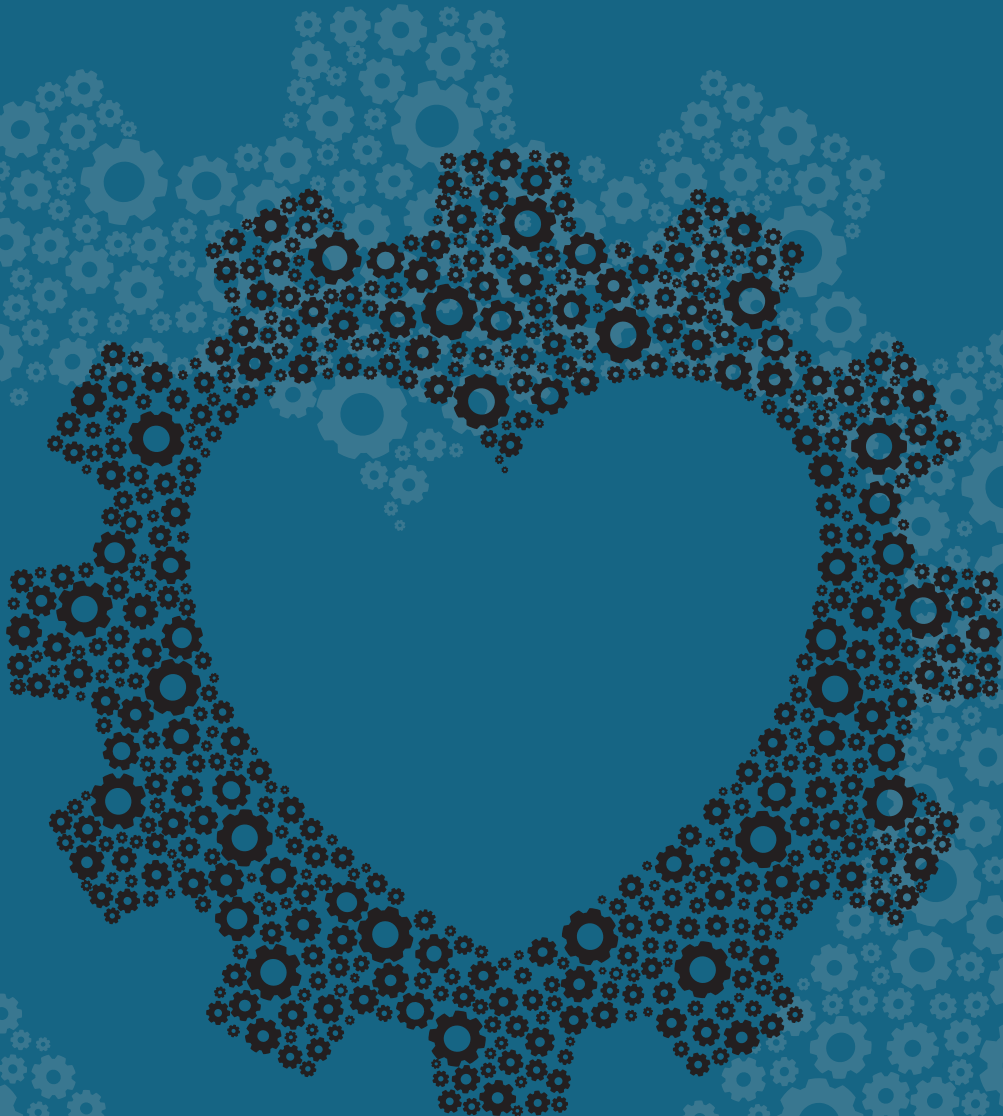


Working with a chronic condition

# Strengthening self-control in a supportive work environment



Astrid Bosma

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**Astrid Bosma**

The studies described in this thesis were carried out at the Amsterdam UMC, VU University Amsterdam, Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Amsterdam, the Netherlands.

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VRIJE UNIVERSITEIT

WORKING WITH A CHRONIC CONDITION

**Strengthening self-control in a supportive  
work environment**

ACADEMISCH PROEFSCHRIFT

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# Chapter 1

## General Introduction



## General introduction

*I would like to start this thesis with a case, not just any case, my case. I know from my own experience what it's like to work with a chronic condition, the challenges you face and mistakes you make when trying to stay at work despite your limitations. Soon after entering the labor market as a young and ambitious veterinarian, I came to the realization that this job was not compatible with my work capacity because of my own physical limitations. For me, this was a turning point in my life. Work was (and still is) of great importance to me, so what do you do? The completion of another master's degree provided me with the opportunity to work in a different field, more suitable to my work capacity. Although with the necessary ups and downs, at this moment I am able to stay at work in a happy and healthy way. Luckily! But this is just one case, many others working with chronic conditions may not be so fortunate, possibly ending up with long term sick leave or even losing their job. To make matters worse, it is hard for these workers to return to work after long term sick leave or job loss. Knowing this and the increasing number of people with one or more chronic conditions in the workforce, it is of significant importance to prevent work-related problems and facilitate sustainable employment for these workers. With this thesis, I want to contribute to this important endeavor.*

### Chronic conditions in the working population

For many of us, work is an essential part of our lives as it gives purpose to life, fosters social contact and contributes to one's quality of life (1, 2). However, working with one or more chronic conditions can present all kinds of challenges which could hamper participation in the workforce (3, 4). And that is precisely why we, in this thesis, have focused on workers with chronic conditions. To achieve the greatest possible impact with this thesis, we have chosen to use the broad term 'chronic conditions', which includes many different diseases and disorders. The exact definition used was: "a condition that is continuing or occurring recurrent for a long time and in which there is generally no prospect of full recovery" (5). Chronic conditions can be either physical or psychological and can be accompanied by pain, fatigue, limitations in functioning or other symptoms. With an aging population, unhealthy lifestyles and better medical treatment, the number of people with one or more chronic conditions will continue to grow in the near future (5-8). It has been predicted that in 2030 around 40 percent of the Dutch population has one or more chronic conditions (9). Consequently, this has an effect on the number of workers with chronic conditions, which will also increase.



Conditions such as musculoskeletal disorders, cardiovascular disease and mental disorders are most often seen in the working population today (7). The level of work participation among workers with chronic conditions varies (9). Generally, workers with chronic conditions work fewer hours than healthy individuals and are more often unemployed (10, 11). However, a large percentage of workers with chronic conditions is able to stay at work, albeit sometimes with the necessary adjustments depending on their physical or cognitive limitations. Work participation largely depends on the degree of self-perceived health and encountered limitations, which can differ per condition and per individual. Workers with none or only few limitations are just as successful in staying employed as workers without chronic conditions (12). Furthermore, people with a better self-perceived health are more often employed, making self-perceived health a determinant of participation in work (13). This reasoning also works the other way; being employed has a positive effect on workers' wellbeing and health. This observation suits the changing conceptualization of health, with health being seen as a more dynamic state, by having 'the ability to adapt and to self-manage, in the face of social, physical and emotional challenges' (14). In other words could be said that the degree of self-perceived health of workers with chronic conditions is influenced by the ability and the possibility to adapt to a new working life with a chronic condition. Being able to adapt to working with a chronic condition, could positively influence self-perceived health, and in turn work participation.

### **Sustainable employment and the importance of prevention**

When work capacity of workers with chronic conditions no longer matches work demands, they could end up on long-term sick leave or lose their job. Return to work after long-term sick leave or job loss is difficult, even more so than for workers without chronic conditions (6, 10). Therefore, preventing work-related problems and facilitating sustainable employment for these workers is what we strived for in this thesis. This way, these workers are able to stay at work in a happy and healthy way. Sustainable employment is a term that needs further clarification, as it can be defined and interpreted in different ways. One way of looking at it, is as the extent to which workers are able and willing to remain working now and in the future (15). But looking at it this way, it seems that the context in which work takes place is of secondary importance. Another definition is the following:

*“Sustainable employability means that, throughout their working lives, workers can achieve tangible opportunities in the form of a set of capabilities. They also enjoy the necessary conditions that allow them to make a valuable contribution through their work, now and in the future, while safeguarding their health and welfare. This requires, on the one hand, a work context that facilitates this for them and on the other, the attitude and motivation to exploit these opportunities (16).”*

This last definition of sustainable employment emphasizes not just the ability of the worker, but also the importance of the work context in enabling the worker to perform tasks and to stay in work. This is in line with the ultimate goal of this thesis, where the work environment has an essential role in supporting workers with (adapting to) a working life with a chronic condition.

Prevention is an important factor when it comes to achieving sustainable employment. That is why the Dutch government and Social Economic Board (SER) have highlighted the importance of prevention and its anchoring in the workplace and in occupational health services (9). According to the World Health Organization (WHO), prevention “covers measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established” (17). In the literature, several frameworks have been proposed to define prevention. Caplan (1964) introduced three different categories of prevention: primary, secondary and tertiary prevention (18). When using these categories of prevention in referral to sustainable employment, primary prevention can be seen as promoting workers’ health and preventing workers from becoming ill or developing chronic conditions. A safe and healthy work environment is hereby of importance, together with lifestyle interventions (e.g. reducing sitting time, healthy eating) in the workplace, which can further contribute to workers’ improved health and wellbeing (19, 20). Secondary preventions entails preventing work-related problems and progression of chronic conditions among workers with already existing chronic conditions, by early identification of health problems and anticipating on possible future problems in work functioning. Tertiary prevention is considered the process of ensuring sustainable return to work or lowering productivity loss, by preventing repeated absenteeism or presenteeism. Gordon (1983) proposed an alternative classification of prevention, which can be used to illustrate the targeted population in this thesis (21). According to this framework, universal prevention includes strategies that can be offered to the full population. Selective prevention refers to strategies that are targeted to subpopulations identified as being at elevated risk for a disorder. Indicated prevention includes strategies that are targeted to



individuals who are identified as having an increased vulnerability for a disorder based on one's individual assessment but who are currently asymptomatic. When we look at this classification in light of this thesis, it shows that we have focused on selective and indicated prevention; the subpopulation of all workers with chronic conditions in a work environment (selective prevention), including the identified workers (e.g. workers who have already disclosed their chronic conditions) (indicated prevention).

### **Supporting workers with chronic conditions with workplace interventions**

Research has shown a multitude of facilitators that could help workers with chronic conditions to stay at work (12, 22, 23). The last decades, efforts have been made to develop workplace interventions to support workers with chronic conditions, aligning with these facilitating factors (24). Concepts such as self-management and empowerment, which already have shown their added value in managing a life with a chronic condition, became of interest as a focal point in these interventions. However, these interventions have shown only limited effect (25, 26). But why is that? And more importantly, what should we do differently when developing a new intervention? When we look at the developed workplace interventions in general, it is clear that the majority of intervention to date merely focus on return to work of workers with chronic conditions (27-30).

Another striking observation is that many workplace interventions are directed at the individual workers, instead of at the organizational level (25, 26, 31). Organizational-level interventions aimed at preventing work-related problems are scarce (32). This is actually at odds with what is stated about prevention and sustainable employment, namely the importance of a joint effort and shared responsibility of all stakeholders involved (employees, organizational representatives and occupational health professionals) (9). A supportive work environment can contribute to the prevention of work-related problems (33). When work-related problems are prevented or addressed at an early stage, workers with chronic conditions can stay at work in a healthy way without progression of symptoms or limitations. To fill the aforementioned research gap, we have designed, implemented and evaluated an organizational-level intervention to create supportive work environments, aimed at preventing work-related problems for workers with chronic conditions (i.e. selective and indicated prevention), with a special focus on the joint effort and shared responsibility of all stakeholders involved.

### **Occupational health care in the Netherlands**

Occupational health care is essential for ensuring safe and healthy work

environments for all employees. Every country has its own policies and national legislation regarding the arrangement of occupational health care (34, 35). The Dutch Occupational Health and Safety legislation states that every employee has the right to occupational health services (36). Therefore, employers are required to have a contract with external occupational health services or a self-employed occupational physician (OP). In these contracts the acquired services are stipulated, taking into account the legal minimum requirements (37). Some large organizations even have their own in-house occupational health services department. In the Netherlands, legislation has regulated employers to have a high degree of responsibility for the health and wellbeing of its employees (38). In this regard, OPs provide advice and guidance to employers and employees on work and health, such as advice on work conditions and risk assessments & evaluations. Although OPs have a variety of tasks, they are often consulted for absenteeism and guidance with return to work of sick listed employees (39). Next to this, OPs can have preventive tasks. However, as a result of this focus on absenteeism and return to work, not much time is left for preventive activities (39). In recent years there is increasing attention to prevention in occupational health care and the need to expand preventive activities of OPs (9). One effect thereof is the obligation by law of providing employees with the opportunity to visit preventive consultation hours of OPs (40). The Dutch professional association of occupational physicians (NVAB) has taken up this challenge of promoting prevention in occupational health care and has included this in their mission statement (41). However, as current trends still show that the share of preventive activities of OPs is low (39), OPs have been given a key role in the organizational-level intervention, thereby strengthening their position regarding preventive activities within organizations.

### **From self-control to sustainable employment?**

After reading the above, I can conclude that it comes down to: 1) people with chronic conditions must take control and adapt to a new challenging working life with their chronic condition(s), 2) all stakeholders must be included when it comes to prevention of work-related problems and sustainable employment of workers with chronic conditions, 3) OPs must increase their share in preventive activities. To start with the first item, taking control of one's health and working life, which is easier said than done. As self-control is a benchmark for adaptation, it is a relevant concept when it comes down to taking control and adapting to new circumstances (42, 43). If you look at self-control in the work context, one could say that it is possible to stay at work with a chronic condition as long as a worker is able to exert self-control at work, thereby adapting to a working life with



a chronic condition. Having higher levels of self-control at work might improve wellbeing and health, thereby facilitating sustainable employment of workers with chronic conditions. An important prerequisite is that workers must be enabled by the work environment to exert self-control, which brings us to the second item, the involvement of the stakeholders, including the ones in the work environment. A question that first comes to mind is 'what does exerting self-control in the work environment actually entail'? If we want the work environment to enable workers to exert self-control, we first have to answer this question. Furthermore, it is not self-evident that every worker has the same level of self-control (44). Supporting these workers with exerting self-control and creating the right conditions at work, enabling them to do so, is crucial. OPs could play a key role in supporting workers with chronic conditions with strengthening their level of self-control, which reflects item three. This way they are able to expand their preventive activities and facilitate sustainable employment of this group of workers. This support must suit the needs of all stakeholders involved, including employees, employers and OPs. An organizational-level intervention representing the needs of all involved and aimed at preventing work-related problems, might be an effective way to strengthen self-control and thereby facilitate sustainable employment of workers with chronic conditions.

### **This thesis and its objectives**

This thesis describes the process of developing, implementing and evaluating an organizational-level intervention to prevent work-related problems, by strengthening self-control among workers with chronic conditions. The primary objectives of this thesis are:

1. To explore the elements of self-control at work from the perspectives of workers with chronic conditions and to gain insight in contextual factors that influence its exertion.
2. To explore facilitators, barriers and support needs for staying at work among workers with chronic conditions and to identify barriers to offering support and opportunities for improving support from the perspectives of OPs and organizational representatives.
3. To develop and evaluate an organizational-level intervention, in which OPs guide organizations with creating a supportive work environment for workers with chronic conditions.

## Outline of this thesis

This thesis is divided into three parts. In the first part, the concept of self-control, as a facilitator for sustainable employment, is explored. In **chapter 2**, a qualitative synthesis is conducted that defines the elements of self-control and presents the contextual factors that influence its exertion.

The second part describes the perspectives on staying at work and supporting workers with chronic conditions. In **chapter 3**, a focus group study is performed in which the lived experiences of workers with chronic conditions are explored. This study provides insight in existing barriers, facilitators and possible support needs for staying at work. **Chapter 4** describes the current practices of OPs and organizational representatives (i.e. supervisors and human resources managers), and provides insight in both barriers to offering support and opportunities for improving support for workers with chronic conditions.

The third part of this thesis describes the development and evaluation of the organizational-level intervention. **Chapter 5** outlines the development of the intervention to create a supportive work environment for employees with chronic conditions. In **chapter 6**, the evaluation of a pilot implementation of the intervention is described, including a process evaluation and feasibility study.

The final chapter of this thesis, **chapter 7**, summarizes and discusses the main research findings. In addition, methodological considerations and the implications for research, policy and practice are discussed.

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# Part I

**Self-control as a facilitator for  
sustainable employment of workers  
with chronic conditions**



# Chapter 2

## Exploring self-control of workers with a chronic condition: a qualitative synthesis

Astrid Bosma  
Cécile Boot  
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Han Anema  
Frederieke Schaafsma



## **Abstract**

Working while having a chronic condition can be challenging. Self-control at work could play an important role for workers with a chronic condition in sustainable work participation. The aim of this qualitative synthesis is to profile elements of self-control at work and to gain insight in its exertion, from the perspective of workers with a chronic condition. Four databases were systematically searched for relevant articles from January 2007 to October 2017 (PubMed, PsycINFO, Embase, and CINAHL). Search terms were related to work, seven prevalent chronic conditions, subjective needs to continue working, and qualitative research. The included articles were thematically analyzed using ATLAS.ti. The search yielded 6,445 articles of which 17 studies were included. Four elements of self-control at work for workers with a chronic condition were identified: disclosure, finding a healthy balance, requesting work accommodations and support, and management of symptoms and limitations in the workplace. These elements of self-control at work for workers with a chronic condition are helpful in developing a strategy for occupational health professionals to support these workers in strengthening their self-control and to facilitate sustainable employment.

## Introduction

The rise of chronic conditions due to lifestyle and an aging population leads to a growing number of people in the working population with one or more chronic conditions (1, 2). Chronic conditions have major economic consequences on the labor market; in Europe, the costs due to lost productivity for cardiovascular disease alone are estimated to be €54 billion/year (2, 3).

In addition to the economic benefits of working, participating in the workforce is important for people's physical and mental wellbeing; it gives purpose to life, fosters social contact and, contributes to one's quality of life (4, 5). However, workers with a chronic condition can experience challenges such as pain, fatigue, physical limitations and psychological distress, all of which can hamper work performance, resulting in loss of productivity, extended or frequent sick leave, or job loss (6-8). Sustainable work participation is of great importance, since returning to work after job loss has proven to be difficult for workers with a chronic condition (2, 9). Fortunately, a large percentage of the working population with a chronic condition is able to keep their job, although this may require adjustments depending on their physical or cognitive limitations (10). Much research has been carried out on relevant factors enabling people with a chronic condition to continue working. This research shows that in addition to disease-related factors, personal and environmental factors are of importance for sustained work (11-13). Self-management and self-control could also be identified as facilitators for workers with a chronic condition to remain productive and continue to work (14).

In recent years, the Dutch government and society have encouraged people with a chronic condition to self-manage and take control of their lives including their work (15). Self-management and self-control both illustrate the ability to master a life with a chronic condition and maintain quality of life (16-18), however, there is a difference between these concepts. Although a multitude of definitions is available, self-management can, in a broader sense, be defined as the daily management of a chronic condition over the course of the illness, thereby focusing more on managing symptoms, treatments, and the physical and psychosocial consequences of the condition (19). While self-control is defined as "the capacity for altering one's own responses, especially to bring them into line with standards such as ideals, values, morals, and social expectations, and to support the pursuit of long-term goals" (p. 351) (20).

Self-control is a widely discussed concept in literature, with numerous theories and models being developed and assumptions being made (21). Self-control is about dealing with the dilemma of pursuing long term goals, which is often the desirable behavior, or to go for the immediate satisfaction of short term desires or temptations. Exerting self-control successfully implies effortful controlling one's behavior, profiting the long term goal, while self-control failure is then deduced to choosing the short term desire (22, 23). In the literature a distinction is being made between trait and state self-control, with an individual's trait self-control being relatively stable over time, in contrast to state self-control, which varies per situation and over time. It is assumed that people with high levels of trait self-control are better at controlling their responses and impulses (24). As self-control is said to aid in attaining desired behaviors, it is important to understand the mechanisms behind self-control. The available models on self-control, such as *the discounting model of impulsiveness* and *the reflective-impulsive model of behavior*, discourse underlying mechanisms of self-control and the way one's behavior is controlled. The common denominator in many of the self-control models is that behavior is controlled by an interplay between impulsive processes on the one hand, and rational and deliberate processes on the other hand (22, 25). Another aspect of self-control is the availability of certain cognitive resources that guide behavior, as shown in *the self-regulatory strength model of self-control*. In this model self-control is considered a strength, with the exertion of self-control requiring effort and willpower. Exerting self-control depletes these resources, described as ego-depletion, making subsequent exertion of self-control and changing behavior more difficult (20). According to Duckworth self-control can be seen as "effortful regulation of the self by the self" (p. 2639) (26). A study by De Witt Huberts et al. postulated that, besides the ego-depletion theory, another route to self-control failure is possible, namely justifications. Justification refers to "making excuses for one's behavior, so the prospected failure is made acceptable for oneself"(p. 119) (27). Other studies also suggest that motivation and personal beliefs play a role in the exertion of self-control (28-30). *The shifting priorities model* describes that subjective values, added to the different options of a dilemma, can change over time and per situation. These shifting values can be explained by changes in motivation and determine the main goal for an individual at a certain point in time (23). Kotabe et al captured seven components of the available theories on self-control in an integrative framework, *the integrative self-control theory*, which can be used for identifying forms of self-control failure and possibilities for interventions (31).

Different processes could explain the ultimate behavior that is shown. Impulse control, rational decision making, the availability of cognitive resources, motivation and personal beliefs are pointed out as relevant aspects to self-control and self-control failure. Identifying causes of self-control failure in different settings could provide starting points for intervention development. Research on self-control in the work setting (32, 33), mostly focused on organizational management and job performance. Also in the organization management literature on self-control, depletion of resources is often considered a reason for self-control failure, but as Lian states in the review on self-control at work, a depletion of resources is part of the problem of self-control failure (34). In recent years, existing theories and assumptions about self-control and self-control failure are being challenged. As Milyavskaya et al. recommend in the article on the assumptions about self-control and subsequent recommendations, it is important to focus on the **capacity** of a person to exert self-control, as well as on the **context** in which exertion of self-control occurs (21). In view of this context, *the integrative self-control theory* describes enactment constraints, which are environmental factors that influence the exertion of self-control (31). To the best of our knowledge, there is no research available on self-control in the context of working with a chronic condition. The new definition of health, “having the ability to adapt and self-manage”, as proposed by Huber et al. (p. 2) (14) implies that even a person with a chronic condition can feel healthy. Since self-control can be seen as a benchmark for adaptation (22, 35), having higher levels of self-control at work and having the possibility to exert it might improve wellbeing and health, thereby facilitating sustainable employment for workers with a chronic condition.

Although the literature on factors enabling work participation provides indications of self-control for workers with a chronic condition and what influences its exertion, an in depth understanding of self-control at work and according behaviors is lacking. Using the definition of Baumeister et al. (2007, p. 351) (20), the long-term goal of workers with a chronic condition in this study is seen as sustainable work participation. But what behavior facilitates the pursuit of this long-term goal and what are the influences of the environment on the enactment of this behavior, possibly leading to self-control failure? To encourage self-control at work in workers with a chronic condition, these elements of self-control in the context of working with a chronic condition need to be identified. Besides encouraging workers with a chronic condition in exerting self-control at work, knowing these elements of self-control and possible influences on its exertion could also contribute to policy, practices and future intervention development regarding working with a chronic condition in the work environment. This qualitative synthesis therefore aims to

explore elements of self-control at work from the perspective of workers with a chronic condition and to gain insight in influences on its exertion.

## **Methods**

Qualitative research provides a deep understanding of people's views and experiences and the context in which they occur. A qualitative synthesis allows a researcher to go beyond primary studies, creating a renewed interpretation or conceptualization of a phenomenon that is not merely a summation of original data (36, 37). Aggregating available qualitative studies on continuing to work with a chronic condition in a qualitative synthesis allows for a better conceptual understanding of and new insights into self-control as experienced by workers with a chronic condition.

### **Search strategy**

A structured approach is advised to limit the scope of the synthesis using a focused research question and for aiding in the search strategy (38). In this qualitative synthesis, the research question was formulated using the SPICE (Setting, Perspective, Intervention, Comparison and Evaluation) tool (39). The Setting, Perspective, Intervention and Evaluation were determined: (S): work environment; (P): workers with a chronic condition; (I): self-control and related concepts; (E): experiences of successfully continuing work. SPICE assisted in building the search strategy with relevant search terms. A comprehensive search was performed in the bibliographic databases PubMed and Embase.com, PsycINFO (via EBSCO) and CINAHL (via EBSCO) from January 2007 to October 2017, in collaboration with a medical librarian (author 5). Because of our interest in the current work environment for workers with a chronic condition, the decision was made to use this timeframe of 10 years. Search terms included controlled terms (MesH in PubMed, Emtree in Embase, CINAHL headings and thesaurus terms in PsycINFO) as well as free-text terms. The search strategy included search terms related to (staying at) work, seven chronic conditions, subjective needs to continue working, and qualitative research. Duplicate articles were excluded. The full search strategies for all databases can be found in the Supplementary Information.

Due to the wide variety in chronic conditions in workers, a selection of chronic conditions was made to include in this synthesis. The choice of chronic conditions was based on both the prevalence of the condition in the working population and

the impact of these condition on work ability. Additionally, the aim was to obtain heterogeneity in chronic conditions included in the study. Chronic conditions can vary from one another at different levels, e.g. symptoms, visibility, progression, episodic or continuously present, and the way it can be managed. Therefore a selection of chronic conditions was made, related to a variety of functional systems of the body, both physically as well as mentally. Resulting from this, the following conditions were selected for the focus of this study: 1) rheumatoid arthritis (RA); 2) multiple sclerosis (MS); 3) inflammatory bowel disease (IBD); 4) asthma; 5) diabetes mellitus (DM) type 1; 6) coronary heart disease (CHD); and 7) depression. Worldwide, diabetes and cardiovascular disease (CVD) are prevalent chronic conditions (40, 41). Chronic conditions such as RA, MS, IBD and asthma, although less prevalent as diabetes or CVD, they have an large impact on someone's work ability, even in an early phase of working life (42-45). Common mental disorders, such as depression, seriously impact the level of work participation and are an important cause of long term sick leave (46, 47). The inclusion criteria for article selection included: 1) a focus on staying at work, 2) qualitative or mixed method design, 3) perspectives and strategies of workers with one of the aforementioned chronic conditions for continuing to work, and 4) article in Dutch or English.

### **Study selection and quality assessment**

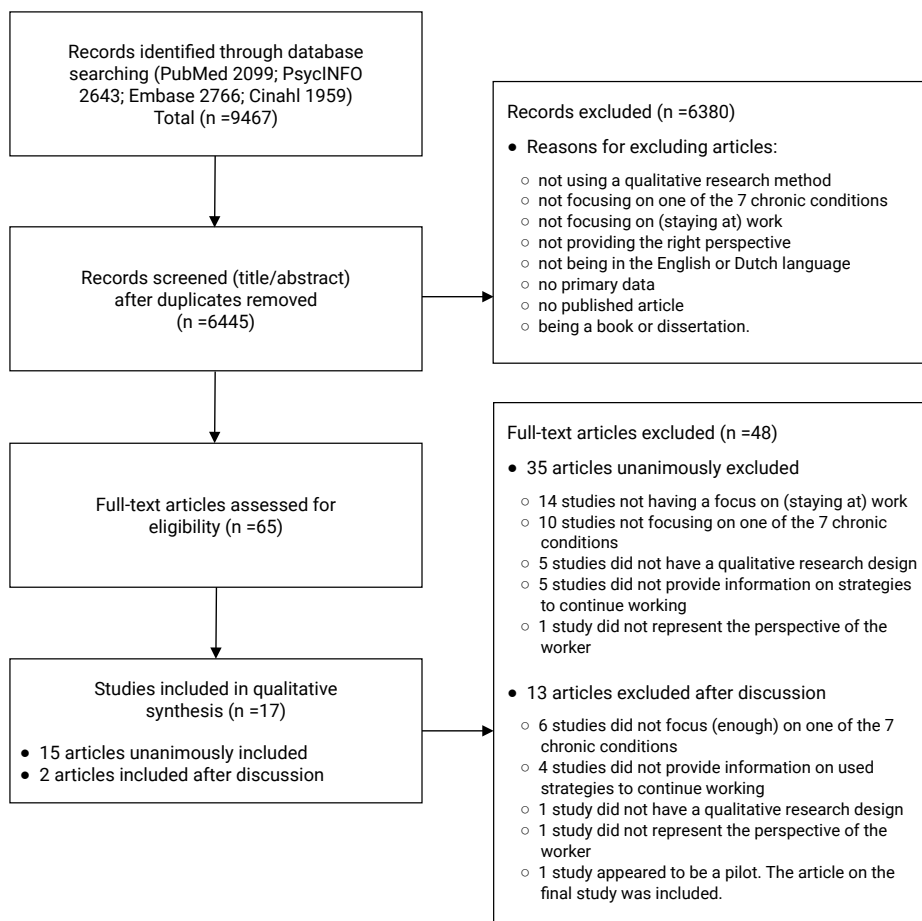
The selection of studies was a stepwise process. The first step of the selection process was screening on titles and abstracts. Covidence, a web-based tool for conducting systematic reviews, was used during the review process to screen titles and abstracts (48). A total of 6,445 studies were screened for titles and abstracts based on the inclusion criteria. Around 25% of the studies (1,725) were screened by authors 1 and 3. During this screening process, comparisons were made and discrepancies (<2% of the studies) were discussed until consensus was reached. In cases of doubt, the articles were discussed with select members of the research team (authors 1, 2, 3 and 7). Consensus was reached on the refinement of the inclusion criteria, after which the remainder of the studies (4,720) was screened by author 1. The most important reasons for excluding studies based on title or abstract were: not using a qualitative research method, focusing on other chronic conditions than selected for this study, not providing the perspective of the worker, and not focusing on (staying at) work. Other reasons for excluding studies were: not being in the English or Dutch language; no primary data; no published article; and being a book or dissertation.

The second step of the selection process was full text screening of the selected articles. All 65 selected articles were screened full text by two authors (1 and 3). The articles were read extensively and for each article the following questions were answered: 1) does it has a qualitative or mixed methods study design? 2) does it provide a clear perspective of the worker with a chronic condition? 3) does it has a focus on one of the seven selected chronic conditions? 4) does it has a broad focus on staying at work? 5) does it provide information on strategies used to continue working? Only after all questions were answered with 'yes', the decision was made to include the article. Differing views were discussed and together with author 7 a decision was made to exclude or include the article. An important discussion point was to include or exclude studies that focused on several chronic conditions, including one of the selected seven chronic conditions (e.g. studies on different types of arthritis, including rheumatoid arthritis). If 50% or more of the research participants in a study suffered from one of the selected seven chronic conditions or a distinction was made clear in the results for the different included chronic conditions in a study, the study was included.

The quality of the included articles was assessed by the same two authors (1 and 3) using the RATS qualitative research review guidelines. The RATS consists of 24 questions on the Relevance of the study question, Appropriateness of qualitative methods, Transparency of procedures and Soundness of the interpretive approach (49). To evaluate the quality of the article, the decision was made to rate each question on a scale from 1 point (poor quality) to 4 points (good quality). Therefore, the quality of each article was rated between 24 - 96 points. No articles were excluded based on the quality assessment.

### ***Included articles***

Sixteen qualitative and one mixed methods study were included in the synthesis (Figure 1). Article topics by condition were as follow: five RA, four MS, three DM type 1, two depression, and one each for CHD, IBD and asthma. Three of the studies used focus groups, while the other 14 studies used individual interviews. The studies were mainly conducted in Europe (n = 10), the other seven studies originated from the United States (n = 3), Canada (n = 3) and Australia (n = 1). The participants had a wide variety of professions. In six studies, some of the participants were unemployed, retired or students. Table 1 shows an overview of the included studies and study characteristics.



**Figure 1.** Flowchart of the selection process and included studies.

### Data extraction and analysis

The data that was extracted consisted of the content of ‘results’ or ‘findings’ sections of the included studies, more specifically this meant the original researchers’ interpretations or key concepts in the primary data. Consequently, quotes delineated in the studies were not extracted for further analysis. Thematic analysis was used as qualitative synthesis methodology to analyze these results and to identify emerging themes in the qualitative studies and the qualitative part of the mixed-method study (50). As with the study selection, data analysis was also a stepwise process (51). In the first step of thematic analysis the text in the



'results' or 'findings' sections of the included studies were coded, using line-by-line coding. Because of the many codes expected to result from this first step, ATLAS.ti was used to assist the coding process and helped to produce an initial list with codes. The first ten percent of the studies were coded by two researchers (authors 1 and 3), after which both authors discussed the codes created, until consensus was reached. The remainder 90 percent of the studies were coded by only author 1.

In the second step of thematic analysis, developing descriptive themes, the data was further analyzed in an intensive and rigorous manner. In order to proceed with the analysis manually, all codes and corresponding quotations were transferred from ATLAS.ti to a separate Word document. This document was used to read, reread and sift through the data identifying similarities and differences between the codes. Similar codes were iteratively grouped into subthemes associated with continuing work. Code grouping and developing descriptive themes were performed in consultation with four researchers (authors 1, 2, 3 and 7) from the research team until consensus was reached. The end result of this step was a list with descriptive themes, which provided more or less a perspective on barriers, facilitators and needs regarding sustainable employment.

