Building a self-management program for workers with a chronic somatic disease
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Chapter 7

A qualitative evaluation of the effects of a self-management program for workers with a chronic somatic disease

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Submitted
Abstract

Objective
To explore the effect of a vocational rehabilitation program for employees with a chronic somatic disease from a participant’s perspective. The training is based on the Chronic Disease Self-management Programme (CDSMP) of Stanford University. The objective of the training is to stimulate self-management behaviour and self-efficacy at the workplace.

Methods
Firstly, semi-structured interviews have been held at the beginning and after the training with 15 of the 17 participants who attended at least four of the six sessions of the program. Secondly, the brainstorm topics generated throughout the training have been collected. The data have been analyzed using content analysis.

Results
The intervention was perceived as acceptable and patients’ reported evidence of behavior change in several of the themes supported by the training. Findings suggest that the participants have gained more knowledge, awareness and self-efficacy in coping with the symptoms of their disease at the workplace. In addition, the communication with colleagues and employer improved for some participants and several behavioural changes were mentioned. Working with action plans and communication strategies were found useful by the participants as well as peer-support from the group.

Conclusion
The intervention seems to have supported participants to cope with their chronic disease at work. This study suggests that self-management training programs can help participants to cope with the consequences of their disease at the workplace.
7.1 Introduction

In 2007, 39 percent of the U.S. working age population had at least one chronic disease such as diabetes, asthma or depression. Prognostic studies predict an increase in the next twenty years of the incidence of chronic diseases like asthma, chronic obstructive pulmonary diseases (COPD), diabetes and rheumatoid arthritis (RA) among the working population.

Many people with chronic diseases are able to lead productive lives if supported to do so. However, a chronic disease, such as RA or COPD, has a multidimensional impact on peoples’ lives, which can result in limitations in performing activities of daily life and at work, and therefore in job loss or permanent work disability. In the Netherlands only one third of the people between the ages of 16 to 64 with a chronic disease has a paid job in comparison to two thirds of the general population. Despite improvements in facilities and medical care, thirty percent of the employees who have a chronic disease experience problems at the workplace related to the disease.

In the past, work disability was defined as result of a misfit between the capacity of the employee and the work demands. Nowadays the cause of work disability is conceptualized as reflecting a complex interaction between the characteristics of both the person and the (work)-environment. Recently, the idea is emerging that interventions to reduce work disability must focus on influencing the characteristics of the person as well as the workplace (supervisor and colleagues, material working conditions) and the (extended) family of the individual. In a systematic review Verbeek et al. propose to classify occupational health intervention programs intentions into three categories: 1) exposure change, 2) skills and behavior change, and 3) health status, disease and disability change. Most existing occupational health intervention programs are intended to change skills and behavior and are focused on empowerment at the workplace, like by acquiring psychological support, communication skills, training in requesting work accommodations and on stimulating feelings of self-confidence or self-efficacy in dealing with work-related problems.

Different studies based on the patient’s perspective provide information that employees with a chronic disease need to acquire empowerment skills to cope with the problems encountered at work because of their chronic disease. There is some evidence that occupational health interventions for employees with a chronic disease based on the empowerment perspective are effective.

There are several programs available for the empowerment of people with a chronic disease. One of the most frequently used programs is the Chronic Disease Self-Management Program of Stanford University (CDSMP) developed by Lorig et al in 2006. The CDSMP is an example of a lay-led health education program aimed at helping participants develop a range of skills and confidence to deal more effectively with their chronic conditions. A Cochrane review on the effectiveness of such self-management programs by lay leaders shows that these programs
can lead to short-term improvements in patients’ confidence to manage their condition and perceptions of their own health. There were also significant improvements in cognitive symptom management of pain, disability, fatigue and depression. The CDSMP has been shown to improve self-efficacy, self-management behavior and health status, while reducing hospitalization and emergency visits. The original CDSMP focuses on personal factors like lifestyle and disease-related factors like coping with symptoms of the disease. However this program does not include work-related factors such as self-management behavior at work. For this purpose, we adapted the original CDSMP to fit the needs of employees with a chronic disease. The process of adapting the intervention and the content of the intervention are explained elsewhere. In the adapted course we stimulate employees with a chronic disease to work on five core self-management skills: problem-solving; decision-making; resource utilization; forming a patient/health care provider partnership; and taking action through weekly action plans. The theoretical basis of the program is the theory of planned behavior. The techniques of the program, like for instance social-cognitive theory and goal-setting theory, have been chosen to influence the determinants of behavior. Furthermore, the interaction in self-help groups can lead to peer-support and social comparison between the participants.

