Building a self-management program for workers with a chronic somatic disease
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Chapter 9

General discussion
Chapter 9

9.1 Introduction

The first aim of this thesis was to develop a short self-management program for workers with a chronic somatic disease aimed at helping workers cope with their disease at work to support long-term job retention and well functioning at work. The basis of the self-management program for workers is the validated Chronic Disease Self-Management Program (CDSMP) of Stanford University. The original 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, focusing on personal factors like for instance lifestyle and coping with symptoms of the disease. The CDSMP has shown to improve self-efficacy, self-management behavior and health status, while reducing hospitalization and emergency visits. As the original program does not include work-related factors such as self-management behavior at work, it does not fit entirely the needs of workers with a chronic somatic disease. In this thesis intervention mapping (IM) was used to adjust the original CDSMP to be more appropriate for workers with a chronic somatic disease, taking into account the work context. Through concept mapping sessions with workers with a chronic somatic disease and health professionals, and a literature review, information has been gathered to be able to construct a CDSMP for work program. The second aim of this study was to evaluate the effectiveness of the adapted program. The modified program, CDSMP for work, focuses on skills and behavior change by improving participants’ action planning activity, self-efficacy and self-regulatory capabilities as well as influencing their attitude and risk perceptions at work. Until now, the CDSMP has not been tested on work-related outcomes, but only on disease-related outcomes. Therefore, and also because we modified the original program, the usefulness and effectiveness of the CDSMP for work program must be investigated before eventually implementing this program in occupational health care in the Netherlands and elsewhere.

The present thesis describes the following research questions: 1) Which problems at work are encountered by workers with a chronic somatic disease? (chapter 2-4); 2) Which solutions are possibly needed for or have to be achieved by workers with a chronic somatic disease to be able to function well at work? (chapter 2-4); 3) Which prognostic factors for work disability are common for different chronic somatic diseases? (chapter 5); 4) Does the CDSMP fit well to approach the problems of workers with a chronic somatic disease, and which adaptations are needed to tailor the intervention for workers with a chronic somatic disease? (chapter 6); 5) Does the CDSMP for work produce the intended outcome on the expected process and impact variables as described in the CDSMP for work model? (chapter 8); and 6) From the workers’ perspective: which elements of the training have been positively and negatively evaluated by the participants? (chapter 7).

The main findings of the studies described in this thesis will now be summarized and discussed. Secondly some methodological considerations, discussions of the results and practical considerations for the future will be addressed.
9.2 Main findings

1) Which problems are encountered by workers with a chronic somatic disease during work? (chapter 2-4)

The results of the concept mapping studies among workers with rheumatoid arthritis, hearing loss and diabetes mellitus, as well as among committed professionals, reflect that workers with a chronic somatic disease encounter a variety of problems at the workplace because of the chronic disease. The problems mentioned were: a misbalance between work demands and the work capacity of the worker, not enough work facilities or work accommodations to be able to cope with the disease, a lack of knowledge about the disease and of skills to be able to handle the disease at work, and insufficient knowledge of facilities and benefits to be able to request work accommodations. The problems mentioned by the workers with the three different diseases were rated differently but the topics mentioned showed many similarities.

2) Which solutions are possibly needed for workers with a chronic somatic disease to stay at work? (chapter 2-4)

The following seven common necessities to be able to function well at work were identified by the workers with a chronic somatic disease: ability to cope with the illness, support of medical professionals, support of management, support of colleagues, support of society and patient organizations, appropriate work conditions, and adequate facilities and benefits. Even though the priority ratings of certain necessities varied between the different patient groups, they all need to be taken into consideration to provide adequate health care. Currently there are hardly any instruments that can be used by health professionals to identify disease-related problems at work. Therefore, on the basis of the results i.e. the common themes as found in chapter 2, a topic list was developed that can help health care professionals to explore work-related problems more effectively in their consultations with patients with a chronic somatic disease.