At this stage, we had not gone beyond the data yet and it was not yet clear what the elements of self-control were. In the final step of the process, analytical themes were developed, providing us with the desired answers. During this step, behaviors that workers with a chronic condition could have control over and facilitate sustainable employment were inferred from the descriptive themes of the previous step. The research team and an expert in qualitative research in the field of qualitative synthesis (author 4) discussed the descriptive themes and inferred behaviors extensively until analytical themes on self-control at work were formulated. In formulating the themes on self-control at work, attention was paid to maintaining the integrity of original data of the included studies, while at the same time not producing excessive detail (52).

**Table 1.** Study characteristics of included studies.

No	Author	Year	Country	Aim of the study	Condition	Methods	Data analysis	Participants in study	RATS score
1	Bogenschutz et al.	2016	United States	To examine barriers and facilitators for employment from the point of view of adults with MS facing employment issues.	Multiple sclerosis	Focus groups	Conventional qualitative content analysis	n = 27*	83
2	Bose	2013	United States	To identify strategies, experiences, and attitudes of people managing diabetes at work.	Diabetes mellitus type 1	Interviews	Coding and memo-writing	n = 45*	82
3	Burda et al.	2012	The Netherlands	To identify successful diabetes-related behaviors for the workplace, to support people with diabetes in applying for and participating effectively in paid work.	Diabetes mellitus type 1	Interviews	Grounded theory approach	n = 47	80
4	Codd et al.	2010	Ireland	To explore how a diagnosis of RA impacts the worker role, and how adaptations may be made to facilitate the maintenance of the worker role.	Rheumatoid arthritis	Interviews	Interpretative phenomenological analysis	n = 10	83
5	Crooks et al.	2011	Canada	To identify the problem-focused coping strategies of academics with MS to remain active in teaching.	Multiple sclerosis	Interviews	Thematic analysis	n = 45*	74
6	Dickson et al.	2008	United States	To explore how attitudes, self-efficacy, cognition, and physical functioning influence self-care among employees with heart failure.	Coronary heart disease	Interviews**	Qualitative content analysis	n = 41*	77

**Table 1.** Study characteristics of included studies (continued).

No	Author	Year	Country	Aim of the study	Condition	Methods	Data analysis	Participants in study	RATS score
7	Holland et al.	2016	United Kingdom	To explore how individuals' motivation to work and organizational policy and practice can lead to voluntary and involuntary forms of sickness presenteeism following onset of RA.	Rheumatoid arthritis	Interviews	Thematic analysis	n = 11*	88
8	Lacaille et al.	2007	Canada	To identify the problems and barriers to employment that persons with IA face at work because of arthritis, understand why these issues are problematic, and identify helpful strategies for maintaining employment.	Rheumatoid arthritis	Focus groups	Descriptive qualitative analysis	n = 36	81
9	Osterholm et al.	2013	Sweden	To explore how men with arthritis perceive their ability to continue working.	Rheumatoid arthritis	Interviews	Empirical Phenomenological Psychological (EPP) method	n = 9	83
10	Van der Meer et al.	2011	The Netherlands	To investigate the experiences and needs of employees with RA treated with anti-TNF therapy with respect to work participation	Rheumatoid arthritis	Interviews	Open axial and selective coding	n = 14	86

**Table 1.** Study characteristics of included studies (continued).

No	Author	Year	Country	Aim of the study	Condition	Methods	Data analysis	Participants in study	RATS score
11	Van der Meide et al.	2017	The Netherlands	To examine the meaning of work in everyday life and the barriers and facilitators of continuing to work from the perspective of people with RRMS.	Multiple sclerosis	Interviews	Thematic analysis	n = 19	89
12	Restall et al.	2016	Canada	To report on people's experiences of work and work disability in the context of living with IBD, and how personal and environmental factors supported or created barriers for them to participate in paid employment.	Inflammatory bowel disease	Interviews	Phenomenological analysis	n = 45*	86
13	Ruston et al.	2013	United Kingdom	To examine ways in which people with type 1 and type 2 diabetes accessed support for and managed their diabetes whilst at work, and identify factors that presented barriers to effective management	Diabetes mellitus type 1	Interviews	Constant comparative method	n = 43	78

**Table 1.** Study characteristics of included studies (continued).

No	Author	Year	Country	Aim of the study	Condition	Methods	Data analysis	Participants in study	RATS score
14	Sallis et al.	2014	United Kingdom	To develop understanding (based on subjective beliefs and experiences) of the type of support individuals with depression may require to retain their employment and avoid sickness absences.	Depression	Interviews	Interpretative phenomenological analysis	n = 7	84
15	Stanley et al.	2007	United Kingdom	To explore the personal experiences of social workers with depression in the workplace	Depression	Interviews	Thematic analysis	n = 50	73
16	Sweetland et al.	2007	United Kingdom	To identify what individuals with MS need from a vocational rehabilitation service so they can be supported in their work setting, and remain at work for as long as they are capable.	Multiple sclerosis	Focus groups	Constant comparative method	n = 24	75
17	Zhao et al.	2017	Australia	To investigate workplace support, experiences, attitudes and perceptions towards employees with asthma, both occupational and non-occupational, and provide recommendations for workplace asthma policies.	Asthma	Interviews	Thematic analysis	n = 25***	84

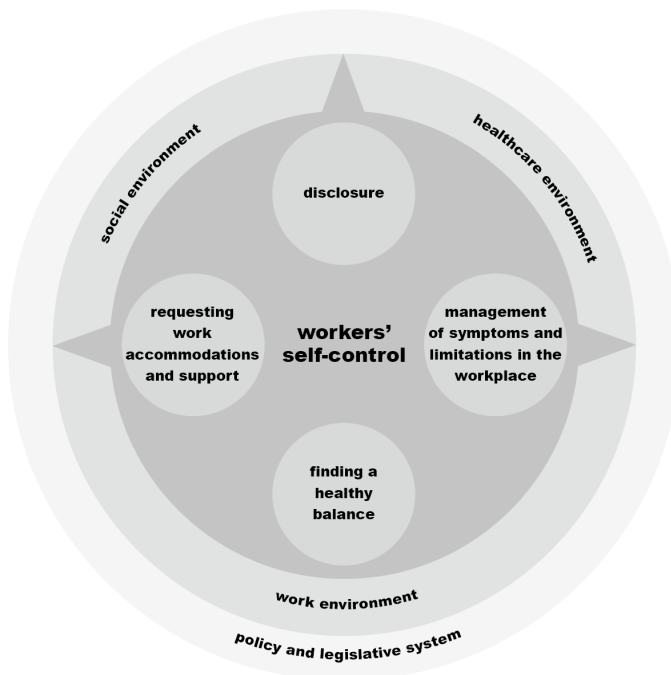
**Note.** \* A number of participants were unemployed, retired or students. \*\* Additional quantitative data was collected. \*\*\* Participants included employees with and without asthma and Human Resource managers.

## Ethics statement

Written confirmation of the Medical Ethics Review Committee was not necessary. The data used in this study was freely available information (in the public domain) and was completely anonymized. The Medical Research Involving Human Subjects Act ('Wet Medisch-wetenschappelijk Onderzoek met mensen') does not apply to this study.

## Results

The analysis revealed four main themes, corresponding to four elements of self-control in a worker with a chronic condition: 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, 4) management of symptoms and limitations in the workplace. In addition to these elements, the influence and interaction of the work, social and health care environments on the exertion of self-control were also identified within the context of the local or national policy and legislative system (Figure 2).



**Figure 2.** Self-control based on the views of workers with a chronic condition.

## Disclosure

Disclosure appeared to be an important element of self-control at work. In some studies, disclosing one's condition at work resulted in a better understanding of one's situation by the employer, supervisor or co-workers, leading to more consideration and support at work (53-57). As described by some studies, this understanding and support in the workplace made it much easier for the worker to request and receive work accommodations and adjust to changing work situations (55-59). Employers and co-workers' level of knowledge of the condition and its impact on productivity influenced the degree of understanding and support after disclosure, as pointed out by some studies (53, 54, 57, 58, 60).

A number of studies pointed out that workers were cautious about disclosure and made a trade-off about what, when and whom to tell for several reasons (54-58, 61). The perceived relationship with an employer, supervisor or co-worker influenced the worker's level of disclosure (62, 63). A relationship that included acceptance, appreciation, recognition and trust facilitated a worker's decision to disclose their condition, as described in a number of studies (53, 54, 59, 63). One study pointed out that having a permanent employee contract may also be a disclosure facilitator in certain European countries (54).

Several studies reported that ideas and views on the possible negative consequences of disclosure also influenced the decision to disclose a chronic condition. Reported negative consequences were job loss (in the future), being viewed as incompetent by an employer, supervisor or co-worker, promotion discrimination, stigmatization, not being taken seriously, being less appreciated, and perceived negative reactions from co-workers such as jokes (55-59, 62-64). Jokes and doubts about a worker's capabilities gave way to not feeling appreciated or accepted (63). Stigmatization appeared to be a particularly important aspect for IBD and chronic mental illnesses such as depression, as it was extensively discussed in the included studies focusing on these conditions (56, 59, 62). Some studies indicated that discrimination and stigmatization was often based on a lack of knowledge about chronic conditions (53, 59, 61).

Several studies mentioned that the invisibility, unpredictability and possible progressive nature of a chronic condition could further complicate disclosure since the condition may lead to a decline in work ability and performance at a certain point in time (54, 57, 58, 60, 62, 64). Without disclosure of this invisible condition, a decline in work performance could be perceived by the work environment as an inability to do the job. While disclosure of an invisible condition could also

lead to doubts about the worker's ability because of a limited understanding of the condition (55-57, 62, 64). As described in some studies, some workers with an invisible chronic condition wanted to maintain invisibility, and had even developed strategies to hide their condition at work. They tried to preserve a positive and healthy self-image, but at the expense of self-care, and sometimes even aggravating their condition (56, 57). Some studies pointed out that with the progression of symptoms or the need to manage the condition at work, the condition became more visible, which resulted in workers being more inclined to disclose their condition (53, 58, 62).

Several studies indicated that in addition to the fear, uncertainty and desire for the chronic condition to remain invisible, other reasons for not disclosing the condition were not expecting support, not wanting to be seen as an exception, co-workers' unease when talking about psychological conditions and a lack of company policy (53, 55, 56, 62, 65).

### **Finding a healthy balance**

Finding a healthy balance is a second element of self-control. Decision making turned out to help workers find and maintain a healthy balance in life, thus enabling them to continue working. These decisions related to the worker's desire to continue working and the strategies that make sustainable work participation possible, such as energy management or job change.

As pointed out by a number of studies, working despite having a chronic condition showed to be of great importance; workers' decisions to continue working were fed by their desire and determination (60-62, 65). Decision making was influenced by the meaning of and attitude towards work and perceptions of the worker's role (60, 65-67). Some studies stated that staying at work after a chronic condition was diagnosed, helped shape the identity and self-image of a worker and gave a sense of normality despite having a chronic condition (65, 67). In part, personal norms and values regarding work determined one's self-image (59). Intrinsic rewards such as having social contacts, the chance to be productive and contributing to society, the possibility of 'escaping' from home and enjoying better mental and physical wellbeing were identified by some studies as being important for a balanced decision to stay at work (54, 57, 58, 60, 65, 66).

A number of studies also referred to financial matters that also influenced a worker's decision to stay at work (54, 59, 64, 66). Workers with a good and suitable job would not change jobs easily because of financial security (54). Conscious



decisions were made to reduce working hours or put one's desire to build a career aside to receive disability or health care benefits now or in the future (54, 59, 64). Some studies addressed cases where the financial advantages of not working exceeded the intrinsic rewards of working, which also influenced a worker's decision to continue working (66).

Finding a healthy balance also appeared to relate to energy management. Having no energy left at the end of a working day had a negative influence on quality of life (57). Numerous studies pointed out that reducing social activities, household chores and leisure time saved enough energy to continue working (59, 60, 62, 63, 65, 67). Changing work routines also saved energy and lowered the impact of a chronic condition on the job (55, 64, 65). Making these decisions appeared to be difficult and in some cases the reduction in social activities was not voluntarily, but instead was forced on the worker because of the lack of energy at the end of the day (57).

As nicely described in one study, in a job, there must be a balance between the work challenges and a worker's trust that the job can be carried out (54). A number of studies pointed out that if it was not possible to fit the current job to the worker's capacities, a decision was made to change to a job that was less demanding and stressful, more protective and with fewer responsibilities (56, 58, 60, 61, 64, 67, 68). This also meant turning down promotions, taking a job below one's level or outside one's expertise, or to start one's own business (57, 64). Some studies made clear that this resulted in the fact that career plan expectations needed to be shifted (54, 59). The unpredictability of a chronic condition also influenced this decision, since accepting new tasks in the future appeared to be difficult if the worker feared not being able to meet specific obligations (57). The decision to change jobs was also influenced by the worker's level of support (64, 67). In addition, some studies revealed the worker's level of confidence in their ability to work and their self-esteem also influenced this decision. The uncertainty of possible progression of symptoms and negative reactions from co-workers and employers lowered confidence and raised feelings of inadequacy, which ultimately led to a job change (57, 64).

Studies showed that changing jobs when having a chronic condition was not easy, especially if jobs with a heavy physical workload were no longer an option (58, 59, 66). When deciding to seek for a new job, both present and future work capacity needed to be considered (64, 68). Gathering information was seen as an important condition for making a balanced decision, including knowing how

the condition will progress, which could prevent hasty employment decisions (54, 61, 68). An understanding and supportive employer could facilitate a worker in finding a new suitable job within the company (54).

### **Requesting work accommodations and support**

Work accommodations and support appeared to be crucial for staying at work and being productive at the workplace. Requesting these accommodations proved to be another element of exerting self-control at work, since the job can be fitted to the worker's capacities. A number of studies listed various types of work accommodations (e.g. technological devices, working from home), which could help a worker with a chronic condition perform the job tasks while managing (or alleviating) symptoms and maintaining productivity (55, 57-61, 64, 65, 67, 68). Numerous studies showed that having job control opportunities such as working from home, starting later or alternating tasks all helped to manage fluctuations in symptoms, since work could be fitted to daily symptoms and more time was available for self-care (57, 59, 60, 63-66, 69).

Studies pointed out that workers were often hesitant to request work accommodations for several reasons, including fear of not being granted accommodations, being seen as not capable of doing the job, feelings of guilt, the perception of being a burden, and wanting to maintain the invisibility of the condition (57, 59, 61, 63, 64). Fear of resentment and jealousy among co-workers was another reason workers did not ask for accommodations (57, 60). Some studies mentioned that an understanding and accepting work environment with a good relationship with employers and co-workers, acknowledgement of the need for accommodations and a worker's proactive attitude, made it easier to request and obtain accommodations (55, 59-61).

Knowledge of the laws and regulations for protection of workers with a chronic condition appeared to be important, and made it easier for the worker to disclose their condition and request accommodations (59, 61). However, as some studies pointed out, many workers lacked this knowledge and were unaware of available resources (57, 59). In addition, employers also needed to have sufficient knowledge of these laws and regulations to be able to correctly interpret and execute those policies and be willing to facilitate accommodations (53, 59, 60, 62). Having a clear policy to facilitate accommodations appeared to be helpful and some studies recommended to promote a transparent policy to all workers, encouraging workers with chronic conditions to express their needs (55, 59).

In addition to requesting accommodations, asking for support from employers, supervisors and co-workers was helpful in managing a chronic condition at work (68). However, studies pointed out that asking for support appeared to be difficult for some workers. Several studies showed important conditions for requesting support, which included accepting the need for support and pointing out specific needs (56-58, 68, 69). Condition unpredictability and symptom fluctuations made it even more difficult to ask for support. The worker's functional limitations as perceived by both the employer and co-workers, and changing support needs over time resulted in having to ask for support over and over again. Therefore, workers valued employers and co-workers enquiring about current needs on a regular basis (63).

Several studies showed that support can come from several directions including work, social and health care environments. A number of studies pointed out that occupational health professionals could offer various forms of support to workers with chronic conditions (56, 61, 68). Occupational physicians' support consisted of assisting in management of the chronic condition in the workplace, advising about work accommodations, explaining worker or employer responsibilities, and helping with communication about the condition at the workplace. This support helped to empower the worker and bolster their confidence (56, 61, 68). Co-worker support appeared to be crucial for a worker who was adjusting to and managing their chronic condition at work and could consist of assuming some of their tasks (58, 63, 65-69). Some studies showed that family and friends also help a worker to adjust to their chronic condition by performing household chores, and talking about the condition and the situation in the workplace (56, 65, 67).

### **Management of symptoms and limitations in the workplace**

The final element of self-control, managing symptoms and limitations, was considered important for staying productive and preventing problems at work (53, 55, 68), especially for physically demanding jobs (58). Several aspects ought to be considered before symptoms and limitations could be properly managed at work. First, studies showed that only after there is worker awareness and recognition of their symptoms and limitations due to their chronic condition (including boundaries) as a possible cause of work problems, action could be taken, support sought and strategies developed (55, 57, 58, 62, 63, 65, 66, 68, 69). A worker's awareness of its symptoms and abilities also made it easier to accept the chronic condition and address the limitations (63, 65). This process of recognition and awareness proved to be difficult and took time to learn (54, 57, 65). Sometimes, reactions from co-workers were needed for workers with a chronic condition to

become aware of unknown symptoms (64). A number of studies pointed out that having the proper knowledge of a chronic condition, including aggravating triggers, and listening to your body were all considered necessary for awareness and recognition of symptoms and consequent appropriate management (54, 58, 62, 63, 68).

Second, worker acceptance of their chronic condition and limitations was needed (65, 67). Studies revealed that this provided the worker with a sense of control, early symptom recognition (62) and insight into ways to adjust to their new situation (67). It appeared to be difficult to accept a chronic condition as the cause of problems at work, in cases where there was a lack of insight or a strong desire to be normal (57, 62).

Finally, several studies indicated that a worker needed to take responsibility for managing their symptoms and limitations at work (53, 55, 66). Responsibility implied an appropriate response to their symptoms and compliance with advice for symptom management in the workplace (55, 68). This was influenced by the level of worker self-efficacy with respect to work and symptom management, and a positive attitude towards work (55, 66). Taking responsibility meant prioritizing management of the symptoms and limitations at work, which required the necessary resources in the workplace, such as time and clean spaces to manage the symptoms (66, 68). A number of studies pointed out that workers who prioritize work over managing their symptoms and limitations responsibly are at risk for a deterioration of their health (53, 58, 62, 65, 66). Reasons for doing this, as described in several studies, were time pressures (including pressure to serve clients), work-related self-image issues, loyalty to co-workers and employer, maintaining condition invisibility, trying to complete tasks without interruption and avoiding lower productivity due to management of symptoms and limitations (53, 54, 58, 65, 66).

Several studies described that workers' feelings of guilt and shame were evoked when they needed to manage their symptoms and limitations at work, especially during work time. In contrast, spending too little time on management of symptoms and limitations at work also evoked guilt (55, 58). Management also included appointments at the hospital or with a care provider, which could be time consuming, making it difficult to plan these appointments (53, 59).

## Discussion

In this study a qualitative synthesis was conducted to explore the elements of self-control at work for workers with a chronic condition and to gain insight in its exertion. Four elements of self-control at work for these workers emerged: disclosure, finding a healthy balance, requesting work accommodations and support, and management of symptoms and limitations in the workplace.

Disclosure of the condition at work creates understanding and support from co-workers, supervisors and employers, and facilitates management of symptoms and limitations and implementation of accommodations. However, disclosure is not an easy task, since it is influenced by the worker's personal beliefs about possible consequences, condition-related factors (e.g., predictability and invisibility of the condition), workplace factors (e.g., co-worker relationships, supervisors and employers), and workplace culture. Since disclosure is an important prerequisite for the other elements of self-control (e.g. requesting work accommodations and managing symptoms and limitations in the workplace), disclosure can be considered a major element of self-control. Disclosure is about controlling the level of information made available about a worker's chronic condition. Studies show that women are more likely to disclose their condition or symptoms, compared to men. However, both men and women point out the importance of receiving emotional support, making it a predictor for disclosure for both genders (70). Although research participants of all, except for one of the included studies, represented both men and women, no separate analysis was conducted for gender differences in these studies. Despite the fact that disclosure is often promoted by society or patient organizations, workers with a chronic condition can remain reluctant to do so because of bad experiences in the past (71, 72). The question still remains of how to address the dilemma "to tell or not to tell". There is no "one size fits all" solution because of personal factors and the variety of work settings that influence disclosure.

Stigmatization is an important aspect of disclosure of chronic conditions, and this is often the result of co-worker and employer's lack of knowledge. Stigma after disclosure is a particular problem for certain conditions, such as mental illnesses, HIV/Aids and IBD (73-75). The difficulty of disclosing certain chronic conditions was described in a review by Brohan et al. on factors associated with disclosure of mental health problems in the workplace (76). Although difficult, disclosure can have a positive effect in reducing the level of stigmatization (77). Condition invisibility and possible stigmatization further complicate the dilemma to disclose

or not to disclose as shown by the theoretical framework developed by Joachim and Acorn (2001). This framework shows that workers with invisible conditions have several options (e.g. non-disclosure, preventive disclosure and protective or spontaneous disclosure) when dealing with their condition, compared to workers with visible conditions (78-80), thereby making their decision to disclose more difficult.

Finding a healthy balance is important for workers with a chronic condition to continue working. The decisions related to finding this healthy balance are based on the desire to continue working and the strategies that make sustainable work participation possible, such as energy management or a job change. This balanced decision making should also be seen in the light of self-control as discussed in the literature. Various models describe self-control as decision making related to sacrificing short-term outcomes in favor of long-term interests, which is in accordance with sacrificing social activities, leisure time or career promotions to achieve sustainable employment (22). This qualitative synthesis has also indicated the relevance of personal values in decision making, which is in line with the review by de Wit et al., who pointed out the importance of personal factors in work participation (81). Balancing both work and a personal life is a challenge for most workers; an imbalance can result in negative health effect such as stress and burnout. These synthesis findings emphasized that having a chronic condition further complicates the matter, since the worker needs to balance their work and personal lives while continuously managing their chronic condition and symptoms. This finding is in accordance with other literature on work-life balance and chronic conditions (82-84). Grawitch et al., who studied work-life balance in light of self-regulation, control and decision making, showed that active decisions need to be made to allocate resources, such as energy which is usually a scarce resource in workers with a chronic condition (85). This lack of resources may also be explained by a greater need for recovery during and after work (86, 87), which may easily lead to a work-life imbalance and thus affect the worker's quality of life in their social domain.

Requesting accommodations and support is crucial for fitting a job to the capacities of a worker with a chronic condition. A work, social or health care environment can be a valuable source of support. Co-workers assuming tasks and talking about living and working with the chronic condition are both valuable forms of support for a worker with a chronic condition. Much research has been done on workplace accommodations for specific conditions and chronic conditions in general including consideration of the need and use of accommodations and

subsequent impact on work outcomes (88-94). Depending on the condition, accommodations can be permanent or temporary, as for example for conditions with an episodic course. Varekamp et al. demonstrated the importance of social support for workers with chronic conditions (7). Talking about personal experiences could help a worker with a chronic condition adjust to symptoms at work, since expressing one's emotions improves psychological and physical adjustment to a condition (95). Byrne et al. also demonstrated a positive association between perceived organizational support and performance in workers with chronic pain (96). However, the focus of this synthesis was on a worker's intention and actions related to accommodation requests. In line with the definition of self-control, "the capacity for altering one's own responses, especially to bring them into line with standards such as ideals, values, morals, and social expectations, and to support the pursuit of long-term goals" (20), requesting accommodations and support could be seen as a worker's response to a pursuit of the long-term goal of sustainable employment. But just as with disclosure, the difficulty lies in the influence of and interaction with the environment. Although the worker is in control of requesting accommodations and support, the worker is also dependent on the reactions and actions of the people in their work environment. Workers who are not able to adequately ask for accommodations may have unmet needs (92, 97), which makes it harder for them to adapt to their new situation. When keeping in mind Huber's new definition of health, "having the ability to adapt and to self-manage", the ability and the possibility to adapt to a new healthy work situation are both important for a workers' wellbeing and health (14).

Management of symptoms and limitations in the workplace is an element of self-control, and enables sustainable work productivity. This requires an awareness of symptoms, acceptance of the chronic condition and limitations, and taking responsibility. Both the work and the health care environment influence how the condition is managed by the individual. Managing of symptoms and limitations at work can be difficult for an individual, since not everyone is equally proficient and there are disparate ways of managing or adjusting to a chronic condition and reasons for doing so. This is illustrated by the shifting perspectives model of chronic illness. Depending on the situation, the focus can be on the illness or on wellness (98). Focusing too much on wellness, thereby ignoring the condition related symptoms or changes, is sometimes seen in work situations when workers prioritize work over managing symptoms and limitations. This behavior can be a sign of lower levels of self-control, whereby the worker is not able to self-manage and can cause possible negative effects on future prospects. The difficulty of managing a chronic condition in the workplace also depends on the

type of the condition. In the synthesis presented here, studies on seven chronic conditions showed differences in individual management of these conditions. A condition such as DM type 1 requires a specific strategy to manage symptoms and limitations, that is distinct from MS or depression. However, for all seven chronic conditions, workers need to take responsibility and respond adequately to symptoms of the condition with long-term goals of preventing condition progression and staying productive at work.

The work, social and health care environment influence and interact with the elements of self-control in the workplace. Based on this synthesis here, the work environment appears to be the most important, since it influences all four elements of self-control for the worker with a chronic condition. An accepting workplace culture and an understanding and trusting relationship with co-workers, supervisors and employers facilitate self-control. The relevance of the work environment for the ability of working with a chronic condition becomes clear with the numerous reviews being performed on the relationship between a work environment and a variety of chronic conditions and disorders. All these reviews showed that a work environment with unfavorable work characteristics, such as low supervisor support, high job strain and a poor social climate at work, has a negative effect on the chronic condition and symptom progression (99-102). At the basis of an understanding and accepting work environment lies the employers and co-workers' knowledge of the presence of a worker's chronic condition and the impact of this condition on their work. Besides the obvious relevance of the health care environment, this synthesis also pointed at the social environment, e.g. family and friends, as an important source of support. However, the importance of the social environment for a worker's ability to exert self-control at work appeared limited compared to the influence of the work environment. This may have to do with the included studies' focus and the search strategy that included the work environment as a major category in the search terms. That said, the social environment is obviously of great importance for maintaining the right work-life balance.

Considering all the theories described in the introduction, different aspects could play a role in exerting self-control or self-control failure at work for workers with a chronic condition. Non-disclosure is an important element. Using the Integrative Self-Control Theory by Kotabe, the conflict between the higher order goal, in this study sustainable work participation, and the desire for the chronic condition to remain invisible, inhibits disclosure of the chronic condition at work. The fact that workers make a trade off what they tell, when and to whom, implies that



disclosure is a deliberate decision, as part of a reflective process. Motivation also appears to play a role in exerting self-control at work, as can be deduced from the subjective value that workers add to work and the worker role and their desire and determination to continue working. Next to the capacity or motivation to exert self-control in workers with a chronic condition, our study shows the importance of the work context in exerting self-control. Characteristics of the work environment, such as the attitude and knowledge of the employer and the presence or absence of a clear policy, can act as enactment constraints for exerting self-control, making it difficult to exert self-control in specific situations. This observation has important consequences for future policy and practice, but also on interventions to be developed for workers with a chronic condition.

### **Strengths and limitations**

The strength of this study is the systematic approach for synthesizing the literature on work participation for workers with a chronic condition in a multidisciplinary team. This synthesis increased insight and understanding of the concept of self-control for these workers, and provided valuable information for the development of interventions aimed at enhancing these workers' self-control. One limitation of our study was the inclusion of seven selected chronic conditions. Outcomes may have differed if other or additional chronic conditions had been included. Another limitation was the ratio of studies of workers with specific chronic conditions (more studies included for RA ( $n = 5$ ) and MS ( $n = 4$ ) compared to the other five conditions). This may be linked to the eloquence of these specific groups, in contrast to for example workers with mental illnesses (103, 104). Also, although we systematically searched four large databases for relevant articles to include in this qualitative synthesis, we did not search in all databases (e.g. Web of Science, Scopus). This may have led to selection bias of the included articles. Possibly, conducting a scoping review prior to this qualitative synthesis could have identified additional databases, which could have provided even more relevant articles. However, we do expect that for the aim of this qualitative synthesis, we managed to include the main elements of self-control at work. Some studies included participants who were on sick leave or currently unemployed, although these participants may have provided valuable information because of their previous work experiences. A final limitation was the underexposure of the interaction with the other domains (social and health care environment), as a consequence of including studies focusing mainly on the work context, while those focusing mainly on the social and/or health care environment were excluded.

## Practical implications

In general, people with high self-control are able to better control their thoughts, emotions, responses and behaviors. Research has demonstrated that practice and training can increase the level of self-control on laboratory-based tasks as well as behaviors associated with good health such as diet, exercise, and alcohol consumption (35). However, a meta-analysis on the effect of training on self-control, shows only a small effect (21, 105). Changing the context in which self-control can be exerted, has shown to be a successful strategy in changing behavior (106).

So how about self-control at work for workers with a chronic condition? Do we expect every worker to exert self-control at work, possibly after training? What needs to change in the worker with a chronic condition or in the work environment to achieve this? It is not realistic to expect high levels of self-control at work for all workers with a chronic condition, because of the complexity of the concept and differences in work situations. Exerting self-control at work is also dependent on the influence of the environment. It is desirable that workers with a chronic condition are aware of the four elements of self-control at work identified in this study, and possibly using them as a first step in taking control over their responses. These elements could also serve as possible starting points for support in improving self-control at work for workers with a chronic condition. Having self-control allows for a better adaptation to new situations, and can lead to improved feelings of health and wellbeing, thereby enhancing the sustained employability of a vulnerable group of workers.

For optimal self-control at work to be exerted, knowledge, attitudes and policies are important aspects to consider for both the worker and his or her environment. Since the work environment plays a crucial role, efforts must be made to increase support in the workplace, so workers with a chronic condition are enabled to exert self-control. This implies that the work environment needs to change to a more supportive work environment.

Because the work environment will not change by itself, proactively educating and raising awareness among employers, supervisors and co-workers is necessary to create this supportive environment. By increasing knowledge and awareness of the impact of a chronic condition on work and work ability and the necessary resources for a working life with a chronic condition, understanding and acceptance by co-workers, supervisors and employers can be raised. Additionally, the value of workers with a chronic condition and the importance of preventing

job loss must be made clear to employers and supervisors in order to make sustainable employment possible. A clear company policy aimed at facilitating all workers with a chronic condition in acquiring accommodations can also be a helpful tool. Occupational health professionals could play a key role in stimulating this supportive work environment and exerting self-control by proactive education and training, creating awareness, providing advice and information to employers as well as workers. Occupational health professionals can use the four elements influencing perceived self-control by workers to structure the information and advice needed to support work participation. Although a standardized approach for supporting workers with a chronic condition would be the optimal long-term solution, however, the question is whether this is feasible with the continuously changing work environment influencing the exertion of self-control, e.g. knowledge and attitude of employers.

Currently, the health care system in most high-income countries focuses merely on the treatment of symptoms of the condition and to a lesser extent on the overall wellbeing of workers with chronic conditions. By addressing the impact of the condition on working life, people become aware of possible work-related problems, thus enabling them to find solutions for these problems at an early point in time. Referring people with a chronic condition to an occupational health professional could be helpful, especially for unpredictable and progressive conditions. This professional could form a bridge between the medical specialists on the one side and the working environment on the other side. An improved communication between medical specialists and occupational health professionals could further aid in preventing work-related problems for these workers.

### **Research recommendations**

Although this qualitative synthesis is a good starting point for investigating self-control at work for workers with a chronic condition, more research is needed, providing more clarity on the underlying mechanisms of successful and unsuccessful exertion of self-control at work. By further exploring quantitatively and qualitatively self-control at work in different contexts and for different chronic conditions, more refined models for self-control at work could be developed. Additionally, more research is needed on the development of interventions that positively influence the four elements of self-control within the worker with a chronic condition as well as interventions that increase the support in the work environment. These interventions could aid workers in the exertion of self-control and employers in planning and providing optimal support for employees with different chronic conditions.

## Conclusion

This qualitative synthesis contributes to the understanding of self-control at work for workers with a chronic condition. Self-control at work means making the effort to change one's life and adjust to new circumstances of working with a chronic condition. The findings indicate that four elements need to be considered: disclosure, finding a healthy balance, requesting accommodations and support, and management of symptoms and limitations in the workplace. The work environment is thereby crucial for a worker's ability to exert self-control. Exerting self-control at work can facilitate workers with a chronic condition and will lead to sustainable work participation.