The aim of this study is to explore in a qualitative way the motivation of participants to follow the course and the experiences of participants during the course. Qualitative research is useful to acquire information about the potential utility of behavioural science theories in health promotion interventions. This paper describes a qualitative analysis of the opinion of the respondents about the course, with a focus on their expectations (before the course) and the self-reported impact of the programme on the participants’ knowledge, attitude and self-efficacy at work (after the course). Through the interviews we try to gain insight in the mechanisms through which the intervention helps participants to cope with their disease at work. The results of this qualitative research are complementary to the results of a quantitative effect-evaluation which will be described elsewhere. Combining quantitative and qualitative methods is common in social research, although qualitative research is not usually used to explore the effects of an intervention. The use of qualitative methods alongside quantitative has resulted from the recognition that qualitative methods can make an important contribution to the results of randomised controlled trials (RCTs), evaluating complex health service interventions.

7.2 Methods

Qualitative study design
Two sets of qualitative data have been used. Firstly, semi-structured interviews have been carried out with the participants of the training. Participants were interviewed during the first week of the course and after the last session by a research assistant (TZ). Each interview was taped and transcribed. All the interviews were guided by a topic list (table 1). Semi-structured interviews have the following advantages: the fixed set of questions guide the
Qualitative evaluation

The interview questions (topic list) covered three main areas: a) problems caused by the chronic disease at work; b) the way participants did come in contact with the course and C) motivation to participate in the course and expectations of the course. Interviews were conducted face-to-face and digitally recorded. They ranged from forty-five to one and a half hours with an average duration of sixty minutes. Data was transcribed verbatim and transcripts coded using Maxqda qualitative analysis software. The main coding categories reflected the questions asked during the interview, with deeper level coding focusing on classification of interviewee contributions, as well as positive or negative stance towards topics raised.

Table 1. Topic list used in the interviews.

<table>
<thead>
<tr>
<th>Before the course:</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>- What is your chronic condition?</td>
<td></td>
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<tr>
<td>- How old are you?</td>
<td></td>
</tr>
<tr>
<td>- What is your occupation?</td>
<td></td>
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<tr>
<td>- What problems do you experience at work due to the chronic disease?</td>
<td></td>
</tr>
<tr>
<td>- What is your motivation for participating in this course?</td>
<td></td>
</tr>
<tr>
<td>- How did you come in contact with the course?</td>
<td></td>
</tr>
<tr>
<td>- What do you expect to learn in the course?</td>
<td></td>
</tr>
<tr>
<td>- What do you want to learn in the course?</td>
<td></td>
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<tr>
<td>- What is your idea of group sessions?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>After the course:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- What have you learned in the course?</td>
<td></td>
</tr>
<tr>
<td>- What is your opinion of the group sessions?</td>
<td></td>
</tr>
<tr>
<td>- Are you confident that your expectations can be achieved?</td>
<td></td>
</tr>
<tr>
<td>- How could the training be improved?</td>
<td></td>
</tr>
</tbody>
</table>

Secondly, the training included different (how many in each program/ course?) brainstorm sessions. We collected and analyzed the content of the topics generated during the brainstorm sessions related to the problems encountered at the workplace, possible solutions at the workplace and what has been learned in the course. The topics have been collected during six courses including 17 participants. Both sets of data has been analyzed using content analysis. 39

