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 from 1972 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
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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.
Chapter 10

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. Aujojdat 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.

References

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