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## **Supplementary Information**

Table 1. PubMed Search

Table 2. Embase.com Search

Table 3. PsycINFO (via Ebsco) Search

Table 4. Cinahl (via Ebsco) Search

Table 5. Elements of self-control addressed by included studies

**Table 1.** PubMed Search

Search	Query	Items found
#7	#6 NOT (("Adolescent"[Mesh] OR "Child"[Mesh] OR "Infant"[Mesh] OR adolescen*[tiab] OR child*[tiab] OR schoolchild*[tiab] OR infant*[tiab] OR girl*[tiab] OR boy*[tiab] OR teen[tiab] OR teens[tiab] OR teenager*[tiab] OR youth*[tiab] OR pediatr*[tiab] OR paediatr*[tiab] OR puber*[tiab]) NOT ("Adult"[Mesh] OR adult*[tiab] OR man[tiab] OR men[tiab] OR woman[tiab] OR women[tiab]))Filters: Publication date from 2007/01/01	2099
#6	#5 NOT (("Adolescent"[Mesh] OR "Child"[Mesh] OR "Infant"[Mesh] OR adolescen*[tiab] OR child*[tiab] OR schoolchild*[tiab] OR infant*[tiab] OR girl*[tiab] OR boy*[tiab] OR teen[tiab] OR teens[tiab] OR teenager*[tiab] OR youth*[tiab] OR pediatr*[tiab] OR paediatr*[tiab] OR puber*[tiab]) NOT ("Adult"[Mesh] OR adult*[tiab] OR man[tiab] OR men[tiab] OR woman[tiab] OR women[tiab]))	2885
#5	#1 AND #2 AND #3 AND #4	3029
#4	"Qualitative Research"[Mesh] OR "Focus Groups"[Mesh] OR "Interview" [Publication Type] OR "Interviews as Topic"[Mesh] OR "Narration"[Mesh] OR "Personal Narratives as Topic"[Mesh] OR "Grounded Theory"[Mesh] OR "Observational Studies as Topic"[Mesh] OR "Observational Study" [Publication Type] OR "Tape Recording"[Mesh] OR thematic analys*[tiab] OR content analys*[tiab] OR focus group*[tiab] OR ethnograph*[tiab] OR ethnograf*[tiab] OR etnograf*[tiab] OR field stud*[tiab] OR participant observati*[tiab] OR participatory research[tiab] OR phenomenolog*[tiab] OR narration*[tiab] OR narrative[tiab] OR qualitative stud*[tiab] OR qualitative analys*[tiab] OR qualitative research*[tiab] OR qualitative method*[tiab] OR multimethodolog*[tiab] OR mixed method*[tiab] OR tape recording*[tiab] OR taperecording*[tiab] OR audio recording*[tiab] OR audiorecording*[tiab] OR audiotape*[tiab] OR observation*[tiab] OR grounded theory[tiab] OR observational stud*[tiab] OR observational research*[tiab] OR ((semi-structured[tiab] OR semistructured[tiab] OR unstructured[tiab] OR informal[tiab] OR in-depth[tiab] OR indepth[tiab] OR face-to-face[tiab] OR structured[tiab] OR guide*[tiab]) AND (interview*[tiab] OR discussion*[tiab] OR questionnaire*[tiab]))	1088453
#3	"Work"[Mesh] OR "Employment"[Mesh:NoExp] OR "Workplace"[Mesh] OR work-life balanc*[tiab] OR life work balanc*[tiab] OR workplace*[tiab] OR "at work"[tiab] OR place of work[tiab] OR work location*[tiab] OR work site*[tiab] OR work place*[tiab] OR job[tiab] OR jobs[tiab] OR worksite*[tiab] OR employment[tiab] OR employed[tiab] OR employabilit*[tiab] OR employee*[tiab] OR labor force[tiab] OR work performanc*[tiab] OR work retention*[tiab] OR work continuation[tiab] OR staying at work[tiab] OR worker*[tiab] OR working abilit*[tiab] OR work abilit*[tiab] OR "working in"[tiab] OR working life*[tiab] OR work life*[tiab] OR working situation*[tiab] OR work situation*[tiab] OR occupational abilit*[tiab] OR occupational activ*[tiab] OR occupational life*[tiab] OR occupational situation*[tiab] OR vocational abilit*[tiab] OR vocational situation*[tiab] OR productivity[tiab]	655760

Search	Query	Items found
#2	"Adaptation, Psychological"[Mesh] OR "Self Care"[Mesh] OR "Power (Psychology)"[Mesh] OR "Health Knowledge, Attitudes, Practice"[Mesh] OR "Attitude to Health"[Mesh:NoExp] OR "Disease Management"[Mesh] OR self care[tiab] OR self manag*[tiab] OR disease manag*[tiab] OR coping[tiab] OR adaptation*[tiab] OR adaptive behavior*[tiab] OR adaptive behaviour*[tiab] OR control[tiab] OR empower*[tiab] OR attitude*[tiab] OR perception*[tiab] OR needs[tiab] OR enabler*[tiab] OR resilienc*[tiab] OR facilitator*[tiab] OR barrier*[tiab] OR strategy[tiab] OR strategies[tiab]	3915074
#1	"Chronic Disease"[Mesh] OR chronic disease*[tiab] OR chronic ill*[tiab] OR chronically ill*[tiab] OR chronic disorder*[tiab] OR chronic condition*[tiab] OR "Diabetes Mellitus"[Mesh] OR diabetes[tiab] OR diabetic*[tiab] OR dm1[tiab] OR iddm[tiab] OR dm 1[tiab] OR t1d*[tiab] OR dm type 1[tiab] OR dm type I[tiab] OR "Coronary Disease"[Mesh] OR coronary disease*[tiab] OR coronary heart disease*[tiab] OR coronary artery disease*[tiab] OR "Inflammatory Bowel Diseases"[Mesh] OR inflammatory bowel dis*[tiab] OR ulcerative colitis[tiab] OR colitis ulcerosa[tiab] OR crohn*[tiab] OR ibd[tiab] OR "Asthma"[Mesh] OR asthma*[tiab] OR "Depression"[Mesh] OR "Depressive Disorder"[Mesh:NoExp] OR depress*[tiab] OR "Rheumatic Diseases"[Mesh] OR rheum*[tiab] OR arthriti*[tiab] OR arthritic[tiab] OR "Multiple Sclerosis"[Mesh] OR "Neuromuscular Diseases"[Mesh:NoExp] OR multiple sclerosis[tiab] OR MS[tiab]	2292313

**Table 2.** Embase.com Search

Search	Query	Items found
#8	#7 AND [1-1-2007]/sd	2766
#7	#6 NOT ('conference abstract'/it OR 'conference review'/it)	3717
#6	#5 NOT (('adolescent'/exp OR 'child'/exp OR adolescent*:ti,ab OR child*:ti,ab OR schoolchild*:ti,ab OR infant*:ti,ab OR girl*:ti,ab OR boy*:ti,ab OR teen:ti,ab OR teens:ti,ab OR teenager*:ti,ab OR youth*:ti,ab OR pediatr*:ti,ab OR paediatr*:ti,ab OR puber*:ti,ab ) NOT ('adult'/exp OR 'aged'/exp OR 'middle aged'/exp OR adult*:ti,ab OR man:ti,ab OR men:ti,ab OR woman:ti,ab OR women:ti,ab))	5399
#5	#1 AND #2 AND #3 AND #4	5830
#4	qualitative research'/exp OR 'grounded theory'/exp OR 'participatory research'/exp OR 'interview'/exp OR 'observational method'/exp OR 'narrative'/exp OR 'audio recording'/exp OR 'thematic analys*':ab,ti OR 'content analys*':ab,ti OR 'focus group*':ab,ti OR ethnograph*':ab,ti OR ethnograf*':ab,ti OR etnograf*':ab,ti OR 'field stud*':ab,ti OR 'participant observati*':ab,ti OR 'participatory research':ab,ti OR phenomenolog*':ab,ti OR narration*':ab,ti OR narrative:ab,ti OR 'qualitative stud*':ab,ti OR 'qualitative analys*':ab,ti OR 'qualitative research*':ab,ti OR 'qualitative method*':ab,ti OR multimethodolog*':ab,ti OR 'mixed method*':ab,ti OR 'tape recording*':ab,ti OR taperecording*':ab,ti OR 'audio recording*':ab,ti OR audiorecording*':ab,ti OR audiotape*':ab,ti OR observation*':ab,ti OR 'grounded theory':ab,ti OR 'observational stud*':ab,ti OR 'observational research*':ab,ti OR ('semi-structured':ab,ti OR semistructured:ab,ti OR unstructured:ab,ti OR informal:ab,ti OR 'in-depth':ab,ti OR indepth:ab,ti OR 'face-to-face':ab,ti OR structured:ab,ti OR guide*':ab,ti AND (interview*':ab,ti OR discussion*':ab,ti OR questionnaire*':ab,ti))	1399275
#3	'work'/exp OR 'employment'/exp OR (work NEAR/3 life NEAR/3 balanc*):ab,ti OR workplace*:ab,ti OR 'at work':ab,ti OR (place NEAR/3 work):ab,ti OR (work NEAR/3 location*):ab,ti OR 'work site*':ab,ti OR job:ab,ti OR jobs:ab,ti OR worksite*:ab,ti OR employment:ab,ti OR employed:ab,ti OR employabilit*':ab,ti OR employee*':ab,ti OR 'labor force':ab,ti OR (work NEAR/3 performanc*):ab,ti OR (work NEAR/3 retention*):ab,ti OR (work NEAR/3 continuation):ab,ti OR 'staying at work':ab,ti OR worker*':ab,ti OR (work* NEAR/3 abilit*):ab,ti OR 'working in':ab,ti OR 'working life*':ab,ti OR 'work life*':ab,ti OR 'working situation*':ab,ti OR 'work situation*':ab,ti OR 'occupational abilit*':ab,ti OR 'occupational activ*':ab,ti OR 'occupational life*':ab,ti OR 'occupational situation*':ab,ti OR 'vocational abilit*':ab,ti OR 'vocational situation*':ab,ti OR productivity:ab,ti	980149
#2	adaptive behavior'/exp OR 'self care'/exp OR 'coping behavior'/de OR 'empowerment'/exp OR 'attitude to health'/exp OR 'attitude to illness'/exp OR 'employee attitude'/exp OR 'self care':ab,ti OR 'self manag*':ab,ti OR 'disease manag*':ab,ti OR coping:ab,ti OR adaptation*':ab,ti OR 'adaptive behavior*':ab,ti OR 'adaptive behaviour*':ab,ti OR control:ab,ti OR empower*':ab,ti OR attitude*':ab,ti OR perception*':ab,ti OR needs:ab,ti OR enabler*':ab,ti OR resilien*':ab,ti OR facilitator*':ab,ti OR barriers:ab,ti OR strategy:ab,ti OR strategies:ab,ti	4632366



Search	Query	Items found
#1	'chronic disease'/exp OR 'chronic patient'/exp OR 'chronic disease*':ab,ti OR 'chronic*ill*':ab,ti OR 'chronic disorder*':ab,ti OR 'chronic condition*':ab,ti OR 'diabetes mellitus'/exp OR diabetes:ab,ti OR diabetic*':ab,ti OR dm1:ab,ti OR iddm:ab,ti OR 'dm 1':ab,ti OR t1d*':ab,ti OR 'dm type 1':ab,ti OR 'dm type i':ab,ti OR 'coronary artery disease'/exp OR 'coronary near/3 disease*':ab,ti OR 'inflammatory bowel disease'/exp OR 'inflammatory bowel dis*':ab,ti OR 'ulcerative colitis':ab,ti OR 'colitis ulcerosa':ab,ti OR crohn*':ab,ti OR ibd:ab,ti OR 'asthma'/exp OR asthma*':ab,ti OR 'depression'/exp OR depress*':ab,ti OR 'rheumatic disease'/exp OR rheum*':ab,ti OR arthriti*':ab,ti OR arthritic:ab,ti OR 'multiple sclerosis'/exp OR 'neuromuscular junction disorder'/de OR 'multiple sclerosis':ab,ti OR ms:ab,ti	3098557

**Table 3.** PsycINFO (via Ebsco) Search

Search	Query	Items found
S6	S5 NOT ((ZG ("adolescence (13-17 yrs)" OR "childhood (birth-12 yrs)" OR "infancy (2-23 mo)" OR "neonatal (birth-1 mo)" OR "preschool age (2-5 yrs)" OR "school age (6-12 yrs)") OR TI (adolescenc* OR child* OR schoolchild* OR infant* OR girl* OR boy* OR teen OR teens OR teenager* OR youth* OR pediater* OR paediatr* OR puber*) OR AB (adolescenc* OR child* OR schoolchild* OR infant* OR girl* OR boy* OR teen OR teens OR teenager* OR youth* OR pediater* OR paediatr* OR puber*)) NOT (ZG ("adulthood (18 yrs & older)" OR "aged (65 yrs & older)" OR "middle age (40-64 yrs)" OR "thirties (30-39 yrs)" OR "very old (85 yrs & older)") OR TI (adult* OR man OR men OR woman OR women) OR AB (adult* OR man OR men OR woman OR women))) Limiters: Publication Year: 2007-2017	2643
S5	S1 AND S2 AND S3 AND S4	3666
S4	DE ("Qualitative Research" OR "Grounded Theory" OR "Interviews" OR "Observation Methods" OR "Narratives" OR "Audiotapes") OR TI ("thematic analys*" OR "content analys*" OR "focus group*" OR ethnograph* OR ethnograf* OR etnograf* OR "field stud*" OR "participant observati*" OR "participatory research" OR phenomenolog* OR narration* OR narrative OR "qualitative stud*" OR "qualitative analys*" OR "qualitative research*" OR "qualitative method*" OR multimethodolog* OR "mixed method*" OR "tape recording*" OR taperecording* OR "audio recording*" OR audiorecording* OR audiotape* OR observation* OR "grounded theory" OR "observational stud*" OR "observational research*" OR (("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide*) AND (interview* OR discussion* OR questionnaire*)) OR AB ("thematic analys*" OR "content analys*" OR "focus group*" OR ethnograph* OR ethnograf* OR etnograf* OR "field stud*" OR "participant observati*" OR "participatory research" OR phenomenolog* OR narration* OR narrative OR "qualitative stud*" OR "qualitative analys*" OR "qualitative research*" OR "qualitative method*" OR multimethodolog* OR "mixed method*" OR "tape recording*" OR taperecording* OR "audio recording*" OR audiorecording* OR audiotape* OR observation* OR "grounded theory" OR "observational stud*" OR "observational research*" OR (("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide*) AND (interview* OR discussion* OR questionnaire*))	504764

Search	Query	Items found
S3	DE ("Work (Attitudes Toward)" OR "Employee Attitudes" OR "Occupational Attitudes" OR "Family Work Relationship" OR "Working Conditions" OR "Occupational Health" OR "Quality of Work Life" OR "Work Load" OR "Employment Status" OR "Employability" OR "Work-Life Balance") OR TI ((work N3 life N3 balanc*) OR workplace* OR "at work" OR (place N3 work) OR (work N3 location*) OR "work site*" OR job OR jobs OR worksite* OR employment OR employed OR employabilit* OR employee* OR "labor force" OR (work N3 performanc*) OR (work N3 retention*) OR (work N3 continuation) OR "staying at work" OR worker* OR (work* N3 abilit*) OR "working in" OR "working life*" OR "work life*" OR "working situation*" OR "work situation*" OR "occupational abilit*" OR "occupational activ*" OR "occupational life*" OR "occupational situation*" OR "vocational abilit*" OR "vocational condition*" OR productivity) OR AB ((work N3 life N3 balanc*) OR workplace* OR "at work" OR (place N3 work) OR (work N3 location*) OR "work site*" OR job OR jobs OR worksite* OR employment OR employed OR employabilit* OR employee* OR "labor force" OR (work N3 performanc*) OR (work N3 retention*) OR (work N3 continuation) OR "staying at work" OR worker* OR (work* N3 abilit*) OR "working in" OR "working life*" OR "work life*" OR "working situation*" OR "work situation*" OR "occupational abilit*" OR "occupational activ*" OR "occupational life*" OR "occupational situation*" OR "vocational abilit*" OR "vocational condition*" OR productivity)	740809
S2	DE ("Adaptation" OR "Adaptive Behavior" OR "Adaptability (Personality)" OR "Self-Care Skills" OR "Adjustment" OR "Occupational Adjustment" OR "Self-Management" OR "Interpersonal Control" OR "Empowerment" OR "Coping Behavior" OR "Health Attitudes" OR "Disease Management") OR TI ("self care" OR "self manag*" OR "disease manag*" OR coping OR adaptation* OR "adaptive behavior*" OR "adaptive behaviour*" OR control OR empower* OR attitude* OR perception* OR needs OR enabler* OR resilienc* OR facilitator* OR barriers OR strategy OR strategies) OR AB ("self care" OR "self manag*" OR "disease manag*" OR coping OR adaptation* OR "adaptive behavior*" OR "adaptive behaviour*" OR control OR empower* OR attitude* OR perception* OR needs OR enabler* OR resilienc* OR facilitator* OR barriers OR strategy OR strategies)	1510716
S1	DE ("Chronic Illness" OR "Chronicity (Disorders)" OR "Diabetes" OR "Diabetes Mellitus" OR "Cardiovascular Disorders" OR "Heart Disorders" OR "Ulcerative Colitis" OR "Colitis" OR "Asthma" OR "Depression (Emotion)" OR "Rheumatoid Arthritis" OR "Arthritis" OR "Multiple Sclerosis" OR "Neuromuscular Disorders") OR TI ("chronic disease*" OR "chronic* ill*" OR "chronic disorder*" OR "chronic condition*" OR diabetes OR diabetic* OR dm1 OR iddm OR "dm 1" OR t1d* OR "dm type 1" OR "dm type I" OR "coronary NEAR/3 disease*" OR "Inflammatory bowel dis*" OR "ulcerative colitis" OR "colitis ulcerosa" OR crohn* OR ibd OR asthma* OR depress* OR rheum* OR arthriti* OR arthritic OR "multiple sclerosis" OR MS) OR AB ("chronic disease*" OR "chronic* ill*" OR "chronic disorder*" OR "chronic condition*" OR diabetes OR diabetic* OR dm1 OR iddm OR "dm 1" OR t1d* OR "dm type 1" OR "dm type I" OR "coronary NEAR/3 disease*" OR "Inflammatory bowel dis*" OR "ulcerative colitis" OR "colitis ulcerosa" OR crohn* OR ibd OR asthma* OR depress* OR rheum* OR arthriti* OR arthritic OR "multiple sclerosis" OR MS)	363883

**Table 4.** Cinahl (via Ebsco) Search

Search	Query	Items found
S6	S5 NOT ((MH ("Adolescence" OR "Child+") OR TI (adolescenc* OR child* OR schoolchild* OR infant* OR girl* OR boy* OR teen OR teens OR teenager* OR youth* OR pediath* OR paediatr* OR puber*) OR AB (adolescenc* OR child* OR schoolchild* OR infant* OR girl* OR boy* OR teen OR teens OR teenager* OR youth* OR pediath* OR paediatr* OR puber*)) NOT (MH ("Middle Age" OR "Adult" OR "Young Adult") OR TI (adult* OR man OR men OR woman OR women) OR AB (adult* OR man OR men OR woman OR women))) Limiters - Published Date: 20070101-	1959
S5	S1 AND S2 AND S3 AND S4	3275
S4	MH ("Qualitative Studies" OR "Ethnographic Research" OR "Grounded Theory" OR "Phenomenological Research" OR "Interviews" OR "Semi-Structured Interview" OR "Unstructured Interview" OR "Observational Methods+" OR "Narratives" OR "Focus Groups" OR "Audiorecording") OR TI ("thematic analys*" OR "content analys*" OR "focus group*" OR ethnograph* OR ethnograf* OR etnograf* OR "field stud*" OR "participant observati*" OR "participatory research" OR phenomenolog* OR narration* OR narrative OR "qualitative stud*" OR "qualitative analys*" OR "qualitative research*" OR "qualitative method*" OR multimethodolog* OR "mixed method*" OR "tape recording*" OR taperecording* OR "audio recording*" OR audiorecording* OR audiotape* OR observation* OR "grounded theory" OR "observational stud*" OR "observational research*" OR ((semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide*) AND (interview* OR discussion* OR questionnaire*)) OR AB ("thematic analys*" OR "content analys*" OR "focus group*" OR ethnograph* OR ethnograf* OR etnograf* OR "field stud*" OR "participant observati*" OR "participatory research" OR phenomenolog* OR narration* OR narrative OR "qualitative stud*" OR "qualitative analys*" OR "qualitative research*" OR "qualitative method*" OR multimethodolog* OR "mixed method*" OR "tape recording*" OR taperecording* OR "audio recording*" OR audiorecording* OR audiotape* OR observation* OR "grounded theory" OR "observational stud*" OR "observational research*" OR ((semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide*) AND (interview* OR discussion* OR questionnaire*))	300058

Search	Query	Items found
S3	(MH ("Work" OR "Work Environment" OR "Work-Life Balance" OR "Employment" OR "Employment Status") OR TI ((work N3 life N3 balanc*) OR workplace* OR "at work" OR (place N3 work) OR (work N3 location*) OR "work site*" OR job OR jobs OR worksite* OR employment OR employed OR employabilit* OR employee* OR "labor force" OR (work N3 performanc*) OR (work N3 retention*) OR (work N3 continuation) OR "staying at work" OR worker* OR (work* N3 abilit*) OR "working in" OR "working life*" OR "work life*" OR "working situation*" OR "work situation*" OR "occupational abilit*" OR "occupational activ*" OR "occupational life*" OR "occupational situation*" OR "vocational abilit*" OR "vocational condition*" OR productivity) OR AB ((work N3 life N3 balanc*) OR workplace* OR "at work" OR (place N3 work) OR (work N3 location*) OR "work site*" OR job OR jobs OR worksite* OR employment OR employed OR employabilit* OR employee* OR "labor force" OR (work N3 performanc*) OR (work N3 retention*) OR (work N3 continuation) OR "staying at work" OR worker* OR (work* N3 abilit*) OR "working in" OR "working life*" OR "work life*" OR "working situation*" OR "work situation*" OR "occupational abilit*" OR "occupational activ*" OR "occupational life*" OR "occupational situation*" OR "vocational abilit*" OR "vocational condition*" OR productivity)	276595
S2	(MH ("Adaptation, Psychological+" OR "Adaptation, Occupational" OR "Self Care" OR "Power" OR "Empowerment" OR "Attitude to Health" OR "Attitude to Illness" OR "Coping" OR "Disease Management") OR TI ("self care" OR "self manag*" OR "disease manag*" OR coping OR adaptation* OR "adaptive behavior*" OR "adaptive behaviour*" OR control OR empower* OR attitude* OR perception* OR needs OR enabler* OR resilenc* OR facilitator* OR barriers OR strategy OR strategies) OR AB ("self care" OR "self manag*" OR "disease manag*" OR coping OR adaptation* OR "adaptive behavior*" OR "adaptive behaviour*" OR control OR empower* OR attitude* OR perception* OR needs OR enabler* OR resilenc* OR facilitator* OR barriers OR strategy OR strategies )	663711
S1	MH ("Chronic Disease" OR "Diabetes Mellitus" OR "Diabetes Mellitus, Type 1" OR "Coronary Disease+" OR "Heart Diseases" OR "Inflammatory Bowel Diseases" OR "Colitis, Ulcerative" OR "Crohn Disease" OR "Asthma+" OR "Depression" OR "Rheumatic Diseases" OR "Arthritis, Rheumatoid+" OR "Arthritis" OR "Multiple Sclerosis" OR "Neuromuscular Diseases") OR TI ("chronic disease*" OR "chronic* ill*" OR "chronic disorder*" OR "chronic condition*" OR diabetes OR diabetic* OR dm1 OR iddm OR "dm 1" OR t1d* OR "dm type 1" OR "dm type I" OR "coronary NEAR/3 disease*" OR "Inflammatory bowel dis*" OR "ulcerative colitis" OR "colitis ulcerosa" OR crohn* OR ibd OR asthma* OR depress* OR rheum* OR arthriti* OR arthritic OR "multiple sclerosis" OR MS) OR AB ("chronic disease*" OR "chronic* ill*" OR "chronic disorder*" OR "chronic condition*" OR diabetes OR diabetic* OR dm1 OR iddm OR "dm 1" OR t1d* OR "dm type 1" OR "dm type I" OR "coronary NEAR/3 disease*" OR "Inflammatory bowel dis*" OR "ulcerative colitis" OR "colitis ulcerosa" OR crohn* OR ibd OR asthma* OR depress* OR rheum* OR arthriti* OR arthritic OR "multiple sclerosis" OR MS)	333794

**Table 5.** Elements of self-control addressed by included studies

No.	Author	Theme			
		Disclosure (13/17)	Finding a healthy balance (15/17)	Requesting work accommodations and support (16/17)	Management of symptoms and limitations in the workplace (14/17)
1	Bogenschutz et al.	X	X	X	X
2	Bose, J.	X	X	X	X
3	Burda et al.		X	X	X
4	Codd et al.		X	X	X
5	Crooks et al.			X	X
6	Dickson et al.		X	X	X
7	Holland et al.	X	X	X	
8	Lacaille et al.	X	X	X	X
9	Osterholm et al.	X	X	X	X
10	Van der Meer et al.	X	X	X	X
11	Van der Meide et al.	X	X		X
12	Restall et al.	X	X	X	X
13	Ruston et al.	X		X	X
14	Sallis et al.	X	X	X	X
15	Stanley et al.	X	X	X	
16	Sweetland et al.	X	X	X	
17	Zhao et al.	X	X	X	X



# Part II

**Perspectives on staying at work  
and supporting workers with  
chronic conditions**





# Chapter 3

## **Facilitators, barriers and support needs for staying at work with a chronic condition: a focus group study**

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## Abstract

**Background:** Working with a chronic condition can be challenging. Providing support to workers with a chronic condition can help them to stay at work and prevent work-related problems. Workers with a chronic condition who successfully stay at work can provide valuable input for the development of effective supportive interventions to prevent exit from work and facilitate sustainable employment. The aim of this study is to explore the lived experiences of workers with a chronic condition and identify existing barriers, facilitators and possible support needs for staying at work.

**Methods:** Four focus groups were conducted between August and December 2017 with workers with one or more chronic conditions (n = 30). Participants included employees and (partially) self-employed workers. All focus group data were transcribed verbatim and thematically analyzed.

**Results:** Disclosure and expressing one's needs were considered important personal facilitators for staying at work. Environmental facilitators included receiving practical information on working with a chronic condition and social and employer support. Environmental barriers were identified in the work environment, the health care system and service provision, e.g., manager and co-worker's lack of knowledge about working with a chronic condition, a lack of focus on work in the course of treatment for a chronic condition, dissatisfaction with occupational physician support, and the absence of support for self-employed workers. Provided support should be available to all workers, and be proactive and tailored to the workers' specific support needs.

**Conclusions:** A variety of facilitators, barriers and support needs were identified in various domains. By addressing environmental barriers (e.g., by integrating work in the course of treatment and creating supportive work environments), sustainable employment of workers with a chronic condition can be promoted.

## Background

Working with a chronic condition can be a struggle, since physical or psychological challenges can hamper work performance, potentially resulting in a loss of productivity, extended or frequent sick leave, or job loss (1-3). The number of people in the working population with one or more chronic conditions will continue to rise due to a variety of reasons, amongst others an aging population, unhealthy lifestyles and unfavorable working conditions (4, 5). Although a large percentage of the working population with a chronic condition is able to work, work participation rates among these workers lag behind the general population (6). Staying at work and prevention of work-related problems among workers with a chronic condition is of significant importance, since return to work after reporting being ill has proven to be difficult (5, 7).

Participation in the workforce positively influences wellbeing and improves quality of life, as it brings purpose to life and fosters social contacts (8, 9). Relevant factors enabling workers with a chronic condition to stay at work have been well investigated, and demonstrate that in addition to disease-related factors, personal and environmental factors are critical for sustainable employment (10-12). A wide variety of interventions have been developed to facilitate sustainable employment for these workers, and are aimed at the work environment (e.g. facilitating work accommodations) or directed at the individual worker (e.g. increasing empowerment and self-management skills) (13-15).

In addition to self-management and empowerment, self-control is a relevant factor for staying at work. Empowerment, self-management and self-control are all concepts that relate to one's ability to master a life with a chronic condition and maintain quality of life (16-19). However, some differences between these concepts can be identified. Self-management can, in a broader sense, be defined as the daily management of a chronic condition over the course of the illness, thereby focusing more on managing symptoms, treatments, and the physical and psychosocial consequences of the condition (20). Although both empowerment and self-control link to gaining control over decisions and actions, empowerment can be considered either a social, cultural, psychological or political process (19). Whereas self-control seems more an internal process, with self-control being defined as 'the capacity for altering one's own responses, especially to bring them into line with standards such as ideals, values, morals, and social expectations, and to support the pursuit of long-term goals' (p.351) (21). This also relates to someone's ability to adapt to new situations (22, 23).

Proceeding from the new definition of health from Huber, 'having the ability to adapt and self-manage' (p. 2) (24), having higher levels of self-control at work and the possibility of exerting self-control can improve wellbeing and health. This then facilitates sustainable employment for workers with a chronic condition. Encouraging people with a chronic condition to take control over their lives and their work has been a focal point of the Dutch government and society for a long time (25). In a qualitative synthesis on self-control of workers with a chronic condition, we specified the desired behaviors that are important to staying at work and the influence of these behaviors and their interaction with the environment. The study findings also showed the importance of support for exerting self-control (26).

Exerting desired self-control behaviors is often not enough to stay at work for workers with a chronic condition. Adequate support is also critical, as stated by the European Chronic Disease Alliance (5). Research has already shown the positive effects of supportive work environments for workers with a chronic condition (27). However, other domains, such as occupational health services and medical health care have an important supportive role as well (28, 29). National policies can also have an important influence on sustainable employment of workers with a chronic condition (5). Effective supportive interventions can help workers with a chronic condition to stay at work and achieve sustainable employment. However, workers' specific support needs must first be identified. Workers with a chronic condition who are successful in staying at work can provide valuable input for these supportive interventions. Therefore, the aim of this study is to explore the lived experiences of Dutch workers with a chronic condition who are successful in staying at work, and to identify facilitating factors, existing barriers and possible support needs for staying at work.

## **Methods**

### **Study design**

Four focus groups were conducted between August and December 2017 with various types of workers with a chronic condition. This qualitative research method was used to gain an in-depth understanding of how workers with a chronic condition successfully stay at work, the barriers they face in their working life and their need for support. The consolidated criteria for reporting qualitative research (COREQ) were taken into account with the study design and reporting (30). Representative quotes from the focus groups were translated by a native English speaker and added to illustrate the findings.

## Recruitment

For the recruitment of participants, several Dutch patient organizations (for patients with physical as well as psychological conditions) were approached with the request to promote the study, by placing information about participation on their website, weekly or monthly newsletter or Facebook page. This information included a brief description of the study and a link to the study's website with more extensive information on the focus groups, inclusion criteria and ways to sign up (registration form, or an e-mail or phone call to the researcher). This brief description of the study and the link to the study's website was also placed in a call on LinkedIn and the Amsterdam University Medical Center (Amsterdam UMC) website. To recruit self-employed workers, an association that represents the interests of Dutch self-employed workers was contacted and a request was made to promote the study on their LinkedIn community. Participants were eligible for participating in a focus group if they met the following criteria: 1) had a physical or psychological chronic condition; 2) had paid work; 3) were over 18 years of age; 4) had proficiency of the Dutch language. Over 100 workers with one or more physical chronic conditions indicated their willingness to participate in a focus group. To create heterogeneous focus groups, participants were selected through purposeful sampling, taking gender, age, chronic condition, and type of paid work into account. Participants were contacted by email with a detailed description of the study and a suggestion for date and time. If participants had additional questions, the researcher (AB) contacted them by telephone for further clarification. Out of 61 eligible participants who were contacted, 30 actually participated in the focus groups. Reasons for not participating were: 1) not being able to attend at the suggested date and time or 2) having symptom aggravation.

## Participants

Four focus groups were conducted with 30 participants in total. The first three focus groups included employees and (partially) self-employed workers (n=26), and the fourth focus group had only self-employed workers (n=4). Almost half of the participants worked less than 30 hours a week, with a minimum of 8 hours per week. Most of these participants worked between 20-30 hours a week. Participants suffered from metabolic conditions, lung conditions, musculoskeletal conditions, neurological conditions, digestive tract conditions or a combination of these. Other participant characteristics are shown in Table 1.

**Table 1.** Characteristics of study participants (n = 30)

Characteristics		Number
Sex	Male	6
	Female	24
Age (years)	Mean	46.6
	Range	23 - 73
Type of employment	Employee	19
	(Partially) self-employed worker	11
Working hours	<30	16
	>30	14

### Focus groups

Focus groups were held at the Amsterdam UMC in Amsterdam, the Netherlands. Each focus group lasted approximately two hours and was conducted in Dutch. The focus groups were moderated by researchers from the research team. An observer was present to assist the moderator and monitor the group interaction. The main researcher (AB), a female health scientist with experience in qualitative research was present at all focus groups, either as a moderator or an observer. During all four focus groups, a secretary was present to take notes. A script with topics and open questions was developed to aid the moderators and ensure comparability of the focus groups, thereby increasing reliability. The open questions were pilot tested with three workers with a chronic condition, one of whom was a participant who was not able to attend a focus group. The other two workers were recruited from the researcher's own network. The focus groups started by the researcher explaining the study aim and informed consent forms were then signed. The first part of the focus group entailed discussing the participants' experiences working with a chronic condition, while the second part focused on their perceived support needs to stay at work. An assignment on 'creating the ideal supporter' was part of the focus group discussion. At the end of each focus group, participants received a gift certificate and travel expenses were accounted for. Data saturation was achieved after the four focus groups.

### Data analysis

All focus groups were digitally recorded and the data was transcribed verbatim. Transcription was performed by a specialized external agency. Summaries of the focus groups were made and sent to all participants for a member check. Thematic analysis was used to analyze the collected data (31). The analytic process included several stages starting with reading and rereading of the transcripts to become familiar with the data. An inductive approach was used to

analyze the data starting with line-by-line coding of the transcripts. During this open coding process, qualitative data indexing software (ATLAS.ti) was used to assist the coding process and helped to produce an initial list with codes. The next stage of analysis was sifting through the data to search for similarities and discrepancies, and ultimately grouping and combining codes into subthemes in an iterative manner. All data was coded by the main researcher (AB) and by two trained research assistants (health sciences interns). Weekly meetings were held to discuss disagreements in the coding and grouping process until consensus was reached. The last stage consisted of discussions among members of the research team (AB, CB, FS, JA) until consensus was reached on the final themes.