Data analysis
To ensure validity of categorization, all the transcribed interviews were independently examined by a research assistant, a senior researcher and the first author (SD) by using constant comparison derived from grounded theory techniques (GTM). 40 GTM is a systematic
generation of theory from data utilizing both inductive and deductive thinking. This involved an interactive process of data collection, coding and analysis. The data was analyzed using thematic content analysis in which outcomes reflect emerging trends in the data as evident from the prevalence of particular categories and the reiteration of particular points of view. A comprehensive list of themes and categories relating to the factors that interviewees perceived as important was drawn up. Disagreements were discussed and consensus regarding content and labeling of coding categories was reached between (SD and TZ). The conclusions drawn concerning the experiences and beliefs of the participants were checked by another researcher (YH).

**Recruitment participants en sample size**

All the participants who participated in the courses that started in March respectively May 2007 were invited to participate in the interviews. Two participants of the 17 participants did not complete the course and refused to be interviewed after the course. There is little guidance regarding exact sample sizes for qualitative research in the literature. Qualitative samples must be large enough to assure that most or all of the perceptions that might be important are covered. Charmaz[41] suggest that the aims of the study are the ultimate driver of the project design, and therefore the sample size.). If a researcher remains faithful to the principles of qualitative research, sample size should generally follow the concept of saturation.[42] An explorative study like this study might achieve saturation quickly. We have the advantage that the large majority of the participants of the training selected, participated in this study. On the contrary the disadvantage is that we could interview not more than 15 participants and that both respondents who stopped with the training refused to participate in the training.

**Intervention: self-management training for employees with a chronic disease**

The adapted chronic disease self-management program for employees consisted of six group sessions of two and a half hours. The content of the course has been described and presented elsewhere.[26] The main topics of the training are presented in table 2. The training is evaluated as well in a randomized controlled-trial (n=104). The results of the RCT are presented elsewhere (submitted). Participants for the course were recruited through companies, and through centres of general practitioners and occupational health services in the region of Arnhem and Nijmegen in the Netherlands. An information letter and leaflet of the course were sent to 82 companies, 88 general practitioners and 10 occupational health services in both municipalities. Also several advertisements have been placed in regional newspapers. The inclusion criteria to select participants for the course were: employees with a diagnosed chronic somatic disease, with a paid job at the moment of the course, who encounter problems at work because of their disease and who are motivated to follow the course. The exclusion criteria were: more than three months totally absent from work and fully work-disabled.
Table 2. Content of the self-management program for employees with a chronic disease.

<table>
<thead>
<tr>
<th>Timing</th>
<th>Lesson</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Week 1</strong></td>
<td><strong>Introduction</strong></td>
<td>- Overview and objectives of the course</td>
</tr>
<tr>
<td></td>
<td><strong>Importance of physical exercise</strong></td>
<td>- Objectives of the participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Inventarisation of problems encountered at work by the chronic disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Introduction to coping with symptoms by using guided imagery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- The importance of physical exercise for people with a chronic disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Introduction to making action plans</td>
</tr>
<tr>
<td><strong>Week 2</strong></td>
<td><strong>Coping with pain, fatigue and stress at work</strong></td>
<td>- When do pain and fatigue interfere with the ability to work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Which situations cause stress, pain or fatigue (at work)?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- How can one deal with stress, pain or fatigue (at work)?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Breathing exercises</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Introduction to cognitive symptom management</td>
</tr>
<tr>
<td><strong>Week 3</strong></td>
<td><strong>Importance of healthy nutrition</strong></td>
<td>- Introduction to healthy nutrition</td>
</tr>
<tr>
<td></td>
<td><strong>Problems encountered at work</strong></td>
<td>- The importance of healthy nutrition for people with a chronic disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Introduction to working with a chronic disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Introduction to the model of work load and work capacity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Solutions at the workplace</td>
</tr>
<tr>
<td><strong>Week 4</strong></td>
<td><strong>Communication techniques at the workplace</strong></td>
<td>- Communication techniques</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- How to communicate with supervisor and colleagues about the problems encountered at work</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- How to communicate with supervisor and colleagues about possible solutions at work</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- How to communicate with family and friends about the problems and possible solutions to combine work and home</td>
</tr>
<tr>
<td><strong>Week 5</strong></td>
<td><strong>Working together with occupational health professionals and HRM advisors</strong></td>
<td>- Working together with occupational health professionals and HRM advisors at work</td>
</tr>
<tr>
<td><strong>Week 6</strong></td>
<td><strong>Plans for the future</strong></td>
<td>- What has been accomplished the past six weeks?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- What have you learned in the course?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Formulating long-term plans</td>
</tr>
</tbody>
</table>
7.3 Results

