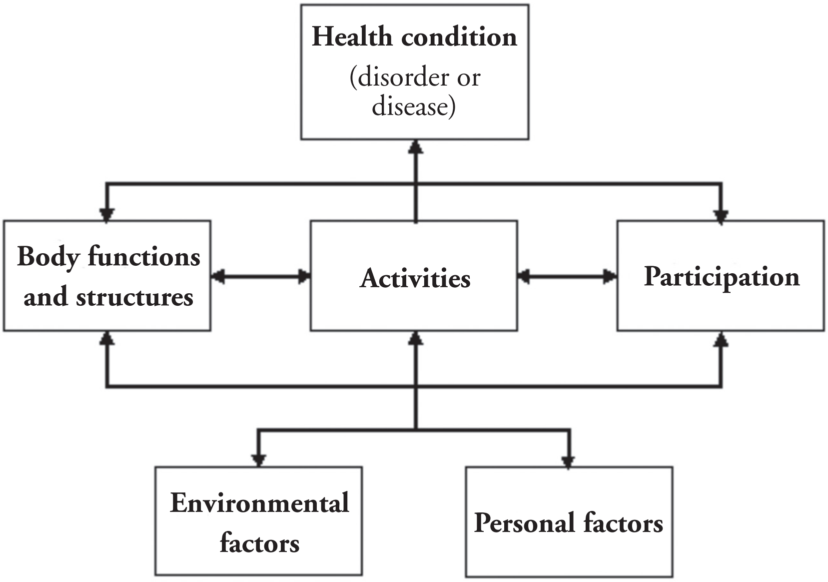

Figure 1. International Classification of Functioning, Disability and health (ICF) model (WHO, 2002)

between a person and his or her direct environment, or more precisely, as a gap between personal capabilities and demands from outside. This gap is not an established fact. It may be narrowed by increasing the capabilities of the individual or by increasing support or reducing demands from the outside world. Second, personal and environmental factors may influence the outcome of the disability process. Either of these can be mobilised to increase personal capabilities or to change environmental demands and support.

Consideration of the ICF model raises awareness of possibilities for the prevention of work disability. Environmental factors such as rehabilitation, specialized computer equipment, adjusted furniture, flexible work schemes or commuting arrangements may help employees to make the most of their work capabilities. Personal attributes such as coping behaviour or ideas about illness may influence capability. Problem-solving capacities or other personal skills may also influence demands from the environment. For instance, communication skills may be used to reduce demands or to organise support in the work environment. Notably, in the case of chronic diseases, personal and environmental factors are often pliable and offer opportunities to prevent work-related disability.

Vocational rehabilitation aimed at job retention for employees with a chronic disease

Work-related problems of employees with a chronic disease may be managed in various ways. Occupational health care, including the assessment of work capacity, personal advice, and temporary or permanent work adaptations can be considered as care as usual in the Netherlands. One limitation is that this kind of care is normally given only in cases of work absence due to sickness. Multidisciplinary vocational rehabilitation is a complementary approach in which a team of different specialists assesses work-related problems and decides on treatment and work adaptations, whether in cooperation with the occupational physician or not. This rather directive approach aimed at job retention has been studied for several diseases including rheumatoid arthritis [22] and fibromyalgia [23]. Other interventions concentrate on specific aspects of long-standing illness and disablement. Fitness training or graded activity programmes can be implemented in attempts to improve the physical condition and consequently the work capacity of an employee. These programmes have been proven to be effective for persons with low back pain [24] or with persistent complaints of fatigue [25]. Other programmes focus on changing ideas about illness. Negative illness perceptions are shown to have a negative influence on coping and functional adaptation [26]. Boot et al. [27] studied the relationship between illness perceptions and work disability for COPD patients and advocated treatment that addresses negative and incorrect illness perceptions [28]. This approach has been used for renal failure patients in the Netherlands [29]. Another approach involves workplace interventions aimed at removing barriers in consultation with others, especially the supervisor, who can play an important role [30,31]. In the Netherlands, Anema studied employees with low back pain and the effects of case management involving all workplace participants on employees' return to work [32].

We chose to focus on the empowerment of employees with chronic disease. We assume that most chronically ill people have physical or cognitive limitations that cannot be remedied by fitness exercise. Furthermore, we assume that a number of chronically ill employees will frequently have negative perceptions concerning control of their illness, chances of recovery or other aspects of their disease, but these are not necessarily incorrect. Therefore, we have chosen an approach that equips employees who need it with insights and skills that will help them to solve problems at work.

Empowerment as a perspective for vocational rehabilitation: the concept of self-efficacy

Empowerment was first explored in the 1980s in the field of community psychology as a means of enabling individuals or groups to gain decision-making power within their community [33]. The concept of patient empowerment was adopted in health care, notably for self-management programmes for patients with chronic diseases. In this context, empowerment is defined as a process to help patients develop knowledge, skills and a heightened awareness of their values and needs. This will enable them to define their goals, take responsibility for their medical treatment and increase their autonomy [34]. This definition implies improved problem-solving abilities, better communication with healthcare professionals and an awareness of health-promoting behaviours.

The empowerment concept seems to be a promising starting point for the development of vocational rehabilitation for employees with a chronic disease who experience work-related problems [35]. What problems an employee does experience will depend on the kind and severity of the disease and consequent limitations, on treatment modalities, work tasks, and personal and external factors; moreover, problems may change over time. One complicating factor is that many persons with chronic disease have more than one illness. The employee has the best knowledge of his or her situation and is in the position to define goals and to initiate action. Thus, the employee is potentially a better target for interventions aimed at job retention than a vocational rehabilitation specialist or a multidisciplinary team that decides what is best for the client. This is in line with the fact that empowerment aims to equip people with long-lasting problem-solving capacities.

Since the introduction of self-management programmes for various chronic diseases in the USA, by Kate Lorig in particular, these programmes have spread, and their effectiveness in health promotion have been reported [36,37]. Self-management programmes are often theoretically founded on Bandura's social learning theory [38-41]. According to this theory, a prerequisite for coping behaviours aimed at solving problems is perceived self-efficacy, which means having the confidence that one is able to practice the required behaviour. Expectations of self-efficacy can be enhanced in four ways: by performance accomplishments (i.e., practicing the required tasks and receiving feedback); by vicarious experience (i.e., seeing others practicing); by verbal persuasion; and by reinterpretation of the physiological symptoms associated with the desired activity. Self-efficacy is shown to be enhanced due to self-management programmes [41].

The enhancement of perceived self-efficacy has been adopted as the main tool in a number of vocational rehabilitation programmes aimed at job retention for chronically ill employees [43,44]. We used the concept of self-efficacy in the development of a group programme aimed at job retention because the group programme offered, in our opinion, several ways to enhance self-efficacy. We assumed that higher self-efficacy will lead to more problem solving and subsequently less job dissatisfaction and fatigue, which in its turn will decrease the chance of job loss (Figure 2).

The drawback of an empowerment approach targeted on individual employees and their attitudes, skills and behaviour, is that it focuses on only one of two parties involved. The prevention of work disability in the case of a serious chronic disease requires the commitment of both the employee and the employer. If an employee is empowered and the employer plays deaf, this approach cannot be considered successful and may even raise frustration. I will return to this issue in the last chapter.

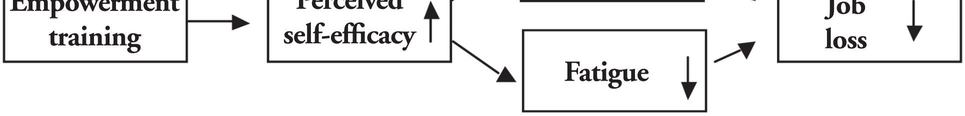

Figure 2. Theoretical model

Research questions

This thesis addresses the following questions:

- What is the employment situation of people with a chronic physical disease and what barriers do they experience at work?
- What is known about the setup, contents and effectiveness of empowerment-oriented interventions aimed at job retention for employees with a chronic physical disease?
- We developed a group training programme aimed at job retention. Is such a programme feasible and are the participants satisfied with it?
- Which problems and strategies to deal with them were elucidated during this training programme?
- Is the intervention effective?

An outline of the thesis

Chapter 2 presents the results of a survey investigating barriers experienced at the work place and trends in the employment of people with haemophilia. The data were gathered long ago, during the economic recession of the 1980s.

Chapter 3 presents an innovative 'patients' perspective' study on working with a chronic disease. Employees with rheumatoid arthritis were not asked what they experience as problematic but what they need in order to stay at work. This is accomplished using a concept mapping study that combines qualitative and quantitative methods. The answers of the employees were compared to those of medical professionals. The major efforts for this study were carried out by Sarah Detaille, Joke Haafkens and Frank van Dijk.

Chapter 4 is a systematic review of empowerment-oriented vocational rehabilitation interventions aimed at job retention for employees with a variety of chronic physical diseases.

The 122 participants of the study presented in Chapter 5 are the same as those studied in the effectiveness study of Chapter 9. We analyse to what extent they experience eight practical and psychosocial aspects of working with a chronic disease as problematic. Furthermore, we examine which kind of work accommodations they prefer.

Chapter 6 describes the development, set-up and contents of the group training programme 'Working with chronic disease' for employees with a chronic disease (Met je ziekte aan de slag). In addition, the design of an effectiveness study is presented.

Chapter 7 focuses on the process evaluation of the training programme. Was recruitment of participants successful? Did we reach the target group? Was the intervention administered as planned? Did the participants follow the programme? Were they satisfied with the various components of the programme? How did they judge its effectiveness? These are the questions answered in this chapter.

Chapter 8 details participants' personal histories. We explore how the participants of the training programme deal with the psychosocial or practical barriers they experience, and we try to find recurring themes, which might clarify the meaning of empowerment in this field.

Chapter 9 evaluates the effectiveness of the training programme. In a longitudinal randomised, controlled trial design, the experimental group and the control group are compared with regard to perceived self-efficacy, job satisfaction, fatigue, job retention and a number of secondary outcome measures after 4, 8, 12 and 24 months.

Chapter 10 summarizes the main findings and reflects on the methodological strengths and weaknesses of the main research project. I finish with a discussion on the issue of chronic disease and employment, a reconsideration of the concept of empowerment and a few recommendations concerning the issue of job retention in those with chronic illnesses.

Acknowledgements

For the development of the training programme 'Working with chronic disease' (Met je ziekte aan de slag), we cooperated with the occupational health service ArboUnie and with Gabe de Vries of the Occupational Therapy department of the AMC. The training programme was performed in collaboration with ArboUnie. The Ministry of Social Affairs and Employment and the Foundation Institute Gak (Stichting Instituut Gak) subsidized the development, the implementation and the evaluation study of the training programme.

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Chapter 2

Employment of individuals with haemophilia in the Netherlands

I Varekamp, C Smit, FR Rosendaal, A Bröcker-Vriends, E Briët, H. van Dijck and TBBM Suurmeijer

Soc Sci Med 1989; 28(3):261-270.

Abstract

A study was performed to determine whether improvements in the treatment of haemophilia over the past 20 years have influenced the prospects of these patients in the labour market. Surveys on the medical and social situation of haemophiliacs in The Netherlands were carried out in 1972, 1978 and 1985. Most of the patients participated in these surveys. Trends in employment do not show either an increase in the number of employed haemophiliacs or a decrease in the number administratively defined as disabled. However, considering the influence of the economic recession on the position of the chronically sick on the labour market and the rise in the number administratively defined as disabled in the Dutch population, haemophiliacs perform well. Sick leave has decreased considerably. Although the employment rate for the group of haemophiliacs is lower than that for the general male population, the level of employment in relation to educational achievements is high and most of the employed do not feel limited in their daily job activities by the haemophilia. Physical mobility is a main factor influencing the employment status but other factors, such as the type of occupation or former occupation and prejudice against people with haemophilia, have to be considered.

Introduction

Haemophilia, a hereditary bleeding disorder that predominantly affects males, is caused by a partial or complete lack of coagulation factor VIII or IX. Depending upon the residual concentration of the relevant coagulation factor distinction is made between severe (0-l% of the normal concentration), moderately severe (l-5%) and mild (5-40%) haemophilia. In severe haemophilia spontaneous haemorrhages occur in joints and muscles. In the milder forms bleeding is encountered only after surgery or trauma. In the long run haemorrhaging in the joints may lead to irreversible damage, notably in the knees, the ankles and the elbows. Since this injury to the joints lessens physical mobility, it is the main cause of disability. Older patients are more likely to be affected since they did not have appropriate treatment when they were young. In the past, treatment of a haemorrhage consisted mainly of prolonged rest. Only in cases of severe bleeding transfusions of whole blood or plasma were administered. Since the end of the sixties these patients receive concentrated blood products that are administered intravenously. Nowadays most of the patients with severe and moderately severe haemophilia are on home treatment whereby transfusions are administered by the patient himself or his parents. Patients who haemorrhage frequently may receive prophylactic therapy consisting of two or three infusions per week.

This three-fold improvement. administration of concentrated blood products, home treatment and prophylactic therapy, was expected to lead to an improvement in the medical and social prospects for haemophiliacs. It was presumed that the decrease in the number of haemorrhages, the prompt treatment and the resulting decrease in damage to the joints would better their position in the labour market.

Haemophilia and employment

Employment is a desirable goal for most people. The employed generally have a higher income, more prestige and more self-respect than those without a job. Often individuals with a chronic disease or a handicap are not blamed for being unemployed. Nevertheless, compared to employed haemophiliacs, unemployed haemophiliacs have more psychosomatic complaints, are not as well adjusted to the problems of life and make fewer plans for the future [1].

A chronic disease or handicap can be an obstacle to getting a job, keeping a job and performing daily job activities. This article concerns the quantity and quality of employment for haemophiliacs. The term ‘quantity’ refers to the number of haemophiliacs

employed in comparison with employment for the general male population. The concept 'quality' was described by Blaxter [2] in her book on disability:
"There were men (. .) struggling arduously and painfully, but nevertheless successfully, to do jobs which were really beyond their reduced physical capacity; on the other hand there were men bored and resentful because the only jobs they could get were, they thought, below their capabilities."
Do employed haemophiliacs reach an occupational level that is comparable to their educational level? In addition to this objective measure the quality of employment from the point of view of haemophiliacs themselves was also investigated by asking whether they experienced restrictions in job performance due to haemophilia.

As for quantitative aspects of employment, international data are far from uniform. Figures on unemployment of haemophiliacs, gathered in 1988 by national haemophilia organisations, were as follows: 0% unemployment in the G.D.R. and Kuwait, less then 1% in Yugoslavia, 8% in the F.R.G and Malta, about 10% in Australia and the U.S.A., 20% in Poland and Argentina, 30% in Portugal and the U.K., 40% in Spain and 60% in Chile [3,4]. However, it is not clear whether these figures apply to some official definition of unemployment or to the number that has no job. Scientific publications on the employment of haemophiliacs are scarce [1,5-11]. Although a proper definition of unemployment is also often lacking and samples are sometimes small, some of them hold enough detailed information to offer the opportunity for a cross-national comparison. Usually employment of haemophiliacs is lower than employment for the general population. In the conclusions and discussion we will put employment of haemophiliacs in international perspective.

Unemployment of haemophiliacs as well as differences in unemployment rates between countries may be due to several factors: physical, social and economical. Most of the time it is a combination of these actors. The physical condition is probably an important factor. Disability due to damage to the joints my make a regular job impossible. Sometimes decreased physical mobility does not make a job impossible but it does reduce job performance, and then it is up to the employer whether the employee keeps his job or not. More precisely, it will often depend on the nature of the labour contract between employer and employee. Blaxter [2] notes that two groups have discouraging 'post-impairment careers': the self-employed who operate on a fee-for-service basis, and those whose labour agreement with their employer was individual and casual. Prejudice may be another cause of the lower employment rate. Haemophilia is a rare disease and laymen are not familiar with it. Many people relate it to 'bleeding to death' and think that the haemophiliac is unable to function well. Inadequate knowledge of haemophilia and modern treatment regimens leads to stereotyped reactions [l2]. A related phenomenon, which may have consequences for employment, is the ‘spread phenomenon’. The able-bodied are inclined to form an image of the handicapped as being inferior not only in physical abilities but also in other respects [13]. An individual may be slightly handicapped in his mobility but capable of performing many jobs, whereas others - employers in this case - might think that because mobility is decreased other capacities may also be reduced. Because of ignorance or the ‘spread phenomenon’ employers may tend to engage someone else instead of the haemophiliac. As has been said, when analysing employment rates of haemophiliacs and differences in rates between countries, it is difficult to differentiate between several factors: physical, social as well as economical. Some remarks however can be made. The inclination of employers not to employ persons with a chronic disease or handicap may cause lower employment rates, but it also may cause employment of lower quality. It is known that people with a handicap are sometimes forced to accept a job below their capability. They face downward social mobility.

In our study we examined:

- trends in the employment of men with haemophilia;
- employment of haemophiliacs compared to that of the general male population;
- occupational level of employed haemophiliacs in relation to their educational level;
- limitations in job performance due to haemophilia;
- correlation between physical mobility and employment situation;
- experiences when applying for a job.

Methods

In 1985 the third Dutch mail survey on the medical and social situation of people with haemophilia was carried out. Earlier surveys were performed in 1972 and 1978 [l4,15]. The questionnaire was prestructured and standardised. Addresses were obtained by updating the mailing lists of former surveys; the Dutch Haemophilia Society and the large haemophilia centres supplied addresses of additional patients. The questionnaire was sent to 1162 persons. Assuming a prevalence of 7-9/100,000 [16,17], we reached at least 90% of the patients in The Netherlands. The response was 81%. For this article only the questionnaires of men between 15 and 65 years of age were analysed. The data were compared to data from the 1972 and 1978 surveys and data on the Dutch 15-65-year-old male population in 1985. When relevant, data are presented separately for severe, moderately severe and mild haemophilia.

The definition on unemployment as used in our survey was: in search of a job and registered with an employment agency. This differs slightly from the definition used in official Dutch statistical analysis: out of work and receiving unemployment compensation or actively seeking work. The percentage unemployed refers to the total group of men between

15 and 65 years of age, as distinct from many official publications in which percentages refer to the labour force. Medical definitions of disability have to be distinguished from administrative definitions in which financial benefits are involved. In this study on the employment situation, data on disability are offered which refer to the administrative definition. The exact definition used was: receiving an income on the basis of one of the two Dutch Disability Compensation Laws (Wet op de Arbeidsongeschiktheidsverzekering, Algemene Arbeidsongeschiktheidswet). This implies a slight underestimation of the number of administratively defined disabled, due to the fact that disabled civil servants receive an income from another fund. The number of people employed, unemployed and disabled cannot be added, because individuals may belong to more than one category at one time. Respondents were classified according to educational level on the basis of the classification system of the Central Bureau of Statistics (CBS). They were grouped into occupational levels according to the Occupational Guide [l8], which distinguishes six levels: 1 = unskilled labour, 2 = skilled labour, 3 = lower employee, 4 = small entrepreneur, 5 = middle employee, 6 = higher vocation.

We developed an instrument that would allow us to measure physical mobility. The respondents were presented with 10 daily activities and asked whether they found these activities easy. somewhat difficult, very difficult or impossible to carry out. The answers were analysed by Mokken scale analysis [19]; the answers ‘somewhat difficult’, ‘very difficult’ and ‘impossible’, were taken together to obtain dichotomous items. The purpose of this analysis was to see whether it is possible to arrange the activities on a scale from easy to difficult, which would mean that if a respondent gives a positive

Table 1. Mokken scale analysis of daily activities, measuring physical mobility

Activity	Difficulty*	Scalability**
Long distance walks	0.61	0.87
Walking up the stairs	0.70	0.85
Jobs in/around the house	0.77	0.76
Walking 400 m	0.77	0.71
Getting in/out of a car	0.81	0.71
Doing the shopping	0.81	0.74
Getting out of a chair	0.82	0.73
Picking things up from the floor	0.87	0.68
Getting (un)dressed	0.92	0.72
Walking on one floor	0.93	0.83

* Difficulty shows the percentage having no problems with the activity.

** Scalability of all activities h = 0.76 Reliability coefficient rho = 0.93.

answer about a 'difficult' activity, he should also answer positively about an 'easier' activity. Table 1 shows the results of the Mokken scale analysis. The 10 activities form a 'strong' scale (H = 0.76), with a high reliability (r = 0.93). The minimum score, indicating minimum mobility, is 0, and the maximum score, indicating maximum mobility, is 10.

Results

General data

There were 716 persons in the age group 15-64 years; 41% had severe haemophilia, 18% had moderately severe haemophilia and 42% had mild haemophilia. Compared to previous surveys more men with mild haemophilia took part in this survey (Table 2). The age distribution for the survey population differs slightly from that found in previous years. Whereas the mean age was 30 years in 1972 and 31 years in 1978. it had risen to 33 years in 1985. The comparable figure for the general male population was 36 years in 1985 (Table 2). Figure 1 shows the mean score for physical mobility for different age groups.

Table 2. Distribution according to age and severity of haemophilia for the survey populations in 1972, 1978 and 1985

	Survey population			General male population
	1972 (n=276) (%)	1978 (n=403) (%)	1985 (n=716) (%)	1985 [20] (%)
Age				
15-24	41	36	30	25
25-34	29	33	28	24
35-44	17	18	23	21
45-54	9	8	12	16
55-64	4	6	7	13
Mean age	30	31	33	36
Severity				
Severe	36	42	41	
Moderately severe	18	16	18	
Mild	22	27	42	
Unknown	24	14	–	

Table 3. Employment and disability in the survey populations (1972, 1978, 1985) and the general male population (1985)

	Survey population			General male population**
	1972 (n=276) (%)	1978 (n=403) (%)	1985 (n=716) (%)	1985 (%)
Employed*	60	58	59	69
Unemployed*	+	+	6	9
Disabled*	17	22	22	11

*Percentages employed, unemployed and disabled do not add up to 100% because some people were employed and disabled at the same time and others, for instance school-going persons, do not belong to any category.
** [20,21].
+No figures available.

Trends in employment: 1972, 1978 and 1985

Comparison of the survey population in 1985 with the survey populations in 1972 and 1978 shows that the number of employed haemophiliacs has remained fairly stable (Table 3). The data on disability indicate that between 1972 and 1978 the number of administratively defined disabled rose; since 1978 it has remained fairly stable. The data for 1985 are not entirely comparable to those for 1972 and 1978, especially as far

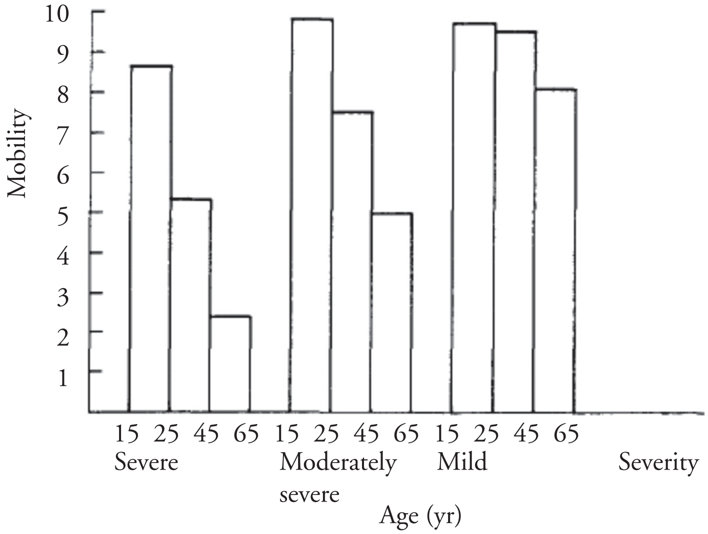

Fig. 1. Mean score for physical mobility.

as disability is concerned. The first two surveys included relatively more patients with severe and moderately severe haemophilia and relatively more young patients. More people with severe and moderately severe

haemophilia 'automatically' cause a higher percentage of disabled, which is counteracted by the fact that more young patients 'automatically' cause a lower percentage. Also in 1972 and 1978 another definition of disability was used, which resulted in a slight overestimation of the number of disabled. However, with these facts in mind, we may conclude that the number of employed has not risen, but the number of disabled has. Sick leave has decreased substantially from 35 days in 1972 and 29 days in 1978 to 15 days in 1985. For that matter sick leave reported for the genera1 male population has also decreased, from 17 days in 1972 and 1978 to 15 days in 1985 [22-24].

Table 4. Employment, unemployment and disability compensation for different age groups*

	Survey population				General male population**
	Severe	Moderately severe	Mild	Total	
Age (years)	(n = 292) (%)	(n = 126) (%)	(n = 298) (%)	(n = 716) (%)	(%)
Employment					
15-24	27	17	44	32	42
25-44	64	76	91	77	87
45-64	48	52	60	55	64
15-64	50	56	71	59	69
Unemployment					
15-24	9	3	4	6	10
25-44	8	11	5	7	9
45-64	–	–	3	1	7
15-64	7	7	4	6	9
Disability					
15-24	8	–	–	3	1
25-44	40	26	5	23	6
45-64	60	48	33	45	25
15-64	33	22	10	22	11

* Percentages of employed, unemployed and disabled do not add up to 100% because some people were employed and disabled at the same time and others, for instance school-going persons do not belong to any category.

**[20,21].

Employment of haemophiliacs compared to employment of the general male population

In 1985 69% of the Dutch male population between 15 and 65 years of age was employed, vs 59% of the survey population (Table 3). However, 10% of the employed haemophiliacs were employed via the Law for Provision of Work for the Disabled (Wet Sociale Werkvoorziening), which offers jobs to individuals with a mental or physical handicap. For the general population this figure was 1.4% [25]. In 1985 9% of the Dutch male population was unemployed; 41 persons of the survey population were registered for employment, which yields an unemployment rate of 6%. Therefore unemployment was lower among haemophiliacs than for the general population. On the other hand the percentage disabled was higher among haemophiliacs. Twenty-two per cent of the survey population was administratively labelled disabled, whereas the national figure was 11%. In the general population disability was concentrated in the age group 45-64 years. This age group is under-represented in the survey population. For this reason comparison between the total survey population and the total general male population will yield an underestimation of the differences. Table 4 shows the disability and employment figures for three age groups.

The Dutch Disability Compensation Laws discriminate between individuals who are completely disabled and those who are partly disabled, the degree of administratively defined disability being dependent on their physical condition and prospects on the labour market. Three-quarters of the disabled haemophiliacs were completely disabled. However being partly or even completely disabled does not automatically mean that one is unemployed. Thirty per cent of the disabled haemophiliacs had some kind of

Table 5. Mean occupational level* of employed haemophiliacs according to educational level

Educational level	Severe (n = 136)	Moderately severe (n = 69)	Mild (n = 201)	
Lower education	2.9	2.5	2.0	(n = 38)
Lower vocotional education	2.9	2.5	2.4	(n = 96)
Middle education	3.5	4.2	3.8	(n = 191)
Higher education	5.3	5.5	5.0	(n = 81)
Total	3.8	3.9	3.4	(n = 406)

*1 = unskilled labour, 2 = skilled labour, 3 = lower employee, 4 = small entrepreneur, 5 = middle employee, 6 = higher vocation.

a job. We conclude that in 1985 haemophiliacs were employed less often than non-haemophiliacs, a fact that is attributable mainly to the higher percentage registered as disabled. In 1985 absenteeism from work due to illness was the same for the survey population as for the general male population: 15 days per year. For individuals with severe and moderately severe haemophilia it was higher, 20 and 23 days respectively; for those with mild haemophilia it was lower, 10 days.

Occupational level and educational level

The employed haemophiliacs were asked about their occupation and the highest educational level they had attained. We wanted to see whether their occupational career met the expectations of their education for it is possible that haemophiliacs, due to their illness, have to accept jobs below their capabilities. General figures are not available. For this reason the relation between education and occupation was compared for individuals with severe, moderately severe and mild haemophilia. If downward social mobility due to haemophilia does occur, this should become apparent in differences between those with severe, moderately severe and mild haemophilia, because many individuals with mild haemophilia are not bothered by their disease and are therefore presumably comparable to the general population. Table 5 shows that the mean occupational level for each educational level is the same for all three categories; individuals with severe and moderately severe haemophilia with lower educational levels even had on the average higher occupations than those with mild haemophilia. Although general figures on occupation in relation to education are not available we know that 43% of the employed males of the general population have blue collar jobs and 57% white collar jobs [26]. For the survey population these percentages were 28 and 72, respectively. From these data it can be concluded that downward social mobility is uncommon among the entire group of employed haemophiliacs as well as each subgroup.

Restrictions in daily work due to haemophilia

A job may pose problems to handicapped or chronically ill individuals; it may be physically too difficult, treatment of the disease may pose practical problems and other problems may arise. We asked the employed haemophiliacs whether haemophilia led to restriction of their daily work performance. If they answered affirmatively, respondents were also asked to indicate which problems were encountered at work. Most of the respondents, 77%, did not consider haemophilia a restriction. A considerable minority, ranging from 12% of the individuals with mild haemophilia to 21% of those with

Table 6. Percentage of employed haemophiliacs, listed according to occupational level, experiencing restriction of daily job activities.

Occupation	Restrictions (%)	
Unskilled manual labour	32	(n = 22)
Skilled manual labour	25	(n = 95)
Lower employee	14	(n = 112)
Small entrepreneur	41	(n = 34)
Middle employee	21	(n = 88)
Higher vocation	12	(n = 60)
Total	21	(n = 411)

moderately severe and 32% of those with severe haemophilia, stated that it was a restriction. The most frequently mentioned problem was 'being bothered by pain', which was indicated by 42 respondents. Other problems had to do with the feeling that they could not meet the requirements of the job: 'having to leave at unexpected moments because of a haemorrhage' (30 times), 'the job is physically too difficult' (18 times), 'to have to ask colleagues for help' (18 times) and 'excessive absenteeism' (17 times).

An interesting aspect is whether restriction of job activities is related to occupational level (Table 6). Manual workers more often experience restrictions in daily job activities than non-manual workers and unskilled manual workers more often than skilled manual workers. The small entrepreneurs suffered such limitations the most. Lower employees and people with higher vocations experienced less restrictions than middle employees. The difference between manual and non-manual workers is easily explained by the difference in requirements concerning physical capabilities. An additional explanation for this as well as for the difference between unskilled and skilled workers is offered by Blaxter [2] in her survey on disability in the U.K.:

"they (persons who retired from work due to disablement) were likely to be semi- or unskilled manual workers, since it was more likely that impairment would not preclude work for non-manual employees, or that their employers, or the employers of valued skilled workers, would be willing to offer adjustments in working conditions so that permanent retirement was not necessary."

As we found many problems among the small entrepreneurs, Blaxter often found for them "unfavourable post-impairment careers" and suggested that the lack of a helpful formal employment structure caused these troubles. Katz [5], coming across the same findings, offered the alternative explanation of self-selection:

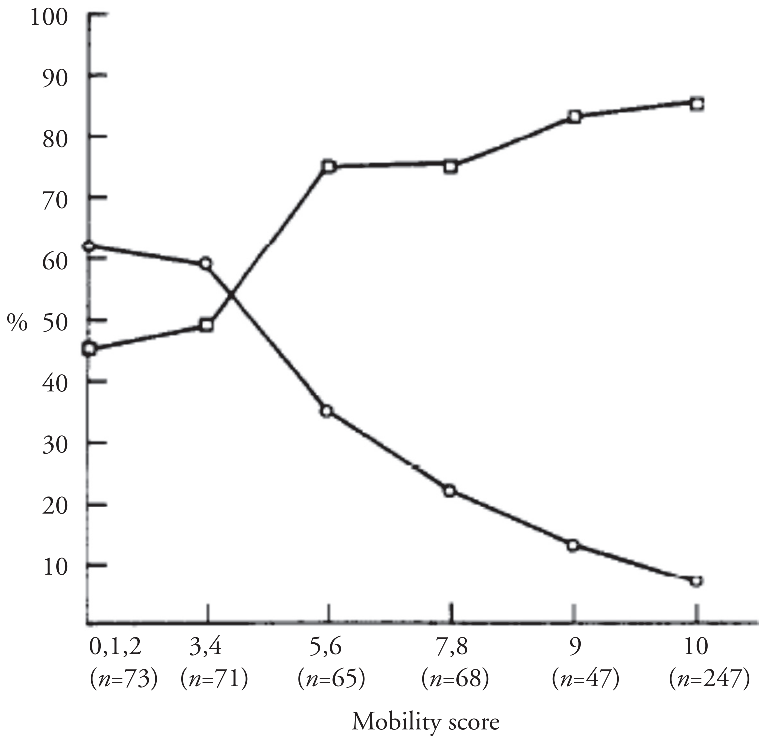

Fig. 2. The percentage employed and the percentage administratively defined disabled for each (group of) mobility score(s). School-going persons are excluded.

"Because of absenteeism and other problems associated with finding and keeping jobs many haemophiliacs feel that self-employment would be the best situation for them."

Employment and physical mobility

To investigate the influence of physical mobility on employment status we determined how many respondents in each group of scores on the mobility scale were employed and how many were administratively defined as disabled. Individuals still going to school were excluded from this analysis. To create groups containing comparable numbers of respondents, data for two or three lower scores were combined (Fig. 2). It appears that the mobility score is only a partial predictor of employment status. Although lower mobility scores are accompanied by a lower percentage employed males, even the group with the lowest mobility scores included employed people: 45% of the patients with a mobility score of zero or one or two were employed, whereas 62% were administratively

Table 7. Experiences when applying for a job: do haemophiliacs mention their haemophilia or not; if so, what happened; if not, why not

	Severe (n = 131) (%)	Moderately severe (n = 62) (%)	Mild (n = 161) (%)	Total (n = 354) (%)
Mentioned haemophilia	89	90	79	85
Experience:				
No problem	41	53	58	51
Was not accepted, presumably because of haemophilia	34	16	9	20
Does not mention haemophilia	11	10	21	15
Reasons:				
Not important	2	5	7	5
Bad experiences in the past	2	2	3	2
Supposed he would not be accepted	5	3	7	6

labelled disabled. We may conclude that factors other than physical mobility also play a role in the employment situation.

Experiences when applying for a job; prejudice of employers

One of the factors affecting the employment situation may be prejudice. We asked the respondents whether they mentioned having haemophilia when they applied for a job. And if so, whether this produced any problems. And if not, why they did not mention it. Three hundred and sixty-two men were too young or too old to apply for a job or they had not done so in recent years. Of the remaining 354 85% told about having haemophilia at the time of application (Table 7). They told the boss, the personnel manager or the medical officer. Fifteen per cent did not mention having haemophilia. Usually a medical officer was involved in the application procedure; when there was none, a higher percentage did not report their haemophilia. Most respondents thought having haemophilia caused no problems. A large minority of the men with severe and moderately severe haemophilia believed nevertheless that they were not accepted for the job because of haemophilia. It is incorrect to assume that employers are prejudiced in every case. The opinion of the respondent on the reason for rejection is a subjective measure of prejudice. In addition some may have been rejected because they really were too handicapped to perform well. However, 32% of the group with negative experiences had a maximum score on the mobility scale, indicating that nothing was wrong with their physical mobility.

A small group did not mention having haemophilia at all. The main reason given was unfavourable experiences in the past or the supposition that haemophilia might be a reason for not being accepted for the job. Others did not mention haemophilia because they thought it was not sufficiently important.

Conclusions and discussion

Comparing the employment situation of Dutch haemophiliacs in 1985 with that in 1972 and 1978, we see that the percentage employed has remained roughly the same. The number of administratively defined disabled increased between 1972 and 1978 and then remained stable. Sick leave has dropped substantially over the years and compares well in 1985 to sick leave data for the general population. In 1985 only a small percentage of employed haemophiliacs experienced restriction of job performance due to haemophilia.