### **Ethical considerations**

All participants signed an informed consent form at the start of the focus group. Written and oral information was provided to all participants on the confidentiality and anonymity of the results of the study. The Medical Ethical Committee confirmed that ethical approval was not required because The Medical Research Involving Human Subjects Act ('Wet Medisch-wetenschappelijk Onderzoek met Mensen') does not apply to this study.

## **Results**

Themes were identified after data analysis of the lived experiences of workers with a chronic condition. The themes related to personal and environmental factors that helped workers with a chronic condition to stay at work (disclosure, communication and expression of one's needs, decision-making based on what is important in life, perseverance and securing boundaries, and environmental facilitators). Themes also included remaining barriers in various contexts (knowledge and regulations in the workplace, occupational and medical health services, and social security) and the needs for support to stay at work for workers with a chronic condition (support available to all workers, characteristics of the ideal supporter, and how and when to offer support). An overview of themes is presented in Table 2.



**Table 2.** Overview of themes

<b>Personal and Environmental facilitators</b>	Disclosure
	Communication and expression of one's needs
	Decision-making based on what is important in life
	Perseverance and securing boundaries
	Environmental facilitators
<b>Environmental barriers</b>	Knowledge and regulations in the workplace
	Occupational and medical health services
	Social security
<b>Support needs</b>	Support available to all workers
	Characteristics of the ideal supporter
	How and when to offer support

## Disclosure

Many participants had disclosed their condition to their employer and co-workers. They determined the right moment to disclose their condition; as long as the participants were able to function at work and the condition was not visible, they often did not feel the urge to disclose their condition. Disclosure brought these workers understanding and support, making it possible for their employers to consider their condition and create work accommodations. One participant explained his sense of relief after having disclosed his condition to his employer, and thus making it possible to be himself at work again. Some participants just felt that disclosing their condition was the right thing to do, since their condition is part of who they are.

*"In solidarity with my colleagues, with whom I always have a very involved relationship, I had something like this: 'this is going on in my life, so just as I tell you what I do over the weekend, I also tell you about this (the chronic condition)'." (FG1, employee)*

Some participants had not disclosed their condition to their employers. Just having started a new job, or fear of losing their jobs were mentioned as reasons for non-disclosure. One participant explained that she kept getting better at making excuses for her inability to perform certain tasks and even wondered herself why she did not disclose her condition.

### **Communication and expressing one's needs**

Many participants stated the importance of clear communication and expression of their support needs. Several participants had requested support (e.g., work accommodations) from employers and co-workers when needed. Some participants struggled with the dilemma of asking for help or doing a task themselves. Requesting support did not come naturally for all participants, it sometimes took a while to cross this threshold as expressed by this participant:

*"One day you are able to do it (certain tasks), while the other day....But that really means, and that is a victory I have had to achieve for myself, is that I have to ask. If I do not succeed, then I must say it, because someone else [...] no one sees that I am sick." (FG1, employee)*

### **Decision-making based on what is important in life**

Many participants expressed their motivation to work and had the desire to stay at work. They spoke extensively about the meaning of work as a facilitator (e.g. financial security, social contacts, participating in society) and the importance of work in relation to other life domains. The right balance between work, health and personal life was important for staying at work. This meant having a job that matched their capacities. In addition, participants also had to make decisions based on what they thought was important in life and on how they wished to spend their energy. For some participants, this meant not going to a party or other social event. Others stated that their personal life had become even more important after their diagnosis. Therefore, some had chosen to work fewer hours a week or in a less demanding job, thereby saving enough energy for other activities. One participant explained that she sometimes made a conscious decision to participate in a certain activity for the sake of her mental wellbeing, knowing that she would suffer the consequences later on:

*"Sometimes, I make a conscious decision to go beyond my physical limits because I know I will feel a lot better mentally. I prefer to lie down on the couch the next day like a dead bird and having enjoyed something that I really wanted to do, than be at home and feeling physically okay and think, shit now, I am not part of that (social activity)..." (FG3, employee)*

### **Perseverance and securing boundaries**

Several participants pointed out that they want to be positive, stay busy and do not like to complain despite their pain or other symptoms. This perseverance helped them to stay at work.

*"I have been in a Facebook group of the Rheumatism Fund and there were only people complaining, 'Oh, I have such pain today, yes, so do I'. You know, I got out, I was in it for two days, and I was completely mad. I don't want to be negative, I want to be positive, I want to move forward, I want to look the other way." (FG1, employee)*

At the same time, guarding boundaries was another crucial facilitator for workers to stay at work. Many participants expressed their difficulty with maintaining boundaries and saying "no" if their workload was too great. Some self-employed workers pointed out that they could decide for themselves how much work to take on. This helped them find the right balance between work, health and personal life. This flexibility was considered to be the great advantage of being self-employed. However, for most self-employed participants, this flexibility was not the reason for becoming self-employed, since the majority had already been self-employed prior to their diagnosis. Having a partner as main breadwinner facilitated this flexibility.

*"You know, and now I can just say 'no, I can't do it next week', while I have a very empty agenda, so to speak, but I, there is no one checking up on me." (FG4, self-employed worker)*

### **Environmental facilitators**

Participants considered the support they received from multiple directions as an important facilitator. A partner who helps with household chores and provides emotional support, and an employer who looks after their employees by thinking about solutions to work-related problems were mentioned as important for staying at work. One participant explained how his employer paid for a stay in a spa in Montenegro after his health insurance no longer covered these expenses. Several participants indicated the relevance of recognition by managers and supervisors. One participant illustrated this by describing that her employer paid for her new education, which enabled her to switch to a suitable job within the organization.

*"They themselves have looked at what is useful to do within the organization, what is needed, the study is also paid, that is really ideal." (FG3, employee)*

Some participants mentioned patient organizations or other groups that provide practical information and support. One participant described the availability of such an organization located in the hospital:

*"I always saw it as a kind of tourist office, they had all sorts of information, they had contact with physiotherapists, they knew everything about high / low desks, rolling stools that were good for people with Bechterew's disease, they had all sorts of information and they were indeed constantly calling out 'do you need something, are you doing well at work?'" (FG3, partially self-employed worker)*

### **Knowledge and regulations in the workplace**

Many participants spoke about their colleagues and managers' lack of knowledge on working with a chronic condition. Although not intentional, this lack of knowledge led to unpleasant situations in some cases:

*"Because my supervisor, who thought for me: 'I will make the decision for her whether she is allowed to do this or that or that. Or being capable of.' And that is of course, without any consultation, a painful matter. And of course, very frustrating." (FG2, employee)*

This lack of knowledge coincided with prejudices about certain chronic conditions and a worker's ability to perform with their condition. A possible result was patronizing or a permanent take-over of certain tasks by co-workers. Some participants explained that this presented a barrier for disclosure or requesting support.

*"But, I am not so fond of patronizing, it is not meant to be wrong, it is only: 'Oh, how are you now'? Well, it makes me itch when I think about it and that's why I have sometimes said: 'Did I do right to disclose?'" (FG1, employee)*

Participants also mentioned their struggle with rules and regulations within their organizations and how these were applied by managers or supervisors. Several participants mentioned that in some cases regulations were applied at random and not in a fair way.

*"Organizations have their own rules, which are then applied randomly." (FG2, employee)*

### **Occupational and medical health services**

Some participants expressed their dissatisfaction with the current guidance and support from their occupational physicians. This was given as a reason for not seeking additional support from these professionals. Being on the side of the employer, a lack of knowledge of chronic conditions or not giving useful advice

were underlying causes for this negative attitude toward occupational physicians.

*"And then at some point he did have a tip, the think-along tip, so I work three days, right, 20 hours. Yes, then I could divide those 20 hours over 5 days. Well, I didn't think that was such a good tip." (FG2, employee)*

A major barrier brought up by a large number of participants was the health care professionals and medical specialists' lack of attention to employment and paid work during the course of treatment, despite the importance of work for these workers.

*"It would also be nice if a specialist already offered this (information on working with a chronic condition), because working is just very important for everyone. I think that this subject (work) is underexposed, also by the hospital itself, but that is my experience." (FG2, employee)*

In some cases, this led to advice by medical specialists to quit working or at least reduce working hours:

*"I do not cooperate with him (the specialist). He really finds it amazing that I am still working. He says: 'Then reduce (in working hours) a little, then reduce a little.'" (FG2, employee)*

All participants had to deal with doctor or hospital appointments and visits to other health care professionals, such as a physical therapists. These appointments had a significant impact on their work, because in most cases they were forced to plan their appointments during working hours. According to participants, it would be helpful if these appointments could be made in more suitable hours, thereby lessening the impact on their work.

*"The physical therapist for people with rheumatism is available on Tuesday afternoon at one o'clock and Friday afternoon at one o'clock. And if you work all day, then one o'clock is a terrible time [...] then you have to exercise for an hour, get stressed out back to work and then you actually still have to work. But you actually don't have the energy anymore to work. So, you know, it (the consultation with physical therapists) just has to be offered in the evening too." (FG1, employee)*

## Social security

Several of the participants identified the complexity of the Dutch Social Security Institute (DSSI) as a barrier. They explained that they had received or still receive a (partial) benefit from the DSSI. The DSSI enforces many rules, sometimes even contradictory, which makes it a complex, hard-to-understand system as expressed by some participants. This has also led to much distrust towards the DSSI. One participant illustrated her feeling of being thwarted by the DSSI instead of helped:

*"I am still able to work, I still work now. So I can work and then you get advice: 'why don't you do volunteer work?' And now, I get the advice: 'You have to work fewer hours because otherwise we will give you a fine and we have to reclaim your benefit and everything.' So, next month, I'm going to work fewer hours, but only on paper. So I am actually going to work my own hours, sort of like doing volunteer work in my own job or something." (FG1, employee)*

None of the self-employed workers had occupational disability insurance. The difficulty of finding insurance with an already existing health problem and the size of the premium served as barriers for obtaining this insurance for self-employed participants. The absence of this financial safety net created feelings of insecurity. Additionally, the self-employed participants spoke about their difficulties with receiving support; they have no one to turn to compared to employees who can ask for help from their employer or occupational health professional. Some self-employed participants explained that they sometimes ask their physical therapist, specialist nurse or friends for advice on how to cope with certain problems.

*"So, there is no contact person, there is no one focused on self-employed entrepreneurs, and therefore there is absolutely no help, you must have had very good assertiveness training first before you can get any help at all." (FG4, self-employed worker)*

One participant spoke of the lack of information provided by the DSSI. She knew the DSSI could offer some support, however, when she contacted them, no one could help her.

*"But for work things you actually have nothing. But it seems, although there is nothing on writing, but the DSSI can certainly help you make your work easier. [...] But there is nobody (at the DSSI) available. If you call the DSSI nobody knows anything." (FG4, self-employed worker)*

### **Support available to all workers**

Participants pointed out that support should be made available to all workers, employees as well as self-employed workers, even for people with a chronic condition who would like to enter the labor market. By paying more attention to paid work in the treatment processes of chronic conditions, support can be made available to all these workers. Some participants suggested an occupational physician at the outpatient clinic, since this would make support available for all who need it.

*"In my ideal situation, there is a company doctor at an outpatient clinic where you don't have the hassle that a medical specialist says A and a company doctor says B, but that together they eh. And then, the company doctor is also accessible for people like us who are self-employed, but also for people who are looking for a job. They (people looking for work) also do not have a company doctor." (FG2, self-employed worker)*

More support for self-employed workers must also be made available, as illustrated by one participant describing her search for someone who could offer support:

*"Yes, I am very much looking for someone who can help me. And I am also wandering in the desert of a rehabilitation doctor, company doctor, 'Heliomare' (a rehabilitation clinic), and what else..." (FG4, self-employed worker)*

### **Characteristics of the ideal supporter**

Support should meet certain criteria as expressed by all participants. Support must be easily accessible, based on equivalence and the supporter must assume the possibilities of the worker. Other participants added the importance of the supporter having a proactive and personal approach, and considering the person's work as well as their personal situation and mental wellbeing. One participant pointed out that support should be based on workers' motives to work.

*"But, say in the guidance there must be an eye on one's motivation. For some, the motivation to work is pure money, so okay, [...] but how are we going to ensure that I have my money at the end of the month? [...] now you are being thwarted in working while your motivation is in the work itself. So I think there should also be an eye on that." (FG1, employee)*

Several participants pointed out that the person offering support should serve as a coach or sparring partner. A wide variety of supporters were mentioned when asked who is the most suitable person to take on this supporting task: specialized nurses, social workers, occupational therapists, independent advisors, experienced experts or occupational physicians. Occupational physicians were often mentioned by participants in paid employment, since they could play a bridging role between the employee, employer and medical specialist.

### **How and when to offer support**

Several participants indicated that support should be set up prior to the start of problems. Another participant mentioned that support should be offered throughout a working career. The majority of participants pointed out the importance of customizing support, since every worker has his or her own needs.

*"It's about searching for that piece of customization, you would want someone who makes a tailor-made suit for you, I say." (FG3, self-employed worker)*

Participants spoke about the various areas where support is needed. It became clear that information is needed on the rights and obligations of employees and employers with regard to sick leave and social security. Practical advice on work accommodations and job coaching were also mentioned as areas for support. Some participants spoke about the need for a sympathetic ear whenever they just want to talk.

*"Of course, there is always a bit of emotion added, we all have bad moments, that we are at the end of our rope, for whatever reason. I need a listening ear and understanding, recognition." (FG4, self-employed worker)*

## **Discussion**

This study described the lived experiences of workers with a chronic condition, who were successful in staying at work. Facilitating factors were identified in the personal and environmental domains. Disclosure, being clear about one's needs, knowing what is important in life and making subsequent decisions are important to staying at work. Environmental support (e.g. social and employer support) was an important facilitator. Despite the fact that these workers were able to stay at work with their condition, barriers still remained. Barriers in the work environment, the health care system and with the national occupational



health and social security services included: lack of knowledge, lack of a clear policy and compliance to regulations in the work environment, dissatisfaction with occupational physicians' support, lack of focus on work in the course of treatment of chronic conditions, the complex system of the DSSI and the absence of a financial safety net for self-employed entrepreneurs. The need for support to facilitate workers staying at work also included support being available for employees and self-employed entrepreneurs, proactive support and support customized to a worker's individual needs.

### **Comparison with the literature**

Multiple models on work and work disability demonstrate the complex system of sustainable employment for workers with a chronic condition and the various stakeholders involved. It becomes clear that workers with a chronic condition have to deal with many people in multiple domains, e.g. medical specialists and nurses in the health care system, employers and co-workers in the work environment, occupational health professionals, and family and friends in the social environment (32). The self-control model we developed in our qualitative synthesis illustrates the behaviors that can help with staying at work, and the influence of various contexts on behavioral expression. The facilitating factors identified in this study correspond in a large part with the behaviors in our model, e.g. disclosure, requesting accommodations and support, and finding a healthy balance (26). Moreover, these facilitating factors are also in line with several motivators (e.g. meaning of work) and success factors (e.g. perseverance) for staying at work, as described in a qualitative study by De Vries et al. (33). Additionally, the identified barriers make it clear that it is not just the work environment that is important for staying at work, but also occupational and medical health services and social security services are relevant.

The importance of support for self-employed workers with a chronic condition was identified in a study by Adam et al. (34). Financial, practical as well as emotional support are all relevant (35, 36). Self-employed workers lack access to support in contrast to employees who can turn to their employer, occupational physician or other occupational health care professional (37). The Netherlands is not the only country with this problem for self-employed workers. A study by Torp et al. conducted in Norway also described this and the subsequent need for a network of professional support for self-employed entrepreneurs (35). Providing occupational health services in hospital outpatient clinics might be a good addition to the existing Dutch care models, and make services more available to all workers.

A study by Mittag et al. comparing social security in the Netherlands, Finland and Germany, pointed out that 'structured, close communication' between stakeholders is a facilitator for a successful return to work. According to the article, the DSSI is committed to coordinated and structured practices (p. 1087) (38). The participants' views on DSSI's complexity and lack of support makes us suspect that this does not always work out as planned. The lack of information provision, as indicated by some self-employed workers in our study, was also addressed by other self-employed workers with a chronic condition. In a group discussion with a number of self-employed members from several patient organizations, the respondents explained that vital information on starting entrepreneurship was not promoted by the DSSI (36).

### **Strengths and limitations**

This study illustrates the success stories of both employees and self-employed workers with a chronic condition who are still in paid work, the barriers that still remain and subsequent support needs. However, some limitations to this study have to be mentioned. Although attempts were made to create heterogeneous groups of participants, we did not fully succeed in this. A large proportion of participants suffered from specific physical chronic conditions, such as rheumatism and multiple sclerosis. None of the participants had a psychological disorder, despite the efforts to recruit workers with psychological disorders. This may be a result of the eloquence of these specific groups, in contrast to workers with mental illnesses, for example (39, 40). Adding focus groups with workers with psychological disorders might have revealed other barriers or support needs, such as dealing with stigmatization. Although disclosure was an important aspect among the participants of this study, research conducted on the various barriers for workers with psychological disorders, shows that stigmatization and discrimination after disclosure is a particular problem for this group of workers (41-43). A study by Brouwers et al. also shows the different factors that influence the outcome of disclosure, e.g. workplace, financial and employee factors (43). Second, none of the participants worked in a profession requiring heavy physical labor. Sustainable employment in jobs with a heavy physical workload is even more challenging. The absence of workers in these physical demanding jobs in this study, may be caused by the fact that workers with a chronic condition are less likely to work in these kind of professions since they often have already switched to less physically demanding jobs to continue working or end up taking sick leave. Third, only a small proportion of participants in the focus groups were male. Only a small number of men signed up in comparison to the number of women. All men were contacted for participation in a focus group. A possible

explanation could be that women might be more willing to disclose their condition and talk about their situation in a focus group than men (44).

### **Implications for practice, policy and research**

Staying at work and preventing work-related problems at an early stage are important to workers with a chronic condition. The work environment, the health care system and national regulations and services can guide and support workers to stay at work. Barriers and support needs identified in this study have implications for policy, practice and research. Interventions aimed at eliminating environmental barriers, e.g., training employers, optimizing occupational health services and integrating work into medical health care could have a large impact on sustainable employment, and these actions are recommended by European organizations committed to improve work participation for workers with a chronic condition (5, 45).

Receiving support is important to all workers, since participants pointed out that every worker should have access to occupational health services, including self-employed workers. The coverage of occupational health services in the Netherlands (80%) is the percentage of workers with access to these services (46). Although this number looks promising, it does not provide a complete picture. The fact that workers have access to occupational health services, does not mean they will actually use them, as in the case of participants dissatisfied with the offered support. Additionally, provided support does not always meet workers' needs. More tailored support should be made available, since every worker has specific needs. A proactive approach with an eye on all domains of life (work and personal situation), as indicated by our participants, was also described in a focus group study by Vooijs et al. (12). Improving support from medical health care by focusing more on work and employment in the course of treatment, will aid workers with a chronic condition to manage work-related problems at an earlier stage. Failure to discuss work in the health care consultation room was identified as a problem several years ago (47). In addition, collaboration between occupational physicians, medical specialists and employers is critical. Currently, the collaboration between occupational physicians and other medical specialists is suboptimal (48).

The integration of work into the course of treatment is relevant for health care professional training (e.g., medical specialists or specialized nurses). Including work as a theme in health care professional training can help create awareness about the meaning of work for patients. Inter-disciplinary cooperation between

occupational physicians and other physicians can possibly be improved by stating shared goals or joint educational programs (48). Occupational physicians in an outpatient clinic of the hospital makes them better accessible for workers as well as health care professionals for advice on work-related problems. Current support by occupational physicians should be more tailored to workers' support needs and information on policy and regulation should be made available in a clear and understandable way to employees and employers. Last, policy makers in the Netherlands should think about ways to support self-employed workers with professional, practical and financial advice.

More interventions are needed on integrating work during treatment and medical specialists' decision-making processes. Considerable research has been conducted on employees with a chronic condition in comparison to self-employed workers. Although this study tries to fill this gap, more research is needed on self-employed workers with a chronic condition and the optimization of their support system.

## **Conclusion**

Personal and environmental facilitators help workers with a chronic condition to successfully stay at work. However, barriers to sustainable employment still remain in the context of their work environment, the health care system and the provision of occupational health and social security services. Support to all workers with a chronic condition, employees and self-employed workers, is needed and should be tailored to the specific needs of the individual worker.

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# Chapter 4

## **Supporting employees with chronic conditions to stay at work: perspectives of occupational health professionals and organizational representatives**

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## Abstract

**Background:** Supporting employees with chronic conditions can prevent work-related problems and facilitate sustainable employment. Various stakeholders are involved in providing support to these employees. Understanding their current practices and experienced barriers is useful for the development of an organizational-level intervention to improve this support. The aim of this study was to explore the current practices of occupational physicians and organizational representatives, identifying both barriers to providing support and opportunities for improvement.

**Methods:** Two focus groups with sixteen occupational physicians and seven semi-structured interviews with organizational representatives were held between January and June 2018. Data was analyzed using thematic content analysis.

**Results:** Several barriers to offer support were identified, including barriers at the organizational level (negative organizational attitudes towards employees with chronic conditions), the employee level (employees' reluctance to collaborate with employers in dealing with work-related problems), and in the collaboration between occupational physicians and organizational representatives. In addition, barriers in occupational health care were described, e.g. occupational physicians' lack of visibility and a lack of utilization of occupational physicians' support. Opportunities to optimize support included a shared responsibility of all stakeholders involved, actively anchoring prevention of work-related problems in policy and practice and a more pronounced role of the health care sector in preventing work-related problems.

**Conclusions:** Preventing work-related problems for employees with chronic conditions can be achieved by addressing the identified barriers to provide support. In addition, both occupational physicians and organizational representatives should initiate and secure preventive support at the organizational level and in occupational health care. These insights are helpful in developing an intervention aimed at supporting employees with chronic conditions to stay at work.

## Background

Having a chronic condition can have a significant impact on one's working life. Fatigue and physical or cognitive limitations among employees can result in productivity loss, sick-leave, and/or job loss. Staying at work is important for both physical and mental wellbeing and contributes to one's quality of life (1, 2). Chronic conditions in the workforce also impact employers. Aside from the financial burden of productivity loss and extended or frequent sick-leave, employers face the practical challenges of securing continuity of skilled personnel and providing employees with needed support and accommodations (3, 4). With the number of employees with one or more chronic conditions increasing, preventing work-related problems and facilitating sustainable employment for these employees has become more important than ever (4, 5).

Prior research has identified various factors that facilitate sustainable employment for employees with chronic conditions, including work-related, disease-related and personal factors. Our earlier studies among employees with chronic conditions already showed the importance of disclosure and employees expressing their needs to enable them to stay at work (6). Furthermore, various aspects of the work environment contribute to sustainable employment, such as organizational culture, employee-employer relations, company policies and organizational support (7, 8). Organizational support and a supportive work environment enable employees with chronic conditions to talk about their condition and ask for support or accommodations if needed, thereby creating the right circumstances for them to stay at work (6, 9). Therefore, aside from employees with chronic conditions, other stakeholders both within occupational health care and within organizations, can play a role in sustainable employment by providing support to these employees.

Countries vary in how they arrange their occupational health services and which professionals are responsible for this provided care and support to employees with chronic conditions, e.g. occupational health professionals, general practitioners. Even between organizations the way in which occupational health services are organized, can differ. In the Netherlands, employers are required to provide occupational health services to their employees, either through an in-house occupational health services department or by having a contract (specifying services and tasks to be performed) with external occupational health services or a self-employed occupational physician (OP). In this context, OPs facilitate sustainable employment by providing employees and employers with support and advice related to work and health (10). In recent years, the Dutch

government has increased the focus on the prevention of work-related problems by adding an amendment to the Occupational Health and Safety legislation which requires organizations to ensure that their employees have the opportunity to access preventive consultation hours with OPs (11). However, the role of OPs in preventing work-related problems and promoting sustainable work participation remains relatively small, as they are still mostly dealing with employees with existing problems or cases of absenteeism (12, 13).

Aside from OPs, organizational representatives (e.g. management, supervisors, and human resources managers) are relevant stakeholders, as they have an essential role in ensuring organizational support and creating supportive work environments (14). However, organizational support is not always provided and the support that is offered may not always meet employees' needs. This may be related to a lack of knowledge or awareness among organizational representatives of the impact of a chronic condition on working life, as shown in a study by Koprina et al. (15).

Improving support within the work environment could help employees with chronic conditions to stay at work and facilitate sustainable employment. Although many workplace interventions have been developed in the past several years to support these employees, a large proportion of these interventions focus merely on return to work or a reduction in sickness absence. Furthermore, most existing workplace interventions target only individual employees rather than the organization as a whole (16-18). At present, interventions aimed at the organizational level, directed at **preventing** work-related problems and improving sustainable employment among employees with chronic conditions (i.e. selective or indicated prevention (19)), are scarce (20). Moreover, implementation of organizational-level interventions is complex due to the involvement of various stakeholders (21).

As we intend to develop an organizational-level intervention aimed at improving support in the work environment for employees with chronic conditions, it is important to first understand the barriers that relevant stakeholders experience when providing support, as well as the opportunities for optimizing this support. Insight in their perspectives can aid in the development of this organizational-level intervention, which could in turn facilitate sustainable employment for employees with chronic conditions. Therefore, the aim of this study is to explore the perspectives of OPs and organizational representatives on current practices and the barriers they face when it comes to providing support and to identify opportunities to improve support for employees with chronic conditions.

## Methods

### Study design

For this study, qualitative research methods were used to capture the perspectives of different stakeholders in the work environment on barriers to and opportunities for improvement of support. Between January and June 2018, focus groups and semi-structured interviews were conducted with OPs and organizational representatives (supervisors and human resources managers). Focus groups were held to explore the perspectives of OPs. Due to time constraints of the organizational representatives, semi-structured interviews were chosen to explore their perspectives. The consolidated criteria for reporting qualitative research (COREQ) were used when designing and reporting the study (22).

### Recruitment

OPs in the Netherlands regularly meet in continued medical education (CME) groups to discuss cases or topics related to occupational health care. We aimed to include a purposive sample of both self-employed OPs and OPs employed through external occupational health services or within an in-house occupational health services department, of different sizes of organizations. To achieve this, we emailed the chair of two CME groups with a description of the project and a request to use one of their meetings for a focus group session. These CME groups were recruited through the professional network of the researchers and both agreed to participate.

Organizational representatives were recruited through the researchers' professional and personal network and via snowball sampling, with the intention of including representatives of different sizes of organizations. They were contacted by email with a detailed description of the study and asked to participate in an interview. When participants agreed to participate, a date and time was set at the convenience of the participants. One of the organizational representatives who was contacted was not able to participate in an interview due to time constraints.

### Participants

Two focus groups were held, in which a total of sixteen OPs participated. The first focus group consisted mainly of OPs employed within an in-house occupational health services department of a large organization. In the second focus group, the majority of OPs was self-employed. Self-employed OPs often worked for small- and medium-sized organizations. A total of seven interviews were conducted with organizational representatives of different organizations. Two organizational

representatives worked at the same organization. Further characteristics of participants are shown in Table 1.

**Table 1.** Characteristics of focus group and interview participants

<b>Characteristics</b>		<b>Number</b>
<i>Occupation</i>	Occupational physician	16
	Supervisor	3
	Human resources manager	4
<i>Sex</i>	Male	12
	Female	11
<i>Size of participant's organization</i>	Large (>500 employees)	16
	Medium (50 – 500 employees) / Small (<50 employees)	7

### **Data collection**

Both focus groups were held at the pre-arranged locations of the CME meetings. Each focus group lasted approximately one and a half hour and was conducted in Dutch. The focus groups were moderated by the primary researcher (AB), a female health scientist with experience in qualitative research. During both focus groups, an observer was present to assist the moderator with monitoring group interaction and taking notes. The focus groups started with some information on the personal background of the researcher. Thereafter, the aim of the study, including the definition of a chronic condition as used in this study (a condition that is continuing or occurring recurrent for a long time and in which there is generally no prospect of full recovery (23)), was explained. This broad definition includes various types of diseases and disorders, both physical and psychological. A script with topics and open questions was developed to aid the moderator and ensure comparability between the focus groups. Topics discussed during the focus groups included: (1) current experiences with supporting employees with chronic conditions and a reflection on an OP's specific role, (2) barriers to providing support, and (3) potential ways to achieve or create optimal support for employees with chronic conditions. The semi-structured interviews were held at the organizational representatives' work locations and were also conducted by the primary researcher (AB), with no observer present. Interview duration ranged from 25-60 minutes. The researcher started with introducing herself (in case the participant did not know the researcher prior to the study) and explaining the aim of the study (as described above). An interview guide with open ended questions was used to structure the interviews, with topics similar to those in the focus groups. Afterwards, both focus group and interview participants received a gift certificate. As no new themes emerged at

the end of data collection, it was concluded that data saturation was achieved. Therefore, no additional focus groups or interviews were conducted.

### **Data analysis**

The focus groups and interviews were digitally recorded and transcribed verbatim. Summaries of the focus groups, with the main findings on the discussed topics, were made and sent to all participants for member-checking (i.e. to check whether participants agree with or have feedback on the summary made). No feedback or additional comments were received from the focus group participants. With the semi-structured interviews, no member-checking was carried out, as the researcher ended each interview with a small summary of main points mentioned by the organizational representative. Thematic analysis was used to analyze the collected data (24). The analytical process consisted of several stages, starting with reading and rereading the transcripts. An inductive approach was used to analyze the data, starting with line-by-line coding, thereby using qualitative data indexing software (ATLAS.ti) to assist the coding process. Next, data was searched for similarities and discrepancies, and ultimately grouping and combining codes into subthemes in an iterative manner. The primary researcher (AB) and third co-author (NS) coded all the data. Disagreements in the coding and grouping process were discussed until consensus was reached. The final step, conducted by all researchers in the project team, consisted of clustering the subthemes into main themes. The project team consisted of three health scientists and two OPs. A native English speaker translated representative quotes from the focus groups and interviews, which were added to the text to illustrate the results.

### **Ethical considerations**

Written informed consent was obtained from all focus group and interview participants. Oral and written information was provided on the confidentiality and anonymity of the results of the study. The Medical Ethics Review Committee of the VU University Medical Center determined that an ethical approval was not required because the Medical Research Involving Human Subjects Act ('Wet Medisch-wetenschappelijk Onderzoek met mensen') does not apply to this study.

## **Results**

The perspectives of OPs and organizational representatives on barriers to provide support and opportunities for improving support were captured in ten themes. An overview of themes and subthemes is presented in Table 2.



**Table 2.** Overview of themes and subthemes

<b>Barriers to provide support</b>
1. Negative organizational attitudes towards employees with chronic conditions <ul style="list-style-type: none"> <li>• Not wanting to retain employees with chronic conditions and contribute to their sustainable employment</li> <li>• Employers' financial considerations and fear of high costs</li> <li>• Employers' mistrust and co-workers' jealousy towards needed accommodations</li> </ul>
2. Employees' reluctance to collaborate with employers in dealing with work-related problems <ul style="list-style-type: none"> <li>• Employees' non-disclosure of their chronic condition</li> <li>• Employees' lack of cooperation</li> </ul>
3. Lack of skills and knowledge of how to support employees with chronic conditions <ul style="list-style-type: none"> <li>• Employers' lack of knowledge of rules and regulations</li> <li>• Too much medicalization of support</li> </ul>
4. Suboptimal collaboration between OPs and organizational representatives <ul style="list-style-type: none"> <li>• Not meeting each other's expectations in terms of performance</li> <li>• Questioning OPs' objectivity</li> <li>• Impeded communication due to privacy legislation</li> </ul>
5. Lack of utilization of OPs' support <ul style="list-style-type: none"> <li>• Employers and employees fail to seek preventive support from OPs</li> <li>• Employers do not refer employees to preventive consultation hours</li> </ul>
6. OPs' lack of visibility <ul style="list-style-type: none"> <li>• Employees' unawareness of the availability of support from OPs</li> <li>• The distance between OPs and organizations</li> </ul>
7. OPs' lack of time and capacity for prevention <ul style="list-style-type: none"> <li>• Too much time is spent on reducing sickness absence rather than on prevention</li> <li>• Shortage of OPs</li> </ul>
<b>Opportunities to improve support</b>
8. Shared responsibility of all stakeholders involved to prevent work-related problems
9. Actively anchoring prevention of work-related problems in policy and practice <ul style="list-style-type: none"> <li>• Proactive prioritizing prevention in occupational health care</li> <li>• Creating a supportive work environment and developing organizational policy</li> </ul>
10. Increasing the role of the health care sector in the prevention of work-related problems

### **1. Negative organizational attitudes towards employees with chronic conditions**

#### ***Not wanting to retain employees with chronic conditions and contribute to their sustainable employment***

Despite OPs' efforts to educate employers on the added value of employees with chronic conditions, OPs and some organizational representatives described organizations' unwillingness to support and retain employees with chronic conditions. Instead of offering support, cases were mentioned in which needed

work adjustments were not implemented or attempts were made to lay off employees with chronic conditions.