Overview of participants

Fifteen people between the ages of 25 and 64 were interviewed. The participants had different chronic somatic diseases (table 3), two thirds were female. The participants who were interviewed had different types of occupations like mechanic, home care assistant, hospital nurse and teacher. The majority of the participants had a physical demanding work.

Table 3. Demographic variables of the population interviewed.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N=15</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (gender)</td>
<td>10</td>
<td>67%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>35-44</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>45-54</td>
<td>5</td>
<td>33%</td>
</tr>
<tr>
<td>55+</td>
<td>5</td>
<td>33%</td>
</tr>
<tr>
<td>Chronic disease (dominant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>4</td>
<td>26%</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Asthma</td>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>Inflammatory bowel disease</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
<td>12%</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Migraine</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Sector of economic activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education and training</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>Health care</td>
<td>4</td>
<td>26%</td>
</tr>
<tr>
<td>Industrial/energy/manufacturing</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>Retailing/distribution</td>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>33%</td>
</tr>
<tr>
<td>Middle</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>High</td>
<td>4</td>
<td>27%</td>
</tr>
</tbody>
</table>

* Educational levels; low = secondary school or lower vocational education, Middle = intermediate vocational education or high school, high = university level or college degree.

Interviews before the intervention

The quotations of the interviews before the course about the motivation of participants to follow the course have been arranged by the following main topics: a) problems caused by
Qualitative evaluation

the chronic disease at work; b) the way participants did come in contact with the course; and c) expectations of the course.

a) Problems related to the chronic disease at work

Even though participants have different chronic diseases in different stages of development, there are many similarities in the problems they encounter. Symptoms like pain, fatigue, loss of energy, concentration problems, negative feelings and breathing problems were mentioned by most of the participants, with the exception of pain for those with diabetes mellitus. Participants with diabetes mellitus had mostly problems related to virus infections and problems related to the regulation of insulin.

Although the participants have different types of jobs, they all acknowledge to encounter difficulties at work because of their chronic somatic disease, although their problems differ. Especially those participants with a heavy physical workload encounter problems at work due to pain, fatigue and loss of energy.

“What I can do today can be different tomorrow, I know that when I have had a busy day at work, I have to take it easier the next day.”

“I’m a mechanic (by profession). I used to be a program manager. Because of my fatigue I could not continue my job and now I have an office job.”

Other problems participants mention are psychological distress caused by limitations in work performance due to the disease. One participant mentioned having no private life after work. In the weekends the participant was not able to recover from the fatigue.

“At work people are not interested in the disease other people have and express this like ‘oh he again’. In those situations I would like to stand up for myself, I know that I can stand up for myself at work but I don’t do it enough.”

“At this moment I can’t cope with my work because of my asthma. At the end of the day I’m too tired to carry out my tasks. After work and in the weekends I just have to recover from work. This makes me feel depressed.”

b) The way participants did come in contact with the program

Most of the participants did not come up by themselves with the idea of taking the course. Information of the course was usually given by their supervisor, colleagues, relatives or friends. Most of the participants felt supported by their family and working environment to take the course.

“My wife read the information in the newspaper; she said it might be something for you.”
A small minority felt imposed to take the course, especially if the information was given to them by their supervisor. Some participants were asked by their supervisor to take the course in their own time. These participants felt ambivalent towards the support of their supervisor.