Comparing the employment situation of haemophiliacs in 1985 with that of the general male population, we see that fewer haemophiliacs are employed and more haemophiliacs are disabled than in the general population.

A major cause of the low employment rates is the haemophiliac’s physical condition. Individuals with reduced physical mobility are less likely to be employed. However, not everyone with decreased physical mobility is out of work. The questions on problems with daily job activities show that the kind of job, e.g. the distinction between manual or nonmanual labour, plays a major role in the occurrence of problems. The same will probably apply to the matter of employment vs disability: manual labourers will be, more readily defined as disabled than nonmanual labourers.

One out of every four haemophiliacs applying for a job believes he was not accepted for a job because of his haemophilia. And although not all of these men were in optimal physical condition, thus giving the employer a reason for choosing another applicant, 32% were in optimal physical condition as far as joint problems were concerned. This argues for the occurrence of prejudice against men with haemophilia. Katz’ study among haemophiliacs in the U.S.A. In the sixties revealed that discrimination by employers, caused by ignorance of haemophilia, was felt to be one of the major problems encountered on the labour market [5]. We have to bear in mind however that the results of this kind of survey are based on subjective feelings and not on an objective measure of prejudice. In a study on epilepsy it was found that a distinction should be made between ‘felt’ stigma

Table 8. Employment of individuals with haemophilia. An international overview*

Authors	Country	Year of survey	*N*	Characteristics of the survey population	% employed	% unemployed	% school-going	% disabled	Further characteristics
Katz (1970) [5]	U.S.A	1963-64	1055	age: ≥ 16 years	52	20	26	+	general unemployment 5%(1960)
Steinhausen (1977) [6]	Hamburg, F.R.G	1971-73	54	age: 16-60 years, mean = 27, severity of haemophilia: almost all severe or moderately	48	4	43	2	
Markova et al. (1977,1980) [1,7]	Scotland	1974	66	age: ‘of working age’, severity of haemophilia: ± 35% severe, ± 25% moderately severe and ± 40% mild	+	29	+	+	general unemployment 5%
Stuart et al. (1980) [8]	U.K. and Scotland	1978	502	age: 16-65 years, mean = 34, severity of haemophilia: 48% severe, 24% moderately severe and 28% mild	73	18	11	48	general unemployment 7%
Lineberger (1981) [9]	U.S.A. southeastern rural states	1977-79	106	age: ≥ 18 years, everity of haemophilia: salmost al severe	47	44	+	31	
Nimorwicz et al. (1986) 10]	Pennsylvania, U.S.A.		1983 421	age: ≥ 18 years, mean = 34, severity of haemophilia: 53% severe, 18% moderately severe and 29% mild	61	15	7	12	general unemployment 6%

Continued next page.

Table 8. Continued

Authors	Country	Year of survey	*N*	Characteristics of the survey population	% em-ployed	% un-employed	% school-going	% disabled	Further characteristics
Goldsmith (1986) [11]	Massachusetts, U.S.A.	1985	+	age: +	+	3	+	+	general unemployment is higher
	U.S.A, 82 haemophilia comprehensive care centres	1985	7247	age: 0-100 years, unemployment refers to adults	+	9	+	+	
Varekamp et al. (1989)	The Netherlands	1985	716	age: 15-65 years, mean = 33, severity of haemophilia: 41% severe, 18% moderately severe and 42% mild	59	6	19	22	general unemployment 15%

*Percentages cannot be added to 100% because persons may belong to more than one category.
+ No figures available.

and ‘enacted’ stigma. The majority of respondents in this survey referred to the fear of being discriminated against but only a third could cite incidents of enacted stigma [28]. The relatively high occupational level of employed haemophiliacs and the low number of officially unemployed in our survey suggest that for haemophiliacs without joint problems prejudice, resulting in lack of employment, does not play a major role. Perhaps when prejudice does occur the haemophiliac tries once again and is then successful.

It was expected that modern substitution therapy would influence the employment of Dutch haemophiliacs, just as this was expected in other countries. This influence is most clearly seen in the substantial reduction in sick leave. The expected decline in the number of disabled failed to appear. The main reason for this is that such improvements will not become manifest in a few years. Joint impairment is for the greater part irreversible and the survey population of 1985 contained only a few younger individuals who had had appropriate treatment from the beginning. Another cause is that the general unemployment has had a negative influence on the position in the labour market of individuals with a handicap or chronic disease. Whereas haemophiliacs without joint problems may find the labour market reasonably accessible, those with slight impairments will discover that the ‘spread phenomenon’ and higher demands from employers may pose problems. National disability figures are covariant with the unemployment figures [29]. In The Netherlands the number of disabled receiving income through the Disability Compensation Laws has risen from 218,000 in 1972 and 451,000 in 1978 to 545,000 in 1985 which means an increase of 150% since 1972 [25]. We may suppose that part of the disability of the survey population is attributable to hidden unemployment. For 1978 it was calculated that hidden unemployment represented one-third of the disability in The Netherlands [30]. Compared to other groups with chronic conditions Dutch haemophiliacs have maintained their position in the labour market quite well.

The position of the Dutch haemophiliacs differs sometimes from that of haemophiliacs in other countries. Table 8 gives an overview of the international studies in this respect. As has been pointed out physical, social and economical factors affect the employment/unemployment ratio of people with haemophilia. The relative importance of those factors varies in time, causing different levels of unemployment between countries. This makes an international comparison of unemployment rates hazardous. This holds the more so because of methodological weaknesses in some of these studies. Some samples are small or biased. Exact definitions of unemployment are usually not given, so it is not clear whether they refer to official registration for employment, or simply to lack of employment. Also it is not clear whether the percentages refer to the entire survey population, the survey population except school going persons, or the labour force.

General unemployment figures usually refer to the labour force. For these reasons it is more appropriate to compare the employment figures of haemophiliacs. Three studies give sufficiently detailed data to permit longitudinal and cross-national comparison [5,8,10]. A comparison between the situation in 1963-64 and 1983 in the U.S.A. shows an increase in employment and a decrease in unemployment. This is partly explained by the exclusion of the 16 and 17 year olds in 1983. Nimorwicz thinks that a part of the unemployed in 1963-64 have moved to the category of the disabled since in 1963-64 only a limited social security programme for disabled workers was available and not until 1973 were benefits available for the young disabled that were never employed [10]. Recently the employment situation in The Netherlands resembles the situation in the U.S.A. and the U.K.: 59-73% is employed and a rather large group is unemployed or disabled. A remarkable difference between the U.K. and The Netherlands is that in the U.K. employed haemophiliacs often have manual occupations (haemophiliacs 55% manual work; general population 39%) whereas in The Netherlands they are concentrated in the non-manual occupations. Markova [1,7] also noted that the more severe the haemophilia, the more often employment was in manual work, which in her opinion was accounted for by the low educational level.

The rise in employment that failed to appear, despite better treatment facilities, stresses the importance to distinguish between impairment and disability on the one hand and handicap on the other hand as these concepts were defined by the World Health Organisation in 1980 [31]. Whereas impairment of the joints and restrictions in physical mobility decreased, the handicap did not: economic independence in terms of earning a living is still not attained by many. One could ask whether this is completely attributable to the inaccessible labour market and furthermore how far this 'stability' in employment rates is regrettable. As to the first question we refer to a discussion on the objectives of rehabilitation [32-34]. In this discussion a distinction was made between resource enhancement (development of a person's potentials to render them good coping resources) and resource compensation (replacement of resources, e.g. financial assistance). It was supposed that beyond a certain limit resource compensation is a restraint on successful integration [33]. The Netherlands have Disability Compensation Laws that guarantee 70% of former income, and since 1976 there is a Disability Compensation Law for young handicapped that were never employed. The rise in the number of administratively defined disabled and the slight fall in the number employed between 1972 and 1978 may be attributed to the introduction of this law. As to the second question concerning the 'stability' in employment rates we would reflect as follows: economic independence in the sense of earning a living did not increase in The Netherlands. But in case of employment the occupational level is mostly high. It seems that haemophiliacs are not compelled to accept jobs below their educational level or jobs that are unfit for them. This is different from the English situation, where haemophiliacs more often have manual jobs [8] and the handicapped frequently experience downward social mobility [2]. One explanation for the favourable Dutch situation is perhaps the fact that the educational achievements of Dutch haemophiliacs are good [27]. which gives them a good start on the labour market. Another explanation may be that social security regulations for the disabled are (at least were until 1985) good in The Netherlands in comparison with other countries [35]. This may have prevented downward mobility in the occupational career. From this perspective low employment of good quality is preferable to high employment of bad quality.

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Chapter 3

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.

Introduction

Work disability among people with rheumatoid arthritis (RA) often starts soon after diagnosis (1), and is estimated to occur in 22 to 44% of all cases (2). Although there appears to be a positive trend in the Netherlands and Germany (3,4), the general impression is that work disability is still a serious problem that needs to be addressed (2,4).

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 (5), 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 (4,6,7). In contrast, biomedical factors appeared not to be consistently related to work disability (7). 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 (7).

A number of studies have focused on work-related problems among employees with RA and potential work adaptations. The study by Lerner et al (8), 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 (9) 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 (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.

The present 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.

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. (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 (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 (12). 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 (14). 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 (15) 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.

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
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.

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 (16,17). The Medical Ethics Committee of the Academic Medical Center in Amsterdam approved the study.

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

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.
Theme 3.	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 4.	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.
3.3	The ability to explain their syndrome to their employer.
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)
(Two statements, none of them scored 3 or higher)	
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)
(One statement)	

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* Lengthy sentence structures have been rephrased.

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.

Subanalyses 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).

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.

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.
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.
3.5	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.

Table 3. Continued

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 rephrased.

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 n 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.

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Chapter 4

How can we help employees with chronic diseases to stay at work? A review of interventions aimed at job retention and based on an empowerment perspective

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Abstract

Objectives. A growing number of persons aged 16-65 is hampered by a chronic condition in performing job activities. Some of them quit the labour market prematurely. Vocational rehabilitation used to focus on (re)entering the labour market. Recently more attention is paid to interventions aimed at job retention. Some of these use an empowerment perspective. The objective of this study is to describe the characteristics, feasibility and effectiveness of such vocational rehabilitation interventions in order to decide which approaches are fruitful.

Method. The Medline, Embase, Cinahl and Psycinfo databases were systematically researched for studies published between 1988 and March 2004. Studies were included if they were experimental, included an intervention that aimed at job retention by means of solving work-related problems, used an empowerment perspective and concerned employees with one of the following chronic illnesses: diabetes mellitus, rheumatic diseases, hearing disorders, multiple sclerosis, inflammatory bowel disease, epilepsy, chronic kidney failure, COPD and asthma.

Results. Nine studies were detected. The aims of the intervention programs were to improve psychosocial skills or implement work accommodations. They were structured as individual (6x) or group programmes (3x). They used methods like education (9x), assessment (7x), counselling (5x), training or role playing (5x). The most important outcome measures were employment status (5x), actions to arrange work accommodations (3x), and psychosocial measures like self-efficacy and social competence (3x). Employment status was claimed to be positively influenced in four out of five studies, obtaining work accommodations was successful in all three studies and psychological outcome measures improved in two out of three studies.

Conclusions. There is some evidence that vocational rehabilitation interventions that pay attention to training in requesting work accommodations and feelings of self-confidence or self-efficacy in dealing with work-related problems are effective. There is no evidence for greater effectiveness of group programs compared to individual programs. Attention has to be paid to feasibility aspects such as recruitment of participants and cooperation between medical professionals, occupational physicians, and vocational rehabilitation experts. Medical specialists and nursing specialists should pay more attention to work. Although many studies claim effectiveness, evidence for this was often weak due to short follow-up and the lack of control groups. More rigorous evaluation is needed.

Introduction

An increasing number of people aged between 16 and 65 are hampered by a chronic disorder or handicap in performing job activities [5]. Persons with a chronic disorder are less often employed than others. In the Netherlands, 45% are employed, as opposed to 60% of the general population [3]. If employed, 15 to 58% of them experience difficulties in performing physical, psychosocial or environmental work demands [18]. Factors associated with the employment situation of people with a chronic condition have been the subject of many studies. Apart from the severity of functional impairments, sociodemographic and psychological factors, attitudes and beliefs, job characteristics, social support in the workplace, organizational factors and macro-economic factors are reported as being decisive for maintaining employment [16,6,7]. Only a few studies on work-related problems are qualitative and conducted from a patients' perspective. These patients have rheumatoid arthritis, diabetes or hearing loss and they mention psychological factors such as a lack of self-acceptance and assertiveness, social factors such as a lack of support from colleagues or managers, and insufficient work accommodations as factors which may lead to job loss [19,10].

Vocational rehabilitation used to focus on efforts for persons with a chronic disease or handicap to enter or re-enter the labour market. Recently, more attention has been paid to job retention instead of a return to work, since the idea is emerging that it is easier to maintain a job than to find a new one. At the same time, legislation in the USA and European countries at the end of the 20th century aimed to encourage higher employment rates for people with chronic health conditions. In the USA and the UK, employees are entitled to ask 'reasonable accommodations' of their employers to enable them to continue working [8]. In the Netherlands, recent disability pension legislation has made employees themselves more responsible for job retention.

Another development in the past decade is the gradual replacement of traditional vocational rehabilitation services in which the client has a rather passive role by an 'empowerment' oriented approach. The empowerment perspective in health care originates from patient education and self management practices for chronic diseases. The aim is to provide 'a combination of knowledge, skills and a heightened self-awareness regarding values and needs, so that patients can define and achieve their own goals'[11]. Empowerment in rehabilitation has been conceptualized to include intrapersonal components such as a sense of control or self-efficacy, interactional components such as critical awareness of the resources needed, knowledge and skills for managing resources, and behavioural components such as participatory behaviour and coping behaviours [30].

Vocational rehabilitation interventions aimed at job retention which use an empowerment perspective are promising. In order to advise about future programs we reviewed the literature. We studied the characteristics of these intervention programs, their feasibility and effectiveness. As evidence for effectiveness depends on methodological quality of effectiveness studies, this was assessed as well.

Material and methods

Chronic diseases

Nine rather common chronic somatic conditions were selected which represent diseases of different organ systems, presumably with an impact on work ability: diabetes mellitus, rheumatic diseases, hearing disorders (excluding deafness), multiple sclerosis, inflammatory bowel disease, epilepsy, chronic kidney failure, COPD and asthma. Diseases with dominant psychosocial aspects, such as low back pain, were deliberately excluded in order to focus on the consequences of somatic diseases.

Search strategy

The Medline, Embase, Cinahl and Psycinfo electronic databases were searched for articles with an abstract in English, German, French or Dutch, over the period 1988 to March 2004. References of selected articles were checked for new relevant titles. In addition, experts gave advice about relevant articles. A single search strategy in which groups of search terms for disease (patients), interventions and outcome measures respectively were combined with the Boolean term AND gave only a few results. We concluded that the field of vocational rehabilitation is so peripheral to regular medicine that articles are generally not indexed by combining intervention terms with outcome terms. A separate search strategy was eventually developed for each database in which terms referring to vocational rehabilitation interventions and terms referring to work-related outcome measures were all combined with the Boolean term OR [14]. Subsequently, this search strategy was combined with a specific chronic condition using the term AND. The Appendix presents the search strategies for each of the four databases.

Selection of articles

All titles or abstracts were screened using the following inclusion criteria: the article reports on an experimental study, includes a description of an intervention which might use an empowerment perspective, and the intervention is conceivably aimed at job retention by means of solving work-related problems. Empowerment perspective has been defined as offering knowledge and skills to clients which enable them to adopt an active attitude in defining and solving problems. If there was any doubt about inclusion, the last author (FvD) also screened the abstract. Full text articles of citations meeting these criteria were assessed to see whether the interventions really aimed at job retention and used an empowerment perspective. There were no restrictions concerning methodological qualities or outcome measures.

Data extraction

The following characteristics of the intervention programs were described: chronic disease of the participants, objectives of intervention, intervention methods, group meeting or individual counselling/training, number and discipline of trainers/counsellors, and recruitment procedure. If available, data on the feasibility of the intervention programs were collected. The following characteristics of the studies were assessed: pretest and/or posttest measurement, use of control group, number of participants, follow-up period, outcome measures and effectiveness.

Results

Search and selection of studies

The initial database search yielded 1849 citations. After deducting double citations, 1505 remained. The numbers were 333 (rheumatic diseases), 204 (epilepsy), 181 (diabetes mellitus), 147 (multiple sclerosis), 85 (partial hearing disorder), 44 (inflammatory bowel disease), 60 (chronic kidney failure) and 451 (COPD and asthma). Twenty-nine citations were selected based on title and abstract. They were assessed anew based on the full text. Finally, nine studies met all the inclusion criteria [1,2,11,16,20,21,22,23,24]. Three studies were found through experts' advice or when checking references. Three authors had published two studies each. The studies covered the following diseases: rheumatic diseases, diabetes, multiple sclerosis, chronic kidney failure, hearing impairment, visual impairment or blindness, and one study combined people with various miscellaneous disorders. No studies were found of patients with inflammatory bowel disease, epilepsy, COPD or asthma.

Table 1. Characteristics of intervention programmes.

Author	Disease or handicap	Objectives of intervention	Intervention methods	Structure of intervention (number of participants per group)	Number and discipline of trainers or counsellors	Recruitment procedures
Getty and Hetu, 1991 Canada	Occupational hearing impairment	To initiate a problem-solving process by offering psychosocial support, making persons understand disorder, consequences and aids, and developing coping skills.	Assessment Education Group discussion Trial of hearing aid Role playing	Group meetings 4 x 2 hrs or 1.5 day, plus follow-up meeting (8 + spouses)	Two occupational health nurses	Invitation during home visit by known nurse
Rasgon et al., 1993 USA	Kidney failure in-centre dialysis	To maintain employment by learning to fit dialysis in life, changing perceptions of unemployability, and increasing feelings of being in control.	Psychosocial assessment Education Counselling	Individual counselling, several sessions	Clinical social worker	Referral by physician to social worker of dialysis centre prior to dialysis
Rasgon et al., 1996 USA	Kidney failure home dialysis	To maintain employment	Psychosocial assessment Education Counselling	No clear information, probably individual counselling, several sessions	Social worker + nurse educator	No information, probably similar to Rasgon, 1993
LaRocca et al., 1996 USA	Multiple sclerosis	To examine employment experiences and offer information and referral services in order to alleviate stress and enable persons to continue working	Assessment Education Counselling	Individual counselling, 2x 1 hr, and possibility for extra counselling	Psychologist + employment specialist	Invitation by telephone after screening during regular visit MS Centre
Petermann et al., 1997 Germany	Diabetes type 1	To improve social competence in work and non-work situations Reflection	Education Group discussion Role playing	Group meetings 4 x 3 hrs (6-8)	Two diabetes educators	Invitation during stay in hospital for insulin regulation

Table 1. Continued.

Author	Disease or handicap	Objectives of intervention	Intervention methods	Structure of intervention (number of participants per group)	Number and discipline of trainers or counsellors	Recruitment procedures
Allaire et al., 1997 USA	Arthritis or rheumatic disease	To enhance sense of control and self-efficacy and to enable participants to solve their work-related problems	Education Peer interaction Individual exercises	Group meetings 10 x 3 hrs (8-12)	Volunteers or staff of patient organization (no clear infortion on number)	No clear information
Rumrill and Garnette, 1997 USA	MS, spinal cord lesion, blindness and deafness, and other	To increase self-efficacy in work accommodation request process, knowledge about legal rights, behavioural activities related to job accommodation	Assessment of work barriers and accommodation needs, Education (written material), Training, including role playing	Individual training, 1x	Rehabilitation professional	Flyers and announcements to rehabilitation centres, referral from practitioners, advertisements, mail solicitation
Rumrill, 1999 USA	Visual impairment and blindness	To increase confidence, knowledge and activity concerning the process to get work accommodations	Assessment of work barriers and accommodation needs Education Counselling Training, including role playing, monitoring	Individual training, 2x	Rehabilitation professional	Referrals from local independent living centres, vocational rehabilitation agencies, ophthalmologists, student disability service programmes, consumer advocacy organizations
Allaire et al., 2003 USA	Rheumatic diseases	To identify work barriers and accommodations, acquire knowledge of legal rights and skills in requesting work accommodations	Assessment of work barriers and accommodation needs Education Counselling / Training	Individual counselling 2 x 1.5 hr	Rehabilitation counsellor	Recruitment through rheumatologist who sent a letter and screening form

Characteristics of intervention programs

Table 1 summarizes the characteristics of the interventions. Job retention was the ultimate goal for all studies apart from Allaire et al. (1997), who combined job retention with job attainment for unemployed persons [1]. Most authors mentioned several - often related - objectives which are thought to contribute to job retention. The phrasing of the objectives reflects the occupational background of the trainers or authors. The objectives can be classified in the following categories (not in table):

- to increase knowledge (about the disorder and its consequences, legal rights and work accommodations)
- to gain a clear understanding of work-related problems or work barriers
- to increase feelings of control (general control or perceived self-efficacy in the process to request work accommodations)
- to develop skills (coping skills and social competences)
- to increase activities aimed at work accommodations

Ensuing from specific objectives, combinations of the following topics were discussed with the participants: information about chronic disorder and its social consequences, job-related interpersonal and emotional issues, assertiveness and communication skills, work barriers and work accommodations, strategies to get work accommodations, and legal rights (not in table).

Six interventions consisted of individual training or counselling sessions. One of these was intended for significant others as well. The number of sessions varied from one to several. The other three interventions were group programs. The number of these two or three hour group meetings varied from four to ten, the number of participants per group varied from six to twelve patients, except for the hearing impairment group. This group tended to be quite large due to the presence of accompanying spouses. Two group interventions were run by two trainers at the same time, the intervention in the third study presumably had only one trainer.

All interventions offered education, combined with counselling (5x), assessment (7x), or training, which often included role playing (5x). Once cited methods were trial of hearing aids, reflection, individual exercises, and monitoring. In case of group programs, group discussions, exchange of experiences, role playing and other peer interactions took place during the meetings. Some interventions were more oriented towards the psychological and social consequences of disease for functioning at work, others towards practical solutions of work-related problems. Most interventions were mainly or purely oriented towards work, but some were aiming at a wider perspective. For instance, Rasgon et al. were oriented towards the self-management of disease, choosing an appropriate treatment modality for renal failure and learning how to fit this into one's daily life. However, fitting treatment in working life and changing negative ideas about employment were also objectives of the intervention [22].

Trainers or counsellors had varied occupational backgrounds: psychologist, employment specialist, rehabilitation counsellor, occupational health nurse, social worker, specialized nurse educator, trained volunteer or staff member from a patient organization.

Recruitment procedures varied with respect to the organization that took the initiative, the extent to which people were stimulated to participate, and the magnitude of the group of potential participants. Organizations involved were outpatient clinics, local community health centres, vocational rehabilitation organizations, HMOs, and patient organizations. They often operated in cooperation (not in table). A standard recruitment procedure was an invitation by letter or telephone call after a regular visit to an outpatient clinic. A not intensive, large group approach was used by Rumrill and Garnette who approached potential participants with flyers, announcements about rehabilitation centres and advertisements. In addition, patients were referred by practitioners [24]. Getty and Hetu used an intensive small group approach. Occupational nurses screened employees for audiological problems and, already known to the employees, paid a home visit to the hearing impaired employees and invited them and their spouses to participate [12].

All studies except two used current employment as an inclusion criterion [23,1]. Self-reported worries about future employment problems due to disease were an additional inclusion criterion in two studies (not in table) [17,2].

Feasibility of the interventions

Three studies paid explicit attention to the feasibility of the program. Getty and Hetu were positive about the feasibility of group meetings for hearing impaired workers and their spouses. Their opinion is based on a high participation level (89%) among the first group, due to an intensive recruitment procedure, and successful implementation later on [12]. Allaire et al. (1997) studied attendance and satisfaction with a comprehensive group meeting program for arthritis or rheumatic disease patients. They concluded that the program was promising and patients were satisfied. However, program development and repetition were hampered by difficulties in soliciting program participants, and a lack of volunteers and staff group meeting managers from the patient organization [1]. LaRocca et al. stated that a modest individual job retention program for MS patients was feasible. The opinion is based on the successful cooperation between health care

Table 2. Study characteristics: methodological characteristics, outcome measures and results

Author	Pretest-posttest measurement and use of control group	Number of patients (+ controls)	Follow-up after intervention	Outcome measures	Results
Getty and Hetu, 1991 Canada	Pretest-posttest, without control group	48 and 41 spouses	2 and 3 months (telephone interview and group discussion)	Use of hearing aids Handicap questionnaire	More use of hearing aids 2 pos. and 2 neg. changes in handicap questionnaire (36 items) Increased awareness and self-confidence (qualitative data)
Rasgon et al., 1993 USA	Posttest only, with nonrandomised control group	45 and significant others (+ 57 controls) (64 blue-collar and 38 white-collar workers)	At least 6 months and well over four years on average	Employment status	Blue-collar workers: 47% retained job vs. 24% (controls) (OR=2.8, chi-square=3.78, $p<0.05$) White-collar workers: 47% retained job vs. 48% (controls), not stat. sign.
Rasgon et al., 1996 USA	Posttest only, without control group	30 of whom 19 employed	At least 6 months	Employment status	14/19 persons retained job
LaRocca et al., 1996 USA	Pretest-posttest, with randomized control group	23 (+ 20 controls)	1 year	Employment status	19/23 retained job, vs 19/20 (controls), not stat. sign.
Petermann et al., 1997 Germany	Pretest-posttest, with semi-randomised control group	60 (+ 62 controls)	6 months	Perceived social competence in four domains: mobility at work, work problems, hypos at work, coping with others. Metabolic control.	Exp.: improvement in coping with others (before: 14.7 after:13.7, $p<0.05$) Exp. better metabolic control ($p<0.005$) Controls: improvement in hypos at work (before: 14.9 after:13.4, $p<0.05$)

Table 2. Continued

Author	Pretest-posttest measurement and use of control group	Number of patients (+ controls)	Follow-up after intervention	Outcome measures	Results
Allaire et al., 1997, USA	Pretest-posttest, without control group	141 of whom 37 employed	6 months	Employment status	34/37 employed persons retained job 24/104 unemployed persons gained job Increased self-confidence (qualitative data)
Rumrill and Garnette, 1997 USA	Posttest only, with stratified randomised control group	18 (+ 18 controls)	8 weeks	Self-efficacy in accommodation request process ADA knowledge test Work accommodation process activity scale	No stat. sign. improvement in self-efficacy (exp.59.9 vs. contr. 51.2) More ADA knowledge ($p<0.001$) More requests ($p<0.001$), meetings with employers ($p<0.01$), and implementation of work accommodations ($p<0.01$)
Rumrill, 1999 USA	Posttest only, with stratified randomised control group	23 (+ 23 controls)	16 weeks	Self-efficacy in accommodation request process ADA knowledge test Work accommodation process activity scale	Improvement in self-efficacy (exp. 59.4 vs. contr. 45.3, $p<0.001$) More ADA knowledge ($p<0.01$) More requests ($p<0.001$), meetings with employers ($p=0.001$), and implementation of accommodations ($p=0.16$)
Allaire et al., 2003 USA group	Pretest-posttest, with stratified randomised control	122 (+ 120 controls)	24-48 months	Time to job loss permanent job loss	Delay in job loss ($p=0.03$) Temporary or permanent job loss 25/122, compared to 48/120 (controls) (OR=0.58, $p=0.05$)

providers and employment specialists. However, recruitment of patients during the regular visit to the MS centre was problematic, as MS patients were seldom interested in the program. On the other hand, if they were, they were enthusiastic. Nevertheless, they mainly followed counsellors' recommendations in minor or very concrete problems. More complex and subtle problems, for instance involving intellectual dysfunction, family problems, and emotional distress were avoided. The authors conclude that clients apparently did not want to anticipate future problems. Yet, when they occur, it is probably too late to intervene [17].

Methodological quality of the studies and outcome measures

Table 2 presents the study characteristics. All studies were quantitative, although some also collected qualitative data. Four studies used a randomised control group (RCT), two studies used a semi- or nonrandomised control group and three studies had no control group at all. Four studies used only posttest measurement. The total number of patients in experimental groups varied between 18 and 141. Numbers of controls varied from 18 to 120. Follow-up varied from eight weeks to 24-48 months. The longer follow-up periods were used when job retention was the outcome measure.

Data on the following outcome measures were obtained:

- employment status or similar concepts, such as temporary or permanent job loss (5x),
- actions to get work accommodations (3x),
- self-report instruments to assess psychological measures such as self-efficacy or social competence (3x),
- knowledge of disability regulations (2x),
- disease or disability symptoms (2x).

Outcome of the interventions

Employment status was measured in five studies. Two of the three studies using a control group reported effectiveness. Forty-seven percent of blue-collar workers with chronic kidney failure kept their job after a follow-up of at least six months, compared to 24% of the control group. The intervention made no difference for white-collar clients [22]. Employees with rheumatic diseases had a job retention rate of 97/122, compared to 72/122 in the control group after 24-48 months follow-up. However, the effect had almost faded for those followed for four years [2]. Employees with multiple sclerosis had a job retention rate of 19/23 after a one-year follow-up, compared to an even higher retention rate of 19/20 in the control group. On the other hand, this was not statistically significant, three out of four who lost their job in the experimental group were already on sick leave at the start of the intervention, and the retention rate was high for both groups [17]. Two studies measured job retention without the use of a control group. Fourteen out of nineteen employed persons with chronic kidney failure retained employment after at least six months [23]. People with rheumatic diseases showed a job retention rate of 34/37 after a six month follow-up [1].

In three studies the participants' actions to arrange work accommodations were measured. A higher use of hearing aids was reported after following a group training course for hearing impaired employees. There was no control group, but the authors argue that these participants with occupational hearing loss had not previously sought medical or audiological advice themselves. The focus on hearing aids during the intervention makes it convincing, in their opinion, that the result is a consequence of the group meetings [12]. Rumrill studied a varied group of chronic diseases (1997) and people with visual impairment or blindness (1999) who received almost the same intervention. He reported more requests for work accommodations, more meetings with employers to discuss them, and more implementations of accommodations, compared with a control group. He also reported more knowledge about disability regulations (the Americans with Disabilities Act) [24,25].

Three studies, all with a control group, collected psychological outcome measures. A pretest-posttest design was used to study the effectiveness of a psychotherapy oriented training for young adults with diabetes type 1. The experimental group showed an improvement in coping with others in general (5 items 5 point scale, before-after = 14.7-13.7), but no differences in dealing with work-related problems or mobility at work. The control group performed even better in dealing with hypoglycaemia at work (5 items, 5 point scale, before-after = 14.9-13.4). The authors stated that they possibly took the target group too wide. Only offering training to those patients who actually experienced difficulties at work or in social relations estimated to be 20-40%, would probably have given more impressive results [21]. Two studies investigated perceived self-efficacy in the process of requesting work accommodations. Both used a post-test only design. In the first no statistically significant improvement in self-efficacy was found compared to the control group (experimental 59.89, control 51.17, range 10-100). This was explained by a high sense of self-efficacy from the beginning. The second study showed improved self-efficacy (experimental 59.39, control 45.26, range 10-100) [24,25].

Two studies measured health related outcomes. Employees with diabetes showed a better metabolic control [21]. Persons with occupational hearing impairment showed no clear improvement in experience of handicap [12].

In two studies qualitative data were collected on psychological functioning. Participants in the studies on hearing impairment and the study of Allaire et al. (1997) on arthritis and rheumatic diseases expressed greater self-confidence as an effect of the intervention. Furthermore, information about legislation on work accommodations, and understanding strengths and limitations in job performance were mentioned as helpful by the participants in Allaire's study [12,1].

Discussion

Nine studies were found on the effectiveness of empowerment based intervention programs aimed at job retention for employees with a chronic somatic disorder. The selected studies varied in intervention methods, recruitment procedures and outcome measures. This heterogeneity makes it impossible to combine the results in a meta analysis. However, it offers the possibility to reflect on the potential benefits of the variety of approaches. All intervention programs combined education with other methods like counselling or training. These methods might all contribute to empowerment, offering a combination of knowledge and skills, so that patients can define and achieve their own goals. Which type of intervention method is working best can not be concluded. As increased self-confidence was mentioned by several participants as important, methods aimed at increasing this seem worthwhile to include.

Most studies measuring job retention reported effectiveness. All studies measuring participants' activities to implement work accommodations showed positive results. Studies measuring self-efficacy or social competence had varied results.

Although many studies claimed effectiveness, it was not always supported by strong evidence based on a strong study design. Three studies did not make use of a control group. The number of participants in some studies was low. The follow-up period was seldom more than one year. Only the studies of LaRocca et al, Petermann et al, and Allaire er al (2003) meet the methodological criteria of pre testing, use of a control group, a sufficient number of participants and long follow-up period [2,17,21].

A drawback of our review is the limited number of studies we found, reflecting presumably that part of the interventions will not be scientifically evaluated. The evidence based medicine tradition is not yet adopted fully in the field of occupational medicine.

Our results have implications for vocational rehabilitation practices aimed at employees with a chronic condition, and implications for future research. Firstly, the feasibility of vocational rehabilitation programs is a prerequisite for their effectiveness. A main reason why so few rheumatic arthritis patients participate in vocational rehabilitation programs is that medical professionals are unaware of these programmes [9]. It is important that medical specialists and nursing specialists pay more attention to work-related problems of patients, and it is important for them to cooperate with employment or vocational rehabilitation specialists, especially where recruitment procedures are involved for this kind of intervention programs.

Secondly, the large variety of secondary objectives which are thought to contribute to job retention show that interventions may focus on different aspects of the employee and his or her environment. This requires a comprehensive conceptual model to understand work-related problems and work disability. The International Classification of Functioning, Disability and Health (ICF) of the World Health Organization offers a model of disability in general which is applicable to work disability. In this model disability is considered as the outcome of a process in which biological, psychological and social factors are interrelated [27,29]. The model presents a social rather than a medical perspective in which disability is perceived as an aspect of the relationship between a person and his environment, or as a gap between personal capabilities and demands from outside which may be reduced by increasing capability or by reducing demand. The model includes interventions intended to reduce the disability outcome. These can be directed on the individual, e.g. behaviour changes, or directed on external support, e.g. modifications to the physical and social environment. The model illustrates why an employee with a chronic condition experiences problems in a unique way, depending not only on the severity of functional limitations but also on job demands, support from colleagues or managers, personal skills, organizational features and social regulations.

Thirdly, the great variety of intervention methods points to the lack of clarity concerning the effectiveness of methods. When a vocational rehabilitation intervention contributes to the objective of job retention, it is not clear how this objective is achieved. One can simply inform people about the consequences of chronic disorders and practical solutions for work-related problems. Or try to change their mind about their potentials in a psychotherapy-oriented intervention, or offer training in dealing with work barriers and negotiating about work accommodations. Some authors state that a purely educational approach is insufficient for behavioural change [26,13]. This corroborates the qualitative findings in the studies presented which stress the importance of self-efficacy or self-confidence as an intermediate factor. Whether these psychological states are best improved by counselling, role playing or other kinds of training and to what extent group meetings are beneficial is unclear. Bandura's social cognitive theory which is often used in the field of health education and health behaviour and which is cited in some of the studies cited might be helpful. Bandura hypothesizes self-efficacy as a prerequisite for changes in behaviour. He mentions several sources for improvement of self-efficacy, including learning through personal experience, learning through observations or through other people, and verbal persuasion [4]. These three sources are used in role playing, in exchanging experiences in group meetings, and in counselling. Future studies should pay attention to these theoretical aspects [16].