*"And what I also see is that when people are young and they have a medical condition, employers have a tendency of: 'Well, he still has to work for so many years, so we actually want to get rid of him.'" (Occupational physician)*

Ignorance about the condition or potential solutions to otherwise retain these employees were described as possible causes. In contrast, one organizational representative presented her organization as a 'social firm', with employing people with a distance to the labor market as its primary focus.

### ***Employers' financial considerations and fear of high costs***

Some organizational representatives spoke of the financial considerations when providing support and the fear of high costs, e.g. for implementing necessary accommodations. Moreover, OPs felt that the Dutch Occupational Health and Safety legislation negatively influenced how organizations support and attempt to retain employees with chronic conditions, by placing a great financial responsibility on employers in case of sickness absence:

*"Employers have to contribute so much financially and for so long, in case employees who have a disability are unable to do their job, so that employers literally select their employees." (Occupational physician)*

### ***Employers' mistrust and co-workers' jealousy towards needed accommodations***

Several organizational representatives sometimes felt feelings of mistrust towards employees and had doubts about whether accommodations were really needed. Some even felt that employees took advantage of the provided support. In that case, they sought the advice from OPs for confirmation. Moreover, implementation of accommodations could evoke feelings of resentment or jealousy among co-workers, as these might impact their workload (e.g. by transferring tasks to co-workers) or because co-workers would have liked to receive the same accommodations or privileges. This made it more difficult for supervisors to implement accommodations.

## **2. Employees' reluctance to collaborate with employers in dealing with work-related problems**

### ***Employees' non-disclosure of their chronic condition***

Employees' non-disclosure was mentioned by several organizational representatives as an important barrier to provide support, as this complicated communication between them. Some of these organizational representatives emphasized the importance of a relationship build on trust and having sufficient communication skills to bring about disclosure of the chronic condition by the employee, which were not always present.

*"In some cases, everything is out in the open, and the relationship between manager and employee is just fine, so then it is clear. But for many it is not, and that makes communication sometimes difficult." (Organizational representative)*

In contrast, an organizational representative of a small organization indicated the open workplace culture, where disclosure and expressing needs were fostered. This workplace culture, combined with short lines in communication made it easier for a supervisor to offer support and arrange accommodations, which was echoed by OPs of small organizations.

### ***Employees' lack of cooperation***

Several organizational representatives described their difficulties with supporting employees who were not willing to cooperate or to take responsibility for dealing with their chronic condition at work. According to them, this lack of cooperation was the result of various causes, e.g. shame, denial and not accepting how the diagnosis had impacted their work ability. Some organizational representatives mentioned the struggle with getting through to employees and described that they sometimes even felt they needed to impose necessary adjustments on employees (e.g. reduction of working hours). Moreover, some organizational representatives indicated that they perceived a lack of necessary skills to adequately guide employees with the process of acceptance. For one other organizational representative, this lack of cooperation evoked the feeling that the employee did not want to stay at work:

*"Sometimes you have a sort of gut feeling, which has to do with someone not cooperating in making concrete agreements, that someone refuses to take yes, some kind of responsibility, all kinds of clues that made me think: 'do you really want to stay at work?'" (Organizational representative)*

According to organizational representatives and OPs, actively asking for and being receptive to support were considered crucial in order for them to be able to support employees with chronic conditions and prevent work-related problems.

### **3. Lack of skills and knowledge of how to support employees with chronic conditions**

#### *Employers' lack of knowledge of rules and regulations*

According to several organizational representatives, difficulties with supporting employees also related to supervisors' lack of knowledge with regard to laws and regulations that deal with employees' health. The complexity and changing regulations, and having limited experience in dealing with these laws and regulations were described as underlying causes for this lack of knowledge. Supervisors often turned to their human resources managers whom fulfilled an advisory role in how to comply with the existing laws and regulations.

*"Yes, and I know very little about legislation and regulations, for example. I just rely on a human resources manager. That [legislation and regulations] changes all the time. Yes, now I have had a bit more to do with it, it is quite complex..."*  
(Organizational representative)

An organizational representative of a small organization explained the difficulty he had with understanding the complex rules and regulations when starting the company. He considered supporting employees with chronic conditions as a learning process with trial and error.

#### *Too much medicalization of support*

Several OPs and organizational representatives mentioned struggling with the medicalization of offering support to employees with chronic conditions in the work setting. Although they all wanted to support the employees, they did not want to put too much emphasis on the medical issues and negative consequences of the chronic condition on work, but rather wanted to focus the support on what could be done in the work environment to help these employees.

### **4. Suboptimal collaboration between OPs and organizational representatives**

#### *Not meeting each other's expectations in terms of performance*

OPs and organizational representatives described several occasions in which their expectations of each other's functioning were not met, criticizing each other's performance. Some organizational representatives felt irritated about the defensive or in other cases passive attitude on the part of the OP. Whereas others



complained about OPs refraining from any concrete advice, for example after referring an employee for a preventive consultation.

*"You get that in your report: 'employee is not sick, so can just go to work'. Yes, duh! I knew that. That was not my point." (Organizational representative)*

Several organizational representatives emphasized the necessity of having clear mutual expectations and for them to clearly communicate their explicit request for advice to OPs.

Meanwhile, some OPs were critical of those at the supervisor level for failures to signal problems or to follow-up on their advice. According to some OPs, the size of the organization also influenced this, highlighting that small organization more often follow-up on OPs' advice.

*"My experience is that in small companies there is much more cooperation with me and they listen much better [to my advice]." (Occupational physician)*

### **Questioning OPs' objectivity**

Some organizational representatives questioned OPs' objectivity and pointed out that OPs often take the side of employees. Moreover, they felt that OPs are sometimes too protective of employees. One organizational representative described that she felt that OPs let themselves be persuaded by employees to extend the period on sick leave.

*"In this case, I always contacted the occupational physician in advance if I knew of an upcoming appointment, to see, gosh, what is reasonable [for this employee]? What is possible from a medical point of view? And I noticed that the occupational physician let himself very much, yes, be persuaded by an employee, while I thought is it really all that bad?" (Organizational representative)*

### **Impeded communication due to privacy legislation**

Although both OPs and organizational representatives highlighted the importance of clear communication between them, they explained that this was being complicated with the renewed European privacy legislation (General Data Protection Regulation). This new law prohibited OPs from discussing the details surrounding the condition of the employee with organizational representatives.

## 5. Lack of utilization of OPs' support

### *Employers and employees fail to seek preventive support from OPs*

OPs explained that employees with chronic conditions often visit them only after problems have arisen, making it more difficult to provide preventive support. According to some OPs and organizational representatives, most employees want to continue their work as much as possible and manage their situation themselves, instead of asking an OP for support. As a result, OPs were often not aware of the number of employees with chronic conditions in the organization, and therefore the extent of the problem. Moreover, several OPs indicated that employers or supervisors too often try to solve work-related health problems themselves, instead of seeking the advice from their OP:

*"As a self-employed OP, I work for several smaller organizations, many of which using their own 'self-management model'. Since then [the use of 'self-management models' in organizations], there are a thousand doctors on the work floor. Employees no longer have to go to the occupational physician, because they [supervisors] know everything about Parkinson's disease and diabetes." (Occupational physician)*

### *Employers do not refer employees to preventive consultation hours*

Organizational representatives indicated that they only occasionally refer employees to a preventive consultation with their OP in order to obtain advice on preventing work-related problems in the future. One representative pointed out to experience a feeling of taboo around preventively referring employees to the OP within their organization. In addition, the organizational representative of a small organization explained that he had never thought about the possibility of preventively referring an employee to their OP.

*"I have never really thought about it [preventively referring employees]. [...] But I think yes, that would certainly, in view of prevention on the long term, be a wise thing to do." (Organizational representative)*

On the other hand, the organizational representative of the 'social firm' explained that employees are clearly informed about the possibility of preventively consulting the OP and that their preventive consultation hours were widely used.

## **6. OPs' lack of visibility**

### ***Employees' unawareness of the availability of support from OPs***

OPs talked about their lack of visibility to both employers and employees, which in turn negatively impacted their accessibility. Some OPs described that employees are not always aware of the existence of an OP or the possibility to consult an OP, as illustrated by the quote below. In addition, OPs described that many employees persist in their idea that OPs are only available for sickness absence consultations.

*"With a larger organization, you are more like a mountain [clearly visible], but with many smaller organizations, employees say: 'oh, I didn't know we had an occupational physician at all.' Yes, then they get sick and get called in by me, only then do they know..." (Occupational physician)*

### ***The distance between OPs and organizations***

Some organizational representatives spoke of the psychological and physical distance they felt between them and their OP. One organizational representative expressed that the psychological distance he felt to the OP from the external occupational health service, negatively influenced accessibility of their OP:

*"No, I have to be honest, I do not even know the name of our occupational physician..." (Organizational representative)*

While on the other hand, another organizational representative spoke of the ideal situation of their OP's weekly consultation hours at the workplace. Also OPs mentioned the distance between organizations and OPs; a greater physical distance made it harder for them to provide adequate support to employers and employees. For some of them this was even a reason for not wanting to work through a case management agency anymore. In order to reduce the threshold for employers and employees to seek support from them, several OPs mentioned making regular visits to the workplace.

## **7. OPs' lack of time and capacity for prevention**

### ***Too much time is spent on reducing sickness absence rather than on prevention***

According to OPs and organizational representatives, current legislation has pushed OPs more towards dealing with sickness absence, as social security is getting stripped further and further, making it more difficult for employees to receive benefits (e.g. disability benefits). Moreover, OPs described making agreements with organizations about the number of hours they work and the tasks they should perform, with organizations often demanding to focus mostly

on absenteeism. Several OPs explained that as a result, they spend the majority of their working hours on reducing sickness absence, leaving less time available for preventing work-related problems and preventive support.

*"Well, we now have such a nice new amendment of the labor legislation, which states that occupational physicians must be provided with more time for prevention. But when I look at my clients [organizations], they want to [focus on prevention]... but in the end there is also a limit to my agenda. You have agreed to one day a week [number of days working for the organization], but if absenteeism increases rapidly, then that is what you focus on." (Occupational physician)*

### **Shortage of OPs**

In addition, some OPs and organizational representatives spoke of the current shortage of available OP capacity. One representative described the difficulty of finding a new OP after their current OP gave notice of his resignation. Some OPs also described the problem of there being a shortage of OPs, as indicated by the many job offers.

*"But yes, that also applies to our occupational group... shortage. I am approached several times a week, eh, for cooperation, if I want to do a job. Then I wonder, you know? That is a problem." (Occupational physician)*

## **8. Shared responsibility of all stakeholders involved to prevent work-related problems**

Both OPs and organizational representatives stated that it is everyone's social duty to keep employees with chronic conditions at work. Preventing work-related problems and facilitating sustainable employment requires a joint effort and shared responsibility of all stakeholders involved (i.e. stakeholders in organizations, including employees and in occupational health care).

*"I sometimes say to a manager: 'It is simply a social obligation that we have, to retain the people with a chronic condition as well. That you have a diverse team. Yes, you also have an exemplary role, if there is a problem, we will solve it. No nagging about that.'" (Occupational physician)*





## **9. Actively anchoring prevention of work-related problems in policy and practice**

### ***Proactive prioritizing prevention in occupational health care***

Both OPs and organizational representatives emphasized that OPs have to be more proactive in taking up more preventive tasks and motivating organizations to focus more on prevention instead of reducing sickness absence. This requires OPs to make their role clear to supervisors, human resources managers, and employees, and to show to the organization their added value in preventing work-related problems. OPs indicated that, to ensure the embedding of prevention in occupational health care, they have to practice what they preach and negotiate the allocation of preventive tasks in their contracts.

*"As an occupational group, we are simply too much driven by that whole absenteeism and uhm, we just have to have the guts to say: 'well, and from now on there are no extra absenteeism consultation hours, but instead more consultations about prevention.'" (Occupational physician)*

Moreover, several organizational representatives pointed out that occupational health services could also play a more pronounced role in proactively promoting preventive support by addressing the importance of prevention, taking preventive measures, and guiding and educating organizations on how to support employees with chronic conditions.

### ***Creating a supportive work environment and developing organizational policy***

According to OPs, as well as organizational representatives, an organization should ensure a work environment in which employees feel supported by their organization. Furthermore, there should be a clear organizational policy that illustrates an organization's view on preventing work-related problems among employees with chronic conditions, and that facilitates the implementation of accommodations and preventive support.

*"Actually, it would be very nice if this is in the mission statement of a company: 'for people who are chronically ill, our goal is to let people work optimally for as much as possible, for example. And we do this and this and this [to accomplish the mission statement] and that is what we're training our executives for' you know. That's a really nice idea I think, if that's clear. Yes, so that... look, if it [working with a chronic condition] is not an issue you don't need that information at all, but at the same time it is also nice to work in such an organization, where it is just transparent." (Organizational representative)*

An OP indicated that a change in work culture within an organization is sometimes required to achieve such a supportive work environment.

### **10. Increasing the role of the health care sector in the prevention of work-related problems**

OPs stressed the important role of general practitioners, medical specialists, and specialized nurses in preventing work-related problems for employees with chronic conditions. Although in the Netherlands, the health care sector is not responsible for occupational health care, OPs described several aspects within the broader health care system that could improve the prevention of work-related problems. First, more attention on employment and paid work in the course of treatment. Second, if health care professionals would refer people with a (newly diagnosed) chronic condition to the OP more often, it would enable OPs to offer support and advice on preventing work-related problems at an earlier stage. Third, OPs indicated that a good collaboration between themselves and health care professionals is essential for providing adequate support and the implementation of accommodations which are fitted to the needs of employees with chronic conditions.

*“What you see is that employment is gradually coming into those guidelines [of medical specialists], but it is not yet in the minds of all specialists and care providers in health care. That’s one thing. And they don’t think in terms of functioning, like a rehabilitation doctor does or we do [...]. And that, this other way of thinking, that is what I really miss the most.” (Occupational physician)*

## **Discussion**

This study described the experiences and perspectives of OPs and organizational representatives on barriers to provide support and opportunities to improve support for employees with chronic conditions in order to prevent work-related problems and facilitate sustainable employment. OPs and organizational representatives identified various barriers for providing support, including negative organizational attitudes towards employees with chronic conditions, employees’ reluctance to collaborate with employers in dealing with work-related problems, OPs’ lack of visibility and a lack of utilization of OPs’ support. OPs and organizational representatives also identified opportunities for improving preventive support and sustainable employment for employees with chronic conditions. Opportunities included a shared responsibility of all stakeholders involved for preventing work-related problems, actively anchoring

prevention of work-related problems in policy and practice and increasing the role of the health care sector in the prevention of work-related problems.

### **Comparison to the literature**

Our study identified several barriers to provide support in the work environment, e.g. negative organizational attitudes towards employees with chronic conditions, employees' non-disclosure or employers' lack of knowledge of the rules and regulations, which are in line with other studies (25-28). In view of negative organizational attitudes towards employees with chronic conditions, financial considerations were of importance. In the Netherlands, employers can apply for financial compensation and premiums to reduce costs for the support of employees with chronic conditions. However, little use is made of these possibilities, because of a lack of knowledge of their availability and the complexity of the terms (29). When comparing our findings to the perspectives of employees with chronic conditions, two qualitative syntheses show us that these employees often struggle with prejudice, judgement and mistrust in the work environment, and that employees try to avoid a negative image, which relates to the negative organizational attitudes we found in this study (30, 31). Employees' non-disclosure and a lack of cooperation hampered the offering of support by organizational representatives. This correlates to two of our earlier studies among employees, which identified disclosure as an important facilitator for staying at work. However, whether employees disclose their chronic condition is very much dependent on the context, being more likely to disclose in a supportive work environment (6, 9). This endorses the need for creating supportive work environments as found in this study, which is in line with other studies (32-34). A more pronounced role of the health care sector in preventing work-related problems, as identified in this study, was also mentioned by employees with chronic conditions, and reflects the importance of making work an essential part in the course of treatment (6, 31).

Also barriers in occupational health care were found, such as a lack of use of OPs' support. The desire of employees and employers to solve problems on their own, was seen as one of the reasons for this. However, our study among employees also showed dissatisfaction with support offered by OPs, which could also be a contributing factor, as this kept employees from seeking additional support from OPs (6). We also found that some organizational representatives appeared ambivalent to refer employees preventively to OPs, which is in line with a study by Paulsson et al., that also showed a lack of use of suggested expertise of occupational health professionals (35). Moreover, we showed that OPs still spend most of their time on reducing sickness absence, as agreed upon in their

contracts with employers. This implies that occupational health care currently revolves around reactive interventions instead of a proactive preventive approach, which was also found in other studies (35, 36). Although the European Union sets basic rules for arranging occupational health services, countries differ in how occupational health services are implemented in their national legislation (37). For Dutch OPs, additional occupational guidelines are available to improve the quality of care. However, these guidelines focus mostly on return to work instead of preventing work-related problems. Moreover, these guidelines are not widely used, due to OPs' doubts about usefulness and feasibility in practice (38). Our study clearly demonstrated that despite being obligated by law and aided by guidelines, it is difficult for OPs to use their full potential in light of preventive tasks and promoting selective and indicated prevention in organizations and in occupational health care.

The suboptimal collaboration between OPs and organizational representatives is another important finding, e.g. organizational representatives' feelings of OPs being on the side of employees. In contrast to employers, many employees with chronic conditions have the impression that OPs mostly represent the interest of the employer (6). This shows the difficult position OPs are in, as they ought to be independent advisors, hired by employers and representing the interests of employees at the same time. Good collaboration and communication between employers and OPs can optimize service provision. A systematic review by Halonen (39) pointed out the importance of a clear set of services with the flexibility to adjust these to organizational needs, a long-term collaboration, trust, frequent contact, and a shared goal between employers and occupational health services providers (39). Moreover, expressing mutual expectations and evaluating offered services adds to the quality of the collaboration (40).

### **Strengths and limitations**

This study illustrated the barriers that OPs and organizational representatives face when it comes to providing support, as well as potential opportunities for improving support for employees with chronic conditions. This study showed the broad perspectives of different types of OPs and of organizational representatives, working for various organizations, using the strengths of two different types of qualitative research methods. Focus groups provided us with a broad insight into OPs' perspectives, whereas interviews allowed us to gain in-depth understanding of the relevance of the particular organizational context. The findings provide valuable input for the development of an organizational-level intervention for improving support for employees with chronic conditions.

However, limitations for this study can also be identified. First, of the approximately 140 CME groups in the Netherlands, we only used two CME groups for a focus group session. Nonetheless, in this explorative study, representatives of different types of OPs (e.g. self-employed vs. employed at an in-house occupational health services department) were present in one or both of these two groups. Second, a relatively small number of OPs and organizational representatives worked for small- and medium-sized organizations. Although including more participants from small- or medium-sized organizations would perhaps have yielded additional findings, we believe that our heterogeneous group of participants identified the most important barriers and opportunities to improve support. A third limitation is that the results describe the experiences and perspective of OPs and organizational representatives solely in the Dutch context. However, although some findings might only apply to the Dutch situation and are difficult to translate to other countries, many findings are also internationally relevant and of value for other countries, e.g. the lack of use of occupational health professionals' expertise and the need for anchoring prevention in an organizational policy. Furthermore, this study showed that making occupational health services mandatory in legislation, does not always have the desired effect.

### **Practical implications**

Preventing work-related problems by providing preventive support can facilitate sustainable employment for employees with chronic conditions, as well as lower employers' financial burden due to sickness absence. Moving towards more selective or indicated prevention requires changes within organizations as well as occupational health care. Based on our findings, several recommendations can be made on how to improve preventive support for employees with chronic conditions.

In general, organizations must pursue a more proactive and preventive approach, focusing more on preventing work-related problems of employees with chronic conditions (i.e. selective or indicated prevention) rather than on reducing sickness absence. Current legislation has shown to be insufficient for promoting prevention. However, as the amendment of the Occupational Health and Safety legislation (i.e. with more focus on prevention) is relatively new, a clear effect may become visible in the near future. More extensively enforcing compliance to this legislation can however be helpful for achieving the change to a preventive approach. In addition, other ways must be sought to move organizations towards the preventive approach. As for many organizations financial considerations are important, the economic benefits of prevention and preventive support must be

made clear. For many supportive activities, it is not always immediately clear whether the costs outweigh the benefits (41). The benefits of providing high quality preventive support to employees with chronic conditions could lie in generating increased employee motivation and satisfaction and a better corporate image, as also seen in the prevention of workplace accidents and occupational illnesses (42). Organizations' awareness of the benefits of preventing work-related problems and preventive support would make it more feasible for OPs to expand their preventive duties.

Making the prevention of work-related problems a shared responsibility of all stakeholders involved, is crucial for improving sustainable employment of employees with chronic conditions. A study by Philips et al. emphasized the importance of the commitment of upper management to retaining these employees (27). Furthermore, OPs or other occupational health professionals could work more closely together with organizations, increasing their visibility, and together develop an organizational policy aimed at preventing work-related problems, tailored to the specific needs of organizations. A study by Schmidt et al. even described that an effective and strategic collaboration between occupational health professionals and organizations led to a shift towards a more preventive approach of utilizing occupational health services (43). To tackle the shortage of OPs, the intake in the training program to become an OP must increase, by making the profession of occupational physician more attractive for young doctors (44). Moreover, in-house and external occupational health services can contribute to the prevention of work-related problems by promoting preventive actions within organizations, for example by educating employers on the importance and potential benefits of prevention. Finally, health care professionals must be educated on the importance of integrating work in the course of treatment and the possibility of (preventively) referring patients to OPs. Joint educational programs can be used to improve this inter-disciplinary collaboration (45).

Although disease-related factors and personal factors also play a role in sustainable employment, there is much to be gained by addressing work-related factors. Prevention in organizations and occupational health care remains difficult, despite the available expertise of OPs on work and health (46). We will therefore use the results of this study for the development of an organizational-level intervention aimed at improving support in the work environment for employees with chronic conditions. By making OPs an essential part of this organizational-change intervention, their visibility will improve. This could put them in a better position to perform their preventive tasks and collaborate closely with all relevant

stakeholders in the organizations to create supportive work environments and prevent work-related problems for employees with chronic conditions.

### **Research recommendations**

This study was a first step in providing insight into the preventive support offered by OPs and organizational representatives. However, more research should be conducted on the economic benefits of preventing work-related problems among employees with chronic conditions (selective and indicated prevention) and how prioritizing prevention over absenteeism could be promoted within organizations. Our findings provided input for the development of an organizational-level intervention to improve support. Subsequently, the implementation process and effectiveness of such an intervention must be explored. As organizations differ in their size, structure, and other organizational factors, the implementation process and effectiveness of the intervention that will be created should be investigated in various types of organizations.

## **Conclusion**

This study showed the perspectives of OPs and organizational representatives on the barriers for providing support and opportunities to improve preventive support for employees with chronic conditions. Barriers were identified at the organizational level (negative organizational attitudes towards employees with chronic conditions), the employee level (employees' reluctance to collaborate with employers in dealing with work-related problems) and in the collaboration between OPs and organizational representatives. In addition, barriers in occupational health care were described, e.g. a lack of OPs' visibility and a lack of utilization of OPs' support. Shared responsibility of all stakeholders involved, actively anchoring prevention of work-related problems in policy and practice and a more pronounced role of the health care sector in preventing work-related problems can optimize preventive support and facilitate sustainable employment for employees with chronic conditions.

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## Supplementary Information

### Interview guideline for Organizational Representatives

- Are you aware of any employees having a chronic condition within the organization?
- How do you reflect on your role regarding (preventively) supporting employees with chronic conditions? What tasks do you see for yourself?
- How do you currently support employees with chronic conditions in their work?
  - Accommodations? Training? Other support?
  - Did the occupational physician play a role in this?
  - Do you refer employees preventively to the occupational physician? Do you have any idea if this helps them?
  - How is your collaboration with the occupational physician?
    - Do you have contact with the occupational physician about employees? Even if they are not (yet) on sick leave?
    - What does that contact consist of? Who initiates this?
    - Could collaboration be improved? If yes, how could this be improved?
- What barriers do you encounter when supporting employees with chronic conditions?
- You want to take the best possible care of your employees. How could (preventive) support for employees with chronic conditions be improved? What could help you with improving (preventive) support to these employees?





# Part III

**Development and evaluation of an  
organizational-level intervention to  
create a supportive work environment**



# Chapter 5

## **Development of an intervention to create a supportive work environment for employees with chronic conditions: an Intervention Mapping approach**

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## Abstract

**Purpose:** This study describes the development of an evidence-based intervention to create a supportive work environment for employees with chronic conditions. Occupational physicians (OPs) play an important role in guiding organizations in this process of organizational change. Supportive work environments can aid in preventing work-related problems and facilitate sustainable employment. Current workplace interventions for employees with chronic conditions are mainly focused on return to work or a reduction in sick leave at the individual worker's level. This study contributes to the literature an organizational-level intervention which utilizes a preventive approach.

**Methods:** Intervention Mapping (IM) is a six-step, structured protocol that was used to develop this intervention. In step 1, a needs assessment was conducted to define the problem and explore the perspectives of all stakeholders involved. The program outcomes and the performance objectives of employees with chronic conditions and occupational physicians were specified in step 2. In step 3, appropriate methods and practical applications were chosen. Step 4 describes the actual development of the intervention, consisting of 1) a training for occupational physicians to teach them how to guide organizations in creating a supportive work environment; 2) a practical assignment; and 3) a follow-up meeting. The intervention will be implemented in a pilot study in which occupational physicians will put their acquired knowledge and skills into practice within one of their organizations, which is delineated in step 5.

**Conclusions:** IM proved to be a valuable and practical tool for the development of this intervention, aiming to facilitate sustainable employment for employees with chronic conditions.

## Introduction

The number of people in the working population with one or more chronic conditions is increasing (1, 2). Work participation rates among those with a chronic condition are lower compared to participation rates of the general population. Working with a chronic condition can lead to certain physical or psychological challenges, possibly resulting in sick leave or job loss. Prevention of work-related problems, sick leave, and job loss among these employees is of great importance since returning to work has proven to be difficult (2, 3).

Much research has been conducted on factors associated with sustainable work participation for employees with chronic conditions, showing that personal, disease-related, as well as work-related factors are of importance (4-6). In the last decade, a wide variety of interventions have been developed to support people with chronic conditions in their work in order to prevent productivity loss, sick leave, or job loss. However, these interventions, addressing factors such as work accommodations, empowerment, and self-management, have shown only limited effects (7-10).

In recent years, people with chronic conditions have been encouraged by the Dutch government and society to take control over their lives, including their work (11). Self-control is a concept that relates to controlling one's responses and behaviors with the purpose of reaching long-term goals (12, 13). An interplay between impulse control, deliberate decision making, and the availability of certain cognitive resources underlie the behavior that is carried out. One's level of self-control can be seen as a benchmark for adaptation (12, 14). Although self-control is often described in relation to health behaviors (e.g. healthy eating) (15), it may also aid workers with adjusting to the new circumstances of working with a chronic condition. Using Huber's new definition of health, "having the ability to adapt and self-manage" (p. 2) (16), having higher levels of self-control at work and the possibility of exerting self-control might improve wellbeing and health, thereby facilitating sustainable employment of employees with chronic conditions.

Interventions aimed at increasing the exertion of self-control can focus on an individual's capacity to exert self-control or on changing the context in which self-control is exerted (17). Based on available literature, it is clear that a person's level of self-control can be increased through training and practice (14). However, a meta-analysis of the effect of self-control training shows only a minor effect (18). Changing the context in which self-control can be exerted has shown to be

a more successful strategy in changing the desired behavior (19). This implies that employees with chronic conditions are more likely to exert self-control in a supportive work environment where they feel enabled to do so.

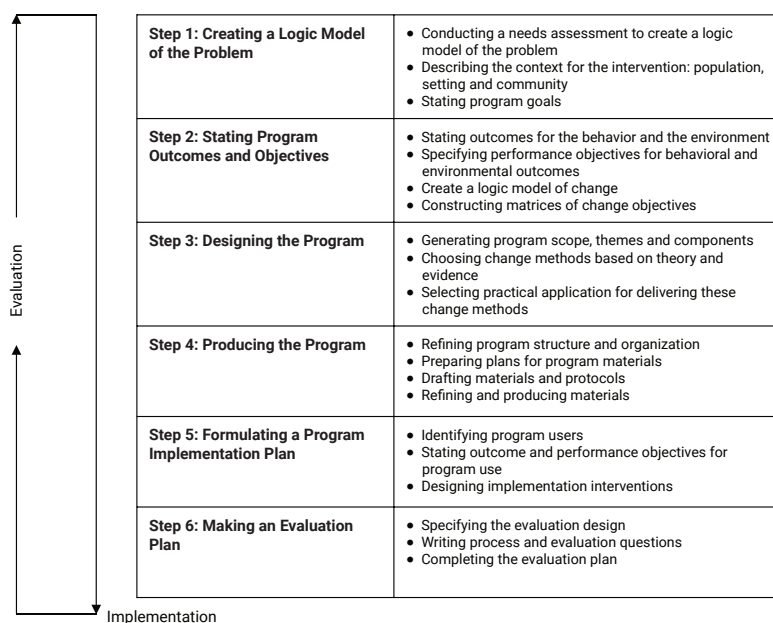
Occupational health professionals could play a key role in increasing the exertion of self-control of employees with chronic conditions, both by supporting individual employees and by helping to create these supportive work environments. In the Netherlands, occupational physicians (OPs) have the task of supporting and advising employees and organizations on issues related to work and health to facilitate sustainable employment (20). In recent years, the Dutch government has emphasised the role of OPs in the prevention of work-related problems, by obligating organizations to ensure their employees access to preventive consultation hours with OPs (21). The preventive role of OPs remains small, however, and they mainly deal with employees with existing problems and cases of absenteeism (22, 23). This is unfortunate given that OPs also have the desire to focus more on prevention (24). Dutch Occupational Health and Safety legislation stipulates that in case of work-related problems or sick leave, both the employer and employee must take responsibility for securing healthy and sustainable employment (25, 26). As a consequence of this shared responsibility, the distance of OPs to the organization is increasing, making them less visible as advisors to employers on health and the prevention of work-related problems within organizations.

Based on the importance of the context in which self-control is exerted, it can be inferred that it is essential that an intervention for employees with chronic conditions should focus on changing the work environment. These interventions aimed at organizational change can result in creating supportive environments, thereby providing employees with chronic conditions with the right conditions to exert self-control and leading to the prevention or early identification of work-related problems. By changing the OP's role and making OPs an essential part of organizational-change interventions, they are able to use their expertise on work and health to guide organizations in creating supportive work environments for employees with chronic conditions. This role enables OPs to collaborate closely with organizations, reducing the distance between employer and OP and supporting and guiding preventive measures within an organization. To the best of our knowledge, no intervention has been developed aimed at increasing the exertion of self-control for employees with chronic conditions by changing the work context. The aim of this study is to develop an intervention for OPs, with the purpose of creating supportive work environments for employees with

chronic conditions, by guiding organizations in making these changes. For the development process, we used Intervention Mapping (IM), which “provides a framework for effective decision making during planning of intervention programs, including the planning of implementation and evaluation” (27).

## Intervention Mapping process

IM is a stepwise protocol used for planning and developing effective behavioral and environmental change interventions, consisting of six steps (presented in Figure 1). The iterative nature of the IM protocol stimulates the use of theory as well as existing and newly-acquired evidence for the intervention development, with the flexibility to go back and forth through the different steps. Involving stakeholders in the process enables the interventions to be fit to the needs and wishes of all involved (27). The relevant stakeholders in this study are OPs, employees with chronic conditions, and organizational representatives (e.g. supervisors/management, co-workers, and the human resources department within the organization). The project team involved in the development of this intervention consisted of two health scientists and two OPs. An IM expert advised the project team during the development process.



**Figure 1.** The six-step Intervention Mapping protocol (adapted from Bartholomew, 2016) (27).

### **Step 1 Logic Model of the Problem**

In the first step of the IM process, a logic model of the problem was created which helped in defining the problem and depicting a representation of the causal relationship between the problem and its causes. As part of this step, a needs assessment was conducted with the aim of assessing the nature and extent of the problem ('what is') and the needs ('what should be') of all the stakeholders. The needs assessment consisted of a qualitative synthesis to gain insight into the concept of self-control and the influence of the environment on the exertion of self-control for employees with chronic conditions (28). In addition, the literature was reviewed and interviews were held with all relevant stakeholders (employees with chronic conditions, OPs, as well as organizational representatives including employers and human resources managers) to capture a complete overview of perspectives.