“My supervisor came with the information of the course. He said think about it, it might be something for you.”

“I felt that my supervisor expected me to take the course.”

c) Expectations of and confidence in the course
Most participants were motivated to take the course in order to learn how to cope with the symptoms and limitations of the disease. Most participants expect to learn in the training how to cope with symptoms like fatigue, pain and concentration problems at work but also at home. Other participants have mentioned that they would like to become aware of their lifestyle patterns and acquire the motivation to change unhealthy habits.

“I expect to learn how to cope with pain, the moment it occurs and that I know how to cope with pain at home and at work.”

“I would like to become conscious of my behaviour and I can’t motivate myself to change my eating habits and other (bad) habits at work.”

Some participants would like to learn to stand up for themselves and feel better about themselves. Other participants mention that they are conscious that they need to change certain lifestyle habits which could affect their disease. Most participants are confident that they will learn something in the course.

“I hope to feel better about myself, to cope emotionally with my illness.”

“My motivation for the course is to learn more about myself, especially what I’m able and not able to do.”

“I have a lot of confidence in the course. My colleague will take the course too and it is so special to see how he opens up to me now about his illness.”

Some participants have no clear expectations at the beginning of the course and one participant is concerned about the diversity of the group and the diversity of topics in the training which might make the training superficial.

“I do not know what to expect from the course. We have just started.”

“There are a lot of different themes in the course and one should take care that the programme does not become superficial especially with the theme work.”
Interviews after the course

The quotations of the interviews after the course about the experiences of participants during the course have been categorized by the following four topics: a) what has been learned in the course; b) experience with group meetings; c) what would they tell to other people with a chronic disease about the course; and d) recommendations / points of criticism.

a) What have you learned in the training and what has changed because of the training?

Most participants report to have accepted the chronic disease because of the course. The acceptation of the disease is associated with the limitations caused by the disease. Participants mention that they have accepted their disease and become more aware of their limitations and as a consequence how far they can go.

“The course has helped me to accept that I have a chronic disease and the idea that I don’t want to be sick. I should also say “no” more often.”

“In the course I have learned to accept my disease and to know how far I can go. I have also learned to come up for myself.”

Some participants have also learned to accept their limitations and to put their limitations in perspective.

“I have become more relaxed at work. I used to defend myself for not being able to do certain tasks at work and I also felt very guilty. Now I think, well I can’t do some tasks but I can do other tasks and my boss and colleagues should accept that. This is an important profit of the course.”

“Before the course I used to be very depressed. Now I realize that other people have much more problems because of their chronic disease than me.”

Participants also mention that they have learned in the training to focus on the activities they can do instead of what they cannot do.

“Before the course I used to focus on the things I could not do anymore, now I focus on the things I can do.”

Coping with symptoms like fatigue and negative feelings

Most participants reported to have gained new knowledge of self management skills to cope with the limitations of the disease. Breathing techniques and relaxation techniques have been practiced throughout the course by a majority of the participants through the action plans. These techniques did not seem to work for everyone, but a majority of the participants tried the techniques at home to evaluate their effectiveness.
“I cope with the disease now through relaxation techniques and I learned to plan my activities better. I feel much better. Before the course I used to be very tired in the evenings after a working day. Now I can stay up longer.”

“Before the course I used to have problems falling asleep, but now I sleep well. Everything is related to each other.”

**Lifestyle**

Some participants have mentioned in the interviews that the training has helped the participants plan their exercises and to sport on a regular basis. Through the training they have gained more consciousness about their physical exercise behaviour.

“The course has put me back on track again, especially with sports but also with breathing and relaxation techniques. Because of the course I realize if I don’t do my exercises now I will have a problem later.”

“The course has not changed my perspective of the future but I have become more conscious that I have to plan my physical exercises. I am so busy with other things that I forget to do my physical exercise. When I plan it, I do them!”

Some participants mention that in the course they have learned to plan their physical exercise and start with smaller goals in order to commit themselves to it. Participants mention in the interviews that the actions plans effectively contributed to changing their behaviour.