Fourthly, future research should have a strong study design, in order to acquire more evidence for effectiveness. Various outcome measures like job retention, behavioural and psychological measures should be used, combined with a pretest-posttest design, randomized control groups, a long follow-up, precise inclusion criteria, and a large number of study participants. As far as job retention is concerned, a follow-up period of years instead of months is preferable. On the other hand, we have to realize that this field resembles the larger field of chronic disease management in which control procedures and a long follow-up raise serious problems, which make the interpretation of differences between experimental and control group notoriously difficult [28].

At the end, one disadvantage of the empowerment perspective should be mentioned. The perspective is based on the employees' ability and responsibility to solve problems. However, we might forget that employees are not the only ones responsible for job retention. Employers should be prompted to take their responsibility as well and national policies should enable them to do so [15,20].

Vocational rehabilitation programs aimed at job retention may be worthwhile. For the recruitment of patients medical professionals, occupational physicians and vocational rehabilitation experts, have to cooperate more closely. In addition, more rigorous evaluation of these programs is needed.

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Appendix Search terms

Medline

Search strategy for work-related terms (explode function), Mesh terms or free text words (all fields): “return to work”[All Fields] OR “workplace”[MeSH Terms] OR “employment”[MeSH Terms] OR “employment status”[All Fields] OR “work disability”[All Fields] OR “sick leave”[MeSH Terms] OR “job satisfaction”[MeSH Terms] OR “work ability”[All Fields] OR employability[All Fields] OR “occupational medicine”[MeSH Terms] OR “rehabilitation, vocational”[MeSH Terms] OR “occupational health”[MeSH Terms] OR “disability management”[All Fields].

Search terms for chronic diseases, all Mesh major topic, except where otherwise specified: Diabetes mellitus/ Rheumatic diseases/ Hearing loss [Majr] NOT deafness [Mesh] OR Hearing impaired persons [Majr]/ Inflammatory bowel diseases/ Multiple sclerosis/ Kidney failure, chronic/ Epilepsy/ Asthma OR Pulmonary disease, chronic obstructive.

Embase

Search strategy for work-related terms (Subject headings, not exploded except where otherwise specified (exp), not focused, or text words (mp)): work resumption OR workplace OR employment OR employment status(mp) OR work disability OR absenteeism OR job satisfaction OR work ability (mp) OR work capacity OR job performance OR employability OR occupational medicine OR vocational rehabilitation OR occupational health OR occupational health service OR disability management (mp)

Search terms for chronic diseases, (all terms exploded and focused, unless otherwise specified) :Diabetes mellitus/ Rheumatic diseases/ Hearing loss (not exp)/ Crohn disease (not exp) or ulcerative colitis (not exp)/ Multiple sclerosis/ Chronic kidney failure/ Seizure, epilepsy and convulsion/ Chronic obstructive lung disease or asthma.

Cinahl

Search strategy for work-related terms (Subject headings, not exploded except where otherwise specified, and not focused, or text words (mp)): job re-entry OR employment (exp) OR work disability (mp) OR work capacity evaluation OR sick leave OR disabled OR job satisfaction OR work ability (mp) OR employability (mp) OR occupational health services (exp) OR rehabilitation, vocational OR disability management (mp) OR job performance.

Search terms for chronic diseases, (all terms exploded and focused): Diabetes mellitus/ Rheumatic diseases/ Hearing loss, partial/ Inflammatory bowel diseases/ Multiple sclerosis/ Kidney failure, chronic/ Seizures or epilepsy/ Lung diseases, obstructive.

Psycinfo

Search strategy for work-related terms: (free text words or Subject headings (DE)): (job-satisfaction) in DE) or ((employee-absenteeism) in DE) or ((job-performance) in DE) or (work-disability) or ((employment-status) in DE) or ((disabled-personnel) in DE) or ((reemployment) in DE) or (return-to-work) or (job-retention) or (job-maintenance) or ((disability-management) in DE) or (occupational-health) or ((vocational-rehabilitation) in DE) or (occupational-medicine) or ((employability) in DE) or ((occupational-adjustment) in DE) or (work-ability)

Search terms for chronic diseases (all subject heading, unless otherwise specified): Diabetes-mellitus/

Rheumatoid-arthritis/ (Hearing-disorders not deaf) or partially-hearing-impaired/ Ulcerative-colitis or colon-disorders/ Multiple-sclerosis/ Kidney-diseases/ Epilepsy or epileptic-seizures or convulsions/ Asthma or Lung disorders or copd (free textsword).

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Chapter 5

Employees with chronic diseases who experience difficulty in the workplace: Identifying problems and potential solutions

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Occup Med (accepted)

Abstract

Background. While many employees who have a chronic disease manage their jobs well, others are hampered in work performance, experience work-related problems and are at risk for job loss.

Aims. To identify the practical and psychosocial barriers recognized by employees with chronic disease who experience work-related problems and to examine preferred work accommodations.

Methods. A questionnaire was sent by mail and completed by current workers who have a chronic disease and experience serious problems at work.

Results. One hundred and twenty-two employees participated in this study. On average, they had been ill for ten years and 44% had more than one disease. The most outstanding work-related problems were psychosocial, including work-home interference and a lack of acceptance of the chronic disease. Performing and finishing work tasks and social relationships with supervisors or colleagues were also felt to be slightly problematic. The most preferred work accommodations included fewer work hours, working from home, a slower work pace and more autonomy in planning work tasks. Almost three-quarters of the respondents were so fatigued that they were at risk of sickness absence or work disability.

Conclusion. A chronic physical disease may lead to both practical and psychosocial problems and serious fatigue. Managing psychosocial problems may decrease fatigue.

Introduction

Chronic diseases and handicaps are becoming more prevalent within the aging labour force of industrialised countries and new measures are needed to prevent work disability. Thirty-seven percent of Dutch employees have a longstanding disease or handicap. While more than half of them state that they are not hampered in work performance, 41% are slightly hampered and 8% are severely hampered [1]. Employees with a chronic disease are more fatigued on average than healthy employees [2]. This may be troublesome in itself and is also a predictor of work disability [3]. Lerner et al. studied a large sample of U.S. employees who had a variety of chronic conditions. Depending on the condition, they found that 22% to 49% of the employees experienced difficulty in meeting physical work demands and 27% to 58% experienced difficulty in meeting psychosocial work demands [4].

Studies have found that physical limitations, physical work tasks, a higher age and a lower educational level are predictors of work disability [5,6]. Recent studies pay special attention to the employees' perspectives on their employment situation. Support from and understanding of colleagues and line managers are found to be important to job retention [7-9]. A lack of family support for employment [10], demanding working conditions and interpersonal difficulties [11] are problematic. Psychological factors include a reluctance to disclose health information, a fear that others may see one as unfairly favoured [11], an inability to cope with the illness [7], an inability to set limits, a negative self image and feelings of hopelessness related to employability [12]. Most of these studies are small, qualitative studies. They are relevant because they point to modifiable factors and identify possible interventions that may remove barriers and reduce the chance of job loss. Training employees to solve work-related problems and educating colleagues and line managers about disability and workplace accommodations may prevent unnecessary job loss.

We studied a group of current employees who have a variety of chronic physical conditions, experience serious work-related problems and fear either job loss or a loss of job satisfaction. These employees were motivated to complete empowerment training. We investigated the following questions:

- What particular aspects of working life do these employees experience as problematic?
- What work accommodations do these workers prefer?
- How do their fatigue, burnout and perceived quality of work scores compare with those of other employees?

Methods

This study is part of a larger research project that includes a randomized controlled trial (RCT) evaluating the effectiveness of an intervention aimed at job retention [13]. The experiences of the participants in this RCT (both the experimental and the control groups) are discussed here.

We offered a group-training programme to help individuals solve problems they experience at work due to their chronic conditions. Participants were recruited via outpatient clinics, occupational health services, patient organisations, employers and a yearly national conference on chronic disease. Participants were eligible for the study if they had a chronic physical medical condition, had a paid job, experienced problems at work and feared the loss of their job or job satisfaction. Workers were excluded if they were on long-term 100% sick leave that was expected to last for several months.

All participants received a baseline mail questionnaire about their health, employment situation, work accommodations, work performance, work-related problems and perceived quality of work.

Work-related problems were measured by examining eight areas: problems with specific work tasks, finishing work, arranging the workplace and equipment, commuting, communicating with colleagues, communicating with the supervisor or line manager, acceptance of the chronic disease and balancing work and life at home.

Work accommodations were measured with Kremer's work accommodations list [14].

Fatigue was measured with the Checklist Individual Strength (CIS), a validated questionnaire for the working population [15]. A score of 76 or higher is considered as a level of fatigue that puts the individual at risk for sick leave or work disability [16].

Burnout was measured with the Utrecht Burnout Scale (UBOS) [17].

Quality of life was measured with the SF-12.

Nine subscales of the Dutch questionnaire on Perception and Judgement of Work [18] measured physical or mental task burdens, work pace, job autonomy, job satisfaction, social relationships with colleagues or supervisors, worry about work and uncertainty about the future.

The Medical Ethics Committee of the Academic Medical Centre in Amsterdam approved the study design and deemed ethical review unnecessary due to the non-medical nature of the research. All participants signed informed consent documents.

Results

Data were collected between September 2006 and February 2008. One hundred and twenty-two respondents participated in the study and completed the questionnaire. The health characteristics of the study population are presented in Table 1. A quarter of the population had musculoskeletal disorders, 23% had nervous disorders and 21% had digestive disorders; 44% had more than one chronic disease. The mean disease duration was 10 years.

Personal and work characteristics are presented in Table 2. The mean age of the participants was 46 years, three quarters of the population were women and most participants lived with a family. Middle and higher educational levels were overrepresented. Almost all of the participants worked in commercial and non-commercial service areas. The great majority had jobs that did not involve manual labour (data not shown) and

Table 1. Chronic disease* and other health characteristics of the study population (n = 122)

	n (%)
Diseases of the musculoskeletal system and connective tissue[1]	30 (25)
Diseases of the nervous system[2]	28 (23)
Diseases of the digestive system[3]	25 (21)
Endocrine, nutritional and metabolic diseases[4]	10 (8)
Neoplasms	6 (5)
Diseases of the respiratory system	5 (4)
Diseases of the circulatory system[5]	4 (3)
Other diseases[6]	14 (12)
One or more additional chronic disease	54 (44)
	Mean(SD)
Disease duration in years	10.2 (9.5)

* International Classification of Diseases, ICD

1) Including rheumatoid arthritis 12x, fibromyalgia or other chronic pain 5x, SLE 4x, arthrosis 3x and Sjögren's disease 2x.

2) Including multiple sclerosis 13x and Parkinson's disease 9x.

3) Including Crohn's disease or colitis ulcerosa 24x.

4) Including diabetes 5x, Graves' disease and other thyroid gland disorders 4x.

5) All heart conditions (4 x).

6) Including HIV 3x, renal failure 2x, visual impairments 2x, and other diseases 7x.

Table 2. Personal and work characteristics of the study population (n=122)

	Mean (SD) or n (%)
Age	45,6 (8,7)
Women %	91 (75)
Living alone (no partner, children or parents) %	34 (28)
Education %	
Lower	4 (3)
Middle	52 (43)
Higher	66 (54)
Branch of industry %	
Agriculture and fishing	0 (0)
Industry and building industry	2 (2)
Commercial services	49 (40)
Non-commercial services	70 (58)
Temporary appointment %	12 (10)
Appointment	
hours per week	30,9 (8.1)
days per week	4,3 (0.8)

almost everyone had a permanent job. On average, the respondents worked 31 hours and 4.3 days a week.

Table 3 shows work performance characteristics. One quarter of the study population received disability compensation, usually partial. On average, participants had been absent due to sickness on 17 working days within the last four months; 22% had no sick leave at all during this period. Almost all of the participants felt either slightly or severely hindered at work due to health problems. Physical work capacity was bad or very bad for 18% of the participants, moderate for 51% and good or very good for 31%. Mental work capacity was bad or very bad for 16% of the participants, moderate for 43% and good or very good for 40%. Forty-five percent of the respondents had contacted their occupational physician over the last four months. Colleagues and supervisors or line managers were almost always aware that the employee had a chronic disease.

Work-related problems are presented in Table 4. They are arranged from the lowest frequency of occurrence to the highest. The arrangement of the workplace or equipment was the least-reported issue; it was problematic for 30% of the population, but was rarely seriously problematic. Commuting was a slight or serious problem for almost 40% of the population. Contact with the supervisor or with colleagues was problematic for almost half of the respondents, but it was severely problematic for only a minority. Performing and finishing work tasks was problematic for a large majority of the participants, but

Table 3. Work performance characteristics (n=122)

	n (%) or Mean (SD)
On disability compensation (partially or 100%)	30 (25)
Sickness absence, nr. of days in last four months	17.0 (22,1)
Hindered at work due to health problems	
No	5 (4)
Yes, slightly	74 (61)
Yes, severely	42 (35)
Work capacity, physical	
(Very) bad	22 (18)
Moderate	62 (51)
(Very) good	38 (31)
Work capacity, mental	
(Very) bad	20 (16)
Moderate	53 (43)
(Very) good	49 (40)
Contact with occupational physician in last 4 months	55 (45)
Frequency in last 4 months, if yes	3.1 (2.1)
Disclosure towards colleagues	113 (93)
Disclosure towards supervisor	117 (96)

most found it only slightly problematic. The great majority (85%) of the respondents found it difficult to accept having a chronic disease. Finding a balance between work and life at home or work-home interference posed a problem for 90% of the participants and was a severe problem for more than half of them.

Table 4. Work-related problems (n=122)

Due to my disease, I experience problems with …	no %	yes, slightly %	yes, severely %
Arrangement of workplace (equipment)	71	22	7
Commuting	61	23	16
Contact with supervisor or line manager	52	34	14
Contact with colleagues	53	41	7
Finishing my tasks	34	48	19
Performing work tasks	16	69	16
Acceptance of having a disease	15	39	46
Finding a balance between work and life at home	10	38	52

Table 5 presents seventeen different work accommodations and the percentages of respondents who do or do not prefer these accommodations and who already receive these accommodations. The large majority of respondents (84%) had experience with one or more accommodations; the average was 3.2 accommodations. Individuals with musculoskeletal disorders had the most accommodations and those with digestive disorders had the fewest accommodations (data not shown). The most common accommodations were the possibility of planning work oneself, alternative or fewer working hours, dropping tasks, a slower work pace, assistance from others and working at home. One out of every five respondents had a special desk or chair to accommodate their needs. Nearly a fifth of the study population had other aids at their disposal, often computer-related aids such as an ergonomic mouse, a special keyboard, speech

Table 5. Work accommodations, realised and/or preferred* (n=122)

Work accommodations	Realised …, and content %	Realised …, preferred more %	Not realised …, but preferred %	Not realised …, not preferred %
Working less hours	26	13	29	32
Other working hours	29	11	20	39
Adjusted breaks arrangement	6	1	18	75
Lower work pace	16	6	28	50
Help of others	16	6	20	59
Dropping work tasks	24	7	22	47
Other work tasks	11	7	8	74
Possibility to plan tasks oneself	34	14	20	31
Acquisition of aids	17	2	12	69
Accommodated desk or chair	16	4	13	67
Utensils/ equipment	2	0	7	91
Working at home	15	6	30	50
Climate (temp., ventilation)	2	2	20	76
Dust-free workplace	2	0	11	87
Commuting	5	0	18	77
Extra training	4	2	27	67
Other work accommodations	9	5	5	81

* The first and second columns add to the total percentage that has realised the accommodations; the second and third columns add to the total percentage that does prefer these accommodations. The last column presents the percentage that neither has nor prefers the accommodation.

Table 6. Quality of life, fatigue, burnout and quality of work of study population (n=122) as compared to reference figures of the Dutch working population.

	Study population Mean (SD)	Dutch working population Mean (SD)
Fatigue (20-140)[1]	88.7 (21.6)	57.2 (23.7)***
Burnout exhaustion (0-6)[2]	3.37 (1.4)	1.57 (1.1)***
Burnout distance (0-6)	2.02 (1.3)	1.54 (1.1)***
Burnout competence (0-6)	4.20 (0.9)	4.14 (1.0)
Social relationships colleagues (0-100)[3]	27.0 (14.3)	22.2 (13.9)***
Social relationship supervisor (0-100)[3]	25.2 (18.5)	23.0 (16.9)
Worrying about work (0-100)[3]	42.4 (39.2)	21.0 (30.0)***
Job satisfaction (0-100)[3]	22.0 (29.1)	12.7 (18.8)***
Work pace (0-100)[3]	51.9 (17.9)	44.0 (15.3)***
Mental task burden (0-100)[3]	78.2 (17.8)	79 (no fig.)
Physical task burden (0-100)[3]	21.4 (19.4)	17.1 (17.5)**
Job autonomy (0-100)[3]	44.1 (20.0)	41.7 (19.4)
Uncertainty about future (0-100)[3]	41.0 (30.2)	32.6 (34.3)**

1) Fatigue scale: a higher score indicates more fatigue. Reference figures: [19] (12,095 employees).

2) Burnout scales: higher scores indicate more exhausted, distanced or competent. Reference figures: [17 (1.018 civil servants).

3) Quality of work scales: a higher score means a more unfavourable situation. Reference figures: [20] (68.775 workers; 13.491 workers for mental task burden; no figure available for SD).

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

recognition software and a headset telephone. Eighteen percent mentioned other work tasks. Ninety percent of the respondents stated that they prefer work accommodations. The mean number of accommodations preferred was 3.9. Working fewer hours and working from home were preferred accommodations, as well as a slower work pace, control over the planning of tasks, alternative working hours, fewer tasks, extra training, assistance from others and a better workplace climate. A large minority of respondents who already had some work accommodations would prefer more of these types of accommodations.

The mean scores of the study population on fatigue, burnout and quality of work measures are compared to Dutch employee reference figures in Table 6 [17,19,20]. The study participants scored much higher on fatigue; 73% had a score higher than the cutoff point of 76, which identifies them as at risk for sickness absence or work disability [16]. Study participants with one chronic disease had a mean fatigue score of 85.2 (SD 22.8), whereas those with two or more diseases had an average fatigue score of 93.2 (SD 19.4) (data not shown). The burnout exhaustion and burnout distance subscales were also significantly higher among the study population, while the burnout competence subscale was similar among the study and reference populations. According to Schaufeli's guidelines [17], the burnout exhaustion and burnout distance scales showed that 78% and 34% of the study population, respectively, was burned out. The study participants had unfavourable scores on several scales measuring quality of work, including social relationships with colleagues, physical task burdens worry about work, job satisfaction, work pace and uncertainty about the future.

Discussion

We studied employees with various chronic physical disorders who experience work-related problems. Although the great majority of the study participants worked in the service sector and had jobs that did not require manual labour, three quarters were so fatigued that they were at risk for sickness absence or work disability. While practical arrangements at the workplace like desk and chair accommodations or computer aids were seldom an issue, the study participants more frequently identified problems with colleagues or supervisors and performing or finishing work tasks. However, the largest issues were acceptance of the chronic disease and balancing work and life at home. The majority of participants preferred further work accommodations, particularly organisational accommodations like the ability to work at home, work fewer hours, work at a slower pace, receive extra training or have more autonomy in work planning.

The quality of this study is that it examined a group of 122 employees with various severe chronic diseases and that we paid particular attention to modifiable factors. Some of our findings suggest that our study selected 'severe cases.' Franssen [21] and Bültmann [19] studied the same population of Dutch employees (the Maastricht Cohort Study; see Table 6) and found that 27% reported experiencing one or more chronic diseases. The mean fatigue score of this subpopulation was 67.7, while the mean score of those who were not chronically ill was 53.4. The chronically ill subjects of these studies were substantially less fatigued than our study population, which had a mean score of 88.7. Other figures also suggest that our study included more severe cases. Almost all of the respondents in this study had disclosed their disease to their colleagues or line managers, while Munir [22] found that only half of the employees with a chronic disease informed their line managers. In addition, 84% of our respondents reported receiving one or more work accommodations; this is a much higher percentage than has been reported in other studies [23,24].

This study has several limitations. The study population was interested in following a vocational rehabilitation program that paid attention to communication at work in order to solve problems. The great majority of participants worked in the commercial or non-commercial service sector. This means that individuals who were not motivated to reflect on and discuss problems were underrepresented; in addition, individuals working in the industrial, transportation or agriculture sectors and employees who did not expect to get permission from their supervisors to follow the rehabilitation program were underrepresented. The results of this study largely correspond with those of other studies. Detaille, Nilsson, Banks and Lacaille examined the importance of social support at work and also found that many respondents experienced difficulties with colleagues or supervisors [7-9,11]. Our finding that acceptance of the chronic disease is slightly or severely problematic for most respondents corresponds with Gustafsson and Detaille's [12,7] findings about the importance of factors like a negative self image, feelings of hopelessness and the inability to set limits or cope with the disease. As mentioned before, Donders, Bültmann and Franssen [2,19,21] found that employees with a chronic disease experienced higher fatigue levels; Franssen also found that having two or more chronic diseases raises the fatigue level substantially. Donders, who used other measurement instruments, found a large difference in emotional exhaustion between chronically ill and healthy employees and small but significant differences in physical workload, decision latitude and social support from superiors and colleagues. She found no differences in work pace or autonomy.

Several studies focus on the relationships between chronic disease, fatigue and psychosocial characteristics like distress, depression or anxiety. Fatigue and psychological distress are related within the general labour force [19] as well as among chronically ill employees [21]. Franssen attributed fatigue among the chronically ill partly to the disease itself and partly to psychological distress [21]; he found psychological distress to be more significant for mental health disorders and gastrointestinal diseases and less important for other diseases. Because our study participants have a much higher mean fatigue score we assume that a substantial part of fatigue may be attributable to psychological distress. The high scores on 'worrying about work' and 'uncertainty about the future' and the reported difficulty in accepting the chronic disease support this hypothesis.

This study has several important implications. This population is working and wants to remain working; their official retirement age is usually far away. Yet many of them feel that they cannot continue to work much longer. The first challenge for this group is to deal with psychosocial problems. Problems with accepting a chronic disease might be related to the typical characteristics of these diseases, which are marked by permanence, unpredictability over time, day-to-day variability and often invisibility [25]. To be confronted with a permanent (i.e., irreversible) disease that may have an unpredictable course alters one's perspective and self-perception [26,27]. Many individuals become depressed, angry or ashamed about their loss of health and loss of work capacity. Time and reflection are required for individuals to adapt to their limitations and to work out a new biography. Acceptance is often the first step and many employees need help dealing with their changed perspectives. The second step is to openly and self-confidently discuss the consequences of a chronic disease for work, including decreased capacity and the need for work accommodations. Although the majority of our respondents were on good terms with their colleagues and line managers, a large minority found that contact was slightly or severely disrupted. This hampers discussions of work-related problems and the possibility of finding solutions. It is difficult for an employee to solve these problems alone. Health care professionals should be alert to psychosocial problems and occupational physicians, human resources managers and line managers should be aware of issues that may affect an employee with a chronic disease. An understanding and flexible employer will be the first step to decreasing distress and possibly fatigue.

Even when psychosocial issues are addressed, fatigue will continue to be a problem for employees who are simply unable to fully perform in a full-time or almost full-time appointment. Many employees would like to work fewer hours or at a slower work pace. They know that continuing to work at a full level requires them to sacrifice their health, their family life, their leisure activities and their social relationships outside of work. The implication of our study is that apart from offering practical and organizational work accommodations (and alternative tasks may be a good work accommodation) the possibility of partial long-term incapacity benefits should be investigated for persons who are able to work part-time. In the Netherlands, partial incapacity benefits for the disabled with less than a one-third loss of work productivity in monetary terms has been cancelled in order to increase employment rates for this group. One of the arguments advanced in favour of a higher employment rate for chronically ill or handicapped persons is that paid labour increases quality of life and can be good for health [28]. This may be true for the general population and for individuals with common, manageable health problems like mild or moderate musculoskeletal or cardio-respiratory diseases [29], but it may not be true for everyone. Research shows that many people with a chronic disease and physical disability are dissatisfied with their work and that a large percentage are satisfied with not being employed [30].

This article does not address exactly how fatigue is related to psychological distress and whether various work-oriented measures may reduce psychosocial problems and consequently fatigue. The larger project of which this study is a part may answer this question. Another issue to be pursued is how far employers are willing and able to make accommodations that enable employees with serious chronic diseases to stay at work over the long term.

In conclusion, chronic physical diseases are widespread in the working population. The work performance of most of these individuals is either not hampered or only slightly hampered by their disease. However, work performance is severely hampered for a large minority of this population; problems manifest not only in physical limitations, but also in psychosocial problems and excessive fatigue. Attention should be paid to these psychosocial problems. Working full-time may be a bridge to far for some members of this group.

Key points

- Employees with a chronic physical disease who experience work-related problems not only face physical limitations but psychosocial challenges as well.
- About three quarters of the employees who experience work-related problems are so fatigued that they are at risk for sickness absence or work disability.
- Employees with chronic diseases prefer work accommodations that offer them more flexibility in the organisation of work tasks and allow them to work fewer hours.

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Chapter 6

Empowering employees with chronic diseases; development of an intervention aimed at job retention and design of a randomised controlled trial

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Abstract

Background: Persons with a chronic disease are less often employed than healthy persons. If employed, many of them experience problems at work. Therefore, we developed a training programme aimed at job retention. The objective of this paper is to describe this intervention and to present the design of a study to evaluate its effectiveness.

Development and description of intervention: A systematic review, a needs assessment and discussions with Dutch experts led to a pilot group training, tested in a pilot study. The evaluation resulted in the development of a seven-session group training combined with three individual counselling sessions. The training is based on an empowerment perspective that aims to help individuals enhance knowledge, skills and self-awareness. These advances are deemed necessary for problem solving in three stages: exploration and clarification of work related problems, communication at the workplace, and development and implementation of solutions. Seven themes are discussed and practised in the group sessions: 1) Consequences of a chronic disease in the workplace, 2) Insight into feelings and thoughts about having a chronic disease, 3) Communication in daily work situations, 4) Facilities for disabled employees and work disability legislation, 5) How to stand up for oneself, 6) A plan to solve problems, 7) Follow-up.

Methods: Participants are recruited via occupational health services, patient organisations, employers, and a yearly national conference on chronic diseases. They are eligible when they have a chronic physical medical condition, have a paid job, and experience problems at work. Workers on long-term, 100% sick leave that is expected to continue during the training are excluded. After filling in the baseline questionnaire, the participants are randomised to either the control or the intervention group. The control group will receive no care or care as usual. Post-test mail questionnaires will be sent after 4, 8, 12 and 24 months. Primary outcome measures are job retention, self efficacy, fatigue and work pleasure. Secondary outcome measures are work-related problems, sick leave, quality of life, acquired work accommodations, burnout, and several quality of work measures. A process evaluation will be conducted and satisfaction with the training, its components and the training methods will be assessed.

Discussion: Many employees with a chronic condition experience problems in performing tasks and in managing social relations at work. We developed an innovative intervention that addresses practical as well as psychosocial problems. The results of the study will be relevant for employees, employers, occupational health professionals and human resource professionals (HRM).

Trial registration: ISRCTN77240155

Background

Persons with longstanding health problems or handicaps have paid jobs less often than healthy persons. The employment rate in several countries in Europe is approximately one third lower for these individuals [1-3]. These figures differ substantially for various chronic diseases. The majority of rheumatoid arthritis patients in the USA and the Netherlands are employed (59% and 56%), although the prevalence of premature work cessation rises steadily with disease duration [4,5]. For inflammatory bowel disease the figures are roughly the same: about 60% [6], or even more [7,8] are employed. For the USA the figures are somewhat higher, for Europe somewhat lower. In addition, patients with chronic obstructive pulmonary disease (COPD) perform rather well: for Dutch patients between the ages of 45-60, 52% are employed [9]. More dramatic are the figures for dialysis patients or people with Parkinson's disease, where less than one third of the patients of working age report being employed [10-12]. For multiple sclerosis patients, comparable figures are available: only 20 - 40 % is employed [13].

If employed, many persons with chronic diseases experience problems at work. Lerner et al. [14] studied a large sample in the USA and concluded that, depending on the chronic disease, between 22% and 49 % of the employees experienced difficulties in meeting physical work demands, and that between 27% and 58 % had difficulty meeting psychosocial work requirements. Compared to healthy workers, chronically ill workers have higher scores on scales measuring fatigue and emotional exhaustion, which are correlated with perceived work stress [15,16]. Research focussing on the patients' perspectives provides insight into possible sources of stress and fatigue, and offers suggestions for remedies. Patients with diabetes, rheumatoid arthritis or hearing loss stated that important factors that helped them to continue working were the ability to cope with the illness, support from management and colleagues, and adequate work conditions [17]. A focus group study among employees with inflammatory arthritis reveals that they faced difficulties managing interpersonal and emotional difficulties at work, in addition to managing fatigue and other symptoms, and that they had trouble managing working conditions [18]. Asked what they expected in the way of work-related support, employees with multiple sclerosis mentioned support with managing work performance and support with managing social and personal expectations [19]. These findings suggest that vocational rehabilitation efforts should pay attention to psychosocial as well as practical bottlenecks at the workplace.

For the past several decades, social policy in many countries has been focussed on helping individuals with a chronic disease or handicap enter or re-enter the labour market, whereas less attention is paid to efforts aimed at helping employees to stay at work. Finding a new job is more difficult than trying to keep one, as one has the extra task of convincing a new employer of one's capabilities. This might be a reason to focus attention on structural vocational rehabilitation efforts aimed at job retention.

A systematic review shows that there is some evidence for the effectiveness of interventions of this kind. However, the number and methodological quality of the studies is not sufficient to tell which one will be most successful [20]. Based on this review and discussions with experts, we developed training for employees with chronic diseases that supports them in solving practical and psychosocial problems. The aim is to prevent the unnecessary loss of their job.

The objective of this article is twofold. First, the development, set-up and contents of the intervention will be described. Second, we will specify the design of the study to evaluate its effectiveness.

Development and description of intervention

Target group and purpose

This intervention is meant for employees with a chronic physical (i.e. not a predominant psychiatric) disease, who experience work-related problems and fear job loss or loss of work pleasure. We decided to include a wide variety of chronic diseases, such as musculoskeletal diseases like arthrosis and rheumatoid arthritis, neurological diseases like multiple sclerosis and Parkinson's disease. We included endocrinological diseases like diabetes, heart failure, pulmonary conditions, inflammatory bowel disease, chronic fatigue syndrome, and visual impairment, as well as any other chronic disease or handicap that results primarily in physical limitations. Work-related problems are broadly defined – they may be practical, social, mental or a combination of the three.

The aim of the intervention is twofold: job retention as well as maintenance or increase of work pleasure.

Program development

We started to carry out a systematic review of vocational rehabilitation interventions aimed at job retention for employees with chronic diseases [20]. Effectiveness studies, though often of low methodological quality, gave evidence of positive effects. This inspired us to develop an intervention of the same kind. Four patient organisations were contacted to ask whether they thought that there was a need for this kind of intervention. Three employees with chronic diseases who had experienced serious work-related problems were interviewed by telephone in order to assess their needs. A first draft of a program was developed, based on international examples. In addition, elements of the program were derived from two current Dutch vocational rehabilitation programs aimed at job retention for employees on long-lasting sick leave. One is tailored to workers with burnout [21], the other to workers with severe depression [22,23]. The pilot version of the training was tested in a group of eight employees. On the basis of the trainers' experiences, the researchers' observations, a pre- and post test evaluation and an interview of the participants by telephone, the pilot version was adapted. In the process of adaptation, decisions were reached about the optimum length of the training period. Elements of the pilot training were prioritised, which resulted in the elimination of several elements.

The most important post-pilot changes included a new final meeting, two months after the sixth meeting. More time was reserved for role-playing, and two individual consultations were added to the first intake consultation. A 'Quality of work' model, used to clarify work-related problems and based on the ICF disability model [24], was not helpful in clarifying work related problems, because many problems experienced at work originated in 'the environment', a concept that is present but not elaborated well in the ICF. Therefore, this model was substituted for a new version that emphasises the positive or negative influence of work tasks, social relationships at the workplace and working conditions on wellbeing at work.

After the decision-making process on the outlines was finished, the essential elements, procedures and objectives of each component of the group sessions, as well as of the individual counselling sessions, were discussed and described in detail in the trainers' manual. Together with the trainers' manual, a textbook for the participants was written. This textbook gives an overview of the content of every group session, homework to be completed for the next session and an appendix that offers theoretical background and exercises. Experts from two patients' associations commented on the training and the textbook.

Rationale of the training

The training is based on a number of notions:

Empowerment

Participants are invited to participate in a program 'to provide knowledge, skills and a heightened self-awareness regarding values and needs, so that patients can define and achieve their own goals', corresponding to the definition of empowerment by Feste and Anderson [25]. Such a program requires an active attitude, in which participants define what is problematic at work and subsequently try to get a hold on their situation. Counselling can be a component of such an empowerment program.

The importance of personal and environmental factors

Work-related problems and work disability can be understood as the result of the specific combination of disease, person and workplace. A serious medical condition can be decisive; causing so many problems that continuing work is impossible. On the other hand, whether an employee with a chronic disease becomes work disabled often depends on factors other than the severity of his disease or bodily impairments. The actual disability may depend on personal and environmental factors that can hinder or promote work capacity and functioning. This point of departure corresponds well with the WHO's International Classification of Functioning, Disability and Health [24,26]. However, the ICF-model is not elaborate enough to serve as a model to clarify work-related problems. These must be understood in a broader context in which work tasks, social relationships at the workplace, working conditions and terms of employment are understood as significant for well-being at work.

Communication is important and can be difficult

Working together and discussing tasks and responsibilities requires communication skills. However, having a chronic disease may hamper communication and have a negative impact on social relationships with supervisors and colleagues. Employees need to explain to the supervisor or colleagues what their disease implies and to elucidate its consequences for work performance. At the same time feelings of sadness, shame or anger about their disease may prevent speaking out [27]. Not speaking out or non-assertive behaviour is an impediment to the solution of work-related problems

Perceived self-efficacy is a prerequisite to resolving work-related problems.

According to social learning theory, active coping behaviour aimed at solving problems will improve when perceived self-efficacy increases [28,29]. Expectations of personal efficacy will be enhanced by performance accomplishments, vicarious experience and verbal persuasion.

The above-mentioned principles resulted in the development of a stepwise intervention for employees with a chronic disease: a) exploring and clarifying work-related problems, b) communication at work, and c) thinking out and realising solutions. It is organised mainly as a group intervention, since group meetings are a suitable method for enhancing perceived self-efficacy.

Set-up of the training

The training is a group training consisting of seven three-hour sessions every two weeks. The last session takes place two month after the sixth session. The group comprises eight participants and one trainer. The trainer is experienced in working with groups, has psycho-therapeutic knowledge of the principles of rational emotive therapy as well as knowledge of occupational psychology and a basic understanding of chronic diseases and their consequences.

Participants are requested to read material from the textbook before each session, and to do homework that is discussed at the start of the following session. The exchange of experiences forms an important part of the training. Guest speakers are invited at three sessions. An actor is invited twice to assist with role-playing. An occupational physician and an employment expert are invited to discuss matters concerning work accommodations, sickness absence, disability pensions and other practical topics. In conjunction with the group sessions three individual consultations are offered: one at the beginning, one halfway through the training, and one after the sixth session. These consultations offer the trainer the possibility of giving feedback, and participants the possibility of discussing anything they want in private, or to pursue questions in greater depth.

Contents

Every session focuses on one theme, which will be discussed briefly.