#### ***Employees with chronic conditions***

Self-control is defined as "the capacity for altering one's own responses, especially to bring them into line with standards such as ideals, values, morals, and social expectations, and to support the pursuit of long-term goals" (p.351) (13). In our study, sustainable employment is considered the long-term goal for employees with chronic conditions. Limited research has been conducted on self-control in the context of work, focusing instead on organizational management (29, 30). The literature available on self-control was not able to provide us with an understanding of which specific behaviors employees with chronic conditions should alter or express to help them reach the long-term goal of sustainable employment. Therefore, we explored available international qualitative literature which examined factors enabling sustainable employment, specifying the desired self-control behaviors important for preventing work-related problems and the influence of the environment on the enactment of these behaviors. Four self-control behaviors from the perspective of employees with chronic conditions emerged from this qualitative synthesis: 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, and 4) management of symptoms and limitations in the workplace. Disclosure of the condition at work can create understanding and support among co-workers, supervisors, and employers, and can facilitate both better management of the condition and the implementation of accommodations. Disclosure is influenced by the personal beliefs of the employee as to possible consequences of disclosure, disease-related factors such as predictability and invisibility of the disease, and workplace factors, including workplace culture and the employee's relationship with their co-workers, supervisors, and employers. Finding a healthy balance is important

for enabling employees with chronic conditions to continue working and relates to the decision-making process of an employee with a chronic condition. Employees make decisions in relation to strategies that make sustainable work participation possible, such as energy management or a job change. Requesting accommodations and support is crucial for fitting the job to the capacities of the employee and adjusting to the chronic condition and limitations at work. An accepting and supportive work environment makes it easier to ask for support and accommodations. Management of symptoms and limitations in the workplace enables sustainable work productivity. This requires an awareness of symptoms, an acceptance of the chronic condition and its limitations, and for the employee to take responsibility for managing these symptoms and limitations. Based on this synthesis, the work environment appears to have an important influence on employees expressing these self-control behaviors. An accepting workplace culture and an understanding and trusting relationship with co-workers, supervisors, and employers facilitates the exertion of self-control (e.g. by lowering the threshold to disclose the condition). The main findings of the interviews with employees with chronic conditions underscored the same self-control behaviors found in the qualitative synthesis and emphasized the importance of a supportive work environment in enabling the expression of these behaviors. In addition, employees spoke of a lack of knowledge, lack of organizational policies, and lack of compliance to organizational regulations, all of which made disclosure and acquiring work accommodation more difficult.

### ***Occupational physicians***

During the interviews, OPs expressed the importance of early identification of work-related problems. Currently, OPs do not have a clear overview of all employees with chronic conditions within the organization, as most employees with chronic conditions consult their OP only in cases of already existing work-related problems or sick leave. Support from and collaboration with the work environment were described by OPs as important prerequisites for sustainable employment for employees with chronic conditions. OPs also stated the importance of a positive organizational attitude towards employees with chronic conditions and a supportive workplace culture. In a study by Abma et al., OPs also stated the importance of clear communication and a supportive organizational culture on sustainable employment. In addition, OPs described their desire to have a more preventive role, instead of focusing a large proportion of their time on return to work or sick leave (24).

### ***Organizational representatives***

During the interviews, employers and human resources managers highlighted the importance of collaborating with OPs and employees, and making sure that mutual expectations are clear. Currently, employers and human resources managers mainly focus on looking at an individual employee's work capacity and, in case of need, facilitating work adjustments. Work adjustments can, however, only be implemented to a certain extent. Adjustments such as task redistribution or shifting work tasks to colleagues is not always possible. OPs and organizational representatives pointed out the importance of having a clear organizational policy for working with a chronic condition and preventing work-related problems within an organization. Literature on the needs and perspectives of organizational representatives has shown the important role of employers and human resources managers when it comes to supporting employees with chronic conditions (31, 32). At the same time, the literature describes a lack of knowledge and awareness among human resources managers and line-managers of the impact of a chronic condition on working life (33, 34). Having a clear company policy, providing early support and accommodations, facilitating good cooperation between managers and employees, and having employees take responsibility (e.g. communicating to managers and making decisions) are some of the factors indicated by employers and human resources managers as facilitating sustainable employment (24, 35).

The results of this first step provide clarity on the behaviors of an employee with a chronic condition, the influence of the environment (work environment and current support from OPs) and perspectives of OPs and organizational representatives on sustainable employment. It is clear that preventing work-related problems and sustainable employment requires the commitment of all stakeholders involved. Employees exerting self-control means executing the abovementioned desired behaviors. However, employees must be enabled and supported by the work environment to actually execute these behaviors. Organizational policies could thereby facilitate sustainable employment for employees with chronic conditions. OPs can fulfil their preventive tasks by offering advice on organizational policy development and guiding organizations towards more supportive work environments.

### **Step 2 Program outcomes and objectives – Logic Model of Change**

In this second step, a logic model of change was created (see Figure 2), visualizing the effects of the intervention on behavior and the environment. As a starting point, the behavioral outcome (the employee with a chronic condition will exert self-control) of the intervention to be developed was identified, after which the

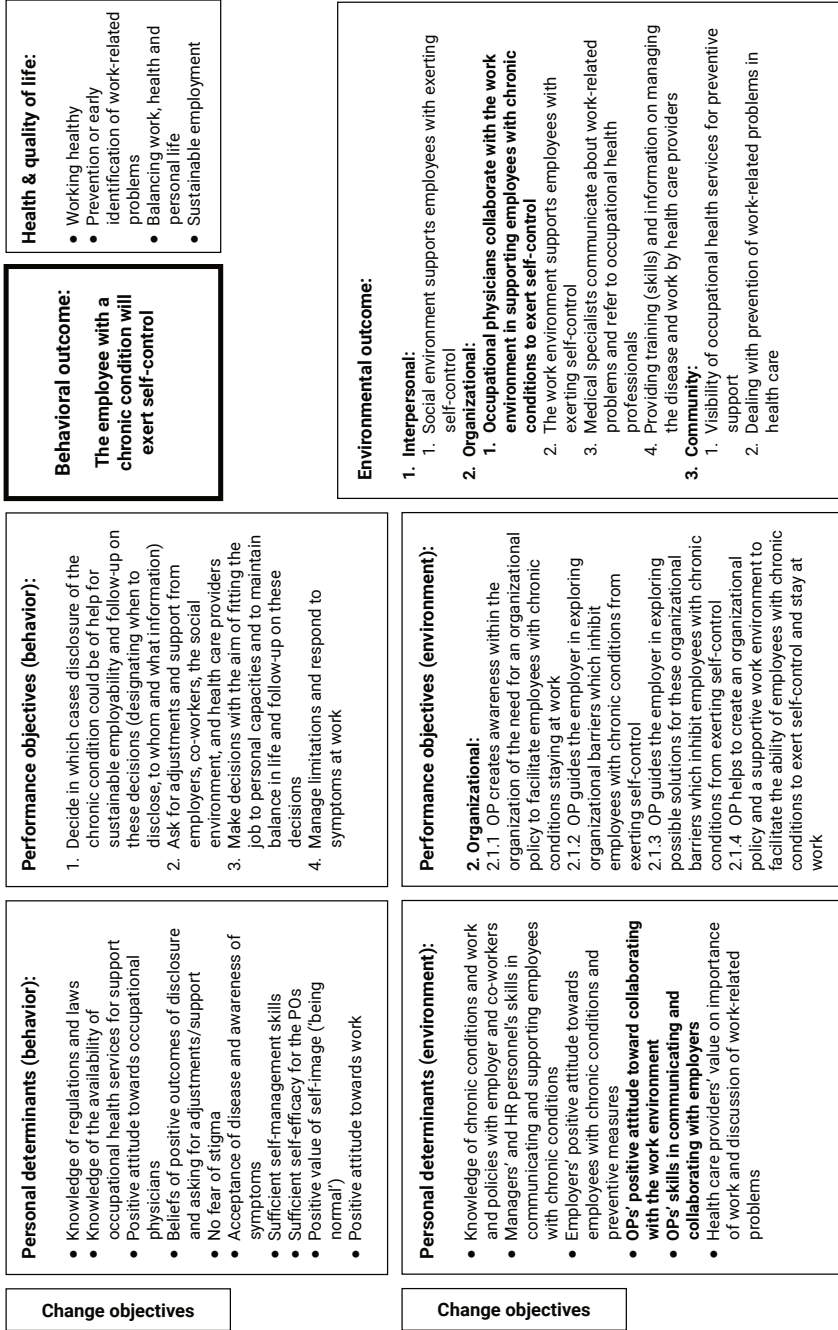


Figure 2. Logic model of change



performance objectives were specified. The performance objectives operationalize what needs to be done in the behavior of the employee with a chronic condition in order to accomplish the behavioral outcome. The performance objectives associated with the behavioral outcome of the employees with chronic conditions are listed in Table 1. These performance objectives are based on the four self-control behaviors described in the needs assessment.

**Table 1.** Performance objectives for an employee with a chronic condition

- 
1. Decide in which cases disclosure of the chronic condition could be of help for sustainable employability and follow-up on these decisions (designating when to disclose, to whom and what information)
  2. Ask for adjustments and support from employers, co-workers, the social environment, and health care providers
  3. Make decisions with the aim of fitting the job to personal capacities and to maintain balance in life and follow-up on these decisions
  4. Manage limitations and respond to symptoms at work
- 

Environmental outcomes can be categorized into different levels, including interpersonal, organizational and community levels. In this organizational intervention, the focus was on the environmental outcome at the organizational level (OPs collaborate with the work environment in supporting employees with chronic conditions to exert self-control), which was considered the most relevant environmental outcome level. Performance objectives were identified for the environmental outcome, with OPs being the environmental agents of importance at the organizational level (see Table 2). These performance objectives show the direct collaboration between OPs and an organization for creating an organizational policy and supportive work environment, thereby indirectly supporting employees with chronic conditions to exert self-control.

**Table 2.** Performance objectives for OPs (environmental agents)

- 
1. OP creates awareness within the organization of the need for an organizational policy to facilitate employees with chronic conditions staying at work
  2. OP guides the employer in exploring organizational barriers which inhibit employees with chronic conditions from exerting self-control
  3. OP guides the employer in exploring possible solutions for these organizational barriers which inhibit employees with chronic conditions from exerting self-control
  4. OP helps to create an organizational policy and a supportive work environment to facilitate the ability of employees with chronic conditions to exert self-control and stay at work
-

Determinants are factors underlying the performance of behavior. The needs assessment provided information on personal determinants on the behavioral and organizational levels that are associated with the performance objectives of employees with chronic conditions and the performance objectives of OPs, respectively. Based on the determinants yielded from the needs assessment and the determinants described in behavior change theories (e.g. Reasoned Action Approach (36), attitude, skills and self-efficacy, and perceived norms were selected. Subsequently, matrices of change objectives were constructed for the behavioral outcome as well as for the environmental outcome by combining performance objectives with determinants for employees and OPs. Change objectives operationalize what employees with chronic conditions as well as OPs participating in the program need to learn or change to meet and/or maintain the performance objectives. Examples of matrices of change objectives for the behavioral outcome and environmental outcome are shown in Tables 3 and 4.



**Table 3.** An example of a matrix of change objectives for employees with chronic conditions  
**Behavioral outcome: The employees with a chronic disease will exert self-control**

Performance objectives		Personal determinants		Perceived norm
		Attitude	Skills & Self-efficacy	
1. Decide in which cases disclosure of the chronic condition could be of help for sustainable employability and follow-up on these decisions (designating when to disclose, to whom and what information)		A1a. Express positive feelings about disclosing the condition and sharing information about the impact of working with the condition to work environment	S1a. Express confidence in the ability to talk about the condition at work	P1a. Perceive the employer to be positive about disclosing the condition
		A1b. State that disclosure helps in gaining adjustments and support	S1b. List strategies that can help with talking about the condition at work S1c. Describe what information will be shared and to whom	P1b. Feel support from employer and colleagues to disclose the condition
2. Ask for adjustments and support from employers, co-workers, the social environment, and health care providers		A2a. Express positive feelings about receiving support and adjustments in maintaining employment	S2a. Express the confidence of recognizing the need for adjustments and support	P2a. Recognize that the employer is positive about asking for adjustments and support
		A2b. State that asking for adjustments and support helps in fitting the job to the capacities and adjust to the condition at work	S2b. Lists the available people (employers, co-workers, social environment, occupational physician and health care providers) and options for support S2c. Lists the laws and policies that protect and facilitate employees with chronic conditions	P2b. Feel support from employer and colleagues to ask for adjustments and support P2c. Feel support from policy and legislative system to ask for adjustments and support

**Table 3.** An example of a matrix of change objectives for employees with chronic conditions (continued)

<b>Behavioral outcome: The employees with a chronic disease will exert self-control</b>			
<b>Performance objectives</b>	<b>Personal determinants</b>		
	<b>Attitude</b>		
	<b>Skills &amp; Self-efficacy</b>		
	<b>Perceived norm</b>		
3. Make decisions with the aim of fitting the job to personal capacities and to maintain balance in life and follow-up on these decisions	<p>A3a. Express positive feelings about making decisions</p> <p>A3b. State that decision making can help with energy management and maintaining balance in work, health and personal life</p>	<p>S3a. Express confidence about the ability to weigh the options and make the right decisions</p> <p>S3b. Lists his/her priorities with regard to work, health and personal life</p> <p>S3c. List the needed information for decision making</p>	<p>P3a. Recognize that the employer is positive about making decisions that help to find the right balance in life</p> <p>P3b. Feel support from employer and colleagues to make decisions that help to find the right balance in life</p>
4. Manage limitations and respond to symptoms at work	<p>A4a. Express positive feelings about taking responsibility to manage the symptoms and limitations at work</p> <p>A4b. State the consequences of not managing the symptoms and limitations at work</p> <p>A4c. State that managing symptoms and limitations will help in staying productive and prevent progression of symptoms</p>	<p>S4a. Express confidence in the ability to recognize symptoms and limitations</p> <p>S4b. Express confidence in the ability to manage the symptoms and limitations at work</p> <p>S4c. List the symptoms that require actions</p> <p>S4d. Recognizes problems in managing symptoms and limitations at work</p>	<p>P4a. Recognize that the employer is positive about managing symptoms and limitations at work</p> <p>P4b. Feel support from employer and colleagues to manage symptoms and limitations at work</p>

**Table 4.** An example of a matrix of change objectives for OPs

<b>Environmental outcome: occupational physicians collaborate with the work environment in supporting employees with chronic conditions to exert self-control</b>	
<b>Performance objectives</b>	
<b>Personal determinants</b>	
<b>Attitude</b>	<b>Skills &amp; Self-efficacy</b>
<b>Perceived norm</b>	
1. OP creates awareness within the organization of the need for an organizational policy to facilitate employees with chronic conditions staying at work	<p>A1a. Express positive feelings about creating awareness within the organization for the need of an organizational policy</p> <p>S1a. Express confidence about identifying relevant stakeholders in the organization</p> <p>S1b. Express confidence in getting across the importance of an organizational policy to relevant stakeholders in the organization</p> <p>P1a. Recognize that the employer is positive about exerting self-control by employees with chronic conditions</p>
2. OP guides the employer in exploring organizational barriers which inhibit employees with chronic conditions from exerting self-control	<p>A2a. Express positive feelings about identifying barriers for exerting self-control by employees with chronic conditions</p> <p>A2b. State that identifying barriers for exerting self-control by employees with chronic conditions is the first step in creating an organizational policy</p> <p>S2a. Express confidence about the ability to guide the employer with identifying barriers for exerting self-control by employees with chronic conditions</p> <p>P2a. Recognize that the employer is positive about identifying barriers for exerting self-control by employees with chronic conditions</p> <p>P2b. Feel support from employer in identifying barriers for exerting self-control by employees with chronic conditions</p>
3. OP guides the employer in exploring possible solutions for these organizational barriers which inhibit employees with chronic conditions from exerting self-control	<p>A3a. Express positive feelings about finding effective solutions for identified barriers</p> <p>A3b. State that these solutions can help with exerting self-control by employees with chronic conditions and can help in creating an organizational policy</p> <p>S3a. Express confidence about the ability to guide the employer with thinking up effective solutions</p> <p>P3a. Recognize that the employer is positive about thinking up solutions for exerting self-control by employees with chronic conditions</p> <p>P3b. Feel support from employer in thinking up solutions for exerting self-control by employees with chronic conditions</p>

**Table 4.** An example of a matrix of change objectives for OPs (continued)

<b>Environmental outcome: occupational physicians collaborate with the work environment in supporting employees with chronic conditions to exert self-control</b>			
<b>Performance objectives</b>	<b>Personal determinants</b>		
	<b>Attitude</b>	<b>Skills &amp; Self-efficacy</b>	<b>Perceived norm</b>
4. OP helps to create an organizational policy and a supportive work environment to facilitate the ability of employees with chronic conditions to exert self-control and stay at work	A4a. Express positive feelings about helping employer in creating an organizational policy A4b. State that an organizational policy can facilitate exerting self-control by employees with chronic conditions	S4a. Express confidence in the ability to help create an organizational policy together with employer	P4a. Recognize that the employer is positive about creating an organizational policy

### **Step 3 Program design**

The intervention was conceptualized and designed in step 3, based on the logic model of change created in step 2. In this step, an initial program plan was conceived with the program components, scope, and sequence. Additionally, theory- and evidence-based methods and practical applications were chosen to influence the change objectives.

The design of the intervention and selection of chosen methods and applications were extensively discussed within the project team to make sure that appropriate methods were used to influence the relevant determinants. As the work environment is crucial for employees with chronic conditions to express the desired self-control behaviors in the workplace (e.g. disclosure and requesting accommodations), the scope of the program was to develop an organization-specific policy and to create a supportive environment for these employees. By changing the role of OPs, they are able to focus more on prevention of work-related problems and support of organizational preventive actions. OPs can fulfil their preventive tasks by guiding and advising organizations in the process of organizational policy development and creating a supportive work environment. Table 5 shows examples of the theoretical methods and practical applications chosen for changing the attitudes, skills and self-efficacy, and perceived norms among the OPs, enabling them to guide organizations in developing an organizational policy and creating a supportive work environment.

When developing an organizational policy and creating a supportive work environment, it is important to include all stakeholders within an organization in the process. The Participatory Approach (PA) is an effective evidence-based approach for addressing and tackling existing barriers in an environment where different stakeholders could have varying perspectives regarding these barriers. The PA is a structured six-step process: 1) creating the right conditions, 2) analysis of barriers, 3) analysis of solutions, 4) plan of action, 5) implementation, and 6) evaluation. It can be used at both the individual or the organizational level to facilitate sustainable employment and the health of employees in an organization (37-39). In this study, the PA will be used by OPs and applied at the organizational level to develop an organizational policy for employees with chronic conditions and to create a supportive work environment. When applying the PA at the organizational level, OPs, employees with chronic conditions, and all other relevant organizational representatives (e.g. supervisors, human resources managers) should be involved in the process. The likelihood of successful organizational change is improved by the joint effort of all relevant stakeholders within the organization.

**Table 5.** Theoretical methods for the selected determinants

<b>Change objective (per determinant)</b>	<b>Theoretical methods</b>	<b>Parameters</b>	<b>Practical applications</b>
CO A1-4	Shifting perspectives	Requires social and organizational skills	OPs form workgroups and organize meetings with different stakeholders (e.g. employees, HR managers and supervisors) in an organization
CO A1-4	Environmental re-evaluation	Stimulation of cognitive as well as affective appraisal for improving appraisal and empathy skills	Stakeholders in the workgroup discuss the benefits of exerting self-control at work for employees with chronic conditions and their employers
CO A2; S2; P2	Organizational diagnosis and feedback	Requires consciousness raising, feedback and communication skills	The workgroup discusses and identifies potential barriers to exert self-control within their organization from different stakeholders' perspectives
CO A3; S3; P3	Participatory problem solving	Requires willingness to accept working group participants as equals; requires creative thinking and appropriate motivation	The workgroup discusses and brainstorm about possible solutions for these barriers to better support their employees in exerting self-control within their organization
CO A4; S4; P4	Structural redesign	Requires management authority and agreement	Agreed solutions are implemented in new or existing policy within a certain timeframe
	Systems change	Methods and actors depend on the level of the system	



Having a process leader to guide all the stakeholders through the different steps is essential when applying the PA. As OPs are considered suitable professionals to guide an organization into a supportive work environment for employees with chronic conditions, the plan was to train OPs in serving as a process leader when applying the PA in an organization. In addition to the knowledge and skills of the PA, it is also essential for the OPs to understand the concept of self-control and the associated self-control behaviors. An understanding of the influence of the work environment on the expression of self-control behaviors by employees with chronic conditions is also essential. OPs can use this knowledge to create awareness within the organization and to provide organizational representatives with information during the PA process.

#### **Step 4 Program production**

The methods and practical applications chosen in Step 3 were operationalized into the final program in Step 4. The structure and organization of the program were explained in a protocol, program materials were developed, and existing materials were reviewed and adapted as needed to address the change objectives.

The program we developed consists of a training, a practical assignment, and a follow-up meeting for OPs. It is suitable for all OPs, whether they are self-employed, working for an occupational health services agency, or working within the occupational health services department of an organization. The training provides the OPs with a) theory and evidence on the self-control behaviors of employees with chronic conditions and the importance of a supportive work environment in expressing these self-control behaviors, and b) information on how to apply the PA and act as a process leader in an organization in order to help the organization create organizational policy and a supportive work environment. During the training, theory on self-control behaviors and the PA will be alternated with short exercises, giving the OPs the opportunity to practice certain steps of the PA. Additionally, these exercises offer ways to reflect on the level of exertion of self-control behaviors in the organization the OP is working for. The training will be given by two members of the project team. At the start of the training, the participating OPs will receive a training manual containing 1) practical information, 2) the slides of the PowerPoint presentation to be used during the training, 3) information on the practical assignment, and 4) background information. At the end of the training, the OPs will receive further instruction on the practical assignment.

**Form 3**

**Barriers for exerting self-control?**

Causes

Barrier 1

Barrier 2

Barrier 3

Causes

Causes

**Form 4**

**What are possible solutions?**

Barrier 1

Solutions

Feasibility?

Barrier 2

Solutions

Feasibility?

The figure shows two forms, Form 3 and Form 4, used in a participatory approach. Form 3 is titled "Barriers for exerting self-control?" and contains three rows. Each row has a box for "Barrier" (labeled Barrier 1, Barrier 2, and Barrier 3) and a box for "Causes". Blue arrows point from each barrier box to its corresponding causes box. Form 4 is titled "What are possible solutions?" and contains two rows. Each row has a box for "Barrier" (labeled Barrier 1 and Barrier 2) and a box for "Solutions" and "Feasibility?". The "Solutions" and "Feasibility?" boxes are separated by a vertical line. Both forms include a logo in the top right corner with the text "Inventarisatie" and "5".

**Figure 3** Examples of forms, used to guide the Participatory Approach

In the practical assignment, the OPs will need to apply the six steps of the PA in one of the organizations they are working for. OPs will start with creating the right conditions for applying the PA in the organization, one of which is creating a working group with employees and organizational representatives. The OP will serve as a process leader to guide this working group during three meetings. During the first meeting, the working group members will analyze and identify existing barriers inhibiting the execution of self-control behaviors within their organization. The second meeting will be used for brainstorming solutions for the identified barriers and a plan of action for the implementation of these solutions. OPs will thereafter monitor the implementation of these solutions within the organization. These solutions provide input for organizational policy and contribute to the creation of a supportive work environment. During the third meeting, the implemented solutions will be evaluated. Forms have been developed for guiding the PA process during the practical assignment. These forms are included in the manual (see Figure 3). Six months after the training, a follow-up meeting will be planned in which experiences with the practical assignment will be shared between the OPs.

### **Step 5 Implementation plan**

Considering program implementation began in step 1 and extended to step 5. In step 5, a plan for the implementation of the program was developed specifying the potential implementers of the program. Program outcomes and performance objectives for adoption, implementation, and maintenance were written, after which matrices of change objectives for implementation were constructed. After selecting the proper change methods and applications, a strategy for adoption, implementation, and maintenance was designed.

Implementation of the program will occur in a pilot study in which the practical assignment will be used to explore the usability, practicality, and effectiveness of the program. OPs who participated in the training will put their knowledge and skills from the PA into practice in one of their organizations. Two important program outcomes were identified prior to the start of the pilot study: 1) the organization is positive about developing an organizational policy and creating a supportive work environment with use of the PA and 2) OPs are able to carry out the PA for the development of this organizational policy. Since this program aims to include all relevant stakeholders in the process, OPs as well as the organizations (including employees and relevant organizational representatives) are important to the successful implementation of the program. However, OPs and employers are considered the most relevant implementers because of their responsibility for

initial implementation actions. Therefore, performance objectives for both these environmental agents (OPs and employers) are specified (see Table 6 and 7).

**Table 6.** Performance objectives for implementation by OPs (environmental agents)

- 
1. OP identifies relevant stakeholders within the organization (e.g. employees with chronic conditions, supervisors, human resources managers)
  2. OP makes the sense of urgency of implementing organizational policy clear to the relevant stakeholders
  3. OP explains and convinces the employer of the added value of the PA for the development of organizational policy
  4. OP initiates the start of the PA in the organization
  5. OP guides the organization through the PA process
- 

**Table 7.** Performance objectives for implementation by the employer (environmental agents)

- 
1. The employer supports the development of an organizational policy for employees with chronic conditions
  2. The employer approves the use of the PA for the development of an organizational policy
  3. The employer facilitates the PA by providing man hours and financial means
  4. The employer actively participates in the PA for the development of an organizational policy
- 

For this pilot study, OPs were targeted through the Netherlands Society of Occupational Medicine and a large Dutch occupational health services agency, and were invited to participate in the program. All OPs working for an organization which they thought might be open to implementing the program were eligible for participation. Since OPs were targeted instead of organizations, it was unclear in advance what type of organizations would ultimately participate in the program. OPs working for a variety of organizations were willing to participate, including organizations in the health care, financial, logistics, industrial and cultural sectors. Since the program developed for this pilot is a universal intervention, it can be implemented in any organization regardless of size, work sector, or the current number of employees with chronic conditions. Given the large portion of the population living with one or more chronic conditions, it was expected that the majority of organizations would have at least some employees with chronic conditions. Prior to the training, participating OPs were sent preparatory questions, the answers of which could be used to further tailor the training to the needs of the participants.

Given that each organization has a different structure, relevant organizational representatives to involve in the program can differ. Identification of relevant stakeholders within the organization by OPs is therefore a first step in the implementation phase. In order for employers to support the development of an organizational policy and organizational change they need to be aware of the importance of such a policy and the influence that a supportive work environment can have on employees with chronic conditions. At the start of the implementation phase, OPs were advised that members of the project team could assist in highlighting the urgency of an organizational policy and supportive work environment and explaining the added value of the PA to the organization (performance objectives 2 and 3 for the OPs).

### **Step 6 Evaluation plan**

In the final step of the IM protocol, a plan for evaluating the effectiveness of the program on the change objectives and the actual behavior was developed. Results of this evaluation are expected in 2021.

## **Discussion**

This study describes the systematic development of a program for OPs using the IM protocol. The program consists of a training, a practical assignment, and a follow-up meeting for OPs. The program aim is to develop an organizational policy and create a supportive work environment for employees with chronic conditions thereby enabling them to exert self-control.

Targeting the workplace has been a focus of many interventions aimed at maintaining health and employment among employees, either on the individual employee level or on the organizational level. Workplace interventions have been developed focusing on issues such as improving employees' lifestyles (e.g. sitting time or nutrition) or preventing work-related stress and injuries (40-43). In the last decade, numerous workplace interventions have also been developed to prevent work disability for employees with chronic conditions (44-47). When taking a closer look at these workplace interventions, three things stand out. First, the majority of these interventions have focused on employees on sick leave and strategies for reduction in the duration of absenteeism and for returning to work (45, 46, 48, 49). The number of interventions aimed at actually preventing work-related problems and promoting sustainable employment for employees with chronic conditions is lacking (50). Second, a large proportion of interventions are directed at employees

with psychological or musculoskeletal disorders (51). Finally, prevention-focused interventions aimed at sustainable employment for employees with chronic conditions are almost always directed towards the individual employee instead of the organization as a whole, including stakeholders within the work environment (52, 53). Different aspects of an organization can be targeted in organizational-level interventions, such as job demands, work conditions, or psychological or social factors (e.g. organizational support). Changing organizational culture and support is challenging but interventions at the organizational-level have been shown to provide a more sustained effect on employees' health in comparison to individual-level interventions (47). The intervention described in this study adds to the literature an innovative, organizational-level intervention with a preventive approach which is aimed at employees with different types of chronic conditions.

With the growing number of employees with chronic conditions, a greater focus on prevention and sustainable employment within organizations is essential. Organizations differ in their ways of dealing with employees with chronic conditions with regard to the level of support offered, including the realization of work accommodations (54). A negative attitude towards employees with chronic conditions, not knowing how to support and accommodate these employees, and lack of organizational policy related to things like work accommodation can all contribute to this problem. In addition, a country's occupational health and safety legislation influences the way employers respond to these employees (34, 54, 55). This same legislation also delineates the roles and responsibilities of occupational health professionals and their subsequent tasks (56, 57). Despite the renewed Dutch labor legislation and focal point of prevention in the mission statement of the Netherlands Society of Occupational Medicine, prevention in occupational health care remains difficult to enact (58). With their pivotal role in occupational health care, OPs have the expertise and ability to encourage and support employers with preventive actions and strategies for work-related problems that employees with chronic conditions may have. By positioning OPs as process leaders during the PA in this intervention, they are in a better position to play a preventive role.

The use of OPs as process leaders in this intervention also has limitations. Firstly, the intervention was tailored to the role of OPs in the Dutch context. In various other countries, the role of OPs differs from the role of Dutch OPs (23, 59). In these other countries, however, different occupational health professionals such as occupational health nurses, return to work coordinators, or organizational psychologists could also fulfill the tasks of process leader (60, 61). Secondly,

occupational health care by OPs in the Netherlands is not freely accessible to all types of workers (62). Self-employed workers, making up 12% of the Dutch working population, are not able to use the services offered by OPs (63), making the intervention not applicable to this group of workers. On the other hand, since this intervention is aimed at changes at the organizational level, all workers within an organization are able to benefit from the changes. This includes temporary agency workers within an organization, who, according to Dutch laws, otherwise would not have access to OPs.

### **Methodological considerations**

Workplace interventions are complex, with numerous stakeholders involved. IM proved to be a valuable tool for the systematic development of this intervention, with several underlying reasons for the practicality of this approach. IM provided us with a structure to start sorting out the causal relationships of the problem and finding out the needs of all stakeholders involved. Based on the causal relations and stakeholders' needs identified in the IM steps, it was clear what changes were necessary. Evidence-based decisions could thereby be made to focus the intervention to match the context in which it must be implemented. Since the program was initiated to support the development of knowledge and skills of OPs, our initial thought was to develop an intervention focusing on the OP. However, the evidence gathered in the IM steps shifted the focus of the intervention and its implementation to the work environment in which OPs would need skills as process leaders. Additionally, IM also provided an understanding of the complexity of the context, guidance on deciding what methods to use, and subsequent practical applications. However, although IM was used to optimize the development of the intervention, some drawbacks of this method could be identified. Following all the steps of the protocol is a time-consuming process. Furthermore, although IM aids in optimizing the effect of the intervention, using IM is not a guarantee for success, as pointed out by the review of Fassier et. al. (64). In this study, the needs assessment (as a first step in the IM protocol) showed the causal relations of the problem. In addition to the employees and other actors within the work environment, the health care environment and the social environment both influenced the possibility of employees with chronic conditions exerting self-control. Because the work environment was of primary importance, the health care and social environments were not targeted in this intervention. Adding elements to the program aimed at influencing the health care and social environments could further improve the effects of the program. IM contributed to the development of a clear implementation and evaluation plan.

### **Practical implications**

Changing employees' behavior is difficult, especially when optimal conditions for carrying out certain behaviors are absent. The same applies for self-control of employees with chronic conditions. Creating a supportive and understanding work environment provides these employees with the ability to exert self-control, while an organizational policy will provide the organization with clear procedures for employers and employees on addressing the prevention of work-related problems. The intervention developed in this study provides OPs with the necessary skills to serve as process leaders in the development of organizational policy and creating supportive and understanding work environments. An optimal work environment for the expression of self-control behaviors can lead to early identification or prevention of work-related problems among employees with chronic conditions and sustainable employment. This will benefit both employees with chronic conditions as well as employers. Once proven effective after the pilot study (expected results in 2021), this program could be imbedded in educational programs for OPs.

### **Research recommendations**

It is to be expected that the effectiveness of the intervention will vary for different work settings. Aspects such as the size of the organization, the number of management layers and types of employees (e.g. white or blue collar) could influence the effectiveness of the intervention. Further research should be conducted to investigate contextual factors and the optimal conditions for implementing interventions in the workplace. The possibility of targeting organizations instead of OPs could also be explored.





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# Chapter 6

## **Participatory Approach to create a supportive work environment for employees with chronic conditions: a pilot implementation study**

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## Abstract

**Objective:** To evaluate a pilot implementation of an organizational-level intervention, with a key role for occupational physicians (OPs). Moreover, to describe three cases of applying the Participatory Approach (PA) to create a supportive work environment for employees with chronic conditions.

**Methods:** 28 semi-structured interviews were conducted with OPs and stakeholders within their organizations. Furthermore, observational data and research notes were gathered. Data analysis occurred through content analysis.

**Results:** Recruitment of organizations was challenging, with a reach of 25%. Dose delivered, dose received and fidelity differed across the three organizations. Organizations were positive about the PA as a method to improve support for employees with chronic conditions.

**Conclusions:** The PA could be of added value for creating a supportive work environment. However, research is needed on activating organizations to improve support for employees with chronic conditions.

## Introduction

Working is of importance for one's quality of life (1). However, working with a chronic condition can raise challenges for employees due to fatigue, cognitive as well as physical limitations (2, 3). At the same time, chronic conditions in the working population can have an economic impact on employers due to productivity loss and absenteeism (4, 5). The number of employees with chronic conditions is rising as a result of various reasons, such as the increase in retirement age, unhealthy lifestyles and unfavorable working conditions (5, 6). Since return to work after long term sick leave or job loss has proven to be difficult for those with chronic conditions, preventing work-related problems and facilitating sustainable employment for this group is of significant importance (7, 8).