3) Which prognostic factors for work disability are common for different chronic somatic diseases? (chapter 5)

On the basis of a systematic review restricted to prospective and retrospective cohort studies, we examined common prognostic factors for work disability among workers with a chronic somatic disease. We selected as good examples for such diseases: rheumatoid arthritis, asthma, chronic obstructive pulmonary disease, diabetes mellitus and ischemic heart disease. Many prognostic factors for work disability were found to be common among the different groups of workers. In short, health professionals have to pay special attention to: (i) workers with a high level of perceived health complaints due to the disease; (ii) workers with disease-specific impaired body functions and mental health impairments, such as pain and swollen/deformed joints in rheumatoid arthritis and depression in ischemic heart disease; and (iii)
workers with daily physical limitations caused by the disease. Special consideration for older workers, women, blue-collar workers and low-educated workers is needed as well. This information can be used in the development and implementation of a generic return to work, or retain of work intervention for workers with a chronic somatic disease. In addition, in the development of a disease-specific intervention e.g. for multiple sclerosis, disease-specific evidence has to be added when available, in this case prognostic factors specific for multiple sclerosis.

4) Does the CDSMP fit well to approach the problems of workers with a chronic somatic disease, and which adaptations are needed to tailor the intervention for workers with a chronic somatic disease? (chapter 6)

The CDSMP has been chosen to be the basis of the self-management program for workers with a chronic somatic disease, as many problems and solutions mentioned in the concept mapping studies with workers and health care professionals, and the prognostic factors found in the literature for work disability are already dealt with in this program. The method of intervention mapping was used to tailor the original CDSMP to be used for workers with a chronic somatic disease, oriented on the work setting. In the first step of intervention mapping (the needs-assessment) we used the results of the concept mapping study and systematic literature review. The aim of the CDSMP for work is to influence the determinants of behavior: the attitude, social influence and self-efficacy of the participants in order to improve self-management at work in the long-term. Different techniques for behavioral change have been used in the self-management program like for example consciousness raising (belief selection, decisional balance), enhancing self-efficacy and social support, skill mastery, goal setting and persuasion of positive outcomes. The method of intervention mapping seemed to be a useful tool to adjust the original CDSMP for workers with a chronic somatic disease.

5) Does the CDSMP for work produce the intended effect on the expected process and impact variables as described in the CDSMP for work model? (chapter 8)

The CDSMP for work has shown to partly produce the expected effects as hypothesized in the CDSMP for work model. At 8-month follow-up, we found a higher score on attitude towards self-management at work for the intervention group (enjoyment) compared with the control group (p=0.030) when controlling for gender, age, occupation and baseline level. Low educated workers in the intervention group improved on the physical quality of health scale after 8 months. The attitude towards self-management at work (importance) improved in the intervention group for older workers and female workers. The results suggest that low educated workers, older workers and women benefit significantly more from the training than higher educated workers, younger workers and men. The results can have practical implications for the selection of patients to be referred to this training. Alternatively, the findings may lead to adaptations of the intervention itself to fit better with the needs of a variety of individuals and groups.
6) From the worker’s point of perspective: which elements of the CDSMP for work have been positively and negatively evaluated by the participants? (chapter 7)

Through semi-structured interviews with the participants of the training we evaluated from the participants’ perspective which parts of the training have been effective and what the effects of the training were in their opinion. The 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 (supervisor, manager) improved and several behavioural changes were mentioned. Working with action plans and communication strategies were found most useful by the participants as well as peer-support from the group. The intervention supported participants to cope with their chronic disease at work.

9.3 Methodological Considerations

Construction of the intervention

In this study the method of intervention mapping (IM) was used to adjust the original CDSMP for workers with a chronic somatic disease. In the first step of intervention mapping (the needs-assessment) we used the results of the concept mapping study and systematic literature review. The method of intervention mapping was useful in providing specific determinants of behavior that were addressed in the new intervention and specific techniques to influence a particular determinant, that we used in the development of the new program. The aim of the intervention was to influence self-management at work, for example improving the competence to ask for support from the colleagues, supervisor or manager to acquire working accommodations, to accept the disease and to cope with the disease at work. The training was aimed at the knowledge, attitude and self-efficacy of the worker. One of our hypotheses is that a self-management program can influence the behavior of the worker so that in the long-term the worker can acquire the accommodations and support he or she needs to be able to function well at work. Nevertheless a limit of the self-management program is that even though the worker may acquire a proactive attitude and behavior through the course, the work environment cannot be influenced directly by the intervention. The worker may therefore still not obtain the work accommodations or social support he/or she needs in order to cope at work.