1. What bothers you; consequences of a chronic disease in the workplace.

The participants get to know each other well in this session; group dynamics and the feeling that one can exchange experiences and practice exercises safely are essential for the success of the training. Attention is paid to possible consequences of chronic diseases in terms of difficulties in performing tasks, in carrying on, and in the risk of sickness absence or work disability.

The 'Quality of work' model is used to explore work-related problems (figure 1). This model contains groups of factors that are known for their influence on quality of work. It is based on theoretical ideas about work demands and work capacity [30], research on employees with chronic diseases, and recent views developed in occupational psychology on work factors that yield or absorb energy [31]. It is explained that, for some factors, it holds that not only 'too high' or 'too much', but also 'too low' may be problematic. For instance a high mental burden can be as problematic as monotonous work without any mental challenge.

Two participants are asked to explore the negative and positive factors of their work in the group. They do so with the help of a large laminated poster of the ‘Quality of work’ model in which plus signs or minus signs show aspects of their work that they experience as positive or negative. The others are asked to fill in the model for the next sessions. The input of all participants will be discussed extensively in the group at least at one session.

2. Insight into yourself: feelings and thoughts about having a chronic disease

Persons with a chronic disease experience that talking about one’s disease or consulting about work accomodations with a supervisor require good communication skills. However, negative thoughts or feelings about the disease can be an obstacle. Feelings of sadness or shame and thoughts of worthlessness can lead to non-assertive behaviour. Feelings of anger may induce aggressive verbal behaviour. The purpose of this meeting is to explore feelings and thoughts. The intention is not to replace them, but to understand how these feelings and thoughts might affect coping behaviour and might lead to ineffective communication. Homework for this session is to formulate predominant thoughts around work and illness. A second task is to request a consultation with the supervisor, to discuss how he or she appreciates the job performance. This is regarded as a preparatory consultation; a following consultation will be about concrete problems and solutions.

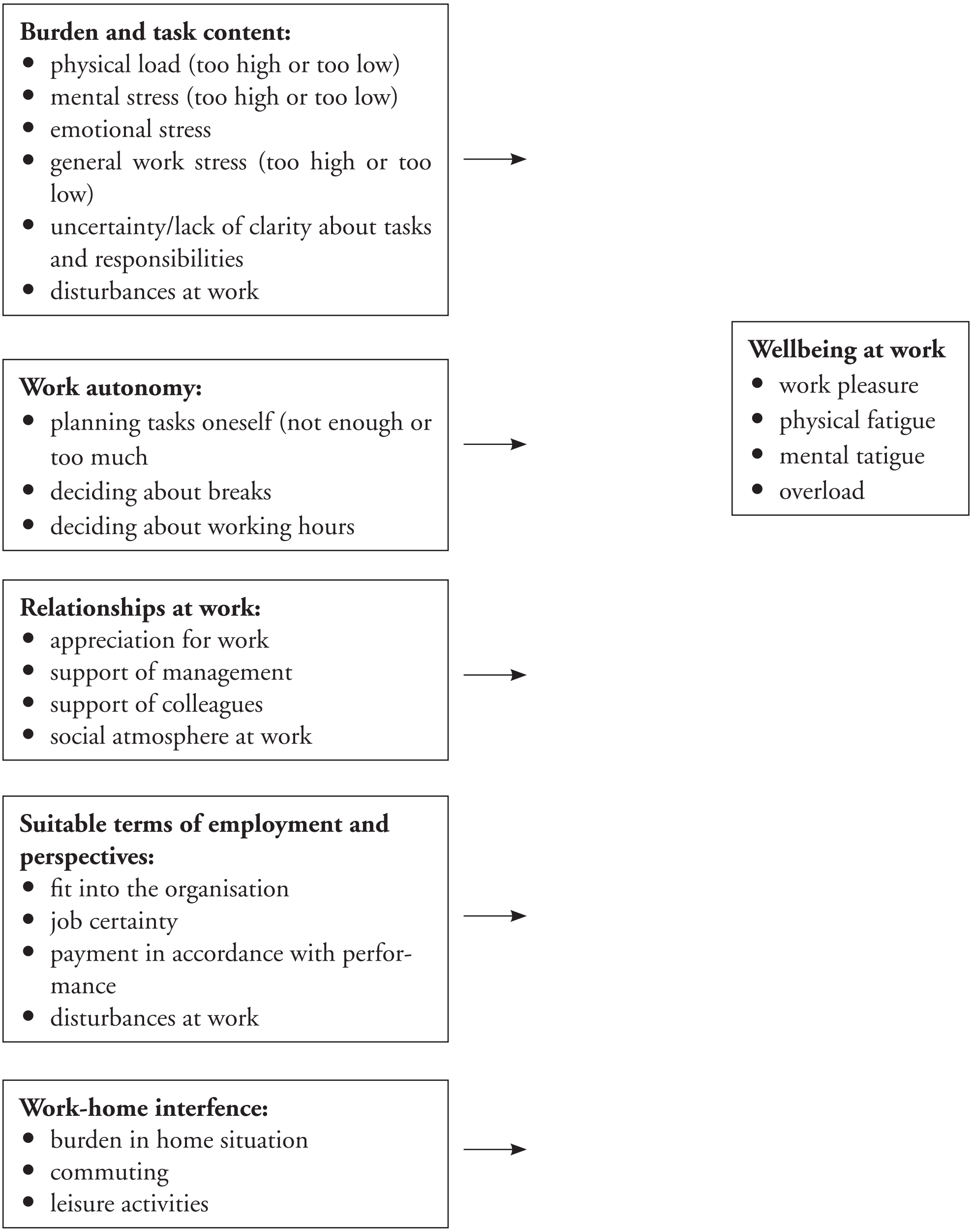
3. Communication: practicing in daily work situations

Employees with a chronic disease do not always stand up for themselves. The actor in this session shows what the difference is between non-assertive, assertive and aggresive verbal behaviour. This is followed by a role playing exercise; the participants explain their chronic disease to ‘a new colleague’, and talk about what consequences it has for daily functioning at the workplace, why this colleague should know about it, and how they would like the colleague to deal with it. The other participants give feedback.

4. Practical matters; the occupational physician, the employment expert, legislation and facilities for disabled employees

The textbook gives an overview of the occupational physicians’ function, as well as legislation concerning sickness absence and work disability. Furthermore, work accommodations and other facilities for disabled employees or their employers are listed. By way of homework every participant formulates one question for the occupational physicain and one question for the employment expert on matters that are relevant to themselves. The guest speakers have received these questions beforehand and discuss

Energy absorbers and energy suppliers



Burden and task content:
- physical load (too high or too low)
- mental stress (too high or too low)
- emotional stress
- general work stress (too high or too low)
- uncertainty/lack of clarity about tasks and responsibilities
- disturbances at work

Work autonomy:
- planning tasks oneself (not enough or too much
- deciding about breaks
- deciding about working hours

Relationships at work:
- appreciation for work
- support of management
- support of colleagues
- social atmosphere at work

Suitable terms of employment and perspectives:
- fit into the organisation
- job certainty
- payment in accordance with performance
- disturbances at work

Work-home interfence:
- burden in home situation
- commuting
- leisure activities

Wellbeing at work
- work pleasure
- physical fatigue
- mental tatigue
- overload

Figure 1. Model 'quality of work'

them in the group. Homework for the following session is to consider which work accommodations might be appropriate, and to initiate a second consultation with the supervisor about work-related problems and solutions. If appropriate, a consultation with the occupational physician of the company is recommended.

5. Communication and standing up for oneself: continuation

Examples and theorising about short-term and long-term functions of different manifestations of verbal behaviour are given to deepen understanding of assertive, non-assertive, and aggressive behaviour. Subsequently, the participants practice with the actor situations they find difficult at work, for instance negotiations with their supervisor or conversations in which they deal with their colleagues' lack of understanding.

6. A plan to solve problems

The homework for this session is to develop a plan to tackle one or more of the resulting work-related problems. This plan is developed along SMART-lines: Specific, Measurable, Acceptable, Realistic, and Time specific. The plans are discussed in small groups and adapted if necessary.

7. Follow-up: what works and what not?

The last session is meant as a follow-up meeting. Experiences with the implementation of the plan are discussed. By way of conclusion the participants write a letter to themselves, in which they describe how far they have gotten and what they want to have achieved in a half year's time. This letter is meant to keep them active and will be sent a half year later.

Methods/Design

Study design, research question, and follow-up

The study is designed as a randomised controlled trial. Eight training groups, with 64 participants in total, will be compared to about 64 persons in the control group. The follow-up is two years, with one baseline questionnaire and four follow-up questionnaires at 4, 8, 12 and 24 months.

The research question is twofold: a) Which work-related problems do employees with a chronic disease experience at the workplace, b) Does participation in the training increase self efficacy, establish work accommodations, decrease fatigue, enhance work pleasure, improve quality of work, and contribute to job retention?

Persons in the control group receive care as usual. However, the usual care for this group of patients for work-related issues varies from nothing at all to counselling or support by occupational health professionals or medical professionals from outpatient clinics.

The Medical Ethics Committee of Academic Medical Center in Amsterdam informally approved of the study idea, but deemed ethical review unnecessary because they perceived no question of 'medical' research.

Inclusion criteria

Participants are eligible for the study when they have a chronic physical disease, have a paid job, experience problems at work, fear losing their job or job satisfaction, and are willing to undertake actions to solve problems. Workers with predominant psychiatric conditions are excluded; people with a chronic physical disease in combination with depressive feelings are not excluded. Workers on long-term 100% sick leave that is expected to continue during the training are excluded.

Recruitment of participants

Participants are recruited via outpatient clinics, occupational health services, patient organisations, employers, and a yearly national conference on chronic diseases. Presentations are given at outpatient clinics and occupational health care services; specialised nurses, medical specialists and occupational physicians are asked to draw attention to the project by offering potential participants a leaflet. The leaflet is also available digitally. Patients' organizations are asked to publish calls for participation in their magazines, electronic newsletters and websites. A mailing is sent to a large number of employers, who publish calls for participation in house organs or approach potential participants directly. Presentations are given for meetings of patient organizations. Potential participants or medical professionals have the possibility to ask for information by mail or telephone.

The training is offered for free eight times in the course of one and a half years.

Organisation of enrolment

Candidates apply by telephone. They can not be presented by others, (e.g. medical professionals). A first check at the moment of registration is on the objective inclusion criteria: chronic physical disease, paid job, and no long-term full-time sick leave.

Candidates receive a written confirmation of their registration, explaining the procedures. Candidates receive the baseline questionnaire and the informed consent form three weeks before the randomisation. After a first and a second reminder, all participants who have returned the questionnaire are randomised.

Randomisation

Since not all questionnaires will be returned, the ideal group size is 18. If four or more persons have the same disease, randomisation is stratified on this disease, in order to prevent a coincidentally large group within the training group that shares the same disease. Randomisation is performed by the researcher in the company of another person, and with help of a computer program generating random numbers. Since ethical considerations preclude individual consultation before randomisation, persons randomised in the training group receive the invitation for a first individual consultation afterwards. If the trainer or the participants decide that the program does not meet the participants' expectations, a new randomisation procedure starts with the remaining persons in the control group.

Outcome measures

Primary outcome measures are job retention, self efficacy, fatigue and work pleasure.

Not having a paid job, or having more than six months full-time sick leave in combination with the expectation that return to work is impossible or improbable is considered as job loss.

Self-efficacy is measured by a situation-specific instrument, measuring self-efficacy in solving work and disease related problems. It is developed according to the principles formulated by Bandura [32]. The fourteen items are measured on bipolar five-point Likert scales.

Fatigue is measured with the Checklist Individual Strength (CIS), a well-validated questionnaire for the working population [33]. It has four subscales: fatigue severity (8 items), concentration (5 items), motivation (4 items) and physical activity level (3 items).

Work pleasure is measured with a subscale of the Dutch questionnaire on Perception and Judgement of Work [34].

Secondary outcome measures are work-related problems, sick leave, quality of life, acquired work accommodations, burnout, and three quality of work measures: social relationships with colleagues and supervisor, and worries about work. These are subscales of the Dutch questionnaire on Perception and Judgement of Work [34].

Work-related problems are measured with eight items: having problems with specific work tasks, finishing work, arranging the workplace, commuting, communicating with colleagues, communicating with supervisors, accepting the disease, and balancing work and life at home. The three answer categories are counted as 0 (no), 1 (yes, slightly) or 2 (yes, severely) and are added up to an index measure.

Sick leave is measured as the number of days on sick leave during the last four months.

Quality of life is measured with the validated SF12 [35].

Work accommodations are measured with the Work Accommodations List [9].

Burnout is measured by the Utrecht Burnout Scale (UBOS) [36].

Sample size and power

The sample size is based on detecting a difference in fatigue, measured with the fatigue severity subscale of the Checklist Individual Strength (CIS). Power calculations have been made with an alpha of 0.05 and a power of 80%. Studies examining the effect of interventions on fatigue of persons with a chronic disease are rare. Stulemeijer et al (2005) studied the effect of cognitive behaviour therapy for adolescents with chronic fatigue syndrome in a randomized controlled trial. In the treatment group fatigue severity decreased from 52.5 to 30.2 (sd = 16.8), compared to a decrease from 51.6 to 44.0 for the control group [37]. Based on these figures, we need 25 persons in the intervention group and the control group each.

Our intervention resembles Stulemeijer's intervention in its aim to decrease fatigue. However, whereas Stulemeijer's intervention focused on the disease and its symptoms, our empowerment training for employees focuses on work related problems and resulting work stress and fatigue. The chronic disease itself will remain and might even progress, which means that fatigue levels comparable with those of the healthy workforce are not to be expected at follow-up. This is the reason why we have chosen a larger sample, of 64 persons in the intervention group and the control group each.

Statistical analysis

Statistical analyses will be performed according to the intention-to-treat principle. Job retention will be analysed using survival analysis. The other variables will be analysed with repeated measurement analysis and mixed linear models._

Process evaluation

The process of the intervention will be evaluated in three ways. First, we will describe the recruitment of participants and evaluate if we reached the target group and if our recruitment methods worked or failed. The researcher keeps a recruitment diary for this purpose. Second, the group sessions and the individual sessions will be evaluated by the trainers. They fill in a process evaluation form and note the attendance of the participants, whether each subject for that session has been discussed, whether the participants experience emotional or cognitive difficulties with the subject, whether they feel involved, and whether the goal of the specific subject is reached. Third, the participants are asked their opinion in the post-test questionnaires. They are asked to evaluate the whole training, the various themes and procedures, and the textbook. They are also asked to evaluate whether skills they wanted to improve have actually improved, whether they have passed successfully through the three stages: clarification, communication and problem solution, and whether they have attained the goal they had in mind beforehand.

Discussion

Vocational rehabilitation interventions for persons with chronic diseases generally focus on entering or re-entering the labour market. Structured vocational rehabilitation interventions aimed at job retention are rare, notwithstanding demands for evidence-based vocational rehabilitation programmes aimed at preventing work disability for this group of employees [38]. Just a few of this kind of interventions could be traced in a systematic review [20]. A reason for this lack of initiatives or lack of documentation and evaluation might be that the societal consequences of work related problems are not felt clearly as long as people are still struggling to retain their jobs. However, when serious problems in work functioning finally result in long-term sickness absence, complete work disability or loss of a paid job, it is difficult to return to work.

The intervention we developed originates from an empowerment perspective and aims to help employees restore the balance of work capacity and work demands. We used a stepwise approach, starting with exploring practical, psychological or social problems, followed by communicating with the supervisor or others at work, and finally developing and implementing solutions.

Most studies on interventions aimed at job retention claim effectiveness. However, these claims are seldom underpinned with a study design offering strong evidence. Studies seldom use pretesting, a control group, a sufficient number of participants or a long-term follow-up. Our study design involves a control group and outcome assessments at five points over two years. We also try to include 128 participants randomised over two conditions.

An inevitable drawback is that participants are not blinded. The research project may trigger the awareness of the problems of participants, which can result in more than usual active coping behaviour in members of the control group.

The results of this study will generate knowledge about the nature of work-related problems and will possibly contribute to better vocational rehabilitation services for employees with chronic diseases. It will put issues at the crossroads of chronic disease and work, and of health care and occupational health on the agenda.

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Chapter 7

Empowering employees with chronic diseases: process evaluation of an intervention aimed at job retention

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Submitted

Abstract

Purpose. Employees with a chronic disease may experience work-related problems that contribute to the risk of job loss. We developed a group-based intervention programme aimed at clarifying problems, making these a subject of discussion at work, and realizing solutions. This process evaluation investigates the intervention's feasibility and the satisfaction of 64 participants in eight groups.

Methods. Data were collected through process evaluation forms and self-report questionnaires.

Results. The recruitment of participants was time-consuming. Highly-educated women working in the service sector were over-represented. The programme was administered as planned, although components were sometimes only discussed briefly, due to lack of time. Satisfaction with the overall programme among participants was high; it was perceived as effective and there were only three dropouts. In particular, the focus on feelings and thoughts about having a chronic disease was highly valued, as were the exchange of experiences and role-playing directed at more assertive communication.

Conclusions. A vocational rehabilitation programme aimed at job retention is feasible and is perceived to be effective. Such a programme should address psychosocial aspects of working with a chronic disease beside practical problems. The recruitment of participants is time-consuming. Cooperation with outpatient clinics is necessary in order to reach all groups of employees with a chronic disease that might benefit from job retention programmes.

Introduction

Employees with chronic disease may be hampered in job performance. Physical, sensory or cognitive limitations, health complaints such as fatigue or pain, psychological distress or medical requirements may hinder the performance of work tasks or even lead to work disability (Lerner et al. 2000; Van Amelsvoort et al. 2002; Donders er al. 2007). Chronically ill employees themselves state that, apart from work accommodations, they need acceptance of having a disease, coping strategies and support from their supervisor in order to stay at work (Detaille et al. 2003). This suggests that vocational rehabilitation aimed at changing personal attitudes and improving personal skills, including communication skills, is needed.

We developed a theory-driven group training programme for employees with chronic disease who experience work-related problems. The programme focused on solving these problems and aimed at job retention and maintenance and an increase in job satisfaction. A stepwise approach was used: first, exploring and clarifying work-related problems; second, a focus on communication at work; and third, developing and realizing solutions. Work-related problems were clarified with the help of the 'Quality of work' model, which emphasizes the energizing or distressing influences of work tasks, social relationships at work, working conditions and work-home interference. The training programme consisted of six three-hour sessions every two weeks and a seventh session two months after the sixth session. One trainer worked with eight participants. At two sessions, there was an actor present for practicing role playing. To discuss personal problems and progress at more length, three individual consultations also took place, one at the beginning, one half-way through the training, and one after the sixth session. The trainers were experienced in working with groups, had psychotherapeutic knowledge of the principles of rational emotive therapy (RET) and occupational psychology, and a basic understanding of chronic disease and its consequences. A pilot version of the programme was first developed and tested. The pilot version was adapted based on the trainers' experiences, the researcher's observations, a pre- and post-test questionnaire and interviews with the participants by telephone.

A seventy-page course book accompanied the training, and participants completed homework for every session. The sessions consisted of four to seven components, including discussion of the homework and preparations for the next session. Each session focused on one theme:

1. Exploration and clarification of practical and psychosocial work related problems with the help of the model 'Quality of work;'

2. Insight into feelings and thoughts about having a chronic disease and how these may influence communication;
3. Communication in daily work situations: theory and role play with an actor;
4. Practical matters: the occupational physician, the employment expert, legislation and facilities for disabled employees;
5. Communication and assertiveness: theory and role play with an actor;
6. A SMART plan to solve problems; and
7. Follow-up: what works and what does not.

Participants were eligible for the intervention if they had a chronic physical disease, had a paid job, experienced problems at work and feared losing their job or job satisfaction. Workers on long-term full sick leave that was expected to extend into the following months were excluded. The candidates themselves had to apply to the programme by telephone, also when they were referred by medical professionals. The training programme was offered free of charge.

A comprehensive description of the set-up and contents of the training programme, its development and theoretical framework is published elsewhere (Varekamp et al. 2008), as well as a systematic review of interventions of the same kind (Varekamp et al. 2006). The effectiveness of this intervention is studied with a randomized controlled trial (RCT) design. The results of the RCT will be published elsewhere.

In this article, we present a process evaluation of eight training courses with a total of 64 participants. A systematic process evaluation can tell us whether the intervention was feasible and describe potential barriers to its implementation. Furthermore, it may clarify how the intervention works and give insight into factors that influence its effectiveness (Swanborn 2004; Baranowski and Stables 2000; Saunders et al. 2005; Jonkers et al. 2007). This knowledge, in turn, offers the possibility to improve the programme. The research questions for the process evaluation are:

- Did the recruitment go as planned?
- Was the target group reached?
- Did participants follow the programme as it was intended?
- Was the programme administered as intended?
- Was the programme tailored to the group of participants?
- Were participants satisfied with the programme?
- Was the programme perceived as effective?

The Medical Ethics Committee of the Academic Medical Center in Amsterdam approved of the study idea, but deemed ethical review unnecessary because they did not perceive the study to be ‘medical’ research.

Methods

The various elements of the process evaluation, and their operationalisation and measurement are presented in Table 1 (Baranowski and Stables 2000; Jonkers et al. 2007). The researcher recorded all recruitment activities and attended the first two training courses. The trainers completed a structured process evaluation form after each group session. Specific barriers or other observations could be noted on the form, in addition to the structured items. Participants filled in a questionnaire at baseline, and again after four, eight and twelve months; opinions about the importance of several themes, satisfaction with various methods used in the training and overall satisfaction were measured on a 1-10 scale. Participant opinions of the trainers' capacities were assessed with an adapted version of the "satisfaction with occupation rehabilitation" instrument by de Buck et al. (2005), consisting of six subscales: expertise (2 items), advice given (4 items), friendly treatment (3), personal attention (3), usefulness of programme (2) and information about programme (2). All items were 5-point Likert items.

The Medical Ethics Committee of Academic Medical Center in Amsterdam approved the study design, and deemed ethical review unnecessary due to the non-medical nature of the research. All participants signed informed consent.

Results

Recruitment of participants

Participants were recruited for the training programme and study from late spring 2006 to January 2008. Participants were recruited via outpatient clinics, occupational health services, patient organizations, companies and so on. Presentations were given to patient organizations, doctors, nurses and social workers in outpatient clinics, professionals at occupational health centers, and to a national conference on chronic diseases. In addition, mailings were sent to several large companies and one patient organization sent a recruitment mailing to their members. Advertisements were published in patient organization magazines, electronic newsletters and/or websites, in staff magazines at large companies and in magazines from an occupational health centre. About 3500 paper leaflets were distributed via outpatient clinics, an occupational health centre and a patient information centre. A digital leaflet was available on several websites. It is difficult to assess the relative success of the various recruitment strategies, as we had no reports of the actions of medical professionals after hearing our presentations or reading about the project. Advertisements in patient organization magazines and/or electronic

Table 1. Elements of process evaluation

Elements	Operationalisation	Measurement						
		Notes res.[a]	Proc. eval. form[b]	Quest. basel.[c]	Quest. 4 mn.	Quest. 8 mn.	Quest. 12 mn.	Quest. 24 mn.
Recruitment of participants	Kind of agencies approached and ways and frequency of approach	x						
Reach of target population	Characteristics of participants			x				
Participation in program	Frequency and reasons for dropout	x	x					
	Frequency and reasons for not attending meeting		x					
Fidelity or extent to which the program was implemented	Extent to which all components were administered as planned		x					
Dose received or fit with the participants needs and capabilities	Trainers' opinion on participants' ability to cognitively and emotionally grasp the components of the program		x					
	Trainers' opinion on commitment and goal attainment of components of the program		x					
Satisfaction of participants with the training program and the trainer	Overall opinion on program (1-10)				x		x	x
	Opinion on various themes (1-10)				x	x		
	Opinion on various methods (1-10)				x			
	Opinion on various skills of the trainer				x			
Effectiveness as perceived by participants	Opinion on effectiveness with regard to three phases					x		
	Opinion on effectiveness of consultation with supervisor with regard to problem solving					x		
	Personal goal and opinion on goal attainment					x	x	
	Opinion on effectiveness with regard to attitudes, skills, work accommodations and situation at home						x	
	Opinion on overall effectiveness							x

a) Notes res: Notes of the researcher about recruitment and on drop outs after contact with trainers and participants

b) Proc. eval.form. Process evaluation forms filled in by trainer after each session

c) Quest. basel, 4 mn., 8 mn, 12 mn, 24 mn: Questionnaire filled in by participants in advance, after 4, 8, 12 and 24 months.

newsletters were successful. Presentations at outpatient clinics were seldom successful; when they were, it was due to interested nurses who advised patients to contact us. Contacts with occupational health services were moderately successful. Contacts with companies were successful if they paid attention to the project in the staff magazine. Table 2 presents figures on the sources of information about the project that the participants encountered (control group included). Recruitment took considerably more time than expected; we estimate roughly that it took 8-10 months of full-time effort for one person to complete. These efforts netted 122 of the planned 128 participants. One of the reasons for recruitment problems, according to some professionals of outpatient clinics and occupational health services, was that these professionals felt restrained from referring persons to the project because of the possibility of randomization to the control group (personal communications to IV). Another possible reason was that occupational physicians were afraid to 'lose' patients when they referred them to the training programme (personal communication to FvD).

Reach of target population

The personal, work and medical characteristics of the participants of the programme are presented in Table 3. Mean age was 46 years, most participants were women, and highly-educated people were over-represented. Mean disease duration was ten years and almost half had more than one chronic disease. Musculoskeletal, digestive and neurological disorders comprised about three-quarters of the group. Fourteen percent had categories of diseases, such as renal failure, poor eyesight, HIV and chronic fatigue syndrome. The great majority of the participants worked in the commercial or non-commercial service sector, for thirty hours weekly, on average.

Table 2. Source of information about the training program for the participants of the study (training participants and controls). More than one answer was possible (n=122)

Sources of information	%
Patient organization: magazine, presentation, website, mailing	34
Companies: house organ or supervisor	21
Occupational health service	20
Outpatient clinic	13
Conference on chronic diseases: magazine or presentation	7
Other	10

Table 3. Personal, medical and work characteristics of the training program participants (n=64)

	Mean (sd) or %
Age	46.1 (8.8)
Women %	83
Living alone (not with partner, children or parents) %	33
Education %	
lower	3
middle	36
higher	61
Chronic disease ICD Classification %	
1. diseases of the musculoskeletal system and connective tissue	28
2. diseases of the nervous system	20
3. diseases of the digestive system	17
4. endocrine, nutritional and metabolic diseases	3
5. neoplasms	11
6. diseases of the respiratory system	2
7. diseases of the circulatory system	5
8. diseases not otherwise specified	14
Disease duration in years	10.2 (9.6)
An additional chronic disease % (co morbidity)	48
Branch of industry %	
agriculture and fishing	0
industry and building industry	0
commercial services	27
non-commercial services	73
Appointment hours per week	30 (8.6)

Participation in the programme

From November 2006 to March 2008, eight training courses took place, including three trainers and 64 participants in total. Two of the trainers gave three courses each and the third gave two courses. Three participants withdrew half way, one due to medical treatment that interfered and two because they were not satisfied with the programme. There were 56 group sessions in total. Overall, there were 55 missed sessions, but in the majority of cases, participants called to say they were unable to attend. The reason most mentioned was illness. Three individual consultations took place with all participants who finished the programme. Forty-eight percent participated in the training programme during working hours, 31% used days off and 20% combined these.

Fidelity or extent to which the programme was implemented

Generally, the intended components of each session were discussed, although some only briefly because of lack of time. One trainer mentioned that explaining the model 'Quality of work,' which emphasizes energizing and fatiguing or distressing factors, took too much time. Another trainer observed that the participants preferred to have time to exchange experiences with each other rather than listen to theoretical explanations, which they felt they could read in the course book. When discussing homework, it was often not possible to discuss each participant's work. When discussing work-related problems in the group using the 'Quality of work' model, only one instead of the planned two participants were often discussed. It was often impossible to have all participants practice role-playing in one session. One of the reasons was that discussing role playing afterwards took a lot of time.

Dose received or fit with the participants' capabilities and needs

According to the trainers, participants had rarely cognitive difficulties with understanding the various components of the training. One thing that some people found difficult to grasp was reflection on their work in terms of subjective perceptions instead of objective facts. Slight or more severe emotional difficulties were met when discussing the consequences of having a chronic disease, feelings and thoughts on having a chronic disease and practical matters. Participation in the groups by individuals was usually high. The session components were almost always 'fairly' or 'completely' achieved. Homework was generally completed by participants. One homework exercise presented difficulties for several participants; they were asked twice in the course of the programme to arrange a consultation with their supervisor. The first session was intended to be a discussion of how the supervisor judged their work performance, the second to discuss work-related problems and solutions. This exercise encountered resistance. Participants tended to delay the consultations and some did not complete them. Some participants said that it was 'pointless,' because of their supervisor's attitude, or they wanted to practice such a consultation beforehand in order to be prepared (see also last paragraph of the results section).

Satisfaction of the participants with the programme

The participants were asked to score how important the sessions' themes were for them on a 1-10 scale (Table 4). The themes 'Insight into feelings and thoughts about having

Table 4. Opinion of the training program participants on the overall training program, significance of themes, course book and methods (n = 64)[a]

	Rating (1-10) Mean (sd)
Overall training program,	
opinion after four months	8.1 (1.1)
opinion after twelve months	7.9 (1.1)
Themes	
Exploration and clarification of practical and psychosocial problems; Quality of work model (session 1)	7.6 (1.7)
Insight into feelings and thoughts about having a chronic disease (session 2)	8.0 (1.4)
Communication in daily work situations and standing up for oneself (sessions 3 and 5)	8.0 (1.4)
Practical matters; the occupational physician, the employment expert, legislation and facilities for disabled employees (session 4)	7.0 (2.0)
A SMART plan to solve problems (session 6)	7.5 (1.7)
The course book	7.9 (1.2)
Methods	
Theory explanation	7.2 (1.6)
Exchanging experiences	8.3 (1.4)
Filling in and discussing own and others' 'Quality of work' model	7.5-7.7 (1.2-1.5)
Role play with actor	8.1 (1.6)
Questioning occupational physician and employment expert	7.1 (1.7)
Having a consultation with the supervisor (homework)[b]	7.2 (1.9)
Having a consultation with an occupational physician (homework)[c]	6.7 (2.2)
Individual consultation with trainer halfway and at the end	7.9 -7.9 (1.4-1.2)

a Including opinion of three persons that dropped out halfway
b Low respons, n = 57
c Low respons, n = 49

a chronic disease' (session 2) and 'Communication and assertiveness' (sessions 3 and 5), were valued highest, with a mean score of 8.0. The theme 'Exploration of practical and psychosocial work-related problems,' which included the explanation of the model 'Quality of work' (session 1), scored 7.6. The theme of the sixth session, developing a 'SMART' personal plan, scored 7.5. 'Practical matters; the occupational physician, the employment expert, legislation and facilities for disabled employees' was evaluated as lowest, with a mean score of 7.0, and a high standard deviation. The training programme as a whole was evaluated with a mean score of 8.1 immediately after completion; this dropped 0.2 points eight months later and 0.3 points 24 months later.

Eighty-six percent of the participants always read the short introductions in the course book to prepare for the group sessions, whereas 95 % had read the entire course book at the end of the training course. The course book was rated with an average score of 7.9. Most valued were the chapters on communication and assertiveness, and on feelings and thoughts about having a chronic disease. Lowest valued, with the highest standard deviation, was the chapter on legislation and work accommodations.

A variety of methods was used in the training programme: theoretical explanation, exchange of experiences, role-playing, and homework, such as completing the model 'Quality of work', or arranging a consultation with a supervisor and occupational physician. The exchange of experiences among participants received the highest mean score among these. Role-playing and seeing and discussing others' role-playing was also highly appreciated, as were the individual consultations with the trainers. Less valued were arranging a consultation with a supervisor and with an occupational physician. Non-response on these two questionnaire items was high, 7 and 15 respectively, which indicates that these arrangements not always took place.

The expertise of the trainers was overall judged very positively (mean score 68 on a 16-80 scale), and the advice given by the trainers was felt to be helpful. The participants felt well-treated and felt that they received personal attention during the programme. They considered introductory information to be sufficient, although this could have been better for a minority. The three trainers were judged almost equally. Satisfaction with the trainers was not lower in the three groups in which the trainers acted for the first time, as compared to the five groups for which trainers were more experienced.

Effectiveness as perceived by the participants

The training programme used a stepwise approach: first exploring and clarifying work-related problems, then focusing on communication at work, and finally working on developing and realizing solutions. Eight months after the start, 84% of the participants found that the first phase worked well, while 69% found that the second phase and 65% found that the third phase worked well (Table 5).

The majority of the participants, 53 persons, had, as part of the training, discussed matters with their supervisor in order to find a solution for work-related problems. Fifty-three percent of them felt this contributed a great deal to solving problems, 40%

Table 5. Success of three steps of the training program, as perceived by the training program participants after 8 months (n=64)

	not successful at all %	a little successful %	amply successful %	completely successful %
1 Clarifying bottlenecks (Model 'Quality of work')	0	16.4	55.7	27.9
2 Discussing bottlenecks at work	3.3	27.9	45.9	23.0
3 Developing and realizing solutions	6.7	28.3	45.0	20.0

said that it contributed somewhat, whereas 6% said that it did not contribute and 2% felt these discussions had worked negatively.

Table 6 presents the effects of the programme on various aspects of working with a chronic disease, as perceived at 12 months follow-up. The participants noticed positive effects most often with regard to how they experienced and dealt with disease and work. This was followed by how matters at work were discussed and how they dealt with the supervisor and colleagues. An effect was noticed least often in work accommodations. After 24 months, 79% perceived a lasting effect, 10% perceived an effect that had faded away, 3% were not sure whether it had lasted, and 8% perceived none or only a limited effect.

In the course of the programme, the participants formulated a plan of action with one or more personal goals. These goals related to work-home interference (78%), feelings and thoughts about having a chronic disease (59%), communication at the workplace (44%), leisure time (33%), work accommodations (29%) or other topics (18%). One year after the start of the programme 6 percent felt that they had not reached the goal that they set in the course of the programme, 38% reached it 'a little,' 36% reached it amply and 20% completely.

Discussion and conclusion

The recruitment for this intervention yielded enough participants but was time-consuming. We enrolled a sample in which higher-educated women working in the service sector are over-represented. The majority of the participants were satisfied with the programme and only a few dropouts were noted. For the most part, the programme was administered as planned, although some components took too much time. 'Quality of work' models and/or homework were not always discussed and not everybody had the opportunity to do role-playing as planned. The participants had no or only minor

Table 6. Effect of training program on work as perceived by the training program participants after 12 months (n=64)

Effect training on …	large negative effect %	small negative effect %	no effect %	small positive effect %	large positive effect %
How I experience my disease and my work	0	3.3	11.7	48.3	36.7
How I deal with my disease and my work	0	3.3	8.3	45.0	43.3
How I discuss matters at work	0	1.7	26.7	41.7	30.0
How I deal with my supervisor	0	0	23.3	51.7	25.0
How I deal with my colleagues	0	0	28.3	56.7	15.0
How my supervisor deals with me	0	0	38.3	43.3	18.3
How my colleagues deal with me	0	0	41.7	38.3	20.0
The situation at home	0	0	43.3	30.0	26.7
Accommodations of my workplace or work tasks	1.7	1.7	53.3	26.7	16.7

difficulties with understanding the materials discussed, but were more often emotionally upset, particularly when consequences of disease or feelings and thoughts were discussed, or during role-playing. Generally, the participants completed their homework, but when asked to organize a consultation with their supervisor, many hesitated to do so; a minority did not complete this assignment. Among those who completed these consultations, most considered it effective for problem solving. The perceived effectiveness of the training programme was highest in how it shaped participants' personal attitudes and lowest in matters that are more practical.