Much research has been conducted on factors that help prevent work-related problems and facilitate sustainable employment among employees with a chronic condition. Self-control at work is one such factor, which can help employees with chronic conditions to stay at work (9, 10). However, contextual factors are essential for the expression of self-control, e.g. factors related to the work environment (11). A supportive work environment could enable employees with chronic conditions to exert self-control behaviors (e.g. disclose the chronic condition and ask for support) and may prevent problems in work functioning. Moreover, a clear organizational policy can aid employees with their requests for work accommodations and facilitate employers (e.g. human resources managers and line-managers) to decide on which actions to take regarding the realization of these accommodations (12, 13). Both occupational health professionals and stakeholders within organizations could contribute to improving support and preventing work-related problems among employees with chronic conditions (i.e. selective or indicated prevention) (14, 15). In the Netherlands, occupational physicians (OPs) provide employees and employers with support and advice related to work and health. However, the share of preventive activities of OPs remains small, as a large part of their time is spent on absenteeism and return to work (16-18).

A pilot implementation of an organizational-level intervention was conducted, using the Participatory Approach (PA), to create a supportive work environment and to develop an organizational policy, enabling employees with chronic conditions to exert self-control. The PA, an effective evidence-based six-step approach, helps to identify and address existing barriers within an environment, in which different stakeholders might have different perspectives regarding these barriers (19, 20).



OPs fulfilled a key role in the intervention, by guiding organizations through the steps of the PA as process leader. By positioning OPs as process leader during the PA, they are in a better position to play a preventive role within the organization (21). Besides OPs, the involvement of stakeholders within the organization is crucial for successful organizational change and is an important condition for applying the PA.

Research has shown that implementing organizational-level interventions is challenging because of the involvement of various stakeholders within organizations and the complexity of many of those interventions (22). Stakeholders can shape and influence the implementation process and outcome (23). Moreover, the implementation process of the same intervention can differ across organizations, due to contextual differences (e.g. number of management layers within an organization). Evaluating organizational-level interventions is important to gain insights into whether and how these interventions could bring about change and to help identify possible causes for a lack of effectiveness (23-25). The aim of this study is twofold. First, to evaluate the pilot implementation of the organizational-level intervention, including a process evaluation and feasibility study. Second, to describe three cases of applying the PA at organizational level and to explore similarities and differences between organizations.

## **Methods**

### **Study design**

A qualitative research design was used to evaluate this pilot implementation and to describe the three cases. Semi-structured interviews were held with OPs and stakeholders within organizations (employees and organizational representatives (e.g. human resources managers, line-managers)). In addition, observational data and research notes were gathered.

### **The intervention**

#### ***Participatory Approach at the organizational level***

The scope of this organizational-level intervention is to create a supportive work environment and develop an organizational policy with the use of the PA at the organizational level, thereby enabling employees with chronic conditions to exert self-control. The six steps of the PA have to be put into practice in an organization, with the OP serving as a process leader. Step 1 of the PA includes OPs approaching and convincing one of their organizations of the need of a supportive work environment and an organizational policy, using the PA as a method to

achieve this. Subsequently, the right preconditions for actually applying the PA have to be secured. One of which is the involvement of all relevant stakeholders in the organization, as a joint responsibility and effort increases the likelihood of successful organizational change (19, 20). Therefore, a working group with representatives of relevant stakeholders has to be assembled. One or more project coordinators within the organization could be assigned to take on this responsibility and other practical arrangements, such as planning meetings. In Step 2, a first meeting will be held in which the working group will identify barriers to the exertion of self-control behaviors in the organization. In a second meeting (Step 3 and 4), the working group will brainstorm on solutions to these barriers and will draw up an action plan for implementation of the selected solutions. An important characteristic of the process leader during these meetings is the neutral position, i.e. focusing on managing the process. In Step 5, the selected solutions will be implemented in the organization. These solutions contribute to the creation of a supportive work environment and provide input for the organizational policy. Implementation of solutions will be evaluated in a third meeting (Step 6). A more detailed description of the PA steps and preconditions to implementation are described in another article (21).



### ***Preparatory training for occupational physicians***

A training was developed that provided OPs with a) theory and evidence on self-control behaviors for employees with chronic conditions (i.e. 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, and 4) management of symptoms and limitations in the workplace) and b) practical information on how to guide organizations through the steps of the PA and act as a process leader. OPs were provided with a training manual, which also included a protocol with the PA steps and forms that could be used during the steps of the PA in practice.

### ***Peer review meeting***

After the initial training session, peer review meetings were planned in which experiences with applying the PA in practice were shared among OPs. OPs from the different training sessions were mixed in two peer review meetings based on their availability.

## **Recruitment**

### ***Recruiting occupational physicians***

Due to their key role as process leaders in the intervention, OPs were recruited instead of organizations. OPs were recruited through the Netherlands Society of

Occupational Medicine (NVAB) and a large Dutch occupational health service. In addition, OPs were recruited through the researchers' network and snowball sampling. OPs were provided with information on participation, which included attending a preparatory training session, a peer review meeting and applying the PA in one of their organizations. All OPs working for an organization of which they thought might be open to applying the PA, regardless of work sector, were eligible for participation. OPs who signed up for participation were contacted by the primary researcher (AB) by telephone for further clarification of the study. As OPs were recruited, the work setting (type or size of organization) in which the PA would be applied, was not clear in advance. All OPs who participated in a training session were invited to participate in an interview to evaluate the pilot implementation.

### ***Recruiting stakeholders within organizations***

For the evaluation of the pilot implementation, stakeholders within non-participating (i.e. working in organizations that were not willing to apply the PA) and stakeholders in participating organizations (i.e. working group members during the PA) were recruited. In non-participating organizations, stakeholders involved in the decision-making process of participation were reached through the OPs of the organization concerned. Within participating organizations, all working group members were approached through the project coordinator. All stakeholders were contacted by email and invited to participate in an interview.

### ***Participants***

Attempts were made to interview as many OPs and stakeholders within the organizations for evaluation of the pilot implementation. 13 OPs attended one out of three training sessions, of which ten OPs agreed to participate in an interview. Of those, three worked for a participating organization. 18 stakeholders took part in an interview; 16 working group members and 2 stakeholders of non-participating organizations. Table 1 shows the characteristics of all interview participants. Ultimately, three OPs and four working group members who were contacted, were not able to participate in an interview, due to time constraints, long-term leave of absence, or because they were no longer working for the organization, or not responding to the invitation.

**Table 1.** Characteristics of interview participants (n = 28).

<b>Characteristics</b>		<b>Number</b>
Sex	Men	9
	Women	19
<i>Type of function</i>	Occupational physician	10
	Human resources manager	4
	Line-manager	6
	Employee (with a chronic condition)	7
	Strategic Advisor	1
<i>Working in participating organization</i>	Yes	19
	No	9

### **Data collection**

Semi-structured interviews, observational data and research notes were used for the evaluation of the pilot implementation and to describe the three cases of applying the PA at the organizational level.

### ***Process evaluation and feasibility framework***

Two frameworks were used for the evaluation. Components of the Linnan and Steckler framework were used for the process evaluation, and included recruitment, reach, dose delivered, dose received, and fidelity. The operationalization of these components and how there were assessed (including some illustrative interview questions) is described in Table 2. Feasibility was based on the Bowen framework, and was assessed by questions related to acceptability, practicality, and satisfaction with the PA (26, 27). In addition, a question was added on the promise of the PA being a successful method for creating a supportive work environment and ultimately improving the exertion of self-control behaviors among employees with chronic conditions.



**Table 2.** Operationalization and assessment of the Linnan and Steckler components

<b>Component</b>	<b>Definitions</b>	<b>Assessment</b>
Recruitment	Recruitment was defined as the procedures used to approach the relevant stakeholders in the organization and convincing them of the need of a supportive work environment and using the PA as a method to achieve this.	<p><i>Observational data and research notes of the peer review meetings</i></p> <p><i>Semi-structured interviews:</i></p> <ul style="list-style-type: none"> <li>- How did you approach the organization?</li> <li>- Did you encounter barriers or facilitators to recruitment?</li> <li>- What are considered the most important reasons for the organization not to participate?</li> </ul>
Reach	Reach was defined as the proportion of organizations that agreed to participate and was willing to apply the PA.	<i>Observational data and research notes</i>
Dose delivered	Dose delivered was defined as the degree to which relevant stakeholders were included in the working group (by the project coordinators) and the attendance of working group members during the meetings (poor – sufficient – good).	<p><i>Observational data and research notes</i></p> <p><i>Semi-structured interviews:</i></p> <ul style="list-style-type: none"> <li>- Did you attend all meetings?</li> </ul>
Dose received	Dose received was defined as the degree to which selected solutions were implemented within the organization (poor – sufficient – good).	<p><i>Semi-structured interviews:</i></p> <ul style="list-style-type: none"> <li>- Were solutions implemented in the organization? And if so, which solutions were implemented?</li> </ul>
Fidelity	Fidelity was defined as the degree to which the OP fulfilled the process leader role and guided the meetings as stated in the protocol (poor – sufficient – good).	<p><i>Observational data and research notes</i></p> <p><i>Semi-structured interviews:</i></p> <ul style="list-style-type: none"> <li>- How did the OP fulfill the process leader role?</li> </ul>

### ***Semi-structured interviews***

At the convenience of the participant, interviews were held at the organization's location or conducted by telephone or videoconference. Interviews lasted approximately 15-45 minutes. Interviews were held in Dutch and conducted by the primary researcher (AB), who has experience in qualitative research. Two interview guides were developed to aid the researcher and ensure comparability of the interviews, thereby increasing reliability. One interview guide contained questions for OPs and stakeholders of non-participating organizations, including questions on the barriers to recruitment of organizations. Another interview guide was intended for OPs and stakeholders of participating organizations, which included topics and open questions related to the components of the two frameworks described above. All interviewees signed informed consent forms and information was provided to all participants on the confidentiality and anonymity of the results of the study.

### ***Observational data and research notes***

Research notes were made during the peer review meetings with OPs, to assess recruitment and reach. Moreover, the primary researcher attended the PA meetings with the working group in the participating organizations, where research notes and striking observations, related to the other components of the Linnan and Steckler framework (dose delivered, dose received and fidelity), were written down. Due to privacy reasons, the peer review meetings and PA meetings were not audio-recorded.

### **Data analysis**

#### ***Semi-structured interviews***

All interviews were digitally recorded and transcribed verbatim by a specialized external agency. No member-checking was carried out, as the interviews were relatively short and the researcher ended each interview with a small summary of main points mentioned by participants. Data were analyzed using content analysis, with a combination of an inductive and deductive approach. Analysis started with reading and rereading of the transcripts, after which line-by-line coding of the transcripts was carried out. Qualitative data indexing software (ATLAS.ti) was used during the coding process. Next, data was searched for similarities and discrepancies, after which codes were grouped together, guided by the steps of the PA and the actions associated with them. All data was coded by the primary researcher (AB). To increase reliability, a second researcher (RS) carefully reviewed 30% the transcripts (several transcripts from OPs and all transcript from one of the three organizations). Findings were extensively discussed amongst





the two researchers and members of the project team. Analysis resulted in rich descriptions of the application of the PA in practice.

### ***Observational data and research notes***

Observational data and research notes were reviewed with the focus to outline the context and to create an objective image of the process (recruitment, reach, dose delivered, dose received and fidelity). Moreover, there were used to either confirm or invalidate interview findings.

### **Ethical considerations**

The Medical Ethics Review Committee of the VU University Medical Center determined that an ethical approval was not required because the Medical Research Involving Human Subjects Act ('Wet Medisch-wetenschappelijk Onderzoek met mensen') does not apply to this study.

## **Results**

### **Approaching organizations to apply the PA (Step 1)**

*Step 1* of the PA, approaching and convincing organizations of the need of a supportive work environment (***Recruitment***) turned out to be challenging for OPs. Several barriers and facilitators influencing this first step were described, e.g. OPs' ease of making contact with the designated stakeholder and the role of the OP in policy setting. Table 3 shows the factors that influenced OPs' level of success in convincing organizations to create a supportive work environment by using the PA, and subsequent barriers and facilitators to these factors.

OPs' efforts to convince organizations ultimately resulted in organizations' decisions to whether or not participate and use the PA to create a supportive work environment and to develop an organizational policy. According to OPs, too much focus on absenteeism instead of preventing work-related problems was an important reason for organizations not to participate. Box 1 provides an overview of the reasons mentioned by OPs and stakeholders of organizations for not participating. The challenges of convincing organizations also became clear during the peer review meetings. Facilitators to convince organizations and possible reasons why organizations would decide to use the PA for creating a supportive work environment, as mentioned by OPs, are listed in Box 2.

**Table 3.** Factors influencing the recruitment process, with subsequent barriers and facilitators.

<b>Relevant factors to recruitment</b>	<b>Barriers</b>	<b>Facilitators</b>
OPs ease of making contact with the designated stakeholder	Time constraints of OPs to initiate contact.  Time constraints of the designated stakeholders.	Having an established and good relationship with the designated stakeholder.
<i>Degree of persuasiveness of OPs in convincing the organization</i>	Difficulty getting the message across when using solely the information in the training manual.  A lack of real life cases or difficulty using them due to privacy reasons.	Using real life cases to support the arguments.
<i>The need for approval from higher management</i>	A larger-sized bureaucratic organization or an organization with many management layers.	The research team providing additional information to higher management in the form of a presentation.
<i>Organization-related factors</i>	No existing policy or an ad hoc way of problems solving within the organization.  A fragmented organizational structure (i.e. an organization with a headquarter and many different local offices).	An existing sickness absence policy (implementing the PA would result in a preventive supplement).  An open workplace culture.
<i>The role of the OP in policy setting</i>	Merely performing executive duties.	Having a say in policy setting.

**Box 1.** Reasons for organizations not to participate

- No sense of urgency to prevent work-related problems / too much focus tackling high levels of absenteeism
- Having other priorities / other ongoing projects
- Lack of resources (e.g. time)
- Current precarious situation of the organization (e.g. economic insecurity, downsizing)
- Preferring or already using other methods to address the issue
- Doubts about the cost-effectiveness



**Box 2.** Facilitators to recruit organizations

- Presenting a business case: what is to gain from a focus on the prevention of work-related problems for employees with chronic conditions?
- Expressing mutual (employer and employee) benefits.
- Storytelling: what can be learned from success stories?
- Expectation management: making sure managers know what to expect (e.g. time investment, costs)
- Use current cases as examples to invigorate OPs' attempts.
- Pointing out the effect on improving corporate identity: with a good image it is easier to attract new personnel.

**Box 3.** Descriptions of participating organizations and reasons to apply the PA

Organization A is an organization in the cultural sector with less than 500 employees. Three departments of the organization participated in the pilot study. These departments together count 120 employees. The organization already had a significant focus on offering support and preventing work-related problems, applying the PA would increase the preventive actions in the organization. Moreover, the opinion of the OP on policy issues and preventing work-related problems was highly valued.

Organization B is a large organization in the healthcare sector. The PA was applied in one department of the organization, consisting of around 230 employees. High levels of sickness absence were already an important item on the agenda. A project on employees' vitality was therefore currently running. Applying the PA was seen as an addition to this project.

Organization C is also a large organization, but then in the logistics sector. This organization has around 400 employees working at the office and another 60-70 employees working in a warehouse. The organization wanted to be prepared for the growing number of employees with chronic conditions in the near future. In addition, applying the PA gave them the opportunity to reflect on their current activities and further improve support and actually develop organizational policy.

**Participating organizations**

In the end, three out of twelve approached organizations agreed to create a supportive work environment and develop an organizational policy, using the PA. According to the Linnan and Steckler framework, *reach* equals 25% (26). In all three organizations, the OPs initially discussed participation with the designated human resources manager. The human resources managers (later serving as project coordinators) were provided with the necessary information in the form of a

copy of the training manual. The primary researcher visited all three organizations for further explanation of the PA and provided examples of stakeholders which could to be included in the working group (e.g. employees with a chronic disease, line-managers, members of the work council). Box 3 provides the descriptions of the three participating organizations and their reasons for applying the PA in the organization.

### **Applying the PA at the organizational level**

#### ***Organization A***

##### *The process of applying the PA*

Dose delivered was sufficient and the application of the PA generally occurred according to the protocol. The project coordinator assembled the working group and planned the meetings. All relevant stakeholders were represented in the working group (e.g. human resources, line-managers, employees (with chronic conditions), member of the work council). The working group members got together in a first meeting to identify the barriers to the exertion of self-control behaviors (**Step 2**), followed by a second meeting to brainstorm about suitable solutions and to draw up an action plan (**Step 3 and 4**). All working group members and OP attended the first meeting. In the second meeting, all group members were present, except for the line-manager. Working group members actively participated during both meetings. Although most working group members felt the liberty to speak their minds, it was also mentioned that the presence of the human resources manager and OP induced reluctance to express one's opinions and raised caution on what was said and how it was said. Moreover, the elusive and abstract topic (self-control behaviors) made it difficult for working group members to identify actual barriers, and to come up with concrete solutions that contribute to a supportive work environment.

Dose received was good, all solutions that were selected were actually implemented in the organization (**Step 5**), i.e. extending the organizational policy on preventing work-related problems and communication training sessions for both employees and line-managers. Employees were informed on the renewed policy during department meetings. All working group members were actively taking part in the implementation process, by planning additional meetings and discussing progress by email. A final meeting to evaluate (**Step 6**) the process and implemented solutions among working group members could not take place as a result of the Covid-19 pandemic.



### *Reflecting on the OP as process leader*

Overall, fidelity was sufficient, the OP fulfilled her process leader role, followed the instructions in the training manual and guided the meetings accordingly. From the start of the PA, the OP had regular contact with the project coordinator to guide and to monitor the process. Although both OP and working group members were generally satisfied with how the meetings were guided, working group members occasionally strayed from the subject, losing sight of what really mattered. While some working group members expressed that more steering of the meetings in the right direction could improve efficiency, one working group member complained of too much steering of the meetings.

The OP was satisfied with her role as process leader. However, executing the PA for the first time and making the PA your own was also challenging. Different opinions were expressed by working group members on whether the OP was the right person to act as process leader. While some working group members pointed out that it was beneficial to have the OP as process leader, as it improved OP's visibility. Others mentioned that someone not associated with the organization would be a more suitable process leader, as an objective and unprejudiced point of view could facilitate the guiding process.

### *Satisfaction with the PA at the working group level*

All working group members had a positive attitude towards the PA. The involvement of the various stakeholders was highly valued. Moreover, the PA increased awareness on the impact of working with a chronic condition and it was considered a quick and easy way of tackling barriers within an organization. Some members considered the meetings as intense because the topic (i.e. self-control behaviors), which was difficult to grasp with no easy solutions. Moreover, participating in a working group was a different kind of work than some working group members were used to.

All working group members agreed that implementation of the solutions could have been even more extensive (e.g. more communication training sessions). A temporary leave of absence of the project coordinator and lack of time of working group members complicated the implementation process. Although arranging practical matters by the project coordinator was doable and did not take a lot of time, it was an extra task on top of the other tasks. Having more than one project coordinator was suggested as point of improvement, so continuity of the different steps could be secured in case of absenteeism. Several working group members felt that the implemented solutions had contributed to more disclosure, a better

working atmosphere and improvement in communication with line-managers within the organization.

### ***Organization B***

#### *The process of applying the PA*

In organization B, a human resources manager together with a business manager served as project coordinators. Dose delivered was poor, as the project coordinators experienced communicational difficulties and serious problems with assembling the working group (i.e. who were relevant stakeholders and how to reach them without stigmatization). Consequently, employees (with chronic conditions) were not invited for the first meeting, and thus not able to identify barriers to self-control behaviors within the organization (**Step 2**). Although it was agreed upon that the project coordinators would present the list with identified barriers (identified by working group members present at the first meeting) to several employees for approval and feedback, this did not occur. Thereafter, seven employees (with chronic conditions) were added to the working group by issuing a broad call for participation. However, doubts were expressed by the project coordinators whether the employees, who signed up, were the right employees to be included in the working group. A second meeting was held with all working group members, to brainstorm about suitable solutions and make an action plan (**Step 3 and 4**). This second meeting started with the expression of feelings of disappointment and frustration by employees (with chronic conditions) for not being invited for the first meeting, which negatively affected the atmosphere during the meeting. Moreover, instead of coming up with solutions, some employees used this meeting to vent their anger and dissatisfaction with the organization's management. In addition, personal problems were raised, unrelated to the project. Heated discussions arose on the to be implemented solutions. One working group member described to experience the meeting as unpleasant, not constructive and demotivating.

The problems encountered with assembling the working group, also influenced dose received, which was poor. Although the project coordinators stated to take on the responsibility to proceed with the implementation of solutions, implementation ceased and no solutions were implemented (**Step 5**). The project coordinators pointed out to have doubts about whether the correct solutions came out of the meeting. Furthermore, it was said that solutions were practically difficult to implement because of the organizational structure. No third meeting (**Step 6**) was planned as implementation ceased after the second meeting.



### *Reflecting on the OP as process leader*

Although fidelity was sufficient, it was being impacted by the problems with assembling the working group. With the absence of employees (with chronic conditions) in the first meeting and turbulent interactions during the second meeting, it was difficult for the process leader to guide the meetings according to protocol and keep track of where the brainstorm was heading to. For the process leader it became clear that it was important to be more involved in the preparatory phase (i.e. assembling the working group). Moreover, it was pointed out by the OP, that being a process leader was challenging, trying to remain in a neutral position and refraining from giving advice and offering solutions. Opinions differed on the added value of an OP as process leader. According to some working group members, this role could also have been carried out by another member of the department, e.g. human resources manager or a corporate social worker. By using the OP as process leader, advice and substantive input of the OP on contextual factors within the organization were missed. Others pointed out that the role of process leader increased OP's visibility.

### *Satisfaction with the PA at the working group level*

On the one hand working group members had a positive attitude towards the PA and improving support for employees with chronic conditions, but on the other hand they were disappointed about how the application of the PA was carried out. Everyone agreed that this suboptimal course of applying the PA mainly originated from the problem with assembling the working group. Moreover, the expression of dissatisfaction and dissension during the second meeting, made the process leader wonder whether the PA would be a more suitable method in an organization which has its organizational structure and policy well under control, using the PA for further improvement of support.

For some working groups members it was insufficiently clear what the organization's long-term goal was concerning the prevention of work-related problems and how applying the PA would help achieve this goal. Moreover, it was felt that more preparation was needed to properly introduce this project to the department, with more explanation about the objective for the organization and expectations of participants. Furthermore, feelings of being the sole drivers of the process and a perceived lack of support from the rest of the organization (e.g. management) for actually applying the PA, were mentioned by the project coordinators. A temporary leave of absence of one of the project coordinators contributed to the difficulty of continuing with the steps of the PA. It was noted that these driving forces were crucial to ensure progress of the project. A more

clear and structured overview of what was expected of the project coordinators and concrete guidelines for the practical arrangements (e.g. pointers for inviting working group members) were mentioned as points of improvement.

### **Organization C**

#### *The process of applying the PA*

Dose delivered was sufficient, with two project coordinators (i.e. human resources managers) working in a structured way, to assemble the working group and plan meetings. All relevant stakeholders were represented in the working group (e.g. human resources, line-managers, employees (with chronic conditions), member of the work council). All working group members were present at the first meeting, to identify the barriers to exert self-control behaviors, which was held at the organization's location. Thereafter, a second and a third meeting were held online (due to the Covid-19 pandemic) to come up with solutions and make an action plan (**Step 3** and **4**). Irregular attendance of working group members during these online meetings was observed. It was pointed out that irregular attendance was a consequence of increased workload and time constraints, which hampered the sense of belonging to a group. Especially during the first meeting, working group members actively participated. Participation was less active in the online setting, as the online meetings were less structured and working group members were more easily distracted. Most working group members felt the liberty to speak their minds during the meetings. However, factors were mentioned that hampered the expression of opinions. As not all working group members were familiar with the OP, feelings of unease were described. Moreover, for some employees with a chronic condition, it was difficult to talk in general terms, as they spoke from their own experience and related everything to their personal situation. One working group member found it difficult to explain the significant impact of working with a chronic condition; as she was doing well at the time of the meeting, barriers were more difficult to identify. A lack of experience with participating in such a working group also made it sometimes difficult to express one's opinion. Finally, for some working group members, their role and the organizations' intended goal for applying the PA was not clear, which hampered the provision of input during the meetings.

Dose received was sufficient, the two project coordinators took on the responsibility for initial operationalizing the solutions (Step 5). A new organization's vision on working with a chronic condition and organizational policy were put on writing. Moreover, communication training sessions for line-managers were held. Due to other urgent matters and time constraints with the project coordinators,





implementation of solutions took a long time, with not all solutions being implemented in the course of the study. However, a plan was made to embed and propagate the new organizational policy in the organization and to launch a newly developed website with practical information regarding working with a chronic condition. As a result of this delay and ongoing implementation of solutions, no final evaluation meeting (**Step 6**) was held.

#### *Reflecting on the OP as process leader*

Fidelity was poor, resulting from the OP's perspective on the process leader role. According to him, it was not his sole responsibility, but rather a shared responsibility with both human resources managers, which was noticeable in his performance (e.g. shifting responsibility to human resources and providing advice despite the required neutral position). Consequently, the project coordinators (i.e. human resources managers) took over the process leader role. Comparable to the other organizations, opinions differed on whether the OP was a suitable process leader. The OP as process leader allowed some working group members to get to know the OP. Others considered human resources managers more suitable process leaders, as this way OPs could take on an advisory role and actively participate during the meetings. An OP not associated with the organization or an external process leader were mentioned as other options. Moreover, it was pointed out that by making the training available to both OPs and human resources managers, the process leader role could be a shared responsibility among them.

#### *Satisfaction with the PA at the working group level*

All working group members were positive about the PA, and the fact that the organization was willing to spend time and resources on improving support for employees with chronic conditions. The project coordinators were considered important driving forces of the project. Although they had a clear goal in mind, time constraints and initial uncertainty of what was expected of them in terms of practical arrangements, made it a challenging process. Moreover, the major role of the project coordinators in guiding the PA and implementing solutions, resulted in uncertainty about the progress and state of affairs among other working group members. More extensive information on the tasks, expectations and responsibilities of the different stakeholders in the working group was given as point of improvement.

Furthermore, support and commitment of the upper management was considered crucial, to ensure good embedding in the organization. This awareness resulted in a request for approval from upper management during the application of the

PA. Despite this, there were concerns with some working group members on securing changes in the long-term and whether this approach will ultimately have any effect, especially on employees with chronic conditions in the warehouse.

## Discussion

This study described the evaluation of a pilot implementation, including process evaluation and feasibility study. Furthermore, it described three cases of applying the PA at the organizational level. Recruitment was difficult; convincing organizations of the need to create a supportive work environment for employees with chronic conditions and using the PA as a method to achieve this was a major challenge for OPs. Only three out of 12 organizations were willing to participate (i.e. reach of 25%). Reasons for not participating included, organizations not having a sense of urgency to prevent work-related problems and having other priorities. Of the three participating organizations, one organization (A) generally applied the PA according to protocol. In contrast to the other two organizations (B and C), where dose delivered, dose received and/or fidelity were poor. Especially in organization B, problems with assembling the working group (**Step 1**), lead to a poor dose delivered and dose received. Overall, working group members were positive about the PA and improving support for employees with chronic conditions. Both barriers (e.g. not being able to express one's opinion) and facilitators (e.g. availability of driving forces) were identified that influenced the process of applying the PA. Although the process leader role increased OPs' visibility, opinions differed on the suitability of OPs as process leaders.

### Convincing organizations to apply the PA

This study made clear that convincing organizations to create a supportive work environment, by applying the PA, turned out to be a major challenge. A striking observation was that all three organizations that were willing to create a supportive work environment, were already focused on offering support, preventing work-related problems and employees' health. This existing preventive focus and motivation to improve support for employees with chronic conditions could explain why these organizations were more open to applying the PA, unlike the organizations which did not see the sense of urgency to prevent work-related problems. A good relationship between OP and stakeholders within the organization further facilitated this process. Moreover, stakeholders valuing OPs input and advice was essential for convincing organizations to apply the PA. Research showed that an effective and strategic collaboration between



occupational health professionals and organizations, led to a shift towards a more preventive approach (28).

### **Comparison of participating organizations**

#### *The process of applying the PA*

Whereas in organizations A no major problems occurred in the process of applying the PA, we observed poor dose delivered and dose received in organization B. We found that regular contact between process leader and project coordinator and close monitoring of the progress, as in organization A, facilitated the implementation process. On the other hand, when major problems occur early in the process of applying the PA, as in organization B, this can have major consequences for the continuation and level of success of the PA. Moreover, a skewed relationship between working group members was an important barrier to the selection and implementation of solutions. In organization C, dose delivered was influenced by the irregular attendance of working group members. The Covid-19 pandemic could have played a role in this, due to the online setting of the meetings. A joint effort, and equal input and voice of all working group members in identifying barriers and selecting solutions, are important aspects of the PA. For employees (with chronic conditions) or other stakeholders not being able to provide input in every step of the PA, the power of the approach could have been compromised (19). When comparing our findings to the literature, one study using the PA showed much less deviation from the protocol and adequate dose delivered and dose received (29). While another PA study also described less implementation of solutions than initially expected (30).

#### *Reflecting on the OP as process leader*

In this study, OPs were deployed as process leader, which meant that they had to take a neutral position, refraining from using their expertise and providing advice. As shown in organization C, fidelity was difficult. In the Netherlands, OPs have an advisory role, which required them to adjust to their new role as process leader. Moreover, doubts were described in all three organizations on the suitability of OPs as process leader. The attitude towards OPs could have contributed to this. Feelings that OPs are on the side of the employer, as described in one of our earlier studies among employees with chronic conditions (10), could have hampered the expression of opinions, out of fear that it will be used against them. On the other hand, the role of process leader increased OPs' visibility, which might improve the use of OPs' support (e.g. using preventive consultation hours). Furthermore, the PA enabled OPs to proactively initiate and pursue prevention within an organization, whereas OPs currently largely focus on reducing sickness absence

(31). In contrast, in another PA study, using occupational nurses as process leaders, no doubts on the suitability of the process leader were expressed (29).

### ***Satisfaction with the PA at the working group level***

Despite the encountered difficulties, working group members in all three organizations were satisfied and positive about the PA. The involvement of all stakeholders, a key feature of the PA was highly valued. Our study also showed that human resources managers in all three organizations took on most of the work, e.g. in project coordination and the progress of the PA. These driving forces were crucial for applying the PA, which was also found in another study implementing a participatory program (32). However, project coordinators have to feel supported by higher management and other stakeholders in the organization, which was clearly not the case in organization B. Literature also shows the importance of commitment of higher management on retaining employees with disabilities (33).

Although the intention was that the implemented solutions contributed to a supportive work environment and the development of an organizational policy, we found that there was a need for a clear organizational goal at the start of the PA (i.e. in organizations B and C). That way, the PA could be used to work towards that goal and could help identify barriers and select solutions, instead of the solutions determining the end goal. This need for a clear goal could be related to the complexity of self-control behaviors, being a more difficult topic compared to addressing more concrete problems, such as preventing hand eczema (29).

### **Strengths and limitations**

This study showed the challenges of implementing an organizational-level intervention and illustrated the factors that can influence the process of applying the PA at the organizational level across different organizations. This is valuable information that can be used to further optimize and develop the intervention. Using qualitative research methods yielded understanding of how attitudes and actions of OPs and working group members as well as contextual factors affected the implementation process. However, also limitations of the study must be mentioned. The most important limitation was that only three out of 12 organizations agreed to participate and applied the PA, resulting in an incomplete picture of the application of PA at the organizational level. Only organizations which were motivated to support employees with chronic conditions and prevent work-related problems participated in the study. Applying the PA in organizations which did not already have a focus on preventing work-related problems would have yielded other valuable information. Furthermore, in some cases there was



a long time (> 1 year) between the PA meetings and the final interview, which increased the chance of recall bias. Another barrier of this study was the Covid-19 pandemic which influenced the implementation of the PA and its evaluation in the organizations. The effect of the pandemic varied, such as switching to online meetings or having less resources (e.g. time) to implement solutions, depending on how organizations were affected by Covid-19 regulations.

### **Implications for practice and research**

The results of this study imply that the PA could be of added value for organizations in creating a supportive work environment and developing organizational policy, enabling employees with chronic conditions to exert self-control. However, convincing organizations to create a supportive work environment and apply the PA, is a first major challenge. Exploring how to activate and persuade organizations to improve support for employees with chronic conditions and take a preventive approach would be an important next step. The literature already shows the need for more knowledge and awareness on the impact of having a chronic condition on work within organizations (8), which is currently often insufficient. OPs should take on a proactive role in improving knowledge and raising awareness, by providing advice to employers. Moreover, good employer practices and corporate social responsibility should include preventing work-related problems and facilitating sustainable employment for employees with chronic conditions. Financial and economic considerations could play an important role in many organizations when deciding on supportive actions (34). Showing the economic benefits of preventing work-related problems among employees with chronic conditions and preventive activities, might facilitate an organizational change to a preventive approach. Furthermore, OPs must persist in their attempts to increase prevention within organizations. Their increased visibility might lead to organizations more often obtaining OPs' expertise on preventing work-related problems.

When looking at the process of applying the PA within the organization, this study has provided several points of improvement and aspects to consider. For this study, OPs were the professionals who attended the training sessions. Seeing the great involvement of human resources managers and their responsibility for coordinating the PA, opening up the training to OPs as well as human resources managers could improve the implementation process. Moreover, by tailoring the training sessions to the competencies of OPs and human resources managers, both professionals could act as process leader within an organization. In addition, more research is needed to evaluate the role of other professionals as process leader, such as an external expert (e.g. OP not associated with the organization) to guide the process.