“Because of the course I now step five minutes three times a week and this goes very well. Before the course I thought that I had to step for fifteen minutes like the doctor said but the course made me realize that five minutes is better than nothing. If I continue like this I will reach the fifteen minutes a day!”

**Communication with colleagues and supervisor**

Participants have learned in the course to communicate about the perceived limits of the disease with their working social environment and to do so in a more direct manner.

"I can now communicate in a different manner without hurting others feelings or accusing other people. It has helped me to communicate with colleagues. Now I can say no in a different and easier way."

“If I am too sick to go to work or feel sick at work, I communicate this with my boss and colleagues so that they can find a solution for my tasks. I have learned to do this. I have a lot more energy now.”
“I have learned to communicate in a direct manner. Through the action plans I have succeeded to make two appointments with my supervisor to talk about the disease.”
“The action plans have also helped me to communicate with my colleagues about my disease. I feel much more relaxed now.”

**Perceived social support:**
Most participants pointed out that the training has helped them to achieve more social support and helped them to communicate better about their disease with colleagues and employer but also with their family members and with health professionals.

“I feel much more support from my boss, colleagues and family. They all ask me now how the course was and what I have learned this week.”

“I have much more support from my husband and my children. I have rheumatoid arthritis in my hands and in the course I have learned that it’s OK to ask for help when needed. My husband and children support me in the household now.”

“I used to feel alone when going to the rheumatologist. Because of the course I realize that we work on the same problem together.”

**Planning of tasks at work**
Participants reported to have learned how to plan and prioritize their tasks at work. This has helped participants to cope better with their disease at work.

“I have gained a lot more regularity in my work. I have achieved this by planning my work better and to make better agreements at work with other people. I also oblige myself now to stick to the agenda. If tasks are too big to carry them out at once I make several tasks out of one task making it easier for myself to accomplish. By planning my work, I have a better overview and makes my work easier to handle.”

**b) Experience with group meetings**
Most participants report the group meetings as beneficial. Some participants have mentioned that in the training they have learned to think in terms of possibilities. Participants appreciate learning from others and to hear the experiences of others. Listening to other people’s stories helps participants realize that they are not alone. Group meetings can also help participants to put their problems into perspective by social comparison as there are always other people in the group who are in a worse position.
“I like to hear the experiences of other people and then I say to myself look, my disease or situation is not as bad as that of other people. Look at all the things I can still do!”

“I liked the fact that there were people in the group with different diseases. I used to think that other diseases were not as bad as mine, but now I realize the opposite.”

“I liked the group training. Most people feel alone at work with a chronic disease, but possibly also at home. Within this group you realize that you are not alone. The group support makes one stronger!”

c) What would you tell other people with a chronic disease about the course?

Some participants define self-management as the fact that one has to accomplish the actions oneself and one is responsible for his/her own actions. Some participants comment in the interviews that the action plans are a good method to encourage people to work on certain behavioural goals. The action plans make it possible to operationalize long-term goals into short-term goals.

“You have to do a lot of the work yourself. If you are not open to the idea of working on yourself you should not take the course. That is part of self-management! No one tells you how to do it!”

“I would recommend the course to everyone who has a chronic disease! The action plans are great!”

“I liked making the action plans, because you have to accomplish the actions yourself!”

“The course has encouraged me and supported me to work on my future.”

“Even my colleague walked around with such depressive feelings which I found very special. He had never spoken to me about it before. After the first time on the way back from the training he simply told me. That is the profit from this training.”

d) Recommendations / points of criticism

During the interviews, some comments on the training emerged. Some participants found the handbook difficult to follow during the course as the content of the handbook did not correspond exactly with the content of the course. One of the participants expected more open discussions in the training and did not appreciate that trainers followed the protocol of the course. One person with diabetes mellitus expected to learn specific information about
coping with diabetes, most themes did not apply to her situation. Some participants found the training too short and the group too small to be able to learn from each other.

“The handbook for the participants should include an index so that one can find the information quicker during the training.”