We have to be careful with conclusions based on the study process evaluation forms. The forms were completed by the trainers themselves and were likely correct as far as objective facts are concerned. The validity of some answers may be questionable, however, as trainers gave subjective judgments on whether the programme's components were tailored to the participants. Furthermore, they give an overall response for the whole group, rather than individuals. However, the forms are of special value when the three trainers showed consensus on less positive aspects or when they noted barriers. For instance, there was consensus on the lack of time for some components, all three observed that some components are likely to raise emotional difficulties and all noted that consultations with the supervisor are often met with resistance.

Another weakness of this study is that we do not know what proportion of the target group was reached. We did not approach a known group of employees with chronic diseases. Instead, information about the project was disseminated through various channels and potential participants had to contact researchers to participate. The consequence is that we do not know how many employees who experience serious work-related problems were not interested in our programme or did not enroll for other reasons. We do know that the group we reached was a selected group in terms of socio-demographic characteristics.

What can we learn from the study results? We know that our programme is implementable. At some sessions, there was inadequate time for complete participation. Lengthening the duration of the sessions or adding sessions are options. However, this may make the programme too time-consuming. Reducing the time to discuss personal experiences is not an option. Because participants have three individual consultations with a trainer, and because lack of personal attention appeared not to be a problem, it is presumed to be better to accept this programme design but to indicate at the beginning of the sessions that not everyone may receive equal attention in all components of the programme. We found in the pilot phase that participants with a variety of chronic physical diseases could be put together in the same group. People experience the general aspects of chronic diseases as more important than the disease specifics. Finally, we learned that the theme 'Practical matters' was not highly valued by a quarter of the participants. It is worth considering whether this theme can be addressed in another way.

What are the working elements of the training programme? The trainers observed that many of the components raised emotional feelings, and it is interesting to note that these components were often highly valued. Apparently, many participants realized that going through a phase of mourning and learning to accept having a chronic disease is difficult, but it assists in learning to cope. This brings us to our assumption that participants needed to pass through three phases: clarifying, communicating and solving problems. We understood the earlier phases as necessary to accomplish the last essential phase and understood this final phase implicitly as organizing work accommodations. However, it appears that organizing work accommodations may be the primary problem for some persons; for others the main problem is in the earlier phases of accepting the chronic disease and learning to communicate about it and/or in maintaining an enjoyable life outside work. These issues appear to be relevant for many participants, and are therefore noteworthy.

Another remarkable phenomenon was that many participants showed resistance to a consultation with their supervisor, but in the end, the majority felt that it helped in solving problems. This shows, as we have seen in other studies (Detaille et al. 2003; Post et al. 2005) that a good relationship with the supervisor is very important.

Recruitment for programmes like this is known to be problematic (Varekamp et al. 2006; Foster et al. 2007). One reason is the randomization procedure, but recruitment through professionals in outpatient clinics was also problematic compared to recruitment with the help of patient organizations. Disseminating this kind of programme through normal health care channels appears not to work; lack of interest in work-related problems among many health care professionals is a primary reason (Van Weel et al. 2006). Physicians and nurses should be encouraged in the course of their education and by post-graduate courses to pay attention to the working life of their patients; there is little chance for referral of patients to vocational rehabilitation programmes without conversations about these matters. It is positive that practice guidelines for physicians increasingly pay attention to work-related problems of patients. Maybe incentives like co-authorship of a scientific article may help to raise interest in this kind of research and development projects. In addition, focus on specialized nurses as collaborating partners may prove beneficial, as these professionals concentrate more on the social consequences of chronic disease.

Working together more intensively with outpatient clinics in the future would have the added advantage of contact with a more diverse group of potential participants. Heavy manual work and low education are prognostic factors for work disability among employees with chronic disease (Detaille et al. 2009). We do not know why we had only a few participants working in industry, and fewer men and less-educated people than expected. Research into whether similar communication-focused programmes are attuned to the culture and working conditions outside of the service sector is necessary. We need to know why less-educated people seldom applied for the study, as well as whether and how more men can be convinced to participate in empowerment programmes, which focus on sometimes emotionally disturbing topics.

Several vocational rehabilitation approaches aimed at job retention for people with chronic or longstanding disease have recently been developed, varying widely in approach. Multidisciplinary rehabilitation has been developed for rheumatoid arthritis patients (De Buck et al. 2005). This is an outpatient clinic-based intervention where medical and psychosocial specialists combine their expertise in advising the patient and his or her occupational physician on aspects of work. A completely different approach is the participatory workplace intervention (Anema et al. 2007). This focuses on the employee and supervisor and aims to improve their ability to solve work-related problems with the help of a mediator. Our intervention aimed at improving the problem-solving skills of the employee. Every approach will have advantages and may be most effective in a specific context. More research is needed on what kind of rehabilitation method best suits a particular employee and circumstances. The extent to which employers are willing to accommodate the workplace to employees with a chronic disease or handicap also needs research.

We may conclude that empowering employees with a chronic disease with help of a group training programme is feasible and highly valued.

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Chapter 8

Facilitating empowerment in employees with chronic disease: qualitative analysis of the process of change

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Abstract

Introduction: In the field of healthcare, empowering patients who have a chronic disease is defined as increasing their knowledge and skills, in order to enable them to define their treatment goals and take personal responsibility for their medical treatment. Our goal was to explore the nature of empowerment for employees who have a chronic disease and who experience work-related problems.

Methods: We used an explorative qualitative approach to document, from a professional perspective, the experiences of patients who participated in an empowerment training program. The researcher and the three instructors identified several themes which appeared to be important to many participants. These themes were fine-tuned and illustrated using brief case histories.

Results: We identified seven themes and characterized them in terms of employee tasks. These included: 1) developing a realistic understanding of one's abilities, 2) standing up for oneself in a self-confident way 3) maintaining social relations based on mutual understanding with supervisors and colleagues, 4) collecting and assimilating knowledge of one's options, rights and duties, 5) consulting others and negotiating with regard to work accommodations, 6) planning one's job so as to provide personal satisfaction, and 7) maintaining a social life outside work. Not every employee is faced with all of these tasks, but most have to deal with several.

Conclusion: Empowerment presupposes that employees with a chronic disease can act to solve problems at the workplace. The experiences during a comprehensive empowerment training illustrate that a process of reflection on personal emotions and a cognitive process of exploration and identification of bottlenecks at work may precede these actions. Our primary contribution is the aforementioned list of seven common tasks that many workers have to perform. Disseminating the list can support employees who have a chronic disease and may also be useful for their managers, HRM staff, occupational health and other healthcare workers.

Introduction

Many employees with a chronic disease manage their work well. However, many others are hampered in job performance and experience problems at work. Health complaints, physical or cognitive limitations, pain, fatigue or medical requirements may hinder the performance of specific work tasks or may even lead to work disability. The employment rate of persons with a chronic disease is, depending on the disease, slightly or considerably lower than for healthy persons. For instance, the majority of rheumatoid arthritis patients of working age in the USA and the Netherlands are employed (59% and 56%) [1,2], and for inflammatory bowel disease or COPD the figures are roughly the same or even better [3-6]. More dramatic are the experiences of dialysis patients and people with Parkinson's disease or multiple sclerosis. Only 20 – 40% of them report being employed [7-10].

Yet, some employees with a chronic disease or handicap leave the labor market unnecessarily. Twenty percent of a large group of individuals with chronic diseases on incapacity retirement in the Netherlands judged their retirement unjustified [11]. Accommodations in the work place can be a solution to work-related problems and may prevent unnecessary sickness absence or job loss. In order for managers to implement appropriate accommodations it is necessary that employees understand their problems, discuss these with their supervisors or colleagues and reach a solution. This is not always easy. Recent research into the experiences of employees with rheumatoid arthritis, diabetes and hearing problems showed that it was critical for such individuals to accept their condition themselves, to have the support of their supervisor and to practice good coping strategies [12,13].

We developed a vocational rehabilitation training program for employees with chronic diseases. These should be distinguished form other longstanding diseases. There are many longstanding common health problems, according to some responsible for 'about two-thirds of sickness absence, long-term incapacity and ill-health retirement' [14], that are essentially manageable, for instance with graded activity interventions or cognitive behavioral therapy. Non-specific low back pain is an example of such a common health problem. Chronic diseases are by definition diseases that do not go away. Apart from this permanency, other characteristics are unpredictability over time, day-to-day variability and often invisibility [15]. Although a clear distinction cannot always be made, it is important to discriminate between chronic diseases that are irreversible and mild or moderate cardio-respiratory, musculoskeletal or other longstanding but not necessarily irreversible conditions. Our group training program is designed for employees with a variety of serious chronic physical diseases who experience problems at work because of their medical condition. In contrast to a traditional approach in which an expert defines what the problem is and provides advice, we selected an 'empowerment' approach. The training supports the employees in clarifying barriers after which they are encouraged to develop solutions themselves. A literature review shows that, although a sound study design was often lacking, there exists moderate evidence for the effectiveness of empowerment-based interventions in terms of employment, implementation of work accommodations and psychological outcome measures [16].

Our training program offered us the possibility to achieve a better understanding of working with a chronic disease. We could observe which problems employees actually encountered, how they discussed remedies in the group or with the trainer, how they practiced communication and negotiation with their supervisor or colleagues and reflected on that in the training group. Often, the participants reported how problems eventually were addressed at work. In this explorative study we try to understand what empowerment actually means for this group by describing from our professional perspectives the experiences of a significant number of participants. We have chosen to consider these experiences in terms of tasks. Not every employee is faced with all of these tasks but many have to deal with at least one, or more often several, of these. The tasks can be illustrated using brief case descriptions or case histories. We hope that our study will help employees as well as vocational rehabilitation professionals, supervisors and HRM professionals to recognize and solve work-related problems.

Preceding the results we will discuss developments in empowerment theory, the set-up and contents of the training, and the methods used in this study. Our results section begins with one elaborate case history that illustrates how different tasks can be interrelated. This study is part of a larger research project which includes a randomized controlled effectiveness study.

Empowerment of employees with a chronic disease

Empowerment was first explored in the 1980s in community psychology as a means of enabling individuals to gain decision making power within their community. Empowerment was seen as a multilevel construct through which individuals, groups, organizations, the community and social policy are seen as mutually influential [17]. More recent research agendas have distinguished various empowerment processes and outcome measures at the level of the individual, the group and the community [18].

The word 'empowerment' was adopted in healthcare, notably in the management of chronic diseases, under the full term 'patient empowerment'. Patient empowerment is defined as a process to help patients develop knowledge, skills and a heightened awareness of values and needs. In turn, this enables them to define their goals, take responsibility for their medical treatment and increase their autonomy. This definition implies improved problem solving abilities, better communication with healthcare professionals, and often an awareness of health-promoting behaviors [19]. Empowerment-oriented interventions based on this definition focus on attitudes, knowledge, skills and behavior without reference to social inequality or society at large.

The term empowerment asks for some special considerations when using it with respect to the labor market and in occupational health. There are no fundamental conflicts of interest between healthcare providers and healthcare consumers. Basically both parties see effective medical treatment as a primary goal, although patients may find themselves in an unequal power relationship with healthcare professionals, due to the professional autonomy of this group [20]. Social relations in the labor market, however, are different from those in healthcare, which requires a careful interpretation of the empowerment concept. Employers and employees have shared as well as conflicting interests, which can become problematic in the case of employees with health problems. Both parties benefit from good interpersonal relations in which employees perform optimally. Conflicting interests arise when employers and supervisors aim for a high level of labor productivity and consequently a high workload, whereas employees with a diminished work capacity strive for a lower workload. In everyday reality employees with a chronic disease are confronted with a wide variety of attitudes and actions from employers, line managers, supervisors and HRM-professionals. Employees may even notice management struggling with conflicting interests and ethical considerations. Some will experience support in their striving to keep employed, while others are confronted with a wish to maximize production and minimize costs. These potentially conflicting interests demand an interpretation of the concept of empowerment that is not limited to intrapersonal aspects. A critical awareness of the sociopolitical context must be integrated to fully appreciate empowerment [21]. The empowerment of individual employees will be useless if the government and employers' organizations ignore or disrespect employees with health problems [22].

A short description of the setup and content of the training program

The training focuses on solving work-related problems and aims at maintaining or increasing work satisfaction and job retention. A stepwise approach is used, first exploring and clarifying work-related problems, second focusing on communication at work, and third developing and realizing solutions.

The group training sessions involve one instructor and eight participants. There are six three-hour sessions every two weeks and a seventh session two months after the sixth session. To discuss personal problems or to elaborate issues, there are three individual consultations, one at the beginning, one halfway the training course, and one after the sixth session. A textbook accompanies the course and participants must prepare homework for every session. Each session has a theme:

1. Exploration of practical and psychosocial problems according to the ‘Quality of work’ model (Figure 1)
2. Insight into feelings and thoughts about having a chronic disease
3. Communication in everyday work situations: role play part one
4. Practical matters; the occupational physician, the employment expert, legislation and facilities for disabled employees
5. Communication and standing up for oneself: role play part two
6. Solving problems
7. Follow-up: what works and what does not?

A comprehensive description of the development, setup and content of the training course is published elsewhere [23].

Methods

Eight groups of eight participants each were enrolled in our training courses. The researcher (IV) attended the first two training courses and the preceding pilot training course and reported her observations. The instructors (AH, SL, CEMK) filled in a process evaluation form after each group session and made notes after each individual consultation.

Shortly after the beginning of the project, the researcher asked the instructors to make notes about cases they deemed relevant. The criterion for relevancy was that the case illustrated how participants dealt with work-related problems. An initial listing of several case histories let us identify recurring themes. These themes can be understood in terms of ‘tasks that have to be performed’ by the employees. The researcher discussed a classification of six tasks with each of the instructors individually. This resulted in additions, amendments, and further case histories. All the authors collaborated in a consensus meeting to arrive at the next version, which featured seven tasks. The result was a more precise description of the tasks and brief case histories. The final version was revised and commented on by all the co-authors; if necessary, case histories were added. Cases were de-identified by changing personal characteristics in order to respect privacy.

Energy sinks and energy sources

Burden and task content:
- physical load (too high or too low)
- mental stress (too high or too low)
- emotional stress
- general work stress (too high or too low)
- uncertainty about tasks and responsibilities
- disruption at work

Work autonomy
- planning tasks oneself (insufficient autonomy or too much)
- deciding on break times
- determining work hours

Relationships at work:
- feeling appreciated at work
- support of line management or supervisor
- support of colleagues
- social atmosphere at work

Suitable terms of employment
- fit into the organization
- job certainty
- payment in accordance with performance

Work-home interference
- problematic home life
- commuting
- leisure activities

Figure 1 (simplified) THE 'QUALITY OF WORK' MODEL

Results

Marian is 53 years old and has suffered from rheumatoid arthritis for twenty years. She has a full-time administrative job at the distribution center of a supermarket chain. Fatigue and pain are frequently troubling her. Her predominant attitude is: 'I refuse to accept my medical condition; I want to do my job the way I used to do it.' Sometimes she feels her coworkers do not understand her condition. In her opinion the fact that her condition is not visible contributes to negative perceptions among her coworkers. In addition to an eight hour working day, Marian commutes three hours a day. In the end she feels overburdened.

Her occupational physician has advised that Marian try to transfer to an establishment of the company in her place of residence. She talks with the line manager of this establishment, but this does not sound promising: he seems to hint that Marian may not be very productive given her health status. He does agree to forward Marian's case to a hiring committee for a second opinion. They will probably offer Marian a 6-month trial transfer. Marian is afraid that she will not get a fair chance because of the skepticism of the line manager right from the beginning. She is afraid that she may have to return to her current workplace after six months. By that time, others will have taken over her job, and than she is even more in a mess.

She is angry: 'I have worked hard for thirty years and have always received good performance evaluations. Now I am facing difficulties and they let me down.'

What does empowerment mean in this case? First of all, Marian realizes that she has to change her attitude toward her disease: 'I will have to accept that my work capacity is lower'. Furthermore, she has set herself two targets. She wants to learn how to explain her disease to others and she wants to prepare a transfer proposal case. Using a role play situation, she practices telling a new colleague about her rheumatoid arthritis and what its consequences are at work. She explains that sometimes she feels very fatigued. When colleagues ask her to pay attention, she can request a few minutes of personal time. She explains that although she may be quiet when she is exhausted, this does not mean that she is angry with her coworkers. After the role play, Marian becomes emotional and she remarks that she found the exercise exhausting. Her role play partner tells her that, as a colleague, he would appreciate understanding her medical problems. Then she practices a consultation with a line manager in which she asks for permission to explain the consequences of her disease to colleagues during a group meeting. The first time she is put off by the role play partner (line manager): 'Okay, you can just go round to everybody individually.' But this is not what Marian wants. She does not want to have to recount her story ten times and risk becoming emotionally worn out. The other participants in our training session encourage her, by telling Marian ‘You shouldn’t let your line manager boss you around’. The second time she is more forceful with her ‘manager’ and he agrees to her proposal to speak to her colleagues all at the same moment.

Marian’s second and most important target is the upcoming discussion about transferring to a new workplace that is closer to where she lives. The participants discuss how Marian should tackle this problem. The instructor recommends: ‘Feel strong and focus on what you want to achieve, which is to get a transfer.’ Another participant remarks: ‘Whose problem is this anyhow, yours or your manager’s?’ This comment reflects the sense of guilt that many participants often feel about their inability to perform certain types of work. The employment expert gives her this piece of advice: ‘If you are to be assessed in six months’ time, you should find out right now what the assessment criteria are. Otherwise they may surprise you.’

Two weeks later Marian recounts how she felt confident about the actual discussion with the hiring committee, including the new line manager. ‘I was determined and forthright.’ She told the manager that she did not need six months to prove herself, and that she could do it in two months. However, she did agree to give up some administrative tasks and she will lose some of her salary. This change of tasks was actually one of Marian’s requests, so that she would have more energy. Also, she has asked for a follow-up evaluation with the line manager after two months. At that time she plans to verify whether her expectations are aligned with the line manager’s expectations.

Two months later Marian gives her training group an update. She likes her new workplace, especially because it is so close to home. She has more leisure time, goes to a fitness center and she enjoys every day. She has consulted the occupational physician about what work accommodations may be appropriate for her and she was surprised to find out that she could have whatever accommodations she felt she needed to be able to work effectively. In the beginning she was very worried about her six-month probationary period, but she is now much more relaxed about it. To date her new line manager has not asked Marian how she is getting on. However, more senior managers have expressed interested in how she is doing. In the last counseling session the instructor advises her to contact the HR department about her case. Four months later, Marian informs us that she has been given permission to stay.

Seven tasks that employees with a chronic disease often have to deal with

1. To develop a realistic understanding of one's abilities

If one wants to solve problems, first of all it is necessary to understand both one's limitations and possibilities. Questions to answer include 'where am I now' and 'what do I want,' in terms of one's career and one's life. Many participants experienced their job as one big tangle of stress and problems. Implicit but predominant negative thoughts were: 'I achieve less than my coworkers' or 'There is no point in trying to change things'.

The 'Quality of Work' model helped participants to understand their problems. Just as important was listening to others in the training group. They often heard stories that resonated with their own experiences. Our sessions led certain participants to realize that denial, anger or feelings of guilt were still present even though they believed that they had more or less had come to terms with their chronic disease. Recognizing these emotions helped them move forward in a grieving process. This was an important first step in considering the consequences of their disease and in accepting that they may need accommodations at the workplace.

Martin is 38 years old and has become seriously visually handicapped over the past eight years. He uses a software-based screen magnifier for his computer. He finds computer use fatiguing. Usually he is completely exhausted at the end of each day. Nevertheless, he avoids talking about his handicap and he is inclined to think: 'My problem is not very major, I can't complain.'

The others' narratives encourage him to admit that he routinely denies his handicap. Martin decides to discuss his condition with his supervisor.

George is a 38 year old psychiatric nurse. Seven years ago he was diagnosed with Crohn's disease and was away from work for an extended period. Two years ago he got depressed. Since then he has felt that he is a failure in life. He feels that his supervisor sees him as a failure too, and does not respect him.

Through the help of the 'Quality of Work' model and by listening to the others in the training group, George learns to accept his limitations and he develops a realistic perspective. He puts it aptly: 'I have to reinvent my life.' He decides to apply for a job elsewhere, which he gets.

2. To stand up for oneself in a self-confident way

Successfully negotiating special needs accommodations at work requires self-respect which is the first step in developing self confidence attitude.

Some participants experienced feelings of sadness, anger or shame, or thought that they were less valued than their coworkers. This sometimes made them avoid their supervisor. They often passively did what they were told and they were easily overruled by their colleagues.

Listening to others and telling their own stories helped some participants realize that they were less assertive than they thought they were. Discussing work situations helped them realize that they sometimes failed in clear communication. Role play exercises showed them other ways to approach situations. They began to understand how they could influence situations by becoming more self-reliant and assertive.

John is a 46 year old ICT-worker. He has chronic obstructive pulmonary disease (COPD) for over ten years. 'It feels like I run a marathon every day.' His subconscious thought about his performance at work is that he is an underachiever. 'Thinking something like that makes you start avoiding other people, which in turn causes stress' he says. The consequence was that he would work beyond his capacity, and would be fatigued all the time. He lost his job after a clash with his line manager. Now he works elsewhere on probation.

Through talking about his problems and experiences, John gains an understanding of his feelings and thoughts in respect of his disease. In his new job he does not avoid the line manager and his colleagues and he tries to set realistic work goals given his condition.

Charlotte is 52 years old and has a heart condition. She qualifies for a partial (25-35%) work disability pension and works part time as a domestic servant in a home for the elderly. She says: 'My work performance is below par, so I never talk to my supervisor.' She avoids contact with this woman. At the same time she is upset about the situation and she would like to rearrange her work in a more satisfying way.

During a role play scenario, she practices how to confidently start a conversation with her superior. The first time she asks timidly whether her 'superior' possibly has time to talk with her and she immediately hears excuses. The second time she clearly articulates what she needs and she secures a meeting with her supervisor to talk about her difficulties.

3. To maintain social relations with supervisors and colleagues on the basis of a mutual understanding

Employees interact with others. Their supervisor assigns tasks and they work on those tasks together with their colleagues. Cooperation is more than simply performing an activity with someone else. It requires being on good terms with others and promoting a good mutual understanding.

Some participants felt they were misunderstood at the workplace, especially if their disease was invisible. When they felt that this negatively impacted social relations, this caused feelings of insecurity and frustration.

They learned that others at the workplace are more likely to be understanding when the disease and its consequences in terms of pain, fatigue, physical or cognitive limitations or medical requirements are explained to them. They also noticed that they themselves may misjudge their colleagues' intentions. They were inclined to interpret a colleague's sullen behavior as rejection, although the colleague may very well have been grumpy for an entirely different reason. They learned how important it was to validate these assumptions.

Evelyn is a 45 year old employee at a post office. She is less productive than her coworkers, due to Parkinson's disease. Her workload has been modified due to her condition, but she notices that this has made some of her colleagues irritated. She realizes that not everybody understands her health problems.

She uses role play to explain the consequences of Parkinson's disease at work. Then she explains these issues to her colleagues in real life. Since then they tend to ask her how she is doing more often.

Gertrude is 48 years old and suffers from Sjögren's syndrome. She used to get on well with her colleague Mary. Since her illness, she has felt rejected by Mary which gives her wretched feelings.

During the training sessions, Gertrude realizes that she might be mistaken and she is encouraged to talk things through with Mary in person. Because of this, the tension between them disappears and they discuss how their misunderstanding may have come about.

4. To collect and assimilate knowledge of one's possibilities, rights and duties

Physical or cognitive limitations lead to reduced ability to work. Special accommodations at work aim to prevent overburdening by reducing work tasks or improving an individual's work capacity. Sickness absence and work disability legislation all deal with these issues as well. Legislation requires that employees inform themselves about special needs accommodations at work, the financial arrangements involved and their legal rights and duties.

Participants in our sessions often realized that they were insufficiently well informed in this regard. For instance, they did not know that it is usually possible to visit an occupational physician for advice, even without a referral. Or that Dutch sickness absence legislation requires the employer to cooperate with the employee to formulate a back-to-work plan in cases of long term absence. This means that the employee himself must also be actively involved in the process. Some participants were worried about their financial needs and were not familiar with Dutch incapacity benefits legislation. In short, participants often did not know what steps they could take themselves. They ended up being too passive and simultaneously became frustrated because of the lack of progress.

In the training sessions, their problems at work served as a starting point to acquire specific knowledge about their options given the government's legislation. This information encouraged them to consider their options more fully. For instance, new ideas and initiatives included encouragement to explore special needs accommodations at work, incapacity benefit regulations or the possibility of a different type of job with their current employer or with a new employer.

Steven is 32 years old and is employed at a small software company. He has Crohn's disease for the past five years and he is often on sick leave. He feels that he keeps letting his employer down. Moreover, he misses out on annual pay rises and he receives no bonus for unused sick days. At the same time he thinks: 'At least I have a job, who else would employ me given my disease?'

Steven is a family breadwinner and the financial aspects of his role are very important. He asks the employment specialist about partial work disability and partial incapacity benefits. He gets a clear idea of his options and decides to find a better paid job elsewhere and work fewer hours a week.

Grace is a 46 year old editor who has had rheumatoid arthritis for the past seven years. She is overworked; ten or twenty hours of overtime is normal at her publishing company. She feels that her colleagues will see her as ill-qualified for her job if she does not accept the long hours.

During our sessions, Grace asks the occupational physician and employment expert how she can request less overtime from her employer. At the end of the training sessions, she knows her rights as stated in sickness absence legislation, and she understands what responsibilities her employer has in her case.

5. To consult others and negotiate work accommodations

When employees have identified the bottlenecks at work and have some idea about the kind of arrangements they would need, the next step involves consulting others, negotiating with supervisors and standing up for one's rights.

Participants sometimes waited for things to happen and would become frustrated when nothing came about. When they themselves took action, they found it difficult to discuss their limitations and to properly articulate problems which they would normally minimize, out of habit. When they talked to their supervisors and nothing happened, they got all the more frustrated. They were inclined to see their problems as problems they were responsible for. They were often too concerned about the supervisor's interests and convinced that there was no good answer to their problems. Sometimes they felt they needed to devise a plan alone, instead of working with the supervisor to develop a strategy collaboratively.

They learned that they should make their problem a joint problem and address it piecemeal. By doing this they can keep the issue on their supervisor's radar.

Ingrid is 43 years old and enjoys her job as a university researcher. She has MS and uses a wheelchair. She needs several practical work accommodations, like a more spacious place to work on the ground floor, a disabled toilet, accessible furniture and a personal printer. Some accommodations can be readily addressed, others will take time. However, Ingrid acts as though she doesn't need special accommodations because she does not want to inconvenience others. She says to technical support personnel that there is no hurry to install a new desk: 'I'm managing just fine, I can wait.' She does this even though it causes her significant inconvenience to make do with an unsuitable work environment. The large room that she would need on the ground floor would require a colleague being moved to a smaller room. This troubles her.

She learns that she shouldn't be concerned about her colleague; that is an issue between her colleague and her supervisor. She learns to keep reminding her supervisor until the alterations have been completed. Ultimately she ends up feeling like a valued member of the department again.

Louise is a 47 year old employee at a primary school. She has developed renal insufficiency in the past five years and she works long hours. She does not want to ask for a workload reduction because she thinks that it may burden her colleagues.
She learns to specify clearly that she can no longer manage her work hours and articulate the consequences for her task load and her schedule. She is surprised to find that it is possible to adapt both her task load and schedule.

6. To organize one's job in a way that it still gives satisfaction

A job offers income, status, social relationships and a defined structure for both each day and each week. Furthermore, it offers self-fulfillment. People flourish and have energy when their work gives them satisfaction. This does not hold true for everything that one does at work, but there should be a sufficient number of energizing tasks.

Some participants stated that, because of their chronic disease, they were relieved from their tasks to such a degree that the real challenge was gone. Others had changed for a physically less demanding job and found that it ultimately did not satisfy them.

They learned to recognize that this was the real problem. Their tasks needed to be adapted to their skills or they had to find another job that they liked, either with their current employer or with a new employer.

Elisabeth has arthrosis and Crohn's disease. She works as a secretary and is in a back-to-work program after a burnout. The incapacity benefits agency has advised her to cut down from 4 x 8 hours a week to 4 x 6 hours a week. However, this increases her stress because she tries to do the same amount of work in fewer hours.
She has agreed with her husband that she will work 4 x 8 hours and he will do more household chores. She has given up some of her less enjoyable work tasks and has taken on more organizational tasks that she does enjoy.

Patricia is a 43 year old woman who has Ménière's disease for the past six years. She used to enjoy her job as a medical receptionist. Her neurologist advised her five years ago to find a part time job as a secretary. However she does not like her new work at all and she finds it mentally draining to go to the office each day.

The training sessions helps her realize that she could have continued her old job, notwithstanding her physical limitations. She starts applying and finds a part-time job in her former occupation.

7. To maintain a social life outside work

People need social lives outside work, complete with leisure activities and social relationships. This offers the opportunity to recover from fatigue and become re-energized.

Some participants felt that continuing with their current job required so much energy that housekeeping, leisure activities and social relationships were severely affected. As a consequence, life became even harder. One individual in our program became socially isolated.

We recommended giving a higher priority to their non-work time instead of clinging to their job at the cost of everything else. This made it possible for some participants to escape the downward spiral.

Marit is a 34 year old fundraiser with very poor eyesight. Although the loves her job, she experiences significant stress at work and she is often exhausted at the end of the day.

The training forces her to think about what she really wants. She wants to be more relaxed in her job and her private life. She starts trying out various leisure activities that will give her energy.

Bernard is a 57 year old divorced school teacher. He has HIV and has never really come to terms with it. Nobody knows, not even his children. Contact with his colleagues and with the principal is poor and he feels like burnt out. Besides, he is socially isolated and has started to neglect household chores.

He has feelings of shame and sadness about his disease, but he realizes that he is not the only one in the group who feels depressed on account of his disease. This wakes Bernard up to think about his situation and make choices. Little by little he starts to understand that he allowed his colleagues to intimidate him as a result of his feelings of shame. This is the reason for his exhaustion and social isolation. He starts to connect with others in his private life and resumes contact with children and friends.

Discussion

The aim of our study was to show how employees with a chronic disease participating in an empowerment training program experience their work-related problems and how they learn to manage these. We articulated three steps in advance of the program: clarification of problems, communication and problem solving. The efforts to clarify and manage the problems can be formulated in terms of themes or tasks: 1) developing a realistic understanding of one's abilities, 2) standing up for oneself self-confidently 3) maintaining social relations based on mutual understanding, 4) acquiring knowledge of one's options, rights and duties, 5) negotiating with regard to work accommodations, 6) planning one's job so as to provide personal satisfaction, and 7) maintaining a social life outside work. Not every employee in the training was faced with all of these tasks, but most had to deal with several.

Our study is an explorative qualitative study. It offers, from a professional point of view, insight into the problems that individuals encounter and the processes they go through. It is clear that employees experience various difficulties, depending on the nature of their disease, work requirements, atmosphere at work and personality. Our conclusions are based on a large amount of data. They consist of observations from the researcher and the three instructors, who led eight training groups and an additional pilot training group. These included 72 employees. In addition, all the instructors conducted three individual counseling sessions with each participant. In total, our conclusions are based on our experience with 62 group sessions and 197 individual consultations.

Our study has several limitations. We studied how employees resolved problems using techniques learned in our specific intervention program. The nature of the intervention may have limited the number of tasks people report that they are confronted with. Our empowerment-based training program focused on clarification, communication and problem-solving. A different kind of intervention might have revealed other important aspects. Another limitation of the study is that it is based on the instructors' and researcher's perspectives. There were only a few dropouts in the training programs and the average evaluation of the program was 8.1 (scale 1-10). Especially topics like 'Insight into yourself: feelings and thoughts about having a chronic disease' and 'Communication and standing up for oneself' scored high in the evaluation of the participants. However, notwithstanding the satisfaction of the participants with the program, the instructors' and researcher's perspectives might be biased.

How do the results of this study compare to other studies? Healthcare best practices for patients with chronic diseases concentrate on supporting individuals in self-managing their disease. A number of effectiveness studies have been published regarding self-management training and related interventions based on psychosocial theories of health behavior [e.g. 24-27]. These studies are usually restricted to measuring attitudes, skills and knowledge or describing process variables and the nature of the intervention. The actual processes that individuals undergo and their changing perspectives are rarely discussed. Qualitative medico sociological research offers a view that is better aligned with our findings. In his sociological and autobiographical retrospective on living with cancer, Nijhof [28] describes individuals who are confronted with a chronic disease as persons who set foot on unfamiliar territory: 'What does this disease mean? Which things can I still do, and which can I no longer do?' Also, what they will tell others and how they will tell them becomes an issue. 'Will they believe it? Or will they think that it is not really serious, or even more serious?' Nijhof names this searching for a path through an unfamiliar territory 'work.' He joins Strauss and Corbin [29] who speak about 'trajectory work' in their research. Individuals experience an incurable disease as a series of phases: acute or less acute change, recovery, stability, instability and possibly deterioration. The disease is not something that happens to people, but something that needs to be managed: one tries to control its course, to treat symptoms, and to live with the resulting limitations. Most of the time people cannot manage on their own. They need to make arrangements with the help of others, and every new phase demands readjustment. In addition to this 'practical' work, a serious chronic disease requires 'biographical' work. The disease disrupts individual biographies and individuals are faced with the task of redefining their identity and that of their next of kin. Charmaz [30], who performed many in-depth interviews with chronic diseased in the US, speaks of a 'loss of self': the image that people had of themselves and which is linked to American values of freedom and independence gets lost. This loss might get even worse when physical limitations prevent people going out, when they lose social connections and get dependent from others.

The aforementioned studies do not address the combination of chronic disease and employment, maybe because many individuals with a chronic disease already have lost their jobs. Nevertheless, there are many analogies with our study. Employees with a chronic disease see themselves as being burdened with all kinds of practical 'work': discussing work-related problems, figuring out their options, standing up for their rights, and maintaining social relationships. Notably, biographical work deserves attention.

It turns out that employees with a chronic disease see themselves as underachievers, with accompanying feelings of worthlessness. One of the participants expressed this aptly by saying: ‘One has to re-invent oneself.’ These findings are also consistent with a qualitative study on rehabilitation programs for women with chronic musculoskeletal pain [31]. These women found the process in which they regained their self-respect the most valuable contribution to their recovery.

What are the practical implications of this study? We identified a number of recurring themes which presumably are all relevant for at least a number of employees with a chronic disease. We illustrated these themes with cases in their actual social context. These themes and brief case studies may clarify for employees what problems they face and how they can address these issues. For instance, one of the most important tasks that employees face turns out to be communication with others, in order to request accommodations at work. When employees learn why communication can be difficult and how it can be improved, this can be very helpful to their work life.

The findings of this study are also relevant for ‘the other party’ involved. Employers and managers need to know what concerns employees who have a chronic disease. Unpredictability over time, day-to-day variability, permanence, and invisibility are relevant characteristics of chronic diseases [15]. The themes identified illustrate what it means for employees to have to cope with these aspects of chronic disease. These require a flexible and compassionate employer attitude which should include open-mindedness as to the diversity of this group [15]. They wish to be judged not only on their limitations but also on their qualities. They also want recognition for the importance of a job that they do wholeheartedly and that gives them satisfaction.