Another limitation of this study is that the vision of HRM advisors and supervisors has not been taken into account when constructing the intervention. It should be considered in the future to discuss the content of the training with committed supervisors, managers and HRM professionals as they may give insight to other topics for the training and might place the training in a different perspective. Also in the future it should be considered to involve supervisors, managers and owners of small and medium-sized companies in activities of the program. There are different options. To begin with, the course leader could inform the supervisor, after prior informed consent of the employee, that one of his or her employees
is involved in the training and send him or her information about the training. Secondly, the supervisor or manager could be approached and motivated to play a substantial role for a specific employee in providing follow-up care after the training. However, privacy aspects should be carefully protected and of course prior informed consent of the employee is essential. A third option could be to organize a general information session for supervisors and managers in a company or working in a specific sector such as the healthcare or construction sector, on how to support workers with a chronic disease better. This session should not focus on specific employees or supervisors.

**Internal validity**

We have chosen to discuss here the internal validity of drawing causal inferences about the intervention in the randomized controlled trial study. The most common threats to internal validity in this study are a regressive fallacy, a possible contamination of the control group, insufficient validity of the self-efficacy assessment instrument used, and flaws in the interpretation of the results. Firstly a limitation of our study could be the regressive fallacy. The control group has just like the experimental group improved on the scale self-efficacy. The parallel improvement on the self-efficacy scale is presumably related to a phenomenon often observed in health conditions that vary over time with ups and downs, that is also often present in chronic medical conditions: the regressive fallacy. People will look out for interventions when they are feeling at their worst and will improve as a consequence. But also due to more ‘spontaneous’ variations in health and other conditions described as “regression to the mean”, their condition will improve with time when people are at first selected on having a high level of problems. Some health problems might cure spontaneously or disappear also leading to the regressive fallacy mentioned earlier.

Another limitation of this study can be the contamination of the control group through reactivity to the measurement used in the study. The control group has filled in the questionnaire twice which might have caused workers in the control group to score better on the scale self-efficacy after 8 months. Due to reactivity of measurement, workers in the control group could have become more conscious of the self-management behavior associated with a chronic disease. As a consequence, they might have adopted self-management behavior more often at work, and this might have led to an improvement on the self-efficacy scale. Another phenomenon that might lead to an improvement of the control group is the use of care as usual in the Netherlands which is rather well-developed. This is not a contamination of the control group but a well-developed health care system nevertheless might decrease the contrast between both study groups and so interfere with the results of the study.

Insufficient validity of the self-efficacy assessment instrument used can also be a threat for the internal validity of the study. In the scope of this study we have not found any results on the outcome self-efficacy at work. In previous studies on the CDSMP carried out by Lorig et al.\(^3\) a positive effect has been found between the program and self-efficacy to manage the disease in general. Although Lorig et al. have developed different self-efficacy scales like the
‘Sample questionnaire for the chronic disease self-management program-2006’ in our study we decided not to use these as the scales do not include items on self-efficacy at work. At the beginning of our intervention study in 2006 there were no validated self-efficacy at work scales available. We considered to use the General Self-Efficacy Scale as this scale has been validated in the Netherlands. But considering that Elzen et al. 2008 found no results with this scale while testing the CDSMP in the Netherlands and that the questionnaire focuses on the general self-efficacy of the person and not self-efficacy in the context of work we decided not to use this questionnaire. For these reasons we have constructed our own ‘self-efficacy at work’ questionnaire based on the results of the concept mapping study with workers and health professionals and using information on the construction of questionnaires based on the ASE model. In the scope of this study it was not possible to validate the self-efficacy scale with a factor analysis as the group was too small. Nevertheless the internal consistency of the scale was found to be good (Cronbach’s alpha of 0.8). Until now still no validated self-efficacy at work questionnaire for workers with a chronic disease exists.

Caution is necessary in interpreting the current analyses, as a relatively large number of outcome variables were tested in a small group. The randomized controlled trial was not powered on all the predictor outcomes and the effect sizes could not be calculated for all the primary outcome measures, but were estimated based on similar studies using the same primary outcome. The limited number of participants in the trial may also have led to a type 2 error (false negative) for the physical component score of health-related quality of life scale in the complete study population (SF-12) (p=0.052). This means that the null hypothesis, in this case there is no difference between the experimental group and the control group, is accepted incorrectly while there could be a true difference: the randomized controlled trial failed to reject the null hypothesis. Many intervention studies in the behavioral and social sciences are willing to accept an alpha-level of 0.10 as significant to prevent the chance of making a type 2 error. Also in most articles based by Lorig et al. the results of the CDSMP are presented with an alpha-level of 0.10. Because we used an alpha level of 0.05 we may have been too rigid for such a small group.