“I did not like the way that the trainers strictly followed the protocol of the course; I expected more open discussions in the training.”

“I found the training too short. In six weeks it is impossible to address all topics deeply.”

“I expected to learn more about coping with my diabetes. A person with diabetes does not feel pain or fatigue so most themes did not apply to my situation.”

“The group was too small, I would have appreciated if the group was larger as one learns from the experiences of others.”

Results brainstorm topics during the course
Table 4 presents the list of brainstorm topics assembled during the courses, divided in: 1) problems encountered at work; 2) solutions to deal or cope with these problems; and 3) tools for self-management the participants learned to use during the course. The problems encountered at the workplace can be summarized as a perceived lack of understanding and support from colleagues and supervisor. Furthermore participants perceive that they have to solve all the problems by themselves and that they are very much influenced by the problems at the workplace. The solutions offered in the brainstorm sessions can be summarized as to communicate more with colleagues and supervisor in order to create social support at the workplace. Another solution offered is to be aware of limitations and to communicate limitations and own boundaries at the workplace. Another suggestion was to arrange tasks at work in a different manner in order to be able to cope with the workload.

7.4 Discussion

This qualitative study from the participant’s perspective suggests that the adapted CDSMP for employees has in general resulted in positive effects on the employee’s working life and well-being. Some participants seem to have achieved more awareness about the limitations caused by the chronic disease and possible solutions to deal with the limitations at the workplace. Improvements in awareness and behaviour have occurred in the field of lifestyle, coping with symptoms such as fatigue and psychological distress because of work limitations. Some participants have mentioned that they experienced more tranquillity, felt less fatigued, felt less guilty and could communicate better their limitations to colleagues and superiors. There is more regularity and structure applied in the workplace and the communication with
the worker’s employer and colleagues has improved. Working with action plans was found useful and effective. The group meetings provided a feeling of togetherness and helped to place problems into perspective. Participants would recommend the course to others. The problems at work in this population seem to be caused for a large part by psychological distress caused by perceived limitations in work performance due to the disease, a finding similar to those in the study of Munir. Limitations like depression and musculoskeletal pain have been associated with work-related sickness absence in employees with a chronic disease. The results of this study are supported by other qualitative studies on the effects of self-management programs not including work problems, were a wide range of results have been found like for example an increase in knowledge on how to manage the disease, an increase in self-management skills, behavioural changes and improvement in psychosocial coping. A study on self-management of employees with a chronic disease has found that self-disclosure at the workplace can be perceived as a behavior strategy to access work support and adjustments. Self-disclosure is directly or indirectly related to self-efficacy.

The vision and changes mentioned in the interviews could be related to the objective and content of the program that aimed to increase self-management behaviour at work. Participants mention in the interviews that the action plans have helped them to change their behaviour. According to Schweiger et al. action plans support individuals to translate goals or intentions into specific actions. In the interviews the participants mentioned that they appreciated the social support in the group sessions much. Social comparison and peer-support are effective techniques to enhance self-management of a chronic disease. Qualitative methods are useful in giving insight to individual experiences and make it possible to link these experiences to more theoretically based concepts of the intervention. Even though the results of the interviews are promising and give insight in the possible mechanisms of the training, the results cannot replace an quantitative effect-evaluation. Nevertheless even though the interviews have been carried out by a research assistant participants may have felt that they had to give socially desirable answers. The results of the interviews need to be taken with caution as the results are based on a specific sample. Another point of concern is the effects of the program on the long-term. Interventions can lead in the short-term to more perceived self-efficacy and social support while participants are still in the training. Some of the main disadvantages we can associate with the use of semi-structured interviews include participant bias, interviewer bias and the reliability of any data generated during the course of the interview. Like in focus groups the interviewer needs to be aware of his or her responses and comments to the respondent so as not to bias the responses given. Reliability is a concern with qualitative research in general and an interviewer needs to be conscious of how data is gathered during the conduct of the interview. Family members, colleagues and superiors are inclined to be interested in the well-being of the person during and just after the training. We can not conclude from this evaluation what the long-term effects are on the levels of perceived social support and self-efficacy. For this purpose, a longitudinal study is needed following the participants, a half, one or two years, depending on the outcomes taken and preferably with a study on a larger scale. In general, skills-based programs like the CDSMP seem to be effective in the long-term, in contrast to programs only based on peer-support.
Table 4. Topics raised during brainstorm sessions in the self-management program.

