Empowerment of employees with a chronic disease
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Chapter 1

General introduction
Chapter 1

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)](attachment://Figure1.png)
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](image-url)
Chapter 1

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.

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References

Chapter 1


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