We advocate policies aimed at job retention for employees with a chronic disease, and for the corresponding attention of employers, HRM-departments and occupational health services. Employers have to issue a clear mission and vision for their company and they have to provide positive support to those supervisors and line managers who need help understanding and managing these issues. One important task, for which they might need assistance, is to communicate openly with their employees about job limitations and mutual expectations. When employers and society at large are aware of these requirements, empowerment may lead to a ‘multilevel’ interpretation, encompassing individuals, companies, professional associations and social policy.

In order to reach a more comprehensive understanding of working with a chronic disease, more research is needed on the process of completing ‘tasks,’ for instance in respect of which factors are stimulating and which are hindering. We need to learn more about the experiences of colleagues, supervisors, HRM-personnel and occupational physicians.

In conclusion, in many cases it is possible to work with a chronic disease. But it is challenging. Individuals may experience uncertainty, physical, cognitive or emotional limitations and medical treatment may interfere. All of these issues must be thought through, addressed and accepted. Then the problems must be made compatible with a regular workday. Employees themselves and others at the workplace should realize that this requires effort from all sides. This exploratory study identifies tasks that many employees with a chronic disease may be confronted with. Knowledge about these tasks may help better support employees and stakeholders to communicate and find solutions.

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Chapter 9

Effect of a training programme aimed at job retention for employees with a chronic disease: a randomised controlled trial on self-efficacy, job satisfaction and fatigue

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Submitted

Abstract

Background. Employees with a chronic physical condition may be hampered in job performance due to physical or cognitive limitations, pain, fatigue or because medical treatment interferes with work. Employees themselves often recognise psychosocial barriers at the workplace. We developed a group training programme aimed at job retention. This study investigates the effect of this intervention on self-efficacy, job satisfaction, fatigue and job retention.

Methods. Participants with chronic physical diseases were randomly assigned to the intervention group (n = 64) or the control group (n = 58). Participants were eligible for the study if they had a chronic physical disease, paid employment, experienced work-related problems and were not on long-term 100% sick leave. Primary outcome measures were self-efficacy at work (14-70), job dissatisfaction (0-100), fatigue (20-140) and job retention measured at 4, 8, 12 and 24 months follow-up. We used GLM Repeated Measures for the analysis.

Results. Loss to follow-up was 7/122. Self-efficacy increased and fatigue decreased significantly more in the experimental group than in the control group (respectively 10 versus 4 points; p = .000, and 19 versus 8 points; p = .032). Job satisfaction increased more in the experimental than in the control group but not significantly (6 versus 0 points; p = .698). Job retention did not significantly differ between groups. The process evaluation revealed that many participants in the control group also undertook actions to solve work-related problems.

Conclusions. Empowerment training increases self-efficacy and helps to reduce fatigue complaints which in the long term could lead to more job retention. Better understanding of ways to deal with work-related problems in chronic diseases is needed to develop more efficient support for employees with a chronic disease.

Trial registration: ISRCTN77240155

Introduction

Many employees with a chronic disease manage their work well, but others are hampered in job performance due to health complaints, physical or cognitive limitations, pain, fatigue or medical requirements. Lerner found that, depending on the medical condition, 22 to 49 % of employees with various chronic conditions experienced difficulties in meeting physical work demands, and 27 to 58 % experienced difficulties in meeting psychosocial work demands [1]. Employees themselves point out the importance of many psychosocial barriers, such as lack of support and understanding of colleagues and line managers [2-4], social stress and lack of job autonomy [5], reluctance to disclose and fear that others may see one as more favoured above colleagues [6], inability to cope with illness [2] or to set limits, a negative self-image and feelings of hopelessness relating to employability [7]. Fatigue scores are substantially higher among the chronically ill than among non-chronically ill employees [8]. Fatigue is assumed to be directly caused by disease and by psychological distress [9].

Employment rates for individuals with rheumatoid arthritis, inflammatory bowel disease, cancer and COPD are lower than for healthy persons, but still most of these people are employed [10-16]. For dialysis patients and people with Parkinson's disease or multiple sclerosis, the disease has a higher impact and the majority is out of work [4, 17-19].

Over the past several decades, social policy in industrialised countries concentrated primarily on stimulating persons with chronic conditions or handicaps to enter or re-enter the labour market. More recently, attention has been paid to efforts that help employees to stay at work [20, 21]. A review of empowerment-based interventions aimed at job retention shows that there is limited evidence that these are effective at enhancing self-efficacy, implementation of work accommodations and job retention [22]. For that reason, we developed a group-based training programme for employees with a chronic physical disease who experience work-related problems. Seven group sessions are combined with three individual counselling sessions. The programme has an empowerment perspective: its aim is to enhance the knowledge, skills and self-awareness of the patients in order to help the individuals solve problems at work [23]. This programme has a stepwise set-up: participants start to explore and clarify practical and psychosocial work-related problems, learn to discuss issues at work and eventually think out and try to realise solutions to their problems. The programme is based on the social learning theory of Bandura [24] that assumes that behaviour change and maintenance are a function of 1) expectations about the outcomes of behaviour and 2) expectations about one's ability to engage in this behaviour. These 'outcome expectations' and 'perceived self-efficacy' expectations are beliefs. Self-efficacy beliefs are specific to particular situations (e.g. work situations). They may be enhanced in a training situation by performance accomplishments, vicarious experience and verbal persuasion.

The aim of this study is to evaluate the effect of the training programme. Fatigue and job dissatisfaction have been shown to be predictors for work disability [20,25,26]. We hypothesise that perceived self-efficacy will improve and that fatigue and job dissatisfaction will decrease to a greater extent in the experimental group than in the control group. We assume that these factors contribute to job retention in the experimental group (Figure 1).

Participants and methods

Study design and power analysis

The study was designed as a randomised controlled trial. Participants were asked to fill in a baseline questionnaire before randomisation and four follow-up questionnaires at 4, 8, 12 and 24 months. Persons in the control group were not restricted to any protocol and we assumed that they would not receive appropriate care for work-related problems and would not organise this for themselves. We called this group a 'no intervention' control group.

The sample size is based on detecting a difference in fatigue, as measured by the fatigue severity subscale of the Checklist Individual Strength (CIS) [27]. Power calculations have been made to detect a mean difference of 15 points with an alpha of 0.05 and a power of 80%, based on Stulemeijer et al. [28]. Based on this study, 25 participants were required in the both the experimental group and the control group. We expected a somewhat lower effect size and decided to take a larger sample. We decided to study eight training groups with 64 participants and a control group comprised of 64 participants.

The Medical Ethics Committee of the Academic Medical Center in Amsterdam approved of the study idea, but deemed ethical review unnecessary because they did not perceive the study to be 'medical' research.

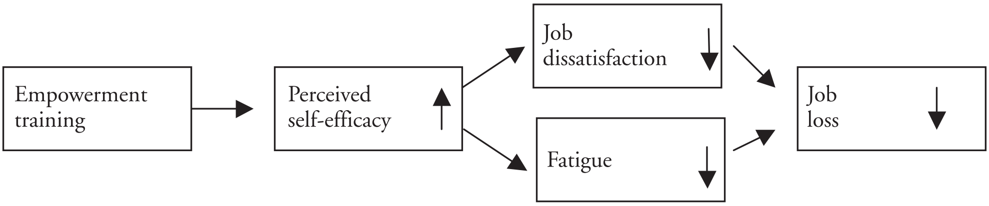

Figure 1. Theoretical model of the impact of empowerment training on perceived self-efficacy, job satisfaction and fatigue, resulting in less job loss.

Recruitment of participants and eligibility criteria

Participants were recruited via outpatient clinics, occupational health services, patient organisations and employers. Presentations were given for patients at meetings of patient organisations, at a national conference on chronic diseases and for medical professionals of outpatient clinics and occupational health services. A leaflet, also available digitally, described the set-up and contents of the training programme and the research project. Patient organisations and employers were asked to publish calls for participation in their magazines, electronic newsletters, websites or house organs. The recruitment focussed on Amsterdam and its environs, but applicants from other regions were not excluded. Candidates had to apply themselves by telephone, even when they were referred by medical professionals.

Participants were eligible for the study if they had a self-reported chronic physical disease, a paid job and experienced problems at work. Workers with predominant psychiatric conditions were excluded; people with a chronic physical disease in combination with depressive feelings were not excluded. Workers on long-term 100% sick leave were only included if they expected to return to work soon. The eligibility criteria were checked at the moment of application by telephone, with the exception of the criterion ‘experience problems at work.’ For practical reasons, we checked this after randomisation during the first individual consultation with the trainer, which also functioned as the admission interview. Candidates received a confirmation of their application together with an information leaflet about the procedures immediately after their application.

Randomisation

Candidates received the baseline questionnaire, information concerning the research project and an informed consent form six weeks before the start of the training programme. A first reminder was sent by mail and a second reminder was performed by telephone or email. The individuals who had sent back the baseline questionnaire and the informed consent form were randomised. Block randomisation for each of the eight training programmes was performed with the help of a computer programme that generates random numbers. Participants randomised in the training group received an invitation for the admission interview with the trainer. If participants decided not to have an admission interview or if it was decided that they did not meet the inclusion criterion ‘experience problems at work’, they were excluded from the research project. In that case, because we wanted a full training group, we randomly picked a person from the control group to participate in the intervention group.

Neither the participants nor the primary researcher were blinded to the treatment assignment. Participants could not be blinded due to this form of intervention. Blinding the researcher was impractical for the data analysis. Assessment bias by the researcher was probably low because the assessment was performed by the participants themselves in the self report questionnaires. Data entry decisions in the case of ambiguous data were recorded.

Intervention

The training focused on solving work-related problems and was aimed at job retention and the maintenance or increase of job satisfaction. A stepwise approach was used: first, work-related problems were explored and clarified; second, communication at work was addressed; and third, solutions were developed and realised.

The training was a group training programme with one trainer and eight participants. It consisted of six three-hour sessions every two weeks and a seventh session two months after the sixth session. To discuss personal problems and progress more in-depth, three individual consultations took place at the beginning of training, half way through the training and after the sixth session. The trainers were experienced in working with groups, had psychotherapeutic knowledge of the principles of rational emotive therapy and occupational psychology and had a basic understanding of chronic diseases and their consequences.

A course book was provided for the training, and the participants prepared homework for every session. Every session focused on one theme:

1. Exploration and clarification of practical and psychosocial problems
2. Insight into feelings and thoughts about having a chronic disease
3. Communication in daily work situations: role play with an actor
4. Practical matters: the occupational physician, the employment expert, legislation and facilities for disabled employees
5. Communication and standing up for oneself: continuation of role play
6. A plan to solve problems
7. Follow-up: what works and what does not?

A comprehensive description of the development, set-up and contents of the training is published elsewhere [29].

Participants in the control group were asked after four and eight months whether they themselves or others had taken measures to solve work-related problems.

Outcome measures

Job loss occurs over a long period, has a large variance and can be skewed. For that reason, it is impractical to use it as the only main outcome measure. Because job loss is mediated by other variables, we used the following primary outcome measures: self-efficacy, fatigue, job dissatisfaction and job retention.

We developed a situation-specific self-efficacy questionnaire according to the principles formulated by Bandura [30]. This questionnaire measures the perceived self-efficacy in solving work- and disease-related problems with 14 5-point Likert scale items. The instrument had a Crohnbach's alpha reliability of .80 at baseline and .87 after 12 months.

Fatigue was measured with the Checklist Individual Strength (CIS), a well-validated questionnaire used for the working population [27]. A score of 76 or higher on the CIS is considered a fatigue level that puts the individual at risk for sick leave or work disability [31].

Job dissatisfaction was measured by using a subscale of the Dutch questionnaire on Perception and Judgement of Work [32].

Job loss was defined as having no paid job or being on full-time sick leave for more than 6 months, combined with the expectation that a return to work is improbable or impossible.

Job retention interventions are rare and evidence of their working mechanisms is lacking. Thus, we decided to use a number of secondary outcome measures: work-related problems, sick leave, quality of life, acquired work accommodations, burnout and quality of work.

Work-related problems were measured with eight items: having problems with specific work tasks, finishing work, arranging the workplace, commuting, communicating with colleagues, communicating with supervisors, accepting the disease and balancing work and life at home. The three answer categories were counted as 0 (no), 1 (yes, slightly) or 2 (yes, severely) and were added up to a summary measure.

Sick leave was measured as the self reported number of days on sick leave during the last four months.

Quality of life was measured with the validated SF12, which distinguishes physical and mental quality of life [33].

Work accommodations were measured with the Work Accommodations List of Kremer [16].

Burnout was measured by the Utrecht Burnout Scale (UBOS) [34].

Quality of work was measured with three subscales of the Dutch questionnaire on Perception and Judgement of Work [32]: social relationships with colleagues, relationships with the supervisor and worries about work.

Statistical analysis

Statistical analyses were performed with SPSS 16.0 according to the intention-to-treat principle, meaning that we analysed the cases as randomised to the training programme and the control condition. Continuous outcome measures were analysed at baseline and follow-up with the two-way mixed between-within subjects analysis of variance. General linear models were chosen for this repeated measurement analysis. In case of a significant ($p < .05$) Mauchly's W test for sphericity, the corrected Greenhause Geissers F was presented. We first evaluated the effect of time only and subsequently the interaction effect of time and group to see if there was a significant effect of the intervention. We used the effect size partial eta squared to interpret the size of the effect for which we used the following rule of thumb: .01 = small, .06 = moderate and .14 = large [35]. For job retention we calculated the odds ratio of job loss in the intervention group compared to the control group. In the case of missing questionnaires at 8 or 12 months, the last observations were carried forward and used for the repeated measurements. Cases were not analysed if questionnaires were missing at 4 or 24 months. Participants who were not at work because of long term sick leave or temporary job loss at a measurement moment were not included in the analysis of work-related outcomes.

Results

Study population

We recruited participants for the training programme and the study from June 2006 until January 2008. The training programmes were executed between November 2006 and September 2008. A total of 142 employees applied for the study, of which 132 sent back the baseline questionnaire and were randomly placed in each study group (Figure 2). Ten people dropped out of the intervention group before the intervention started. Six of them did not attend the admission interview, one had a negative outcome from the admission interview because there were apparently no problems at work and three withdrew after a positive outcome. The final study group consisted of 122 participants, 64 of whom were allocated to the training group and 58 to the control group. Initially, 68 participants were allocated to the control group. Ten of them were randomised at

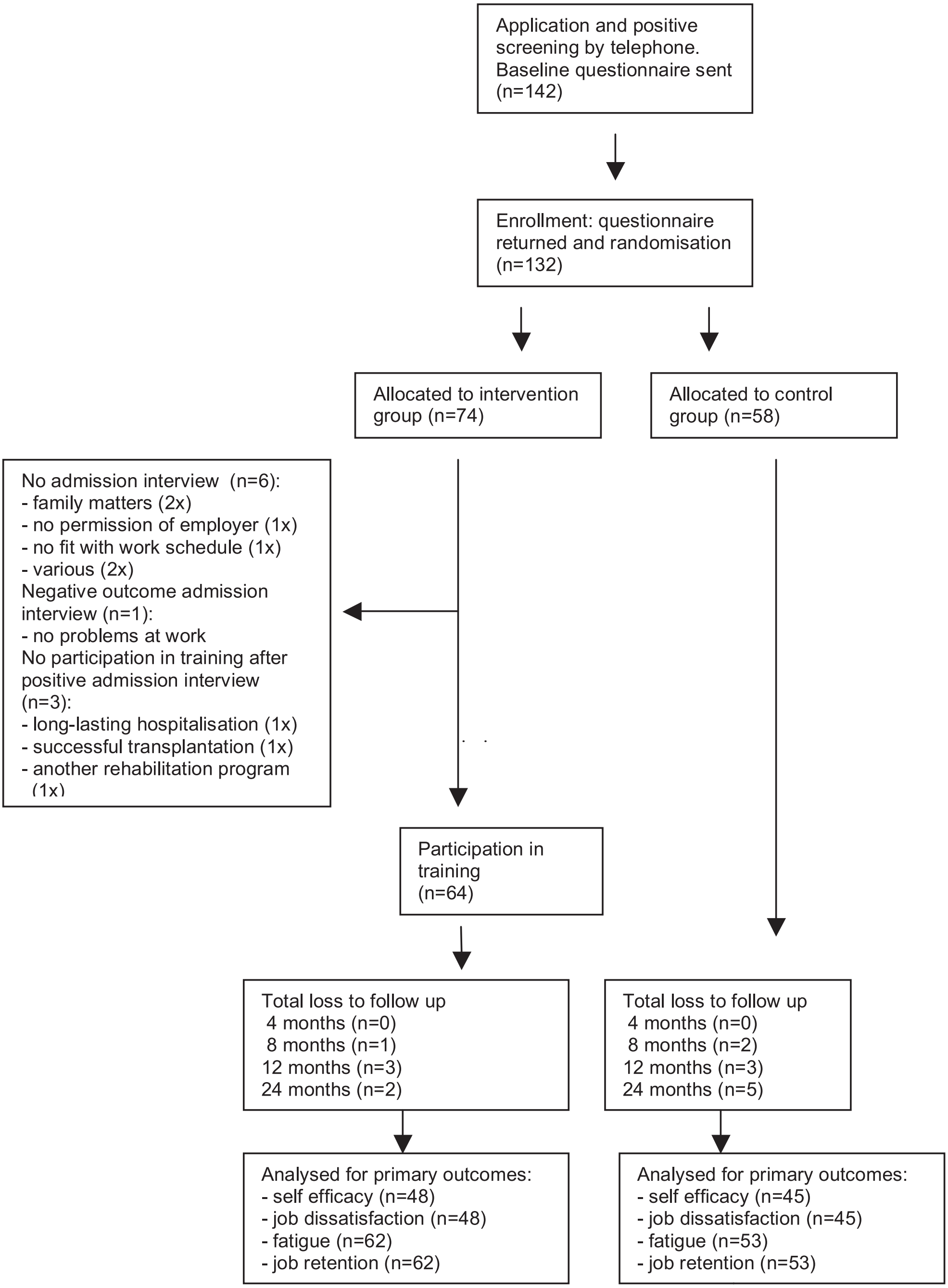

Figure 2. Recruitment, allocation and study withdrawal of participants

Table 1. Chronic disease* and other health characteristics of the study population (n = 122)

	n (%)
Diseases of the musculoskeletal system and connective tissue[1]	30 (25)
Diseases of the nervous system[2]	28 (23)
Diseases of the digestive system[3]	25 (21)
Endocrine, nutritional and metabolic diseases[4] 10 (8)	
Neoplasms	6 (5)
Diseases of the respiratory system	5 (4)
Diseases of the circulatory system[5]	4 (3)
Other diseases[6]	14 (12)
One or more additional chronic diseases	54 (44)
	Mean(SD)
Disease duration in years	10.2 (9.5)

* Following the International Classification of Diseases, ICD 10.

1) Including rheumatoid arthritis 12x, fibromyalgia or other chronic pain 5x, SLE 4x, arthritis 3x and Sjögrens disease 2x.
2) Including multiple sclerosis 13x and Parkinson's disease 9x.
3) Including Crohn's disease or colitis ulcerosa 24x.
4) Including diabetes 5x, Graves' disease and other thyroid gland disorders 4x.
5) All heart conditions 4 x.
6) Including HIV/AIDS 3x, renal failure 2x, visual impairments 2x, and other diseases 7x.

a later stage to the training group, when participants allocated to the training group withdrew from the study.

Three participants in the intervention group dropped out of the training programme halfway. Two of these dropouts were dissatisfied with the intervention. The third underwent medical treatment that made it impossible to continue the training programme. She applied for psychotherapeutic care. We have included these three participants in the analysis. After 4, 8, 12 and 24 months, 122, 119, 116 and 115 participants were present in the study population. One-hundred-twelve participants filled in all five questionnaires; six participants had one missing measurement, two participants had two missing measurements and two participants had three missing measurements (not in figure).

The baseline disease characteristics are presented in Table 1. Twenty five percent had musculoskeletal disorders (e.g. rheumatoid arthritis, Sjögrens syndrome, SLE, arthritis or other diseases). Twenty three percent had neurological disorders, mainly multiple sclerosis or Parkinson's disease. Twenty one percent had digestive disorders, mainly

Table 2. Personal, work and additional medical characteristics of the study population (n = 122)

	Experimental (n = 64) % or mean (sd)	Control (n = 58) % or mean (sd)
Age	46.1 (8.8)	45.0 (8.7)
Women	83	66
Living alone (not with partner, children or parents	33	22
Education		
lower	3	3
middle	36	50
higher	61	47
Branch of industry		
agriculture and fishing	0	0
industry and building industry	0	3
commercial services	27	55
non-commercial services	73	41
Appointment		
hours per week	30 (8.6)	32 (7.5)
days per week	4.2 (0.8)	4.3 (0.7)
One or more additional chronic diseases	48	40
On disability compensation (partially or 100%)	25	25
Sickness absence. Nr of days in last four months	14 (20.5)	20 (25)
Hindered at work due to health problems		
no	3	5
yes, slightly	70	51
yes, severely	27	44
Work capacity, physical		
(very) bad	13	24
moderate	55	47
(very) good	33	29
Work capacity, mental		
(very) bad	14	19
moderate	47	40
(very) good	39	41

Crohn's disease or ulcerative colitis. Disease duration was ten years on average, and 44 % suffered from more than one chronic disorder. Seventy three percent had a score higher than 76 on the CIS fatigue scale, indicating a fatigue level at risk for sick leave or disability (not in table).

The personal, work and additional medical characteristics are presented in Table 2. The mean age of the study population was 46 years, and three-quarters of the participants were women. Most participants lived with a partner and/or children. Higher educated persons and persons working in the service sector were overrepresented. The participants worked 31 hours per week on average, and a quarter was officially labelled (partially) work disabled. Absence due to sickness during the four months before baseline was 17 days on average, with a standard deviation of 23 days. Almost all participants felt slightly or severely hindered at work due to health problems. Respectively, 31 and 40 % felt that their physical and mental work capacity was good or very good. There were slight differences between the experimental group and the control group with regard to sex, education, branch of industry, comorbidity, sick leave and work capacity.

Four months after the start of the study, 71% of the control group stated that they or others had undertaken measures to solve work related problems; after eight months, 61% of the control group stated that they or others had undertaken these kinds of measures because of the allocation in the control group. Sixteen participants of the control group took actions that resembled the training programme (e.g., psychosocial support from a psychologist, psychotherapist, social worker, job coach, career coach or some kind of self-management program).

Primary outcome measures

Table 3 and Figure 3 present the primary outcome measures at baseline and follow-up measurements. After two years, the perceived self-efficacy had increased 10 points for the experimental group, for the greater part in the first four months, and 4 points for the control group. There was a statistically significant effect for time, which means that the entire study population improved significantly in the course of two years (F = 28.7, p = .000), with a large effect size. There was also a significant interaction effect, which means that the intervention had a significant effect in the course of two years (F = 5.6, p = .000), with a moderate effect size.

Overall, job dissatisfaction decreased slightly for the experimental group, remained stable for the control group, and showed an unsteady pattern with a high standard deviation. There was no statistically significant effect for time, nor a significant interaction effect.

Fatigue decreased 19 points for the experimental group and 8 points for the control group. There was a statistically significant effect for time (F = 10,0; p = .000) with a moderate effect size, and a significant interaction effect for time and intervention (F = 2,7; p. = .032), with a small/moderate effect size. Fatigue complaints decreased till the

Table 3. Effect of intervention on self-efficacy, job dissatisfaction and fatigue. Repeated measurement based on intention to treat analysis.

	Experimental Mean (sd)	Control Mean (sd)
Self-efficacy (14-70)*	(n=48)	(n=45)
Baseline	45.4 (8.4)	50.0 (9.0)
4 months follow-up	53.1 (8.3)	52.3 (10.2)
8 months follow-up	54.9 (8.4)	53.7 (9.0)
12 months follow-up	55.3 (10.2)	53.7 (9.6)
24 months follow-up	55.8 (8.5)	54.4 (9.5)
Time effect F = 28.7; p = .000; partial eta squared = .240.		
Time * interaction effect F = 5.6; p = .000; partial eta squared = .058.		
Job dissatisfaction (0-100)*	(n=48)	(n=45)
Baseline	21.4 (25.8)	23.0 (31.9)
4 months follow-up	18.4 (26.50	22.8 (32.50
8 months follow-up	19.5 (28.7)	26.8 (29.9)
12 months follow-up	19.4 (28.9)	24.9 (32.7)
24 months follow-up	15.0 (22.3)	23.1 (28.3)
Time effect F = 0.9; p = .480; partial eta squared = .009.		
Time * interaction effect F = 0.6; p = .698; partial eta squared = .006.		
Fatigue CIS (20-140)*	(n=62)	(n=53)
Baseline	88.2 (22.3)	90.1 (20.7)
4 months follow-up	84.9 (25.7)	82.9 (24.4)
8 months follow-up	77.0 (24.2)	84.0 (24.5)
12 months follow-up	74.9 (25.9)	80.8 (27.5)
24 months follow-up	69.6 (28.2)	81.9 (24.9)
Time effect F = 10.0; p = .000; partial eta squared = .082.		
Time * interaction effect F = 2.7; p = .032; partial eta squared = .023.		

* High value = more of the measured concept.

end of the second year in the experimental group; they stabilised during the second year in the experimental group.

Table 4 presents the employment figures after two years. Fifty-four of the 62 participants (87%) in the experimental group retained their job, of which two participants were on short-term sick leave or on long-term sick leave but expecting to return to work. Forty-eight of the fifty-three participants in the control group (91%) retained their job, of which four persons were on short-term sick leave or on long-term

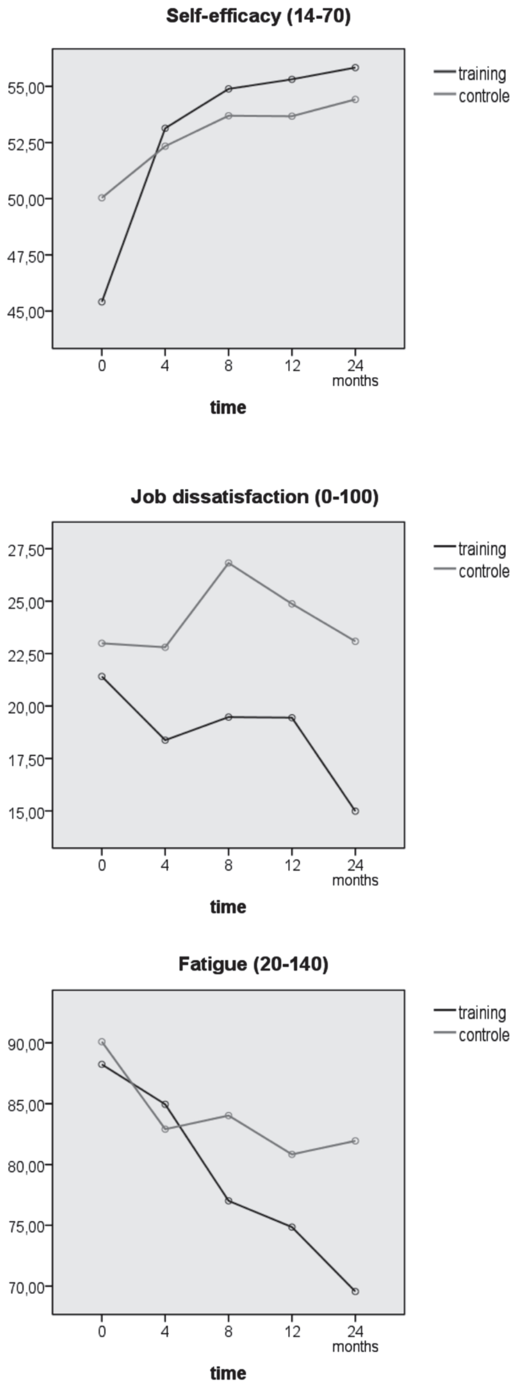

Figure 3. Effect of intervention on self-efficacy, job dissatisfaction and fatigue. Repeated measurement based on intention to treat analysis.

Table 4. Job loss after two year (n=115)

Experimental (n=62)	n (%)	Control (n=53)	n (%)
Job maintenance	54 (87.1)	**Job maintenance**	48 (90.6)
Working	52 (83.1)	Working	43 (81.1)
On 100% sick leave (≤ 6 months or probably /surely returning to work)	2 (3.2)	Working self-employed after dismissal	1 (1.9)
		On 100% sick leave (≤ 6 months or probably /surely returning to work)	4 (7.5)
Job loss	8 (12.9)	**Job loss**	5 (9.4)
Dismissed or resigned	2 (3.2)	Dismissed or resigned	1 (1.9)
Retired (65 years)	1 (1.6)	Incapacity benefits	2 (3.8)
Incapacity benefits	4 (6.5)	On 100% sick leave (> 6 months and probably/ surely not returning)	2 (3.8)
On 100% sick leave (> 6 months and probably/ surely not returning)	1 (1.6)		

OR = (8x48)/(5x54)= 1.42; 95% CI = 0.44 – 4.64.

sick leave but expecting to return to work, and one person was dismissed and had started to work self-employed. Of the eight participants in the experimental group who did not retain a job, two participants were dismissed or had resigned, four participants were on incapacity benefits, one person was on sick leave for more than six months and thought that a return to work was unlikely or impossible, and one person had retired at the age of 65. From the five persons in the control group that had not maintained a job, one person was dismissed or had resigned, two persons were on incapacity benefits and two persons were on 100% sick leave and thought that return to work was unlikely or impossible. Job loss was greater for the experimental group, but not significantly greater, with an odds ratio 1.42 (95% CI 0.44 to 4.64).

Secondary outcome measures

Table 5 presents the secondary outcome measures at baseline and after 24 months for the experimental group and the control group. Sick leave dropped significantly for the whole study population, but not more for the experimental group than for the

Table 5. Secondary outcome measures, at baseline and after two years. Repeated measurement based on intention to treat analysis (n=115).

Sick leave, nr of days during the last 4 months (0-87)	Experimental	Control
	(n=46)	(n=46)
baseline	10,7 (13.1)	22.5 (25.7)
24 months follow-up	6.2 (16.0)	14.9 (24.5)
time effect F = 3.4; **p = .019**; partial eta squared = .036.		
time * interaction effect F = 1.6; p = .190; part. eta sq. = .017.**		
Quality of life SF12 **physical** (0-100)*	Experimental	Control
	(n=61)	(n=51)
baseline	44.9 (24.2)	41.7 (19.7)
24 months follow-up	57.0 (26.9)	49.7 (27.8)
time effect F = 6.7; p = .000; partial eta squared = 0.57.		
time * interaction effect F = 1.0; p = .428; part. eta sq. = .009.		
Quality of life SF12 **mental**(0-100)*	Experimental	Control
	(n=62)	(n=53)
baseline	45.3 (17.5)	43.5 (18.6)
24 months follow-up	58.2 (16.0)	50.0 (17.9)
time effect F = 9.0; p = .000; partial eta squared = .074.		
time * interaction effect F = 3.0; p = .019; part. eta sq. = .026.		
Work-related problems (0-16)	Experimental	Control
	(n=48)	(n=45)
baseline	6,8 (2,9)	6,8 (2,8)
24 months follow-up	3,8 (2,6)	4,7 (2,7)
time effect F = 24.4; p = .000; partial eta squared = .212.		
time * interaction effect F = 1.9; p = .105; part. eta sq. = .021.		
Nr of work accommodations (0-17)	Experimental	Control
	(n=54)	(n=48)
baseline	2,9 (2,1)	3,4 (2,5)
24 months follow-up	2,8 (2,6)	3,4 (2,6)
time effect F = 0,7; p = .549; partial eta squared = .007.		
time * interaction effect F = 1,5; p = .208; part. eta sq. = .015.		
Burnout, exhaustion (0-6)*	Experimental	Control
	(n=48)	(n=43)
baseline	3.3 (1.4)	3.4 (1.4)
24 months follow-up	2.5 (1.5)	2.6 (1.3)
time effect F = 10.0; p = .000; partial eta squared = .101.		
time * interaction effect F = 0.2; p = .940; part. eta sq. = .002.		

Table 5. Continued

Burnout, detachment (0-6)*	Experimental	Control
	(n=48)	(n=42)
baseline	1.9 (1.3)	2.0 (1.2)
24 months follow-up	1.5 (1.1)	1.9 (1.2)
time effect F = 2.6; p = .044; partial eta squared = .028.		
time * interaction effect F = 0.7; p = .602; part. eta sq. = .007.		
Burnout, competence (0-6)*	Experimental	Control
	(n=48)	(n=43)
baseline	4.2 (0.9)	4.2 (0.9)
24 months follow-up	4.5 (0.9)	4.5 (0.8)
time effect F = 4.4; p = .002 ; partial eta squared = .047.		
time * interaction effect F = 1.3; p = .281; part. eta sq. = .014.		
Social relationships with supervisor (0-100)*	Experimental	Control
	(n=47)	(n=45)
baseline	26.0 (16.4)	21.6 (18.8)
24 months follow-up	19.2 (15.3)	18.9 (18.1)
time effect F = 2.4; p = .064; partial eta squared = .025.		
time * interaction effect F = 0.5; p = .675; part. eta sq. = .006.		
Social relationships with colleagues (0-100)*	Experimental	Control
	(n=47)	(n=45)
baseline	27.4 (15.1)	26.7 (13.3)
24 months follow-up	21.0 (14.3)	19.5 (12.9)
time effect F = 8.6; p = .000; partial eta squared = .087.		
time * interaction effect F = 0.2; p = .903; part. eta sq. = .003.		
Worries about work (0-100)*	Experimental	Control
	(n=48)	(n=43)
baseline	44.8 (39.6)	39.5 (39.0)
24 months follow-up	29.2 (39.0)	33.1 (36.1)
time effect F = 5.4; p = .001; partial eta squared = .057.		
time * interaction effect F = 2.0; p = .105; part. eta sq. = .022.		

*Quality of life: high value = high quality

*Burnout: high value = more of the measured concept

*Social relationships and worries: high value = more problematic**

Box M's assumption of homogeneity of correlations violated control group. Physical quality of life improved significantly for both groups, but not more for the experimental group than for the control group. Mental quality of life improved significantly more for the experimental group. Work-related problems decreased for both groups, but not more so for the experimental group. The number of work accommodations decreased somewhat for both groups. The burnout exhaustion, detachment and competence scales presented a significant improvement in time, but the experimental group did not perform better than the control group. Social relationships with the supervisor did not improve significantly in time; social relationships with colleagues improved and worries about work decreased significantly, but the experimental group did not perform better than the control group.

Discussion

At the two-year follow-up, self-efficacy and fatigue improved significantly more in the experimental group than in the control group. Job dissatisfaction and job loss did not significantly differ between the experimental and the control group. Even though many of the secondary outcome measures improved for the whole group, only mental quality of life improved significantly more in the experimental group. The number of work accommodations had not increased.

This study has several strong features. We evaluated a theory-driven, carefully developed and pilot-tested intervention. The quality of delivery of the intervention was good with most participants participating in all sessions. We used an RCT-design that controlled for influences other than the intervention. In addition, with two years, we had a long follow-up. We measured the outcome five times in the course of follow-up which provides the opportunity to study how the intervention affects outcomes over time. We had a very high response rate that remained stable over time which increases the reliability of the results. The process evaluation of the intervention showed that the majority of the participants were very satisfied about the training programme and thought that it had an effect on how they dealt with various work- or disease-related problems. Only two participants dropped out because of dissatisfaction [44].