Which problems do you encounter at work?:
- To be lived by others
- Not to take own importance into account
- Taking problems over at work
- Colleagues and boss are too individualistic
- No commitments/ no good appointments with others at work
- No solidarity at work
- To be too much influenced by processes at work
- Colleagues and boss don’t understand my illness

Which solutions are needed at the workplace?
- To create support
- To create commitment from the people around you
- To communicate more with boss and colleagues
- To think ‘together we stand stronger’
- To share problems encountered at work
- To prioritize tasks
- To be aware when you are lived by others and say “not now” to them.
- To take enough breaks at work
- Avoid being carried away by other people’s problems

Which tools for self-management at work have you learned in the CDSMP?
- To make action plans
- To be aware of problems and solutions
- To consciously convert knowledge into actions
- Not being alone and not having to do it alone
- To accept that I have an illness
- To express emotions and thoughts better
- To put things into perspective
- To be aware that I am not my illness
- To listen to other people
- To use techniques to cope with the illness
- To use meditation in order to cope with pain
- To use breathing techniques
- To relax more
- To communicate using the I form with colleagues, boss, family and friends
- To sport more / to stay fit in order to cope with chronic disease
- To not worry about work at home in the weekends
- To structure and plan work
- To feel less guilty towards colleagues and boss

Another point for consideration is the impact of organizational factors like for instance company policy and culture on the effectiveness of an intervention. More research is needed about the adoption and implementation of the program in different contextual settings as this is one of the common problems that have been associated with the failure of self-management program implementation. A possible limitation of the study design is the use
of semi-structured interviews. The questions used were both structured and open-ended in order to direct the focus of the interview and at the same time allow each subject to reveal issues that mattered to them. The semi-structured format with guided questions prevented the interviews from becoming too long, but it may have inhibited subjects from revealing themes that this study did not identify like negative consequences of the program. Two participants refused to participate in the interviews; as both did not finish the course, it would have been relevant to know why they stopped prematurely. Interviews with these drop-outs could have provided extra information about which participants may well or not benefit from a self-management group intervention.

Another possible point of concern is that it remains unclear whether the effects of the training are positive from the employer’s and colleague’s perspective. One of the participants mentioned to have learned “not to take work home so often”. Other participants stated that they have to say “no” more often at work. Even though this is not a topic of the course, it might be a result of gaining more awareness of the limitations caused by the disease and possible solutions. A high level of self-efficacy to cope with the disease at work might in the short-term have a negative influence on work-performance and might have negative effects from the perspective of employer and colleagues. It is expected however that on the long-term a higher level of self-efficacy leads to less sickness absence and possibly a higher quality of work performance of the tasks that the employee can carry out. The CDSMP was designed to mainly improve self-efficacy, which has been proven to be an important mechanism to improve health status and work performance. A study by Boot et al. found out that employees who ignore their limits and postpone their sick leave, risk overloading and increase the risk of a longer period of sick leave. A study by Stajovic et al. has found a positive relation between self-efficacy, internal attributions (when to succeed) and work-performance. For example employees who fail to perform certain tasks will achieve lower levels of self-efficacy at work if they attribute performance failures to internal causes. Based on these findings, more research is needed on the relation between self-efficacy to manage a chronic disease at work and work performance, taking into account the impact of sometimes not easy to detect contextual factors like the culture at work, type of work accommodations available and the kind of work. We conclude that a self-management intervention seems to activate self-efficacy and perceived social support in the individual and to improve the communication with the social environment at work. Self-management programs seem to help participants cope with the perceived limitations of a chronic disease.

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7.5 References


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