Another limitation for the internal validity of the study might be the short follow-up time (8 months). A longer follow-up period might have resulted in a more adequate evaluation of the program effectiveness. The fact that the attitude improved after 8 months is promising. Probably it takes longer to detect a response shift in the self-efficacy experience and in the behavior of workers with a chronic somatic disease. Other CDSMP studies had measurement moments ranging from six months to two years. It is possible that a period of six months was too short for the program to be effective and to observe improvements in this study population. Varekamp et al. also only found significant effects on self-efficacy after 24 months.
External validity

The external validity addresses how generalizable the study’s inferences are to other populations of workers or patients. Among the most common restrictions or considerations regarding the external validity are the type of research design and the aptitude-treatment interaction. Randomized trials are rightly considered to be the most robust method of assessing the effectiveness of health care innovations. By randomly assigning participants, researchers try to assure that there is no bias stemming from this part of the selection process. Randomized trials estimate the impact of an intervention through direct comparison with a randomly allocated control group that receives either care as usual (often erroneously described or considered as ‘no intervention’) or an purposely applied alternative intervention. The randomization process tries to ensure that, both known and unknown causal or confounding factors are distributed evenly between the trial groups. In this study a non-treatment care as usual control group was formed. However, in intervention studies located in practice, i.e. in the real world, it is not possible to apply a perfect experimental design. People often know that they are being monitored and evaluated for specific purposes which can influence the results. The participants who have not been selected for the experimental group but need help, might often look more actively for other interventions or similar trainings to attend, as an unwanted side effect of the study design. Specially in situations where persons in the control condition have plenty opportunities to strive for alternative solutions, this phenomenon can be a part of a realistic scenario. A possibility to overcome this phenomenon of raising awareness in the control group by the type of study design is the use of a pre-randomization design, i.e. randomization before seeking informed consent, so avoiding (partly) the unwanted raising of awareness in the control group. Still, process and outcome measurements such as the use of a questionnaire, can have a contaminating influence on the control group as has been mentioned earlier.

In the Netherlands, prerandomisation designs are becoming more accepted since the Dutch State Secretary of Health, Welfare and Sport decided that, under certain circumstances, prerandomization is admissible and not in conflict with the law. In health promotion, even though health promotion activities hardly result in adverse health outcomes, the ethical discussion is still present of not informing patients about the positive and negative consequences of an intervention. However, in our intervention study, as we were dependent of the motivation of participants to participate in the study using e.g. advertisements in newspapers, pre-randomization was not possible. In general, pre-randomization may be an alternative in cases where the control group might threaten the interval validity. One variant of this option is that only the experimental group is asked for informed consent. Another variation is that the control group gives consent for research but is unaware of the existence of an experimental group. Pre-randomization is feasible if a researcher for instance could use the patients from an outpatient’s department as the study population. More discussion and research is needed on the use and the effect of pre-randomization in intervention studies.

Another comment to the external validity in intervention studies is the selection of the population that has been studied. One of the most relevant aspects to consider is the
aptitude-treatment interaction. The workers that applied for the program formed a selected group as they could only participate if they were motivated to participate in the training group. Inevitably, this type of training attracts people already more or less motivated to keep on working by themselves. Also most participants of our training were women and worked in the education and health sector. Another issue for consideration is that the training might fit better with the preferences of these workers. More effort is needed to make the training more attractive for men and possibly for workers from other sectors.

Other selection processes are discussed in chapter 7. For example it might be possible that group discussions and training are less attractive for men compared with women. As the training was given during working times this might implicate a bias toward employees which were supported by their employer to take the training. The group of workers who participated in the study came relatively often from the education and health services sector. This reflects a selection in the type of employees (type of work, educational level, gender and type of work) in the study population. Relevant to mention is the recruitment of participants through public announcements bearing the consequence that we are missing data about the people who did not apply for participation (non-participants). It is therefore clear that the participants differ from the total population of workers with a chronic somatic disease. In our opinion, a diversity of selection processes such as mentioned in this study, can be found in many intervention studies. An example of possible bias in the selection of participants can be the fact that most participants worked in the education and health care sector. Probably employers in the education and health care sector are more keen to support workers to participate in this type of training.