We hypothesised an effect on fatigue based on a study of chronic fatigue syndrome [28]. However, in contrast to the chronic fatigue syndrome, most chronic diseases will remain and might even progress. Thus, fatigue levels comparable with those of the healthy workforce are not to be expected at follow-up. Nevertheless fatigue complaints continued to diminish in the second year for the experimental group, whereas they stabilised after the first year for the control group. This indicates that the new attitudes and skills acquired in the intervention group probably need time to be fully realised. We hypothesised that the intervention would increase self-efficacy leading to increased skills in communicating about the disease at work, better realisation of work accommodations and thus a decrease in fatigue and job dissatisfaction. We expected that the whole process would lead to less job loss in the long term. We could show the increase in self-efficacy and decrease in fatigue but not an increase in the number of work accommodations. In our process evaluation, we found that psychosocial factors may have a beneficial effect on their own, apart from their possible beneficial influence on the implementation of work accommodations. Job retention remained high in the whole group which resulted in too low power to show any significant changes in spite of our long term follow-up. The slightly higher rate of job retention in the control group was at least partly due to the loss to follow-up of three participants in the control group due to severe disease. Based on other work, we assume that in the long run less fatigue will lead to less job loss [25].

Even though the experimental group and the control group were highly comparable for the main characteristics at baseline, they differed slightly in the number of chronic diseases, hindrance due to health problems and work capacity. We did an extra repeated measurements analysis for the primary outcome measures with physical work capacity at baseline as a covariate. The results were similar for the outcome measures self-efficacy and job dissatisfaction. For fatigue, the F-value indicating the interaction effect of time and group dropped from 2.7 to 2.3 and the corresponding significance level dropped from $p = .032$ to $p = .061$. We do not know whether controlling for physical work capacity is an overcorrection, as the experimental group and the control group did not differ in fatigue at baseline.

Another limitation in our study is that we could not analyse work-related outcomes such as self-efficacy, job satisfaction or social relationships at work for twelve participants who were not at work at the specific measurement times because of sick leave or temporary job loss. An additional analysis in which we used the method of last observation carried forward or later observation carried backward did not yield any different results, but for the outcome measure work-related problems, which had decreased significantly more in the experimental group in this analysis.

This RCT was not double blinded. The researcher knew which respondents were in the experimental group or the control group. Two of the researchers (IV and FvD) were developers of the intervention as well, which makes them more interested in a positive study outcome than in a negative outcome. However, as all outcome measures are self report measures, we do not expect that this has caused bias. The most severe limitation of our study is that we could not blind participants for the control group status. Seventy-one percent of the participants in the control group stated that they or others, such as the occupational physician, another medical professional or the supervisor, undertook actions to solve work-related problems. The great majority of them stated that they did so because they were randomised to the control group. Many took steps comparable to the training programme. Thus, participation in the trial probably functioned as an intervention in itself, and this kind of crossover effect could have resulted in an underestimation of the impact of the intervention [36].

Women, higher educated workers and employees working in the service sector were overrepresented in our sample. Also the small loss to follow-up might point to a selection of employees that are highly motivated to stay at work. This selection bias limits the external validity of our study. We do not know whether the effect of the intervention will be higher or lower in other study groups.

Several other studies assessed the effect of job retention programs with a randomised controlled design [37-40] or a non-randomised controlled design [41]. Most did not find an effect on job retention but some found that the intervention decreased fatigue or increased self-efficacy in line with our findings. Purdon et al. studied the effect of a workplace intervention in a large group of 2.845 employees on sick leave for 6-26 weeks. Job retention was not higher in the experimental group. One explanation for this negative finding was that the interventions offered were not always seen as fully meeting the clients' needs. The other explanation was that participants in the control group were very proactive on their own behalf [40]. Two other studies did not find an effect on job loss either [37,39]. However, in one of these, de Buck found a significant difference in fatigue (VAS-scale) between the experimental group and the control group in favour of the experimental group [39]. Rasgon who studied dialysis patients, known for a low employment rate, found an effect on job retention for blue collar workers, but not for white collar workers [41]. Allaire studied rheumatic diseases and found no difference after one year but a significant difference after two years [38]. Rumrill studied self-efficacy in work accommodation request procedures in two controlled studies and found an effect in one study but not in another [42,43].

In future research the problem that participants in the control group or their representatives aim at 'substitution therapies' should be better addressed. One potential solution to this problem is to use a pre-study randomisation design in which participants are randomised before they are asked to consent and in which only participants in the experimental group are asked to consent [45]. Crucial is not to inform the control group about the intervention. Another solution is a study design without a control group, such as an interrupted time series or a pretest posttest design. In that case, we would have to gather more data on general changes in fatigue and job dissatisfaction for this target group or for various groups of diseases with differing long-term prognoses. More knowledge is needed on clinically relevant outcomes and other outcome measures. In addition, a more solid embedding of this kind of research in occupational health care or outpatient clinics could help in incorporating groups that were underrepresented in our project, such as men, less educated people or individuals working in transport or industry.

In conclusion, empowerment training increases self-efficacy and helps to reduce fatigue complaints which in the long term could lead to more job retention. Better understanding of ways to deal with work-related problems in chronic diseases is needed to develop more efficient support for employees with a chronic disease.

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Chapter 10

General discussion

In this chapter, I will present the main findings of the overall research, discuss its strengths and weaknesses and reflect on future research directions. Then I will reconsider the issue of the employability of persons with a chronic disease and the concept of empowerment.

Main findings

The data for the first study were collected in 1985 and compared to earlier study results from1972 and 1978. They showed that people with haemophilia in 1985 worked less often than the general population. Employment figures had not increased since 1972, whereas the percentage of work disabled had increased, notwithstanding the fact that improvements in medical treatment had led to less physical limitations. These figures illustrate the functioning of the Dutch social incapacity benefits regulations (WAO) of that time. The problem of high unemployment as a result of the economic recession at that time was partly resolved by offering elderly and disabled people incapacity benefits. The considerable increase in the number of work-disabled persons gave rise to new social incapacity benefits regulations. Cuts were made in the financial compensation offered to the partially disabled and people applying for these benefits today are more thoroughly assessed in terms of physical disabilities. Employers were confronted with more responsibilities and with substantial financial consequences of absenteeism of personnel. The survey among persons with haemophilia was repeated in 2001 [1]. The percentage of work disabled employees with haemophilia had decreased by then, so the promises of better medical treatment were redeemed eventually. The study conducted in 1985 yielded another interesting finding. It showed that employees with haemophilia held jobs that matched their educational levels, and these were seldom "blue collar" positions. However, individuals in a comparable group of haemophilia patients in the UK often held blue-collar jobs. These types of jobs go hand in hand with physical tasks that may overburden and damage joints. It seems as if the rather generous Dutch social incapacity regulations did prevent people from being forced to accept jobs that were unhealthy for them. It will be interesting to investigate whether the recent changes in the Dutch social incapacity regulations will have an opposite effect.

Chapters 3 and 5 examined the patients' perspectives on working with a chronic disease. Employees with rheumatoid arthritis point to the importance of psychosocial aspects, such as their own self-management skills and support of their supervisors, which they felt to be important in order to maintain employment. Work adaptations as well as support from colleagues and medical professionals were next mentioned as being of essential importance. These medical professionals, when asked what they thought might be important for these employees, had put themselves and effective cooperation between medical professionals on top of the list of important topics. The research on 122 employees with various chronic diseases corroborated the above-mentioned findings on what employees see as critical aspects of working with a chronic disease. Practical issues, such as workplace accommodations were sometimes problematic, but social relationships and finishing work tasks were more often so. However, acceptance of having an irreversible disease and balancing work roles and other roles such as family responsibilities were most often experienced as problematic. This last point was illustrated by the high percentage of respondents who were seriously fatigued. Asked which work accommodations they preferred, the most often mentioned accommodations were organisational adaptations, such as working less hours in a more flexible way or at home.

The above-mentioned research demonstrates many changeable factors that may prevent work disability. Vocational rehabilitation addressing these factors might help employees with a chronic disease. We reviewed the literature on rehabilitation that might support employees to solve work-related problems. We confined ourselves to empowerment-based rehabilitation aimed at a better awareness of needs and improvement of communication skills of employees in order to prevent unnecessary work disability. We found nine studies describing and evaluating these kinds of programmes. More studies likely exist, but they will not always be reported in the scientific literature. The programmes' approaches varied from rather practical, concentrated on obtaining work accommodations within the Americans with Disabilities Act, to psychosocially oriented, with a focus on individual feelings and attitudes, and social relationships. Only four studies were randomised controlled trials and follow-up was mostly short. With reservations because of these methodological shortcomings, we decided that the results suggested effectiveness for these kinds of interventions.

We developed a group training programme that was partly based on these international studies and partly on two comparable Dutch programmes. After a pilot programme, the definitive programme was carried out eight times, with 64 participants in total as part of a randomised controlled trial. The recruitment of participants was laborious; the cooperation of outpatient clinics for this purpose was poor. This might have been partly due to the randomisation procedure, which might disappoint people in case of assignment to the control group. The process evaluation further demonstrated that almost all the participants of the training programme followed it until the end. Participants missed one of the seven group sessions on average, mostly because of health reasons. Most of them judged the intervention to be effective. Discussing psychosocial aspects of being ill was highly valued, as was practicing communication with a supervisor or colleagues by way of role-playing. The majority of participants had the opinion that a consultation with their supervisor had contributed to solving work-related problems.

In a qualitative study, we did analyse what empowerment concretely meant for the 72 participants of the training programme and the pilot programme. The programme used a step-by-step approach, first clarifying problems, then discussing these at work and then developing solutions. We found seven recurring themes in how the participants dealt with these phases. They can be understood as tasks that have to be performed. They ranged from developing realistic plans, acquiring knowledge and feeling more self-confident to relating to the supervisor and colleagues in effective ways, and finding a satisfactory balance between roles at work and life outside of the workplace.

We followed the experimental group and the control group for two years in order to evaluate the effectiveness of the training programme. The experimental group improved significantly more in perceived self-efficacy, fatigue and mental quality of life when compared to the control group. Self-efficacy increased particularly during the first four months in the experimental group. Fatigue complaints decreased till the end of the second year in the experimental group; they stabilised during the second year in the control group. Job satisfaction had decreased in the experimental group and increased in the control group, but these results were unconvincing and not statistically significant. Only a small number in both groups had not maintained employment after two years and the difference was not statistically significant. Sixty percent of the control group stated that they or others had undertaken other specific measures to solve work-related problems, and the great majority did so because they were allocated to the control group.

Methodological considerations

In this section, I will concentrate on the essence of this thesis: the development of the training programme and the investigation of its feasibility and effectiveness. The research project consists of a number of successive steps; the weaknesses and strengths of each step will be discussed.

1. The development of the intervention

The programme was developed based on insights from occupational health psychology, rational emotive theory (RET), social learning theory and the empowerment movement. Occupational psychology focuses on factors leading to work stress and overburdening. These factors were situated in the ‘Quality of work’ model that the participants used in order to clarify work-related problems. RET-theory inspired us to pay attention to negative thoughts and feelings about having a chronic disease and how these might influence communication in an ineffective way. Social learning theory stresses the importance of increasing feelings of self-efficacy. Several ways to increase self-efficacy, for instance role-playing, had a place in the programme. The empowerment movement emphasizes the importance of exploring individual goals and increasing insights, knowledge and skills. These elements were important when devising a plan of action. Several of these theoretical elements were already being utilised in existing international and Dutch programmes. We had studied these beforehand. In particular, we adopted elements of a programme for depressed workers as well as for those with burnout experiences. We delivered one pilot training programme, which was quantitatively evaluated with a pre-test post-test design, as well as qualitatively by way of observation and telephone interviews. Following this pilot period, the actual programme was adapted. In conclusion, we think the intervention has been carefully developed but there is one aspect that we need to consider further. Exchanging experiences was one of the components of the intervention that the participants found very important. There is a risk that participants, by exchanging experiences, increase negative bonding, which may prevent active coping. We do not know whether this might have happened occasionally.

2. Delivering the intervention

The training programme was carried out as prescribed in the manual. The three trainers had experience in group programmes and had expertise in the field of occupational psychology and chronic diseases. Two of them carried out the programme for the first time as part of the effectiveness study, while the other had delivered the pilot training programme as well. It is possible that the fact that two trainers had no experience with this specific programme affected our results. The participants positively judged the trainers' qualities, and were not more positive in reference to the trainers when the programme was performed for the second or third time, so their inexperience appeared not to be very important. In conclusion, we can say that the deliverance of the intervention is one of the strengths of this project.

3. Reach of the target population

The people that applied for the programme formed clearly a selected group. Men, persons with lower educational levels or those working outside of the service sector were underrepresented. It is conceivable that certain employers were not inclined or concretely did not give permission to follow the programme, which means that employees working for these kinds of employers were underrepresented as well. Furthermore, we probably attracted persons who were highly motivated to stay at work and to do their best to solve problems. All these factors can have serious consequences for the external validity of the results. Another point of consideration is whether we were strict enough with regard to the inclusion criterion of 'experiencing work-related problems'. It is possible that some people were not severely hindered at work by their disease, but curious to follow a programme free of charge. This factor was relevant for two of the three persons that dropped out of the programme halfway. Possibly this also was a factor for some of the people with low fatigue scores. In conclusion, the underrepresentation of several groups has to lead to a cautious interpretation of the study results toward populations different from those examined in this study. For example, it is possible that the intervention is less effective for men working in transport or construction. However, it is also possible that the intervention is even more effective. This can be described as a weakness of this evaluation study and a challenge for future studies.

4. Outcome measures

The intended purpose of the intervention is to contribute to insight into work-related problems, knowledge about solutions, and skills to organise solutions. A higher level of perceived self-efficacy should lead to more effective employee behaviours aimed at solving problems, and by consequence more job satisfaction, less work stress and fatigue and a lower chance of job loss. We see that the pathway from participation in the training programme to job retention goes through a number of steps. The nature of work-related problems differs from one person to another, which means that people will emphasise different aspects of the intervention as useful: one person may work more to develop insights, the other to focus on better communication. This means that it makes no sense to assess effectiveness of the interventions for all participants using the same measurements. A second point of interest is that some variables, such as insight, knowledge and skills are only laboriously measurable with self-reported questionnaires. Problem-solving behaviours dealing with barriers at work are not easily measurable when the actual behaviour is different. This implies that we cannot measure all the steps of our theoretical model. In addition, assuming that only a minority of participants might lose their jobs over the course of two years, a significant effect on job retention is achievable only with a very large sample. For this reason and because other outcomes are considered as important as job retention, we have chosen a number of relevant primary outcome measures apart from job retention: perceived self-efficacy, job satisfaction and fatigue. Fatigue and job dissatisfaction are important factors on their own, but they are also predictors of job loss. Besides these primary outcome measures, we did include seven secondary outcome measures, such as sick leave, number of work-related problems, acquired work accommodations, quality of life, burnout, social relationships at work and worries about work, in order to gain knowledge of the various effects of this intervention. What makes the interpretation of the results problematic is that we do not have empirical knowledge about what clinically relevant effects on the primary and secondary outcome measures may be. We calculated the required sample size after consulting research on the effects of an intervention aimed at reducing chronic fatigue complaints. This study showed that many people recovered completely. This will seldom be the case for employees with an irreversible chronic disease, and in retrospect, we were too optimistic about the expected improvement of fatigue complaints. In conclusion, we have chosen a number of relevant outcome measures, but we lack knowledge about relevant clinical effects; on the other hand, we consider the primary and secondary outcomes chosen to still be relevant from societal and scientific perspectives.

5. The study design

A randomised, controlled trial (RCT) is the gold standard for demonstrating the effects of an intervention. Changes in the experimental group can be compared with changes in the control group that did not receive care or did receive care as usual, and it is possible to separate the effects in the experimental group into those due to spontaneous recovery or external factors and those due to the intervention. The RCT presupposes that in the ideal protocol the participants are blinded. However, blinding is not always possible. This may cause participants in a control group to undertake actions because they are triggered by the research project. Also others, like medical professionals, may become more aware of the needs of participants in a control group because they are triggered by a research project, and may undertake extra measures to help them, especially when they are not directly engaged in the research project. Participants allocated to the control group in our study were well aware of their group assignments, just like other persons in their environment, such as medical professionals, occupational physicians or supervisors in the workplace. Seventy-one percent of the 58 people in the control group stated that they or others had undertaken measures to deal with work-related problems. The great majority stated that they had done so because they were allocated to the control group. These alternative actions in the control group are partly to be understood as ‘care as usual’ which means that these persons would have found their way to psychotherapy, occupational health nurses, a self-management course, or adaptations in the workplace anyhow. We cannot estimate how large this part is as practice figures for this population are absent. In the recruitment and informed consent procedures, the attention of potential participants is purposely drawn to work-related problems and the need to find solutions. Filling in a number of questionnaires might have contributed even more to that effect. Furthermore, medical professionals or supervisors may have felt it necessary to compensate for their employees’ allocation to the control group as was seen in a comparable study where rheumatologists were giving extra effort to support patients in the control group [2]. The consequence of this phenomenon is that the internal validity is compromised: the effect of the intervention is underestimated when we compare the experimental and the control group. This is the main weakness of the evaluation study.

6. Response

A strong feature of this study is that the response was very high until the end of the study. There is almost no selective loss to follow-up, which contributes to the internal validity.

7. Data processing and statistical analysis

The data processing has been carried out carefully. Beforehand, we made decisions about coding rules in cases of unclear or missing data. There were consultations with the researcher for cases that were not covered and the decisions were registered. Ten percent of the questionnaires were processed twice, in order to minimize data entry mistakes. Repeated measurement analyses were used for the effectiveness analysis. This is an appropriate method to investigate whether trends in time are attributable to a second independent variable. In these ways, we have guarded the quality of data processing and analysis.

The strength of a chain is in the weakest link. Fortunately, this does not hold for all the links that form a research cycle. It might hold, however, for the second step: it does not make sense to evaluate an intervention that is poorly executed. When no effect is found, we will never know whether this is the case because the idea was after all no good, or because the idea was good but badly carried out. Other weak links will make the chain weaker but it will not break. Sometimes, it appears that the strength of one link is inversely related to the strength of another; this holds especially true for the study design. We used the strongest study method possible, the randomised controlled trial. It appeared to have several disadvantages. The most important of these includes the inability to blind participants for this intervention, which, in this health care context, complicated an appropriate comparison of the experimental and the control groups and was thus a threat to the internal validity of the study. In addition, the RCT design, including a ‘lottery’ for receiving an attractive intervention or not, was in our opinion one of the reasons that physicians and nurses were hesitant to draw the attention of patients to the research project, which thus resulted in a difficult recruitment process. Sometimes, the project even threatened to collapse, although in the end we did include 122 of the 128 participants for whom we had planned. The rather poor cooperation of outpatient clinics and occupational health services in the recruitment operations might also have contributed to a biased sample, which limits the external validity of the results.

Pre-randomisation before the informed consent procedure is mentioned as an alternative to conventional RCTs in cases where a control group deviating from the protocol might threaten the internal validity. One variant of this option is that only the experimental group gives informed consent; another is that the control group gives consent for research but is unaware of the existence of an experimental group [3]. Both variants assume 'standard care' and effects on outcome measures need to be assessed several times for the control group. Standard care for work-related problems was for our respondents mostly minimal or nonexistent, which possibly might have made this option ethically unacceptable for our respondents.

Others have discussed the disadvantages of RCTs in public health as well. They explain the failure to organize RCTs because medical professionals do not want to refer participants to the study and they also cite low external validity among other things and recommend pre-test post-test designs [4]. Victora [5] also discusses the pros and cons of RCTs, advocating RCTs for clinical interventions where the causal chain between intervention and outcome is relatively short and simple. In the case of public health interventions with longer causal pathways and where not blinding participants may lead to crossover effects between experimental and control groups, the author prefers observational studies using process indicators as well. He also points to the importance of investigating the effect of an intervention for different groups or in different contexts, where contextual factors determine whether an intervention has a small or a large effect. For future research on the effectiveness of interventions aimed at solving work-related problems, we should reconsider using pre-test post-test designs or observational studies. Alternatively, we should try to facilitate cooperation with outpatient clinics in order to organise RCTs in such a way that the internal validity is less compromised, for instance by convincing medical professionals that they should not give additional care to the control group. Furthermore, we should study which kind of intervention suits which populations of patients. In the introductory chapter, we discussed other kinds of vocational rehabilitation, which are more directive, aimed at changing personal characteristics like illness perceptions or fitness, or are oriented more at the workplace. Each method has its advantages and disadvantages for different people within various contexts. We did not register ethnic background, but we suspect that ethnic minorities were underrepresented in our intervention. Several other groups were underrepresented as well. Especially workers outside of the service sector should be assessed in future studies. In addition, the perspectives of employers e.g. supervisors and human resources managers on the employability of people with chronic diseases and their experiences with vocational rehabilitation for this group deserve more attention.

Chronic disease, employment and empowerment

Working with a chronic disease, ranging from 'no problem' to 'impossible'

Recent research among Dutch employees shows that 37% have a chronic or longstanding disease. About half of these workers do not feel hampered and 41% feel slightly hampered in work performance. Only 8% of this group feel strongly hampered [6]. We have to consider that these figures include longstanding but still remediable medical conditions such as low back pain. For irreversible chronic diseases, the percentage of employees experiencing problems is presumably higher. Nevertheless, we may conclude that many chronically ill employees perform their work just like others who are not experiencing persistent illness. Studies on the employment situation of diagnostic groups endorse this viewpoint. Employees, employers and health care professionals should be aware of that.

However, there is also a group of employees with chronic diseases who truly experiences problems in the workplace. They have difficulties in performing tasks or experience other obstacles. Sometimes this concerns practical problems, for which work accommodations such as specialized furniture or PC equipment as well as organisational adaptations like assignment to other tasks, lessened or more flexible working hours may be helpful. The above-mentioned National Survey on Working Conditions confirms that a minority of the employees with chronic or longstanding diseases would prefer one or more of these work accommodations [6]. In addition to this, many of these employees' problems relate to psychological and social issues. A number of concerns were situated in this field. Considering the training programme after two years, several participants noted that at the end they had learned to accept their illness or they had a higher awareness of the aspects of their job that caused stress and those that were enjoyable. They had learned to discuss the consequences of their diseases with colleagues or their supervisors, although they still found it difficult to know their bounds and be assertive. Other research also points to the importance of these psychosocial aspects. Aujoulat interviewed 40 persons with various chronic disorders in order to find out what "powerlessness" meant to them [7]. Prominent for these patients, somewhere in their past or at present, were feelings of insecurity and of loss of identity. Insecurity was caused by the unpredictability of the disease and by lack of control over one's body, environment and time management. Loss of social and personal identity was associated with changing or diminishing social roles and the idea of no longer being normal because of feelings of guilt, shame or jealousy. The importance of social factors is now confirmed by ample scientific evidence. Munir, for instance, found that emotional and social support of the supervisor positively influences self-management of the chronically ill at work. Social support by the occupational physician has an indirect effect in that it increases self-efficacy [8]. Employees, employers and health care professionals should be aware of the many troubles that a chronic disease can give an employee and they should have an awareness of the psychological implications. If not, employees with a chronic disease will not understand themselves or they will feel misunderstood by others. Research points to the inadequate attitudes of some occupational physicians in this respect [9]. Additionally, several participants in our study had these kinds of negative experiences with occupational physicians. Maybe the attention of these professionals has been focussed too much on returning to work recently. Medical professionals such as general practitioners, medical specialists or specialised nurses should be aware of the consequences of chronic diseases for workers. They should understand what they can contribute positively when they discuss these issues with their patients or when they cooperate with occupational health care providers in order to address work-related problems. They should learn to avoid negative contributions such as affirming unfitness for work without serious considerations of the possibilities and without consultation of an expert.

There is also a group of employees so impeded by their diseases that employment is questionable. Several national governments advocate the increase of employment of people with chronic diseases, by way of activities aimed at job retention or by offering means for entering or re-entering the labour market. One of the arguments behind this strategy is that working appears to have beneficial effects on physical and mental health (e.g., Waddell and Burton, cited in Dame Carol Black, Working for a healthier tomorrow, 2008) [10,11]. We need to make the necessary reservations here. Research among French elderly people shows that retirement has a positive effect on perceived health, and this effect is stronger for people with a health problem [12]. Dutch research suggests the same for people with physical limitations [13]. One of our study participants noted that he had learned in the training programme that he should not go on working at the cost of himself or his health: ‘When I stopped working, I enjoyed a half year of satisfactory health. My health is getting worse at the moment, but I’m sure that it would have come earlier when I had stayed at work’. A job offers social contacts, income and maybe fulfilment and it structures daily living. These are all quality of life-enhancing factors. However, work may also cause stress, fatigue or other health complaints, and more so for people with chronic diseases. As every physician knows, at a certain point, there is no benefit to be gained for a patient working a fulltime job. Working less hours or quitting the labour market appear to be the only options left to these individuals. Then quality of life must be regained by finding other fulfilments.

Empowerment revisited

The idea of empowerment of people with chronic diseases has two debatable aspects. The first is that others generally decide in which respect people need to be empowered. The second is that it lays the burden of prevention of work disability one-sidedly with the employee.

Empowerment is based on the philosophy of self-determination. Yet, when empowerment projects are evaluated, researchers or health care professionals themselves often define the outcome measures, as Aujoulat notes [14]. Empowerment is often operationalised in terms of self-efficacy or skills in dealing with disease or medical professionals, all of which are oriented to gaining control. Aujoulat's research showed that patients themselves define their own empowerment processes in other terms, as a combination of 'holding on' to previous roles and learning to control disease, and 'letting go', which meant integrating illness as a part of oneself and accepting that some things have become uncontrollable [15]. In our project, which was for that matter not labelled to the participants as an empowerment project, we had decided that empowerment meant that people would be provided with insight, knowledge and skills that would enable them to remain at work. It is acceptable that care providers or researchers decide on outcome measures for an intervention, but we should bear in mind that participants may have other goals or change their objectives. The concept of empowerment may give the incorrect impression that persons in empowerment projects always work on the improvement of capacities that they themselves have decided. Apart from that, the trainers in this project were not fixated on prevention of job loss at any price, as far as I can see. Several participants lost their job in two years time, but did not consider the programme as a waste of time. Some participants gave empowerment their individual twist by asking for a certificate. They planned to present this in case of a future assessment for incapacity benefits. In this way, they thought to convince the social insurance physician that they had done their best to stay at work.

The second issue around empowerment is more serious. Staying at work in the case of a chronic disease that significantly impedes the employee requires the commitment of the employee and of others. Focusing on the empowerment of employees might cause us to think that they are responsible in case of job loss. We realized this asymmetry from the beginning and so did others. When we applied for a subsidy for the development and evaluation of empowerment training for employees, the Ministry of Social Affairs and Employment stipulated as a condition that we also paid attention to the employers' side which we did also in a separate study. In the training programme, it was stressed that endeavours to stay at work might fail when others at work do not cooperate. Some participants did indeed experience these obstacles. A man observed two years after the training, following a hospital stay because of a serious medical complication: ‘When you get ill, the easy way (for the employer) is not to extend your employment contract. It has become clear to me that I cannot be honest about my disease. It is a pity, but this is the reality.’ Another participant was happy to have learned a great deal, but suggested a training programme for employers: ‘I was all alone working on it’. Training programmes like our empowerment training, which aim at enhancing individual problem-solving capacities, fit into the social trend to make people responsible for their wellbeing, just like programmes aimed at changing health behaviours or staying mentally healthy [16,17]. However, work disability is a gap between personal capacities and employers’ or societal demands. It takes two to tango. And a considerate government who as a dancing teacher watches over the rules and takes care when the employee is left without dancing partner.

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Summary

A number of employees with chronic physical diseases meet with difficulties at work. They may have health complaints, such as fatigue or pain. Medical treatment can interfere with work requirements, or employees may be hampered in work performance because of physical or cognitive limitations. In addition, difficulty in acceptance of a chronic disease, feeling uncomfortable when discussing the disease or a lack of understanding on the part of colleagues or supervisors may add to the burden of having a chronic disease. These difficulties at work can lead to job loss in the end. Work-related problems may be solved. A first step is to explore the nature of these problems and then discuss them in the workplace. Clarifying and discussing troubles may in itself improve the situation. Sometimes workplace accommodations are necessary, such as adjusted furniture or special PC equipment or organisational accommodations like flexible working hours, part-time work, working at home or a change of work tasks. In this way, unnecessary job loss may be prevented.

This thesis investigates the difficulties that employees with a chronic physical disease experience and evaluates a training programme aimed at supporting employees to deal with these difficulties. The programme is based on an empowerment perspective: the enhancement of knowledge, skills and awareness of values and needs, which enables the participants to set goals and to discuss and realise solutions. The increase of 'perceived self-efficacy' in terms of the social learning theory of Bandura is a characteristic of the empowerment orientation. The following questions are answered in this thesis:

1. What is the employment situation of people with a chronic disease and what problems do they experience at work?
2. Do vocational rehabilitation programmes based on an empowerment perspective and aimed at job retention exist for this group; are these programmes effective?
3. Is it possible to develop and deliver such a training programme; are the participants satisfied with this programme?
4. Which difficulties and problem-solving strategies are brought forward in this programme?
5. Is such an intervention effective?

Chapter 2 presents a survey carried out 25 years ago among 716 men with haemophilia aged 15-64 years old. Haemophilic bleedings have been well treated since the end of the 1960s when concentrated blood products became available. Furthermore, self-management and prophylactic treatment had been implemented in the 1980s. These improvements were assumed to result in less joint damage, work limitations and work disability. The research questions concentrated on quantitative and qualitative labour participation and perceived barriers at work. Labour participation figures were compared with Dutch reference figures and results of earlier research among men with haemophilia from 1972 as well as with international data. In 1985, 59% of the men with haemophilia were employed, compared to 69% of the Dutch male population; 22% were work disabled, compared to 11% of the Dutch male population. Twenty-three percent of those who were employed were hampered in their work with a main concern being pain. Other issues included not meeting job requirements because of haemorrhages needing medical treatment, physically burdensome jobs, having to ask colleagues for help or excessive absenteeism. Mean sickness absence had decreased over thirteen years from 35 to 15 days per year. However, the employment rate had stabilised around 60% and work disability had increased from 17% to 22%. The percentage working in manual labour was low; this was in contrast with the situation in the UK where more men with haemophilia were working, but often in manual jobs for which they were unfit.

In **Chapter** 3, recent research is presented. The research question of this chapter is what employees with rheumatoid arthritis consider necessary in order to remain at work, and what medical professionals consider their needs. Twenty-one employees participated in a concept mapping study. In this kind of study, qualitative and quantitative methods are combined: each participant mentions issues and then they all prioritise and cluster these issues. The employees collected 59 statements, which have been clustered into seven themes. The most important themes were 1) employer support and understanding, 2) disease knowledge and coping capabilities of the employee him/herself, 3) work accommodations, and 4) support from colleagues, health professionals and the patient organisation. Work accommodations included physical modifications such as a special desk, chair or PC equipment, and organisational accommodations such as flexibility in work pace, in working hours or having the option of working at home. Seventeen health professionals experienced in rheumatoid arthritis participated in a concept mapping study by mail. They mentioned largely the same issues, but with different prioritization. Well-informed and cooperating health professionals were thought to be most important, followed by the employee's coping capabilities and commitment to their work. The themes numbered 3 and 4 in importance referred to financial regulations at the workplace and social security provisions, medication and therapy. A positive attitude of the employer and colleagues, and suitable working conditions occupied the fifth and sixth places.

Chapter 4 is a literature review on 'empowerment'-based vocational rehabilitation interventions aimed at job retention for employees with chronic physical disease.

Empowerment refers to the provision of knowledge, the development of self-awareness of values and needs and the improvement of communication skills or other coping skills of employees, which enable them to solve work-related problems. The databases Medline (Pubmed), Embase, Cinahl and Psycinfo have been searched for articles published from 1988 until March 2004. We found nine articles, three of which describe group programmes and six describing individual programmes. They were aimed at job retention by means of various combinations of sub-objectives: to increase knowledge about the disease and its consequences, legal regulations and work accommodations; to gain an understanding of work-related problems; to increase a sense of control or perceived self-efficacy in the process of requesting work accommodations; to develop coping and social skills; or to increase activities aimed at work accommodations. Four studies had a randomised control group, five studies did pretest-posttest measurements. The follow-up periods varied from 2 to 48 months. Two of the three studies that made use of a control group and assessed job retention as an outcome measure reported effectiveness. Three investigations on the use of work accommodations reported the use of more work accommodations. One study reported a significant improvement in perceived self-efficacy, while another reported no significant improvement. Another article that described several psychological outcome measures reported an improvement in communication with others but no improvement in actual dealing with work-related problems. Two studies explicitly mentioned that the recruitment of study participants was difficult.

Chapter 5 presents a study of 122 employees with a chronic disease who experienced work-related problems. We investigated which barriers they experienced and what work accommodations they preferred by means of a questionnaire. At the same time, they were included in the study population for the randomised controlled trial reported in this thesis. The study participants had been ill for an average of ten years and 44% reported more than one chronic disease. Twenty-five percent had diseases of the musculoskeletal system, 23% had neurological diseases like Parkinson's disease or multiple sclerosis, and 21% had diseases of the digestive system (mainly Crohn's disease and colitis ulcerosa). People with higher levels of education, persons working in the service sector and women were overrepresented. From eight presented problems, special equipment or other arrangements of the workplace and commuting were least often felt to be problematic, followed by relationships with colleagues or the supervisor. The latter was a minor or large problem for half of the respondents. Performing and finishing work tasks were a problem for the majority, but most respondents considered this to be a slight problem. The main problems, and serious ones, included acceptance of having a chronic disease and balancing work and home life. Seventy-three percent had a high fatigue score which labelled them at risk for sickness absence or work disability. Almost every respondent preferred one or more work accommodations, notwithstanding the fact that they already had an average of 3.2 accommodations. In particular, they had preferences for organisational accommodations like working at home, working less hours, slowing the work pace, more autonomy in work planning or further training.

Chapter 6 describes the development, setup and contents of an empowerment-based training programme for employees with a chronic physical disease. The programme is aimed at job retention. We also present the study design of a randomised controlled effectiveness study. A literature review, a needs assessment and discussions with experts led to a pilot group training, tested in a pilot study. The evaluation of the pilot programme resulted in the development of a seven-session group training programme every two weeks. This is combined with three individual counselling sessions. The group has eight participants and is led by one trainer. An actor is invited twice to assist with role-playing. An occupational physician and an employment expert are invited for one session. The programme has three stages: exploration and clarification of work related problems, communication in the workplace, and development and implementation of solutions. Seven themes are discussed and practised in the group sessions: 1) the consequences of a chronic disease in the workplace, 2) insight into feelings and thoughts about having a chronic disease, 3) communication in daily work situations, 4) facilities for disabled employees and work disability legislation, 5) how to stand up for oneself, 6) a plan to solve problems, and 7) follow-up. The inclusion criteria for participants of the training programme and the effecttiveness study are: a chronic physical disease, experiencing work-related problems and fear of job loss or loss of work pleasure. Employees on long-term, full-time sick leave expected to last during the training are excluded. Participants are recruited via occupational health services, outpatient clinics, patient organisations and employers. Sixty-four participants from eight training programmes were planned to be compared to 64 persons who received care as usual. Mail questionnaires had to be completed before the training programme and after 4, 8, 12 and 24 months. Primary outcome measures included job retention, perceived self-efficacy, fatigue and job satisfaction.

