Empowerment of employees with a chronic disease
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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.
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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.
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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 effectiveness 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
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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
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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.
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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.