Selections in a study population are especially relevant in the considerations of a policy maker or a health professional who considers to use the results for the own policy development or practice. Therefore, it is crucial to mention in each study as many details as possible about those selection processes and about the characteristics of the study population that are the result of these processes, in order to inform potential users of the study findings optimally in their decision making. Here we like to refer to what is a standard procedure in evidence-based practice in health care (Step 3): critically appraising the validity of a study, the impact and the applicability or usefulness for the own clinical practice.¹⁴

9.4 Discussion of the results

Can a generic return to work program be effective?

At 8-month follow-up, we found a higher score on attitude towards self-management at work for the intervention group (more enjoying self-management) compared with the control group (p= 0.030) when controlling for gender, age, occupation, educational level and baseline level. Low educated workers in the intervention group improved on the physical component score of the health-related quality of life scale (SF-12) compared with the control group. The attitude towards self-management at work (importance of self-management) improved
in the intervention group for older workers and female workers. The results suggest that low educated workers, older workers and women benefit significantly more from the training than higher educated workers, younger workers and men. A generic program has as limitation that not all the topics are relevant for all participants, for instance coping with pain is mostly not relevant for workers with diabetes mellitus or hearing loss. On the other hand, if we take into consideration the practical side of developing and implementing return to work interventions it is mostly not economically feasible to develop and implement a return to work program separately for every chronic somatic disease and for every group of participants sharing the same relevant characteristics. Another argument against developing separate programs for subgroups is the consideration that a group with a diversity of problems and characteristics may offer participants more opportunities to learn and to support each other than a more homogeneous group. Self-management behavior is also influenced by the attitude and actions of the other participants, and self-efficacy by social comparison through fail or success stories of other participants. The social comparison theory postulates that individuals evaluate their own health status and social situation by comparing themselves to others who are considered to be worse off in order to make themselves feel better about their personal situation. Individuals can also compare themselves with other individuals which they perceive to be better than themselves in order to improve their ‘self-esteem’ or to create a more positive perception of their personal reality. A generic program like the CDSMP by Lorig et al. has as another advantage that it focuses on disease consequences such as common (participation) problems due to the disease and not on the disease itself. This focus facilitates the offer of a generic or general program for a variety of chronic somatic diseases. It is important to note that the results of the randomized controlled trial are in one line with the results of the systematic review that demonstrates that women, low educated and older employees with a chronic somatic disease have a higher risk of becoming work-disabled. Fortunately, the results of our randomized controlled trial postulate that CDSMP for work is effective especially for these high-risk groups of workers.

The results of the concept mapping study suggest that there are many commonalities in the experience of having a chronic disease for workers with different chronic somatic diseases. This suggestion is in agreement with the observation of Lorig that living with a chronic disease involves three types of ‘activities’, no matter what the condition: (1) activities necessitated by the disease, e.g. medications, health professional visits; (2) work of maintaining everyday life, e.g. chores, family responsibilities; and (3) activities of dealing with an altered view of the future, e.g. frustration, anger, depression. Many federal and state governments in the USA and Australia are nowadays beginning to encourage thinking about the integration of arthritis, diabetes and other chronic somatic disease programs as many chronic diseases have common risk and protective factors (behavioral, psychosocial and biomedical), common prevention strategies, and common interventions. For example: about half of the people with diabetes have arthritis in the USA, 25% of the people with diabetes have activity limitations due to arthritis. Both conditions increase with age and are more prominent in women and low educated people. New initiatives not only suggest the need for an integration of different chronic disease programs but also to move beyond a ‘static’ model of adult lifestyle risk.
As many risk factors for developing a chronic disease like diabetes and asthma are already present in utero and early childhood, comprehensive prevention programs are needed based on a life course perspective that recognize the interactive and cumulative impact of social and biological influences throughout life.\textsuperscript{17} Also problems associated with a non-communicable diseases such as obesity and depression require a multifaceted response involving actions outside as well as inside the health system.