Chapter 7 presents the process evaluation of the above-mentioned group training programme and the satisfaction of the participants with this intervention. Eight training programmes, given by three different trainers, with 64 participants in total were evaluated. The process evaluation was based on notes of the researcher about the recruitment process, process evaluation forms completed by the trainers after every group session and questionnaires filled in by the participants. We recruited participants via patient organizations, outpatient clinics, occupational health services and companies. The recruitment took an estimated 8-10 months of full-time work from one person. The recruitment via patient organizations was the most successful, and via outpatient clinics the least. According to some medical professionals, one of the reasons for recruitment problems was that medical professionals were reluctant to refer patients to the project because of the possibility of randomization to the control group. The participants had a mean age of 46 years and had been ill for an average of ten years. Musculoskeletal, neurological and digestive disorders formed two-thirds of the diagnoses of the participants. Women, highly educated people and employees working in the service sector were overrepresented. Three participants dropped out of the programme halfway, two of whom because the programme did not fulfil their needs. All the components described in the trainers' manual were discussed in the group session. Sometimes, components were discussed more briefly than others because of a lack of time. The participants rarely exhibited cognitive difficulties in understanding the materials, but emotional difficulties were sometimes met. One homework exercise, to arrange a consultation with the supervisor, encountered resistance from a number of the participants. The training programme as a whole was evaluated with a mean score of 8.1 just after its close, and with a mean score of 7.8 twenty months later. The themes 'Insight into feelings and thoughts about having a chronic disease' and 'Communication and assertiveness' were highly valued by participants, just like the exchange of experiences and role-playing. This was the case even though discussing feelings and role-playing were perceived as emotionally upsetting. The participants noticed positive effects most often with regard to how they experienced and dealt with disease and work. The least dramatic effect for participants was associated with work accommodations. The great majority felt that discussing matters with their supervisors had contributed somewhat or a great deal to solving problems. At 24 months of follow-up, 79% of the participants judged the overall effect of the programme to be lasting.

Chapter 8 is a qualitative study on how the 72 participants of the training programme and the pilot programme gave empowerment their personal interpretation. The training programme used a stepwise approach, first exploring and clarifying work-related problems, second focusing on communication at work, and third developing and realizing solutions. We, the researchers and trainers, wanted to know how the participants dealt with these issues concretely. For that, we reflected on recurring themes from our professional perspectives. We identified seven themes and characterized them in terms of employee tasks. Not every employee faced all of these tasks, but most had to deal with several. The themes included: 1) developing a realistic understanding of one's abilities, 2) standing up for oneself in a self-confident way 3) maintaining social relations based on mutual understanding with supervisors and colleagues, 4) collecting and assimilating knowledge of one's options, rights and duties, 5) consulting others and negotiating with regard to work accommodations, 6) planning one's job so as to provide personal satisfaction, and 7) maintaining a social life outside of work. The themes were illustrated using brief case histories.

Chapter 9 presents a randomised controlled trial on the effectiveness of the training programme that we described in Chapter 6. Study participants needed to have a paid job and a chronic physical disease that caused work-related problems. Long-term full-time sick leave, which was expected to continue during the training programme, was an exclusion criterion. A sample of 128 persons was computed to be sufficient in order to find a significant difference in fatigue complaints. Primary outcome measures were perceived self-efficacy in solving work-related problems, fatigue, job dissatisfaction and job retention. Fatigue and job dissatisfaction are predictors for job loss. Secondary outcome measures included work-related problems, sick leave, quality of life, realised work accommodations, burnout and three quality of work measures. The study participants filled out a mail questionnaire at baseline, and after 4, 8, 12 and 24 months. Continuous outcome measures were analysed with two-way mixed between-within subject analysis of variance. From the 134 individuals that applied for the project and returned the baseline questionnaire, 64 were randomised to the experimental group and 58 to the control group; ten persons dropped out of the study before the start of the intervention. Three participants of the training programme dropped out halfway through the intervention. Loss to follow-up in the total study inclusive controls was respectively 0, 3, 6 and 7 individuals after 4, 8, 12 and 24 months, respectively. Perceived self-efficacy increased significantly more in the experimental group that in the control group after two years. The increase in the experimental group occurred for the greater part in the first four months. Fatigue decreased significantly more in the experimental group that in the control group. The decline in fatigue complaints continued till the end of the second year in the experimental group; fatigue complaints stabilised in the second year for the control group. Job dissatisfaction decreased in the experimental group and increased in the control group but the difference was by no means significant. In both the experimental and the control group, only a minority of participants had not maintained employment and the difference was not significant. Mental quality of life increased significantly more in the experimental group that in the control group. Sixty percent of the persons in the control group stated that they or others, such as medical professionals or supervisors, had undertaken measures to solve work-related problems because of the randomisation to the control group.

In **Chapter 10**, I looked back on the whole research project. The investigations concerning barriers experienced at work showed that not only physical limitations that resulted from disease are problematic, but mental issues as well. Adaptation to disease and limitations is a challenge in itself. Persons with a chronic disease notice that acceptance is important and that self-management, communication and negotiation skills, and labour relations are essential. Even then, it is a challenge to combine the employee's role with other roles. Severe fatigue complaints are the dominant characteristic of many chronically ill employees who experience difficulties in the workplace. It is dubious whether fulltime employment is achievable and desirable for everyone.

We developed a group training programme for employees with a chronic disease based on a literature review and discussions with experts. Eventually, 61 of the 64 participants of the training programme completed the programme. One of the eight participants on average was absent at each session, mostly because of health problems. Most of the participants considered the training to be successful. The effectiveness study showed that perceived self-efficacy increased and fatigue decreased significantly more in the experimental group over the course of two years; the results on job satisfaction were inconclusive. The training programme did not have an effect on job maintenance. An unexpected finding was that many people in the control group undertook actions to solve work-related problems.

Several measurements and a high response rate until the end of the study are the strengths of this research. The fact that not much men, less educated persons and employees working outside of the service sector participated in the study indicates that the external validity is possibly restricted to a comparable population. The information that many persons in the control group or others in their environment, probably triggered by the recruitment for this project and the subsequent research, undertook measures to solve work-related problems is a threat to the internal validity. An underestimation of the effect of the intervention is the likely consequence. We have no idea how large this underestimation is. Another study design than the RCT appears to be a better option for interventions where participants cannot be blinded and where recruitment and allocation to the control group may lead to a high motivation of people in the control group or their environment to deal with difficulties at work. Another option is to work more closely with outpatient clinics so as to convince medical professionals in the control group not to undertake actions that they would not have done otherwise.

More attention for the psychological consequences of a chronic disease is required in occupational health care. It is important to discuss with employees what a chronic disease means to them, and whether they experience barriers at work. The health care sector should likewise pay attention to the consequences of a chronic disease for employment. Physicians and nurses are often the first ones to have an idea of the consequences of a disease and they are in a position to discuss these with their patients, to consult with the occupational physician or to refer patients to vocational rehabilitation.

The programme that we developed appears to be effective. However, we must realise that merely supporting employees is not enough. A supervisor who thinks along with the employee and an employer who offers the supervisor the possibility to do so are essential. More research should be carried out on the perspectives of employers on the employability of people with a chronic disease. A second issue we want to emphasise for future studies is the needs of groups of employees with a chronic disease that were underrepresented in this research.

Samenvatting

Een deel van de werknemers met een chronische lichamelijke ziekte ondervindt hinder van hun ziekte in hun werk. Het kan gaan om klachten als vermoeidheid of pijn, of hinder vanwege de vereisten die de medische behandeling stelt. Of last in de zin van het niet goed kunnen uitvoeren van werktaken vanwege fysieke of mentale beperkingen. Daarnaast kunnen acceptatieproblemen, ongemakkelijkheid in het bespreken van de ziekte met anderen of onbegrip van collega's en de leidinggevende een extra belasting vormen. Deze 'moeite met werk' kan er op den duur toe leiden dat mensen hun baan verliezen. Werkgerelateerde problemen zijn deels te verhelpen. In de eerste plaats door te onderzoeken wat de knelpunten precies zijn. Een volgende stap is het bespreken van deze knelpunten op het werk. Het onderkennen dat er problemen zijn en het bespreken daarvan kan al een verbetering geven. Eventueel kan het werk aangepast worden. Praktische aanpassingen zoals hulpmiddelen, of organisatorische aanpassingen in de zin van verandering van taken of werktijden of meer flexibiliteit kunnen een oplossing zijn. Op deze manier is onnodig verlies van werk te voorkómen.

Dit proefschrift gaat over de knelpunten die werknemers met een chronische aandoening op hun werk ondervinden en over een training die deze werknemers ondersteunt bij het oplossen van deze knelpunten. Deze training is gebaseerd op het 'empowerment' principe: het vergroten van kennis, vaardigheden en bewustzijn van eigen waarden en behoeften, om de deelnemers in staat te stellen doelen te definiëren, oplossingen te bespreken en te realiseren. Het vergroten van het vertrouwen in eigen kunnen wat dit betreft - 'perceived self-efficacy' in termen van de sociale leertherorie van Bandura - is een onderdeel van deze empowerment benadering. Dit proefschrift behandelt de volgende vragen:

1. Hoe gaat het met mensen met een chronische ziekte op de arbeidsmarkt en welke knelpunten ervaren zij rond hun werk?
2. Zijn er vormen van arbeidsbegeleiding beschreven die uitgaan van een empowerment perspectief en die gericht zijn op behoud van werk; zijn deze effectief gebleken?
3. Is een dergelijke empowerment training in Nederland te ontwikkelen en uitvoerbaar; zijn de deelnemers daar tevreden over?
4. Welke problemen en oplossingsstrategieën komen bij deze training naar voren?
5. Is een dergelijke interventie effectief?

Hoofdstuk 2 beschrijft een vragenlijstonderzoek onder 716 mannen met hemofilie dat 25 jaar geleden in 1985 werd uitgevoerd. De bloedingen waarmee hemofilie gepaard gaat waren sinds het eind van de 60-er jaren goed te behandelen door de beschikbaarheid van geconcentreerde bloedproducten. Daarnaast hadden de thuisbehandeling en de profylactische behandeling hun intrede gedaan. Het idee was dat deze behandelmogelijkheden zouden leiden tot aanzienlijk minder gewrichtsschade, minder hinder van de ziekte op het werk en minder arbeidsongeschiktheid. Het onderzoek richtte zich op werk en werkgerelateerde problemen. De arbeidsparticipatie werd vergeleken met die van de Nederlandse bevolking met gegevens uit soortgelijk onderzoek van 1972 en 1978 en met internationale cijfers. In 1985 had 59 % van de mannen met hemofilie een baan tegen 69 % van de Nederlandse mannelijke bevolking; 22 % was arbeidsongeschikt tegen 11 % van de Nederlandse mannelijke bevolking. Van de werkenden ondervond 23 % hinder op hun werk door de hemofilie. Daarbij ging het om pijnklachten, op onverwachte momenten weg moeten vanwege een bloeding, fysiek te zwaar werk, collega's om hulp moeten vragen en frequent ziekteverzuim. In de 13 jaar tot aan 1985 was het gemiddelde ziekteverzuim onder mannen met hemofilie gedaald van 35 naar 15 dagen per jaar; de arbeidsparticipatie was stabiel gebleven rond de 60 %, maar het percentage arbeidsongeschikten was toegenomen van 17 tot 22 %. Vergeleken met de Nederlandse bevolking verrichtte een kleiner deel van de mensen met hemofilie fysiek belastend werk. Nederland verschilde in twee opzichten van Engeland: daar werkten naar verhouding meer mensen met hemofilie, maar dan vaak in voor hen ongeschikte fysiek zware beroepen.

Vanaf **hoofdstuk 3** hebben we het over recent onderzoek. In dit hoofdstuk staat de vraag centraal wat werknemers met reumatoïde artritis naar hun eigen oordeel nodig hebben om aan het werk te kunnen blijven, en wat medische professionals daarover denken. Eenentwintig werknemers namen deel aan een concept mapping studie. Dit is een werkwijze waarbij kwalitatieve en kwantitatieve methoden gecombineerd worden: de deelnemers benoemen aspecten die zij vervolgens prioriteren en clusteren. De werknemers benoemden 59 aspecten, geclusterd tot zeven thema's. De belangrijkste thema's waren 1) begrip en praktische steun van de leidinggevende, 2) medicatie die een positief effect heeft op vermoeidheid, en kennis en copingvaardigheden van de werknemer zelf, 3) werkaanpassingen, en 4) steun van collega's, medische professionals en de patiëntenvereniging. Bij de werkaanpassingen ging het naast praktische aanpassingen zoals een goede stoel en PC-aanpassingen om organisatorische zaken zoals flexibiliteit in het werktempo, in uren en in de planning van het werk, en de mogelijkheid van thuiswerk. Zeventien medische professionals met expertise op gebied van reumatoïde artritis benoemden in een schriftelijke concept mapping studie deels vergelijkbare thema's. Hun prioritering lag echter anders. Goed geïnformeerde en goed samenwerkende medische professionals stonden bij hen bovenaan. Daarna volgde copingvaardigheden van de werknemers en betrokkenheid van hen bij hun werk. De thema's 3 en 4 hadden betrekking op financiële regelingen ten behoeve van de werkgever of de werkplek, en sociale zekerheid, medicatie en behandeling. Pas op nummer 5 en 6 stonden respectievelijk een positieve houding van de werkgever en de collega's, en werkaanpassingen.

Hoofdstuk 4 is een literatuurstudie naar 'empowerment' interventies gericht op behoud van werk voor mensen met een chronische lichamelijke aandoening. Met empowerment bedoelen we dat deelnemers kennis krijgen aangereikt, een besef van eigen waarden en behoeften ontwikkelen en communicatievaardigheden verbeteren om zodoende zelf knelpunten op het werk op te lossen. In de databases van Medline (Pubmed), Embase, Cinahl en Psycinfo werden artikelen gezocht uit de periode van januari 1988 tot maart 2004. Negen studies werden gevonden. Zes daarvan beschreven individuele programma's en drie studies groepsprogramma's. Behoud van werk trachtte men te realiseren met verschillende combinaties van subdoelstellingen: het vergroten van kennis over de ziekte, de gevolgen daarvan en wettelijke regelingen en voorzieningen; het verhelderen van werkgerelateerde problemen; het vergroten van een gevoel van controle in procedures ter verkrijging van werkaanpassingen; het ontwikkelen van copingvaardigheden en sociale vaardigheden; en het stimuleren van activiteiten gericht op het verkrijgen van werkaanpassingen. Vier studies hadden een gerandomiseerde controlegroep en vijf studies pretest-posttest metingen. De follow-up varieerde van 8 weken tot 24-48 maanden. Twee van de drie studies met een controlegroep en baanbehoud als uitkomstmaat rapporteerden effectiviteit. De drie studies naar het gebruik van werkaanpassingen vonden een toename hiervan. In twee studies waarin het gevoel van persoonlijke effectiviteit onderzocht is werd de ene keer wel, de andere keer geen toename hiervan gevonden. In een derde studie met verschillende psychosociale uitkomsten werd een verbetering in de omgang met anderen gevonden, maar geen verbetering in het oplossen van werkgerelateerde knelpunten. In twee studies werd expliciet de moeizame werving van deelnemers benoemd.

Hoofdstuk 5 is een studie onder 122 werknemers met een chronische lichamelijke ziekte die op hun werk problemen ervaren. In een vragenlijstonderzoek onderzochten we welke knelpunten ze ervoeren en wat hun wensen waren ten aanzien van werkaanpassingen. Deze mensen vormden tevens de studiepopulatie van de effectstudie waarover dit proefschrift verslag doet. De deelnemers waren gemiddeld tien jaar ziek en 44 % van hen had meer dan één chronische ziekte. Een kwart had aandoeningen aan het bewegingsapparaat, 23 % had neurologische aandoeningen zoals de ziekte van Parkinson of multiple sclerose, en 21 % chronische darmaandoeningen, voornamelijk de ziekte van Crohn of colitis ulcerosa. Hoger opgeleiden, vrouwen en werkenden in de dienstverlening waren oververtegenwoordigd. Van acht voorgelegde knelpunten werden de inrichting van de werkplek en het woon-werkverkeer het minst vaak als problematisch ervaren, gevolgd door contact met collega's of de leidinggevende; dit laatste was voor de helft enigszins of een groot probleem. Het afkrijgen van werk en het verrichten van bepaalde taken was voor de meerderheid een probleem, maar meestal geen groot probleem. Het accepteren dat men een ziekte heeft en het vinden van een goede balans tussen werk en thuis was voor de grote meerderheid een probleem en vaak een groot probleem. Drie en zeventig procent van deze onderzoekspopulatie had een vermoeidheidsscore die hen kenschetst als 'at risk' voor ziekteverzuim of arbeidsongeschiktheid. De overgrote meerderheid had wensen op gebied van werkaanpassingen, niettegenstaande het feit dat ze meestal al één of meer aanpassingen hadden. De wensen lagen vooral op het vlak van minder werken, thuis werken, een lager werktempo en meer mogelijkheden om het werk zelf te plannen.

Hoofdstuk 6 beschrijft de ontwikkeling, opzet en inhoud van een 'empowerment'training voor werknemers met een chronische ziekte. De training is gericht op behoud van werk en plezier in het werk. We beschrijven ook de opzet van een gerandomiseerde gecontroleerde studie naar het effect van deze training. Op basis van literatuurstudie, behoeftenonderzoek en gesprekken met experts werd een pilot training ontwikkeld; deze werd na een evaluatieonderzoek aangepast. De training bestaat uit zes tweewekelijkse groepsbijeenkomsten en een zevende na twee maanden. Dit wordt gecombineerd met drie individuele gesprekken: één bij aanvang, één halverwege en één na de zesde groepsbijeenkomst. De groep heeft acht deelnemers en wordt door één trainer geleid; bij twee bijeenkomsten is er ook een acteur en bij één bijeenkomst zijn er een bedrijfsarts en een arbeidsdeskundige als gastsprekers aanwezig. De training gaat uit van een driestappenplan. Eerst worden psychische, sociale en praktische knelpunten verhelderd, dan bespreekt de deelnemer deze op het werk, vervolgens worden oplossingen voor knelpunten bedacht en tracht men deze te realiseren. In ieder van de zeven groepsbijeenkomsten staat één onderwerp centraal: 1) waar heb je last van: de gevolgen van een chronische aandoening voor het werk, 2) zicht op jezelf: gevoelens en gedachten rond een chronische ziekte, 3) communicatie: oefenen met praktijksituaties, 4) praktische zaken: de bedrijfsarts, wetgeving en voorzieningen voor werknemers met een chronische ziekte, 5) communicatie en opkomen voor jezelf: vervolg en verdieping, 6) een plan van aanpak, 7) follow-up: wat werkt wel en wat werkt niet. De inclusiecriteria voor deelnemers aan de training en de effectstudie zijn: een chronische lichamelijke ziekte, een betaalde baan en het ervaren van werkgerelateerde problemen waardoor men bezorgd is het plezier in het werk of het werk zelf kwijt te raken. Langdurig volledig ziekteverzuim dat zich naar verwachting zal voortzetten gedurende de trainingsperiode is een exclusiecriterium. Deelnemers worden geworven via verschillende kanalen, waaronder poliklinieken, patiëntenverenigingen, arbodiensten en een aantal werkgevers. In totaal 64 deelnemers aan acht trainingsprogramma's worden vergeleken met 64 mensen die de training niet volgen. Allen vullen vragenlijsten in vóór aanvang van de training en na 4, 8, 12 en 24 maanden. De primaire uitkomstmaten zijn gepercipieerde persoonlijke effectiviteit in het omgaan met werkgerelateerde problemen, vermoeidheid, plezier in het werk en behoud van werk.

Hoofdstuk 7 presenteert de procesevaluatie van de uitvoering van de hierboven beschreven groepstraining en de mening van de deelnemers over de training. Acht trainingsprogramma's, gegeven door drie verschillende trainers en met in totaal 64 deelnemers, werden geëvalueerd. Dit gebeurde op basis van aantekeningen van de onderzoeker over de werving, proces-evaluatieformulieren die de trainers na afloop van iedere groepsbijeenkomst invulden en vragenlijsten die de deelnemers invulden. De werving van deelnemers kostte naar schatting 8-10 maanden fulltime werktijd voor één persoon. De werving via patiëntenverenigingen was het meest, die via poliklinieken het minst succesvol. Een reden voor de moeizame werving was volgens sommige bedrijfsartsen en andere medische professionals dat zij of anderen aarzelden om mensen te verwijzen naar een interventie waarvoor ze uitgeloot kunnen worden. De deelnemers aan de training waren gemiddeld 46 jaar en gemiddeld al tien jaar ziek. Mensen met aandoeningen aan het bewegingsapparaat, neurologische en darmaandoeningen vormden tweederde van de groep deelnemers. Vrouwen, hoger opgeleiden en werknemers in de dienstverlening waren oververtegenwoordigd. Drie deelnemers beëindigden het programma voortijdig, waarvan twee omdat zij ontevreden waren over het programma. Bij de groepsbijeenkomsten werden alle onderdelen die in de trainershandleiding beschreven waren behandeld. In een aantal situaties werd er minder tijd aan besteed dan gepland. De besproken onderwerpen waren over het algemeen voor de deelnemers goed te volgen, maar waren soms emotioneel belastend. Eén huiswerkopdracht, het aangaan van een gesprek met de leidinggevende, ontmoette volgens de trainers weerstand bij een aantal deelnemers. De deelnemers waardeerden het hele programma direct na afloop met gemiddeld een 8,1 op een schaal van 1 tot 10; twintig maanden later was de gemiddelde waardering 7,8. Onderwerpen die hoog scoorden waren 'inzicht in gevoelens en gedachten rond het hebben van een chronische ziekte' en 'communicatie en assertiviteit'. De uitwisseling van ervaringen en het rollenspel werden hoog gewaardeerd. De deelnemers ervoeren het vaakst effect in hoe ze zelf met hun ziekte omgaan, en het minste vaak wat betreft werkaanpassingen. Het overgrote deel vond dat het aangaan van een gesprek met de leidinggevende bijdroeg aan het oplossen van problemen op het werk. Na twee jaar meende 79% van de deelnemers dat de training een blijvend effect had.

Hoofdstuk 8 is een kwalitatieve studie naar de manier waarop de 72 deelnemers aan de trainingen inclusief de pilot training vormgaven aan empowerment. De training was opgezet als een driestappenplan: het verkennen en verhelderen van psychische, sociale en praktische werkgerelateerde problemen, het bespreken van een of meer problemen op het werk, en het bedenken en zien te realiseren van oplossingen. Wij, de onderzoekers en trainers, wilden graag weten hoe de deelnemers concreet met deze kwesties aan de gang gingen. Hiertoe reflecteerden we op wat de terugkerende thema's waren bij de deelnemers. Wij kwamen op zeven met elkaar samenhangende thema's. Deze zijn te benoemen als zeven opgaven waar de deelnemers zich voor gesteld zagen. Niet iedere deelnemer werd voor al deze opgaven gesteld, maar de meesten zagen zich wel voor meerdere opgaven gesteld als ze hun werk wilden volhouden. Deze zeven opgaven waren: 1) het ontwikkelen van een reëel toekomstperspectief, 2) zelfbewust voor jezelf opkomen, 3) goede relaties met collega's en de leidinggevende onderhouden, 4) kennis vergaren over mogelijkheden, rechten en plichten, 5) overleggen en onderhandelen over werkaanpassingen, 6) het werk organiseren op een manier dat het voldoening blijft geven, en 7) een sociaal leven buiten het werk overeind houden. In het artikel wordt ieder thema geïllustreerd aan de hand van korte casussen.

Hoofdstuk 9 beschrijft een gerandomiseerde gecontroleerde studie naar de effectiviteit van de in hoofdstuk 6 beschreven groepstraining. Deelnemers aan de studie moesten een betaalde baan hebben en een lichamelijke chronische ziekte waar ze in het werk problemen van ondervonden. Volledig ziekteverzuim waarvan te verwachten was dat dit gedurende de training zou voortduren vormde een exclusiecriterium. Op basis van een verwachte verbetering op de CIS vermoeidheidsschaal werd een steekproefgrootte van 128 als ruim voldoende verondersteld. De primaire uitkomstmaten waren persoonlijke effectiviteit, vermoeidheid, ontevredenheid over het werk en behoud van werk. Ontevredenheid over het werk en vermoeidheid zijn voorspellers voor verlies van werk. Secundaire uitkomstmaten waren werkgerelateerde problemen, ziekteverzuim, kwaliteit van leven, gerealiseerde werkaanpassingen, burnout en drie kwaliteit-van-werk maten. De deelnemers vulden bij aanvang, na 4, 8, 12 en 24 maanden een vragenlijst in. Continue uitkomstmaten werden geanalyseerd met 'two-way mixed between-within subject analysis of variance' ofwel 'repeated measurement' analyse. Van de 132 deelnemers die zich aanmeldden, de eerste vragenlijst invulden en terugstuurden werden er uiteindelijk

64 naar de experimentele groep en 58 naar de controlegroep gerandomiseerd; tien mensen vielen af vóór de start van de training. Drie deelnemers aan de training haakten halverwege het programma af. De uitval uit de studie bedroeg na 4, 8, 12 en 24 maanden respectievelijk 0, 3, 6 en 7 personen. Na twee jaar was de persoonlijke effectiviteit in de experimentele groep en de controlegroep toegenomen en in de experimentele groep significant meer dan in de controlegroep. Deze toename in de experimentele groep vond vooral in de eerste vier maanden plaats. De vermoeidheidsklachten waren in beide groepen afgenomen en in de experimentele groep significant meer dan in de controlegroep. De afname zette zich bij de experimentele groep tot aan het eind van het tweede jaar voort, maar bij de controlegroep stabiliseerde het klachtenniveau zich in het tweede jaar. De ontevredenheid met werk was in de experimentele groep afgenomen en in de controlegroep toegenomen, maar het verschil was niet significant. Van de secundaire uitkomstmaten bleek de psychische kwaliteit van leven significant meer verbeterd in de experimentele groep. Zowel in de experimentele groep als in de controlegroep hadden de meeste mensen na twee jaar hun werk behouden. Zestig procent van de controlegroep gaf aan dat zijzelf of anderen vanwege de indeling in de controlegroep activiteiten hadden ondernomen om de werkgerelateerde problemen op te lossen.

In **hoofdstuk 10** kijk ik terug op het hele onderzoeksproject. Uit de onderzoeken naar ervaren knelpunten bleek dat niet alleen fysieke of mentale beperkingen als gevolg van de ziekte problematisch kunnen zijn bij het uitvoeren van het werk, maar ook dat de aanpassing aan ziekte en beperkingen een opgave op zichzelf is. Mensen ervaren dat acceptatie belangrijk is en dat zelfmanagement, communicatie- en onderhandelingsvaardigheden en goede arbeidsverhoudingen essentieel zijn. Dan nog is het een kunst om de rol van werknemer te combineren met andere rollen. Overmatige vermoeidheid is het dominerende kenmerk bij een groot deel van de werknemers bij wie het werk niet vanzelf gaat. Het is dan ook de vraag of fulltime blijven werken haalbaar en wenselijk is voor iedereen.

Op basis van literatuuronderzoek naar arbeidsbegeleiding voor werknemers met een chronische ziekte ontwikkelden we een groepstraining. Deze werd in het kader van een gerandomiseerde gecontroleerde studie acht maal aangeboden aan 64 mensen in totaal. Uiteindelijk hebben 61 deelnemers de training afgerond. Gemiddeld was één van de acht deelnemers bij de groepsbijeenkomsten afwezig, meestal vanwege ziekte. De deelnemers beoordeelden de training meestal als effectief. In de effectiviteitstudie bleek dat de persoonlijke effectiviteit in de loop van twee jaar statistisch significant meer toenam in de experimentele groep. De vermoeidheid nam significant meer af. De maat ‘tevredenheid over het werk’ liet een onduidelijke uitkomst zien. De training bleek geen significant effect te hebben op behoud van werk, maar dat moet bezien worden tegen de achtergrond van het gegeven dat in beide groepen de meeste mensen hun werk behielden. Een onverwachte bevinding was dat veel mensen van de controlegroep gerichte acties ondernamen om werkgerelateerde problemen aan te pakken.

Meerdere meetmomenten en een lage non-response tot het eind toe zijn de sterke kanten van dit onderzoek. Dat relatief weinig mannen, lageropgeleiden en werkenden buiten de dienstensector aan het onderzoek deelnamen is een punt dat aangeeft dat de externe validiteit mogelijk beperkt is tot een vergelijkbare populatie. Daarnaast is het gegeven dat de controlegroep, vermoedelijk voor een deel op gedachten gebracht door de werving voor het project, aanwijsbare stappen ondernam om werkgerelateerde problemen op te lossen een aantasting van de interne validiteit. Een onderschatting van de effectiviteit van de onderzochte interventie is het waarschijnlijke gevolg. We weten niet hoe groot deze onderschatting is. Een ander onderzoeksdesign dan de RCT lijkt een betere optie voor interventies waarbij de werving bij de controlegroep en de omgeving daarvan leidt tot verhoogde motivatie om problemen aan te pakken. Een alternatief is een onderzoekssetting waarbij niet blinderen minder gevolgen heeft, bijvoorbeeld door een opzet in nauwere samenwerking met poliklinieken die het onderzoek mede als ‘hun’ onderzoek zien. Dit zou hen kunnen verhinderen om zelf extra acties te ondernemen voor mensen in de controlegroep.

Meer aandacht in de bedrijfsgeneeskunde voor psychische gevolgen van een chronische ziekte lijkt op zijn plaats. Het is belangrijk om met werknemers te bespreken wat een chronische ziekte voor hen betekent en te overleggen over wat zij als belemmeringen zien. Ook in de curatieve sector is aandacht voor de gevolgen van een chronische ziekte voor het werk van de patiënt op zijn plaats. Artsen en verpleegkundigen zijn vaak de eersten die zicht hebben op de consequenties van ziekte en kunnen deze met mensen bespreken, overleggen met de bedrijfsarts of verwijzen naar arbeidsbegeleiding. Het programma dat wij ontwikkelden lijkt effectief; meer onderzoek is echter op zijn plaats. Daarbij is het belangrijk te bedenken dat een goede begeleiding van de werknemer wel aan te bevelen maar nog niet genoeg is. Een leidinggevende die meedenkt met de werknemer en een werkgever die de leidinggevende de ruimte geeft om mee te denken zijn essentieel.

Dankwoord

Dit onderzoek werd mogelijk dankzij de medewerking van 122 werknemers met een chronische ziekte. Zij onderwierpen zich aan onze loting en vulden vijf maal een lange vragenlijst in. Ook de mensen in de controlegroep werkten vrijwel allemaal tot het eind van het onderzoek mee. Ik wil hen daarvoor hartelijk dank zeggen.

Frank, ik vond het een voorrecht en een genoegen om bij jou mijn promotieonderzoek uit te voeren. In het begin was het een project vol organisatorische obstakels. Ik heb nooit de deur dicht gevonden als ik er niet uitkwam en een en ander tegenzat. Het meedenken over de ontwikkeling van de training, het nadenken over theoretische concepten en interpretaties, de nauwgezetheid waarmee je mijn concepten las, ik heb het zeer gewaardeerd. Overleg met jou is stimulerend en gezellig.

Een nieuwe interventie evalueren betekent dat deze ontwikkeld en uitgevoerd moet worden. Gabe de Vries en Annelies Heutink brachten hun kennis en jarenlange trainerservaring in. Dit resulteerde in een goed doordachte handleiding en een cursusboek. Vervolgens werd de training uitgevoerd, door Annelies, Selma Landman en Kees Koning. Zij deden dit alle drie met een grote kundigheid en betrokkenheid, die niet alleen door de deelnemers maar ook door mij erg gewaardeerd is. Ook de gastsprekers bij onderdelen van de training wil ik bedanken. Jos Veldhuizen in de eerste plaats, voor zijn acteertalent als hij lastige situaties met de deelnemers oefende en hun liet zien hoe je met een andere houding je mogelijkheden bij andere mensen vergroot. Clasien Wiegerinck, Lynda van Cuilenburg en Anneke Stasse wil ik bedanken voor hun bereidheid op de praktische bedrijfsgeneeskundige en arbeidsdeskundige vragen van de deelnemers in te gaan.

Voor een dergelijk project moeten veel deelnemers geworven worden. Voor hun steun aan dit project en hun steun bij het werven van deelnemers, wil ik mijn dank uitspreken aan de Crohn en Colitis Ulcerosa Vereniging Nederland, de Reumapatiëntenbond, de Diabetes Vereniging Nederland, de MS Vereniging Nederland en de Parkinson Patiënten Vereniging.

Als de potentiële deelnemers dan belden om zich aan te melden, dan moest er iemand aan de telefoon zitten. Tilly Gelijsteen en Letty Tendole deden dat, de een als voorwacht en de ander als achterwacht en later omgekeerd. Aan de telefoon zitten betekende: weten waar het over gaat, vragen beantwoorden of naar mij doorspelen, gegevens opnemen en checken, bevestigingsbrieven versturen, afspraken voor de intake maken, en mij helpen herinneren aan dingen die ik dreigde te vergeten. Heel hartelijk dank voor het werk en de prettige wijze waarop we dit samen gedaan hebben.

Een RCT betekent vragenlijsten. Kopiëren, versturen, reminders, geschenkbonnen, vergeten bladzijden navragen en data invoeren. Karlijn van Beurden en Merel van Andel waren als onderzoeksassistent bij dit project betrokken. Zonder hen zat ik nu nog data in te voeren. Dank voor al dit werk.

Hoe dit project zich ontwikkelde bedachten we niet alleen binnen het Coronel Instituut. De begeleidingscommissie heeft vanaf het begin meegedacht over de opzet, de haalbaarheid en het nut van het geheel en voorzag ons van praktische en inhoudelijke adviezen. Henny Overbosch van het Ministerie van Sociale Zaken en Werkgelegenheid was vanaf het begin een warm pleitbezorger van het project. Jan Koopman van ArboUnie Amsterdam zette zich in om een praktische samenwerking met de ArboUnie mogelijk te maken. Wilma Hogers volgde hem in deze functie op. Kerst Zwart van Welder, voorheen het Breed Platform Verzekerden en Werk, kwam altijd kritisch uit de hoek en zag overal mogelijkheden tot samenwerking. Boudien Krol, voormalig collega-onderzoeker van het Universitair Medisch Centrum Groningen en vriendin sinds we daar 20 jaar geleden allebei werkten, bracht haar kennis van het onderzoeksveld in, wat ook resulteerde in een gezamenlijk artikel.

Als onderzoeker heb je feedback nodig. Die heb ik gekregen, van veel collega’s binnen het Coronel. Ik wil mijn collega’s hartelijk danken voor het kritische en opbouwende commentaar dat ik bij onderzoeksbesprekingen en in de wandelgangen kreeg.

Jos, je hebt aan twee artikelen meegewerkt. Bij de effectiviteitstudie heb je vanaf het begin meegedacht, literatuur aangeleverd, de analyses bekeken, en overbodigheden uit de discussie gehaald. Hulp van jou betekent afwisselend stevige kritiek en een hart onder de riem: ‘Niet zeuren, het glas is altijd half leeg bij jou!’ Hartelijk dank voor de samenwerking, en ik hoop je vaker als kamergenoot hier te zien.

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Eddy, dankjewel voor het toch weer leveren van een mooie voorkant voor dit boekje.

We naderen het thuisfront. De helft van mijn thuisfront zit in Leiden. Peter, ik ben blij dat je er bent. Niet alleen voor de leuke dingen buiten het werk, maar ook om je interesse in mijn onderzoek, je analytisch vermogen en de soepelheid waarmee je met mijn ‘werkdipjes’ omgaat. ‘Ik geloof dat je een tobberig typje bent’, zei je toen we elkaar nog niet zo lang kenden. Dat gaat vast niet over, laten we hopen dat het wat minder wordt.

Diederik en Sam, twee jongens thuis is een gezellige afleiding, ondanks ons gekrakeel zo nu en dan. Welke moeder heeft nu kinderen die geregeld vragen: ‘Hoe was het op je werk vandaag?’ Zelfs op zondag!