**Cultural differences**

The CDSMP was originally developed for patients in America with a chronic disease. The content and techniques of the original training are tuned to the American culture and include for example nutritional and daily physical activity guidelines. The Dutch translation of the CDSMP guide for the leaders and of the book for the patients ‘living well with a chronic disease’\textsuperscript{18} is the product of a as literally as possible translation. For the intervention some cultural adjustments have been made like, for example, deleting the chapter on advance directives as this topic is unusual within the Dutch culture. Also the chapter on medication compliance was adjusted. Another reason for adaptations was the need for ‘extra space’ in the six sessions to include work-related topics. The tables with regard to nutritional and physical activity guidelines have been adjusted to the Dutch guidelines. With regard to the course manual, a few minor adjustments have been made like omitting some clapping moments and obliging participants to contact a buddy. The CDSMP is a health promotion intervention to help patients manage their chronic disease. Probably this program fits better to the American culture than the Dutch culture, also because the health care system of America differs from the Dutch system. In the Netherlands all residents are required to purchase a health insurance, which is provided by private health insurers. Health insurances are tightly regulated by the government, and insurers are required to accept every person regardless of current and past health status. The health system provides high quality primary care and general practitioners can provide follow-up care for most chronic diseases. Due to this healthcare system, patients in the Netherlands might be better informed with regard to their chronic disease than patients in America. In America, good care is not available to everyone and is quite expensive. The CDSMP probably focuses on resources and skills that are not available in usual care in America but are already included in the primary health care in the Netherlands. Nevertheless the behavioral change techniques used in the training help participants to become more aware of their needs and the type of health care they can use. This type of knowledge is relevant for every person with a chronic disease, especially in the western society where patients are expected to choose between different types of care. Occupational health care is not a part of primary health care in the Netherlands, similar to the USA, and health professionals in primary health care are mostly not trained to talk about work with their patients. Therefore we may conclude that the CDSMP for work program is an accessible intervention that can provide workers with a chronic disease in America, the Netherlands and presumably in other countries as well, basic knowledge, skills and attitudes about occupational problems, especially for those who are at risk of having serious problems in functioning at work, sickness absence and permanent work disability.
9.5 Recommendations

To use the concept mapping tool

Concept mapping is a standardized tool for developing a conceptual framework of a complex topic. This method can be used for the planning of health promotion interventions or evaluations in public health. We have used the method of concept mapping to be able to make a map of the thoughts and ideas of what workers with a chronic disease and health professionals think that these workers need in order to cope at work. The content of the concept map is mostly a product of the thoughts and ideas of all the participants in the concept map sessions and partly the interpretation of the researcher. We found the method of concept mapping in our study to be a feasible way to explore a complex and new topic and therefore we recommend the technique for other studies. Concept mapping uses a structured approach to achieve a group interpretation of a complex problem, and incorporates statistical tools that provide precise data from qualitative information, this contrary to focus groups. Concept mapping is currently used in a variety of areas like education, health promotion, (mental) health care, and occupational health. The method is applied for a variety of purposes such as for planning, evaluation, theory building, translation of research into practice, curriculum development, and (quality) management. The question arises whether with this technique the theoretical framework constructed, can be generalized to workers with other chronic somatic diseases, from other occupational sectors, from other public health systems and/or countries. Most topics seem to be valid in many work settings and for different chronic somatic diseases but other topics arisen in the concept map are clearly specific for a particular disease. In future studies, the method of concept mapping could also be used to explore the vision of HRM managers and supervisors (managers) on what workers need to be able to cope at work in a specific occupational sector or branch. The general perspective of line managers and HRM managers on what worker with a chronic disease need to cope at work has already been analyzed through concept mapping. Concept mapping with experts in the field of occupational health and chronic diseases could also be used to improve the content of the intervention. Furthermore concept mapping could be used to explore the needs of subgroups of workers, for instance the population of workers with ischemic heart disease is very diverse as some have suffered from an acute myocardial infarction, others have had percutaneous transluminal coronary angioplasty or complete revascularization and others were ‘only’ suffering of angina pectoris. Probably, within the group of ischemic heart diseases, there are groups of patients (workers) with partly different needs that have to be met before they are able to return to work or continue working. Concept mapping could also be used to analyze the needs of workers with a chronic disease in different sectors and branches of the economy, and groups of workers with common occupations such as nurses or cleaners.

Adapt the duration of the training

If we look at the content and length of the training (six weeks), the training might be too short to change the behavior of the participants and may only have an effect on the attitude of the participants. Therefore, in future studies the intervention could either be increased
in length (which might not be feasible) or be combined with an e-health program or with individual coaching on the job through, for instance, a HRM advisor, occupational physician or occupational health nurse, so that the techniques learned in the training can be implemented throughout a longer period. In the training many different topics are only shortly addressed, probably some themes need to be addressed more than once to be able to influence the attitude and behavior of participants. Another argument to reconsider the design of the intervention is the experience that to gain enough skills and self-efficacy certain behavior has to be put to practice frequently and for a longer period. Probably more effects would be found after 12 months as self-efficacy and behavior can only be changed if the person has succeeded to implement the new behavior over a longer period of time. On the other hand ‘self-management skills’ might ware off if the person is not stimulated by his private and working environment to continue self-management. Therefore it is important to involve the private and working environment in the self-management program of the employee as they can play a role during and after the training in encouraging workers to develop and continue self-management.

Make a proper selection of participants
In the future the possibility should be explored to select participants for the training based on the stages of change model (phase of behavior change). The training could then be better tuned to the needs of the participants. Now all topics and all the different techniques which are needed at all stages of change are addressed. The training might achieve more results when it is fitted better to the stage of change of the participants. This stage is partly determined by the specific chronic somatic disease and the duration of the disease. Participants who have already ‘accepted’ the disease might be more motivated to manage their disease. This can influence the results of the training. A solution might be to adapt the training to the needs of certain subgroups, but the acquisition of enough participants presumably will be a problem as it was now quite hard to obtain enough participants for the training. The offering of a training program for specific subgroups seems to be feasible only under specific circumstances e.g. when a large association of diabetes patients, or a large company or sector organization, e.g. representing all regional health care organizations, decides to offer an attractive training program to their members respectively employees. In general, the question will be how to develop a generic short return to work intervention which provides enough content and tools to serve a diverse group of workers. Intervention studies should pay attention to the selection of participants, use techniques proven to be effective and combine different techniques to suit the needs of a broad group. Policy makers and health care professionals should take into account the feasibility of the intervention. As most participants of our training were women and worked in the education and health sector, it might be postulated that this type of group training fits better with the preferences of this type of workers. More effort is needed to make the training more attractive for men and possibly for workers from other sectors.
More knowledge about personal and work-related prognostic factors for work disability

In the systematic review of prognostic factors for work disability in workers with rheumatoid arthritis, COPD, ischemic heart disease and diabetes mellitus, we selected prospective and retrospective cohort studies to be able to detect the risk factors for work disability. In our study we used the quality criteria of the Cochrane collaboration and we developed a best-evidence synthesis to be able to perform a qualitative meta analysis of the results. Through this method we found enough high quality studies for rheumatoid arthritis and ischemic heart disease. Only three medium-quality studies have been found for asthma and no cohort studies have been found for diabetes mellitus. From the findings in this study, we derived recommendations for further research. Firstly, more observational cohort studies with objective data on the effect of coping style and health locus of control on work disability are needed for different chronic diseases but more specially for diabetes and asthma, as these variables can be influenced by self-management programs mostly organized by health care and offered at the workplace. Secondly, more observational cohort studies are needed on the effect of work factors on work disability, as these factors can be influenced by interventions at the workplace. Thirdly, more observational cohort studies are needed for COPD, asthma, and diabetes mellitus. Fourthly, more research and discussion is needed on the advantages and disadvantages of different prognostic models as data may be lost by using a final multivariate model of analysis. A combination of strategies may provide more transparency, a better insight of data, and more efficient control of confounding.

Fit the need of different groups

In the Netherlands, recent disability pension legislation has made employers and workers themselves more responsible for job retention when a worker becomes seriously ill with consequences for the work ability. The financial and social risks for the worker and the employer are high and will become even higher in the near future. Short and effective interventions like the CDSMP for work might help workers in an early stage to cope better with their disease at work. The results of this thesis can have practical implications for the selection of patients to be referred to this training and may lead to adaptations of the intervention itself to fit better with the needs of a variety of individuals and groups. A relevant question is if it would be most useful when we should offer more than one generic type of intervention to fit the needs of a variety of individuals. Gender variations can challenge us to offer different educational approaches to meet different needs as e.g. men might feel more comfortable with more anonymous types of services such as telephone assistance or e-health. Future studies could use and evaluate different types of interventions in one to be able to suit the needs of different individuals or subgroups. An example can be offering a worker or a group workers a self-management program in combination with e-health, or e-health in combination with individual counseling sessions.

Recommendations for practice

Self-management support is strongly emphasized by the Chronic Care Model. The underlying principle of the Chronic Care Model is that clinical outcomes will improve from a more
productive interaction between patients and health care professionals. Existing disease management programs in the USA and the Netherlands include a strong emphasis on self-management support. The Disease Management Association of America considers ‘patient self-management education’ to be one of the six necessary components of disease management. Evidence is emerging that self-management support programs improve a variety of clinical outcomes for different chronic conditions. Data also show that the patient’s motivation and self-efficacy are strong predictors of clinical outcomes. Another goal of self-management support programs is to reduce health care costs and workplace costs related to the reduced productivity of workers with a chronic disease. Offering patients better support will help them to stay healthier and to decrease utilization of health care services, thereby reducing costs for providers, insurers, employers, as well as for the patients themselves. Similarly, some view self-management support as a feasible approach to managing the workplace productivity of workers with a chronic disease by reducing absenteeism and presenteeism (reduced performance).

In America self-management programs for different chronic conditions such as diabetes mellitus and arthritis are covered by Medicare. First, it must be ordered by the physician (or qualified non-physician practitioner) who is treating the chronic disease. Second, self-management must be included in a comprehensive plan of care. Third, it must be ‘reasonable and necessary’, from Medicare’s perspective, for treating or monitoring the beneficiary’s condition. In the Netherlands, self-management is part of primary health care but until now the costs of self-management are not embedded in the reimbursement schemes of the insurance companies for the primary health care system. Until now it is unclear who pays for the costs of self-management and e-health programs. A recent study of the University of Maastricht\(^{20}\) gives insight in the possible economic benefits of e-health for five chronic diseases: asthma, heart failure, thrombosis, diabetes and depression. This study postulates that ‘E-health and self-management’ could have a health gain of 1 billion euro. Nevertheless, in practice there are many institutional problems that impede the dissemination of self-management programs. To begin with the effectiveness and cost-effectiveness of these programs have not been sufficiently proven. Secondly it is unclear what the benefits are of e-health and self-management for the health insurance companies. Probably other parties will benefit more from e-health and self-management like employers, disability pension companies and disability insurance companies. Therefore these parties should also take responsibility in financing these types of initiatives. Most e-health and self-management projects are now subsidized by incidental grants and financial contributions. To guarantee the continuity of these initiatives self-management and e-health should be an integral part of primary health care. We recommend that, other parties such as the employers, disability pension insurance companies and sickness absence insurance companies should co-finance these initiatives. Thirdly, occupational health care should be a part of primary health care, at least for the small and medium-sized companies and the workers involved. Many problems at the workplace can be prevented if problems are detected in an early stage. General practitioners can explore work-related problems in their consultations with patients and can collaborate more closely with specialized occupational physicians in order to provide
adequate care for workers with a chronic disease. Particularly nowadays, as workers in the Netherlands and many other industrialized countries are expected to work until the age of 67, it is important to invest substantially and systematically in lifetime employability. The CDSMP for work program might help workers in an early stage to cope better with their disease at work.

9.6 General conclusions

In this study the validated CDSMP has been adapted to fit the needs of workers with a chronic somatic disease. The method of intervention mapping has been found to be a useful instrument to adapt the training. The CDSMP for work focuses on skills and behavior change by improving participants’ action planning activity, self-efficacy and self-regulatory capabilities as well as influencing their intention and risk perceptions. Different techniques for behavioral change have been used in the self-management program to influence the determinants of behavior such as consciousness raising (belief selection, decisional balance), risk perception, social support, skill mastery and goal setting. The attitude of the participants is influenced by awareness exercises to raise their consciousness on situations at the workplace which are difficult to deal with a chronic somatic disease. Participants are encouraged to formulate possible solutions. Self-management is also influenced by the attitude and actions of the other participants. The social support at work is influenced by encouraging employees to talk about the course and action plans with colleagues and supervisor.

The CDSMP for work has shown to produce some of the expected outcome as hypothesized in the CDSMP for work model. At 8-month follow-up, we found a higher score on attitude towards self-management at work for the intervention group (more enjoying self-management) compared with the control group (p=0.030) when controlling for gender, age, education and baseline level. The physical quality of health (SF-12) improved after the intervention for low educated workers in the intervention group compared to the control group. The attitude towards the importance of self-management improved in the intervention group for older workers and female workers. Positive significant results on the attitude towards self-management at work (enjoyment) were found in female workers.

The results of the concept mapping study and the systematic literature search support the idea that workers with a chronic somatic disease encounter for a large part common problems at work because of the chronic somatic disease. Short effective interventions when offered in an early stage, like the CDSMP for work program might help workers to cope better with their disease at work.
9.7 References