Furthermore, information provision for project coordinators in the training manual should be elaborated. In addition, a clear overview of what is expected of all stakeholders involved during the PA needs to be added to the training manual. Knowing what is expected of every working group member might improve input and could counteract the irregular attendance of working group members during meetings. Finally, as having a clear goal in mind from the beginning of the PA is helpful for the implementation process, more attention must be paid in the training session to shaping and composing the intended goal for the organization.

## **Conclusion**

The PA could be of added value as a method for creating a supportive work environment and developing an organizational policy for employees with chronic conditions. However, we only reached a small number of motivated organizations. Convincing organizations to improve support for employees with chronic conditions and prevent work-related problems, by using the PA, is challenging and requires further research. Moreover, it is not self-evident that OPs must fulfill the process leader role; this role should be tailored to the organizations' needs.



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# Chapter 7

## General Discussion

## General discussion

*Before discussing the main findings of this thesis, I would like to return to my own case. When I started this project, I was rather convinced that I had high levels of self-control. And indeed, the job change from being a veterinarian to becoming a researcher was an excellent example of self-control. On the other hand, this project made me see that self-control is something you have to keep working on, it is a continuous balance within an ever changing situation. And at the same time, I realize that exerting self-control is not something you can do on your own. It requires a joint effort from us (i.e. workers with a chronic condition), stakeholders in the work environment and of course occupational physicians. I truly hope that the findings and recommendations in this thesis can contribute to the transition to more supportive work environments, enabling all workers with chronic conditions to exert self-control and to stay at work.*

Self-control is a concept which evolves around human behavior. Studying this behavior and its interaction with the environment has been an essential part of this project. The aim of this thesis was to develop, implement and evaluate an organizational-level intervention to prevent work-related problems, by strengthening self-control among workers with chronic conditions. Occupational physicians (OPs) fulfilled a key role in the intervention, by guiding organizations with creating a supportive work environment. This current chapter will start with the main findings of this thesis. Next, the methods used in this thesis will be reflected upon. Moreover, disclosure in the work environment, as an essential element of self-control, will be discussed. Finally, prevention of work-related problems in organizations, occupational health care and curative health care will be considered. This chapter will be concluded with recommendations for research, policy and practice.

## Main findings

### **Self-control as a facilitator for sustainable employment of workers with chronic conditions**

Exploring the concept self-control was an essential first step in this project. In chapter 2, a qualitative synthesis showed us four elements of self-control in the context of work, describing behaviors that aid workers with chronic conditions with staying at work: 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, and 4) management of symptoms and limitations

in the workplace. Disclosure of a chronic condition creates understanding and support from employers and co-workers. However, disclosure remains a complicated issue as it is influenced by the worker's personal beliefs about possible consequences, disease-related factors, and factors related to the work environment. As disclosure is a prerequisite for requesting work accommodations and support, deciding to whether or not disclose can be considered an essential self-control behavior. Finding a healthy balance between work, a personal life and managing a chronic condition is important for staying at work and requires decision-making to attain this balance. These decisions are based on the desire to continue working and relate to strategies that make sustainable employment possible (e.g. energy management, job change). Requesting accommodations and support is crucial to create the right match between work demands and work capacities of workers with chronic conditions. Management of symptoms and limitations in the workplace enables workers to sustain work productivity. This requires awareness and acceptance of the chronic condition, and workers taking responsibility for managing symptoms and limitations in the workplace.

In chapter 3, we explored the perspectives of workers with chronic conditions on self-control as a strategy to stay at work. Workers with chronic conditions, being successful in staying at work, emphasized the importance of disclosure of a chronic condition and expressing one's support needs. Moreover, knowing what is important in life and making subsequent decisions were also considered contributing factors. Related to the self-control behaviors of workers with chronic conditions, OPs and organizational representatives pointed out that non-disclosure and a lack of cooperation to deal with work-related problems by these workers hampered the provision of preventive support, as described in chapter 4.

### **The influence of the environment on exerting self-control and preventing work-related problems**

Context is of significant importance for the exertion of self-control behaviors; the work, social and health care environment can impact and influence the exertion of these behaviors and can hamper or facilitate a workers' ability to stay at work, as described in chapters 2 to 4.

The work environment appeared to be the most important for the exertion of self-control, as the work environment interacts with all four behaviors. Looking closer at disclosure and requesting work accommodations and support, the worker is largely dependent on the anticipated reactions and actions of the stakeholders (e.g. line-managers, co-workers) within the work environment. Moreover, workers



with chronic conditions described employers' lack of knowledge of the impact of working with a chronic condition and lack of knowledge of the rules and regulations as barriers to stay at work. OPs and organizational representatives described barriers in the work environment that hamper the provision of support to these workers, including a negative organizational attitude towards workers with chronic conditions and a lack of skills and knowledge of how to provide support.

Workers with chronic conditions pointed out that employer support is an important facilitator to stay at work. Moreover, a work environment in which workers feel supported, including a clear organizational policy, were described by OPs and organizational representatives as opportunities to improve preventive support. These findings indicate that a supportive work environment and a clear organizational policy enable workers with chronic conditions to exert self-control behaviors (e.g. disclose their chronic condition) and can help prevent work-related problems, ultimately facilitating sustainable employment.

The social environment is especially important for finding a healthy balance (e.g. family taking over household chores) and for emotional support. The health care environment has an important role in enabling workers to manage their symptoms and limitations in the workplace, by offering treatment. However, the current lack of attention to employment and paid work during the course of treatment leads to undesirable advice (e.g. to quit working) by medical specialists. The curative health care sector (e.g. general practitioners and medical specialists) could contribute to the prevention of work-related problems, by increasing the attention to work in the treatment process and by health care professionals collaborating with OPs, such as by referring their employed patients with a (newly diagnosed) chronic condition to the OP more often.

### **The role and position of occupational physicians in preventing work-related problems**

Considering the key role of OPs in guiding organizations with creating a supportive work environment, we first explored their current role and practices in preventing work-related problems and offering preventive support to workers with chronic conditions. Chapter 4 shows that the expertise of OPs on preventing work-related problems is insufficiently used. Both employers and workers with chronic conditions often fail to seek advice and support, in combination with employers refraining from referring workers with chronic conditions to preventive consultation hours. A contributing factor could be workers' dissatisfaction with OPs' support,

as mentioned in chapter 3. Moreover, OPs spent most of their working hours on dealing with sickness absence and return to work, leaving less time available for preventive actions. Organizations' demands to focus on sickness absence (as stated in their contracts with OPs) are an underlying cause. Furthermore, OPs' lack of visibility to both employers as well as employees is an additional limiting factor, hampering accessibility of OPs and therefore the ability of OPs to offer adequate preventive support. A suboptimal collaboration, with unclear mutual expectations between employers and OPs, further impedes support to workers with chronic conditions. In addition, more collaboration between OPs and the curative health care sector is needed to prevent work-related problems. These findings emphasized the need for OPs to increase their visibility and to use a proactive approach towards prioritizing prevention within occupational health care and organizations. In this thesis, an intervention was developed, using the Participatory Approach (PA) at the organizational level. With a key role for OPs who, as process leader, guided organizations to create a supportive work environment and to develop an organizational policy. By making OPs an essential part of the intervention, they were able to collaborate closely with the organization, increasing their visibility and expanding their preventive activities.

### **Lessons learnt from implementing the organizational-level intervention**

The development of the organizational-level intervention is outlined in chapter 5. Evaluation of the implementation process of this intervention, described in chapter 6, revealed the challenges that OPs faced when attempting to convince organizations of the need to create a supportive work environment and to develop an organizational policy, by using the Participatory Approach (PA). No sense of urgency to prevent work-related problems or having other priorities were important barriers in the recruitment of organizations.

Three organizations applied the PA to create a supportive work environment and to develop an organizational policy. Overall, organizations were positive about the PA as a method to create such a work environment. The involvement of all relevant stakeholders within the organizations was pointed out as being of added value. However, the level of success of the PA varied across the three organizations, related to differences in the implementation process. Organization A generally applied the PA according to protocol. In contrast to the other two organizations (B and C), where dose delivered, dose received and/or fidelity were poor. Problems early in the process of applying the PA (e.g. with assembling the working group) can have major consequences for the continuation and level of success of the PA. Moreover, barriers were identified that influenced the implementation process,





such as reluctance to express one's opinion, which could have compromised the power of the PA. The availability of driving forces within the organization (e.g. human resources managers) was an important facilitator for the implementation process. With OPs being deployed as process leader, they had to take a neutral position, refraining from using their expertise and providing advice. This required OPs to adjust to their new role, making it hard for them to fulfill the process leader role according to protocol (fidelity). Although the process leader role increased OPs visibility, opinions differed on the suitability of OPs as process leaders. Human resources managers or external process leaders (e.g. an OP from another organization) were opted as alternatives, enabling OPs to perform an advisory role.

## **Methodological considerations**

In this section, I will reflect on the methods that were used in this thesis. First, using qualitative research, to explore the concept self-control and stakeholders' perspectives on staying at work and offering preventive support, will be discussed. Further, patient participation in health care research will be reflected upon.

### **Qualitative research**

In occupational health research, quantitative research methods are often used to gain knowledge of causal relations between the work environment and workers' health. However, studying human behaviors and its interaction with the work environment also requires different research methods. Qualitative research is aimed at understanding people's experiences, behaviors and interactions, using an interpretative and inductive approach (1). As self-control is a concept which evolves around human behavior, exploring self-control and its interaction with the work environment has resulted in a thesis consisting of studies using solely qualitative research methods.

A qualitative synthesis can be used to create a conceptualization of a phenomenon (2, 3). This qualitative research method was used for the conceptualization of self-control in the context of work and formed the basis on which further studies were built. This research method allowed a better understanding and new insights into self-control in work, and showed the complex interactions of self-control behaviors and the environment. However, conducting a qualitative synthesis is a complex and time consuming process (4). Moreover, it is important to consider any influences or biases of the reviewer and how these can impact the interpretation of findings (5).

Focus groups and semi-structured interviews were used to capture the perspectives and behaviors of workers with chronic conditions, OPs and stakeholders within the work environment. Many of these experiences and perspectives answered the 'how' (e.g. how do you stay at work?) and 'why' (e.g. why do you offer little preventive support?) questions, which are almost impossible to retrieve from quantitative data. The findings increased understanding of the complexity of self-control in the work environment and provided valuable input for the development of the intervention. In addition, it allowed us to gain insight in the implementation process. However, limitations to these qualitative research methods need to be mentioned. Similar to qualitative syntheses, there is the risk of researcher bias. In addition, a lack of reproducibility and generalizability are often heard drawbacks of qualitative research. In this thesis, different strategies were used to increase rigor and reliability, which included amongst others triangulation, respondent validation and researcher reflectivity (6). Moreover, in qualitative research, transferability instead of generalizability to other contexts is what qualitative studies are aiming for. In this perspective, transferability refers to how the knowledge, that was generated, can contribute to a better understanding of the way that the environment impacts health. Furthermore, the COREQ checklist was used as a guide for the design and reporting of the studies (7), thereby improving transparency of the conducted research.

### **Patient participation in health care research**

Involving patients in health care research allows for understanding and insights in their lived experiences, which cannot be learnt from literature or a textbook. As workers with chronic conditions were the central focus in this thesis, they were involved in this project at different times and in different ways. The "participation ladder" shows the various levels of participation in research, with the upper three steps being the ultimate forms of participation (patient control, delegation, partnership) (8).

Focus groups were conducted with workers with chronic conditions. However, with focus groups, the level of participation is only limited since these workers had no decision-making power in the research process (9). Moreover, workers with chronic conditions had a vital role in the intervention and contributed to the creation of a supportive work environment. As members of the working group, workers with chronic conditions could provide input on the barriers and solutions to exert self-control in their organization. In this role, they were able to share their lived experiences with other stakeholders within the organization. This latter way of participation could be seen as a form of responsive research, which correlates



with participatory research (9). The assumption that a phenomenon has various or even conflicting meanings for different stakeholders was the basis for responsive research (10). Active participation of all stakeholders and ongoing dialogues are essential for this type of research, with a special focus on experiential knowledge. The final and also ultimate form of patient participation used in this thesis, was me being the researcher in this project. As a researcher and worker with a chronic condition, I was able to use my own experiences, to guide and add another dimension to this research project. Being a qualitative researcher and 'patient' at the same time, made reflexivity even more important, assuring that my personal experiences would enrich the research findings and preventing bias. From my perspective as a worker with a chronic condition, I consider this project a journey of reflection, of recognition, and of revelations on successfully staying at work.

In recent years, patients are increasingly involved in health care research and even in research agenda setting. The slogan "nothing about us, without us" captures the essence of this trend towards involving patients in research as experts or research partners (11). However, including patients in all phases of research can be challenging and requires researchers handing over control and ownership to patients, calling out the need for methodological flexibility and interactive research methods (12, 13).

## **Reflecting on disclosure in the work environment**

In 2016, the Social Economic Board (SER) wrote that workers with chronic conditions should 'self-manage and take control' over their lives, including their work (14). This statement was based on the new definition of health, "having the ability to adapt and self-manage", proposed by Huber et. al. (p. 2) (15). Having higher levels of self-control allows for a better adaptation to a working life with a chronic condition. In this next section, I will discuss disclosure more closely, as an example of a self-control behavior and an essential element of self-control. In addition, I will reflect on the influence that the work environment has on disclosure and on the approach to encourage disclosure.

### **Disclosure, an essential element of self-control**

Disclosure is about controlling the level of information made available on a worker's chronic condition. It has been a much discussed topic during the focus groups and interviews with workers with chronic conditions, organizational representatives and OPs. Disclosure, as the essential element of self-control,

carries significant benefits for workers as well as employers (16). Disclosure helps to create understanding from employers and co-workers, and it is a prerequisite to request work accommodations and support. The need for work accommodations is the most important factor for disclosure (17). However, disclosure can also hold negative consequences, such as stigmatization or even job loss. As a result, workers make a trade-off about what, when and whom to tell. The invisibility of a chronic condition further complicates the dilemma to disclose or not to disclose. A framework by Joachim et al. shows that workers with invisible conditions have several options (e.g. non-disclosure, preventive disclosure and protective or spontaneous disclosure) when dealing with their condition, compared with workers with visible conditions, thereby making their decision to disclose more difficult (18-20). From the perspectives of employers and OPs, disclosure is needed to be able to offer support. Currently, workers with chronic conditions often disclose when they already experience problems, making preventive support difficult. Despite the fact that disclosure is often promoted and encouraged by society or patient organizations, workers with chronic conditions can remain reluctant to do so because of unpleasant experiences encountered in the past (21, 22).

### **An organizational-level approach to encourage disclosure**

With timely disclosure, work-related problems can be identified and addressed at an early stage. To increase one's level of self-control, Milyavskaya et al. recommend to focus on a person's individual capacity to exert self-control, as well as to focus on the context in which exertion of self-control occurs (23, 24). Increasing a person's capacity of self-control includes interventions aimed at the individual worker, as suggested in the recommendations made by the SER (e.g. improving the dialogue by conducting three-way conversations or deploying periodic occupational health checks (PAGO) to initiate a dialogue) (14). In the last decade, interventions at the individual level have been developed to improve self-management or increase empowerment of workers with chronic conditions (25, 26). However, as this thesis emphasized the importance of the work environment on a worker's level of self-control, changing the context in which self-control is to be exerted, was considered a more successful strategy (27). Therefore, an organizational-level approach was chosen in this thesis. By creating a supportive work environment, including a clear organizational policy, the threshold to disclose a chronic condition at an early stage (i.e. prior to the start of work-related problems) is lowered. At the same time, workers with chronic conditions are allowed to choose the option and the moment of disclosure. Research suggests that besides the relationship with the supervisor, the workplace culture and perceived relationship with the organization



as a whole, play a particularly important role in disclosure decisions (16, 17, 28). A supportive work environment is critical to discuss a chronic condition in the workplace (29, 30). Gignac et al. showed that knowing whether the employer has made efforts to create a disability-friendly workplace, was considered an facilitating factor for disclosure (17). Workers who trust and feel supported by their organizations, are more likely to have favorable perceptions of disclosure (28). In addition, workers who report greater workplace support are more likely to experience more positive outcomes of disclosure (17).

## **Reflections on preventing work-related problems among workers with chronic conditions**

With the increasing number of workers with chronic conditions, it is important to prevent work-related problems and to facilitate sustainable employment of these workers (31, 32). Prevention and sustainable employment require a joint effort (14). In this section, I will shed light on the barriers to prevention, including preventive support, within organizations, occupational health care and curative health care.

### **Prevention within organizations**

According to the Working Conditions Act, employers are required to ensure a safe and healthy work environment for its employees. With selective or indicated prevention, employers could aim interventions at subpopulations or identified individuals with a higher risk of encountering work-related problems, in this case workers with chronic conditions (33). However, to date, there is insufficient attention to prevention within organizations (34, 35). Accordingly, this thesis identified several contributing factors to this lack of prevention within organizations.

### ***Organizations perceive workers with chronic conditions as financial risk***

Financial considerations play a major role in the extent to which organizations focus on the prevention of work-related problems among all workers, and particularly workers with chronic conditions. According to OPs who participated in the focus groups, legislation has negatively impacted organizations' attention to prevention and retention of workers with chronic conditions. The Occupational Health and Safety legislation (i.e. the WULBZ and Gatekeeper Improvement Act) states that, in case of sickness absence of an employee, financial responsibility for paying wages in the first 2 years of sickness absence lies with employers

(36). Consequently, employers are inclined to see workers with chronic conditions as a financial liability. As a result, employers will more often select employees on the basis of health and are less willing to retain these workers and invest in their sustainable employment. This great financial risk for employers in the Dutch context differs extensively from other countries. In Germany or Denmark, employers have only limited financial responsibility, being obligated to continue wage payments in case of sickness absence for only 6 weeks and 30 days, respectively, compared to 104 weeks in the Netherlands (37).

Similarly, financial considerations influence implementation of work accommodations at the individual worker level, with accommodation not always being implemented by employers. In the Netherlands, employers can apply for financial compensation and premiums to reduce costs for the support of workers with chronic conditions. However, little use is made of these possibilities, because of a lack of knowledge of their availability and the complexity of the terms (14). In contrast, in the United Kingdom, it is mandatory for employers to implement the recommended accommodations, as failure to do so is against the Equality Act. Research shows that employers often have reservations concerning the perceived value of accommodating workers with chronic conditions, as they may hold the presumption that workers with chronic conditions are less dedicated and less productive (38). In addition, employers believe that the productivity benefits of implementing work accommodations might not outweigh costs to the organization (38). This illustrates employers' lack of knowledge and awareness of the impact of a chronic condition on working life, as also experienced by workers with chronic conditions in the focus groups. Furthermore, it shows the rigid perception that these workers are less valuable than workers without chronic conditions (39).

### ***Organizations determining the content and extent of preventive services and support***

Generally, employers are aware of the increasing number of workers with chronic conditions (40). However, this thesis shows that the extent to which organizations aim at preventing work-related problems of workers with chronic conditions is still low. To improve prevention of work-related problems within organizations, the SER made the recommendation to increase an organization's focus on periodic occupational health checks (PAGO's) (identifying workers with chronic conditions) and possibly using tools to measure work capacity, and linking these to the organization's preventive policy. However, to date, organizations make little use of PAGO's, especially small and medium-sized organizations. At that same



note, this thesis highlights the need for preventive policies. Currently, preventive policies are often lacking within organizations, showing that preventive policies in organizations are still in its infancy (14, 41).

Furthermore, since the amendment of the Working Conditions Act in 2017, organizations are obligated to offer preventive consultation hours with OPs to their employees (36). Although this was an attempt to increase prevention, it has not yet had the desired effect. Our findings illustrate that insufficient use is made of these preventive consultation hours, as employers only occasionally refer workers with chronic conditions to their OP. In addition, employers and workers are not always aware of this opportunity to consult the OP. Besides this lack of knowledge of current legislation, another factor contributes to the problem. Since 2005, employers in the Netherlands are provided with the opportunity to use a more tailored approach for obtaining services from occupational health services. The possibility arose for employers to customize their contracts with OPs, by choosing individual services. This has resulted in occupational health care being more demand-driven, with employers determining the performed tasks by OPs (i.e. buyers' market) (42). This freedom that Dutch employers hold, has resulted in little use of preventive services (35). Compared to the Netherlands, in Finland, employers are obligated to arrange preventive occupational health care coverage for employees (37). Whereas employers in Germany have the task to deploy occupational health management (Betriebliche Eingliederungsmanagement) in order to protect the health of an organization's workforce and secure sustainable employment of all its workers (37).

### ***Perceived benefits and motivation to preventive activities***

In this thesis, OPs tried to bring about organizational change towards supportive work environments for workers with chronic conditions. However, with only limited success. The perceived benefits of prevention have been much discussed among OPs in this thesis. For employers, reducing sickness absence has a short-term effect, by direct lowering of employers' costs. While financial benefits of prevention and preventive support may only be visible in the long-term (43). Even more so, the benefits of prevention are not always quantifiable in terms of financial profits (35). As also suggested by OPs, benefits could also lie in generating increased employee motivation and satisfaction, and a better corporate image (44, 45). Instead of a financial incentive, preventing work-related problems and facilitating sustainable employment of workers with chronic conditions should first and foremost be based on a social responsibility and good employer practices. Good employer practices, originating from an intrinsic motivation to secure a safe and healthy work

environment, increase an organizations focus on prevention (46). Preventing work-related problems among workers with chronic conditions could be seen as Corporate Social Responsibility (CSR), which means the voluntary integration of social and environmental concerns into organizations' decision-making process (47).

### **Prevention in occupational and curative health care**

OPs provide support and advice to employees and employers related to work and health (48). This thesis shows that anchoring prevention in occupational health care is difficult, with several underlying causes.

#### ***The Dutch occupational health care system as a barrier to prevention***

According to the Dutch legislation, employers have to call in OPs for the guidance and advice in case of sickness absence. The 2017 amendment of the Working Conditions Act specifically states that OPs also have an advisory role regarding preventive activities (49). However, this thesis shows that OPs still spend most of their time on reducing sickness absence (reactive occupational health care) and have little available time to focus on preventive activities (proactive occupational health care). OPs in our study stated that they have to be more proactive in taking up preventive tasks and motivating organizations to focus more on prevention instead of reducing sickness absence. This requires OPs to show their added value in preventing work-related problems to the organization and to negotiate the allocation of preventive tasks in their contracts. Similarly, the SER recommended that OPs and occupational health services should invest in promoting preventive support and educating organizations on how to support workers with chronic conditions (14). However, the emphasis of offered services by OPs and occupational health services remains with reducing sickness absence, due to the high demand for these kinds of services from organizations (42). Furthermore, research shows that OPs are not always involved in the formation of contracts with employers (35). The current shortage of OPs, as pointed out in this thesis, further complicates the execution of preventive activities. Task delegation (either horizontal or vertical) of activities related to reducing sickness absence, to other medically trained professionals (e.g. occupational nurses or general practitioners), could partly overcome this problem. The Dutch occupational health care system is different compared to many other countries, where advice and guidance of sickness absence is the responsibility of the curative health care sector. In the United Kingdom, advice regarding return to work is placed with general practitioners. While OPs and occupational health services can be obtained for preventive services (37). In France, the main role of OPs is prevention of work-related diseases and accidents (50).





### ***The separation between the occupational and curative health care sector***

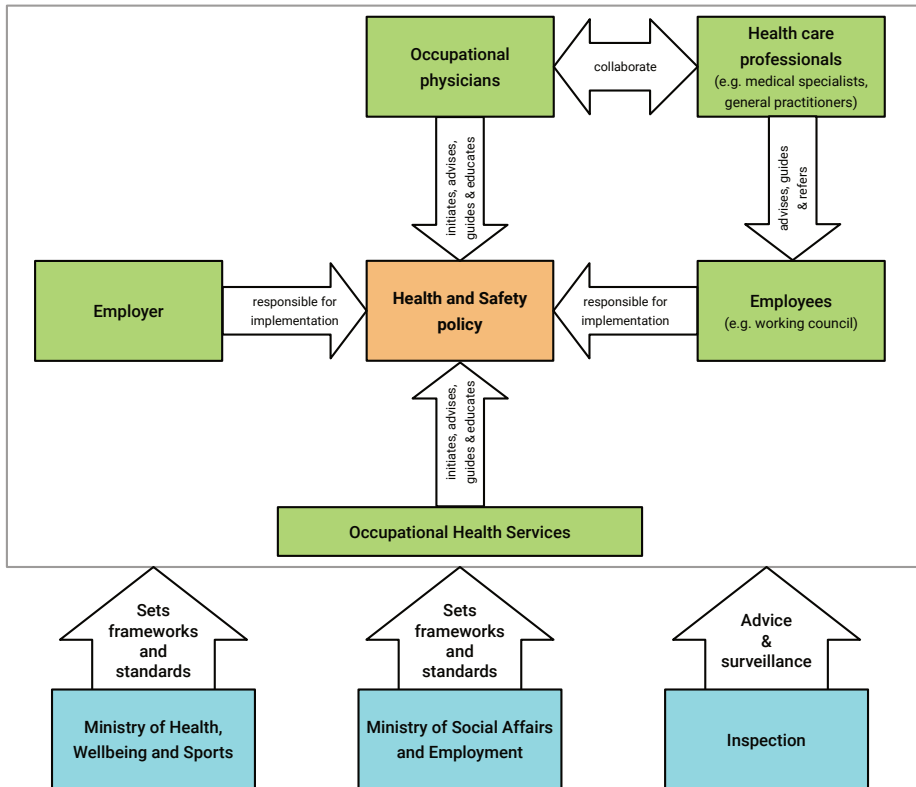
The perceived lack of objectivity and independent judgement of OPs has been described by the SER as a barrier to the use of OPs' expertise by workers (14). However, this thesis adds to the finding that aside from workers, also employers have concerns about OPs objectivity. For both employers and workers with chronic conditions, the feeling of a lack of objectivity hampered obtaining OPs' support and advice. Moreover, the concerns around objectivity influenced the expression of opinion by workers with chronic conditions during the PA meetings, which could have compromised the level of success of the PA. Although OPs are medical specialists, in the current system they are separated from the curative health care sector, with performed services being paid by employers (51). This financial relationship between OPs and employers can be an important factor to this lack of confidence among workers with chronic conditions. While on the other hand, the financial system might also contribute to employers' critical attitude towards OPs' functioning. This shows the difficult conflicting position OPs are in, as they ought to be independent advisors, hired by employers and representing the interests of employees at the same time.

In addition, the current position of OPs outside of the health care system, separated from other medical specialties, has contributed to the suboptimal collaboration between OPs and health care professionals, as observed in this thesis. This separation has led to a lack of confidence in OPs' objectivity with health care professionals. Furthermore, it has resulted in unfamiliarity with each other's work and expertise (52-54), hampering an optimal collaboration between OPs and other health care professionals. Even more so, the lack of attention to employment and paid work in the course of treatment, might also be explained by the current organization of care, with on the one hand OPs dealing with problems related to work, and on the other hand, health care professionals focussing on treatment of the chronic condition. In the present situation, many health care professionals lack the expertise to discuss work-related problems (52, 55) or are unaware of the importance of including work in the treatment process (54).

## **Recommendations for research, policy and practice**

Based on the findings of this thesis and the topics that have been discussed in this chapter, recommendations can be made for research, policy and practice. Making the prevention of work-related problems a shared responsibility of all stakeholders involved is crucial for improving sustainable employment of workers with chronic

conditions. However, the current system is flawed, hampering prevention in organizations, occupational and curative health care. Therefore, change at all stakeholder levels is needed. Figure 1 shows how all stakeholders involved can help prevent work-related problems and facilitate sustainable employment of workers with chronic conditions.



**Figure 1.** Roles and responsibilities in the prevention of work-related problems (adapted from (49))

### Worker-level

Workers with chronic conditions need to be aware of the self-control behaviors and how these can help prevent work-related problems. In addition, they should take the responsibility to address work-related problems at an early stage and show their added value to the organization. Initial evaluation of the implementation process and satisfaction showed that the PA at the organizational level could be of added value with creating a supportive work environment and developing an

organizational policy. However, further research is needed on the effectiveness of the intervention on self-control behaviors of workers with chronic conditions, including the influence of organizational factors (e.g. organizational size and sector, type of employees).

### **Occupational and curative health care level**

OPs and occupational health services should invest in a good and close collaboration with employers, increasing their visibility, and proactively offering preventive services and advice to employers on preventing work-related problems. Subsequently, prevention must become a more extensive component of the contracts between employers and OPs. This requires OPs to be included in the negotiation phase with employers, providing OPs with a strong negotiating position to secure preventive activities in the contracts. However, due to current Gatekeeper legislation, with financial penalties for employers, OPs have limited ability to expand their preventive activities. OPs extending their preventive activities requires a structural change in their duties and responsibilities. One way of accomplishing this is by delegating tasks to other medically trained professionals (e.g. occupational nurses) (56). However, with task delegation, the ultimate responsibility remains with OPs, leading to wonder whether this is a long term solution (57). Another route to change current policy is by reallocating the responsibilities related to guidance of sickness absence, to the curative health care sector, such as general practitioners. Such a structural legislative change in responsibilities provides OPs with the needed time to invest in preventive activities. Furthermore, by integrating occupational health care with curative health care, including a strong and independent position of OPs within the health care sector, the impression of OPs' partiality could be prevented. In addition, the collaboration between OPs and health care professionals can be improved. Research is needed to explore possible solutions to tackle this current system failure, including research on reallocation of responsibilities, positioning of OPs within the health care sector, and alternative financing options for occupational health care. In addition, opportunities to improve collaboration between OPs and health care professionals, including addressing existing misconceptions, need to be explored. Currently, the curative health care sector focuses merely on the treatment of symptoms of the chronic condition. Health care professionals must include employment in the treatment process, facilitating the management of symptoms and limitation in the workplace and early identification of work-related problems. This requires employment to be an integral part of care, and including it in the educational programs of all medical specialties.

## Organizational level

Employers must pursue a more active approach towards creating a healthy and supportive work environment and preventing work-related problems among workers with chronic conditions. Therefore, organizations must become aware and enact on their social responsibility and focus on long-term goals instead of short term profits. Currently, organizations' financial considerations are an important barrier to prevention. However, benefits of prevention may reside in other than economic factors. Further research is needed on how to increase organizations' awareness of these other benefits of preventing work-related problems. In addition, ways to promote good employer practices and corporate social responsibility need to be explored. Moreover, a legislative change to a policy in which prevention and obtaining preventive support for employers is a less optional and more obligatory, could increase prevention within organizations. This also requires more surveillance and extensively enforcing compliance to the legislation by the inspection.

## Conclusion

Self-control is a facilitator for sustainable employment of workers with chronic conditions and helps prevent work-related problems. Self-control includes four self-control behaviors: 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, and 4) management of symptoms and limitations in the workplace. The work environment is of significant importance for the exertion of self-control behaviors. Creating a supportive work environment, including an organizational policy, can help strengthen self-control among workers with chronic conditions. Prevention requires a joint effort of all stakeholders involved. However, prevention in organizations and in occupational health care is difficult. There is too much focus on sickness absence due to current legislation (i.e. WULBZ and Gatekeeper Improvement Act), stating the continued payment of wages by employers and OPs' responsibility for sickness absence guidance. To increase prevention within organizations and providing OPs with the ability to expand their preventive activities, legislative change is needed.



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# Appendix





## Summary

The number of people with one or more chronic conditions in the working population is increasing and will continue to rise due to the unhealthy lifestyles, improved medical treatment and the increase in retirement age. Working with a chronic condition can be challenging, with physical or psychological limitations hampering work performance, potentially resulting in a loss of productivity, extended or frequent sick leave, or job loss. Since return to work after long-term sick leave has proven to be difficult, prevention of work-related problems and facilitating sustainable employment among workers with chronic conditions is of significant importance.

Research has shown a multitude of facilitators that could help workers with chronic conditions to stay at work, including disease-related, personal and environmental factors. Self-control is one such facilitator, as self-control relates to one's ability to adapt to a new challenging situation, in this case referring to a working life with a chronic condition. Having higher levels of self-control at work might improve wellbeing and health, thereby facilitating sustainable employment of workers with chronic conditions. However, not every worker has the same level of self-control. By creating a supportive work environment, workers with chronic conditions are enabled to exert self-control, so that work-related problems can be prevented.

As preventing work-related problems of workers with chronic conditions should be a joint effort and shared responsibility, both stakeholders within occupational health care and within organizations should play a role in providing support to workers with chronic conditions. However, currently, occupational physicians (OPs) in the Netherlands spend most of their time on reducing sickness absence instead of on preventive activities. OPs can play a key role in supporting these workers with strengthening self-control, by guiding organizations with creating a supportive work environment.

This thesis aimed to develop, implement and evaluate an organizational-level intervention to prevent work-related problems, by strengthening self-control among workers with chronic conditions. OPs fulfilled a key role in the intervention, by guiding organizations with creating a supportive work environment.

The primary objectives of this thesis were:

1. To explore the elements of self-control at work from the perspectives of workers with chronic conditions and to gain insight in contextual factors that influence its exertion.
2. To explore facilitators, barriers and support needs for staying at work among workers with chronic conditions and to identify barriers to offering support and opportunities for improving support from the perspectives of OPs and organizational representatives.
3. To develop and evaluate an organizational-level intervention, in which OPs guide organizations with creating a supportive work environment for workers with chronic conditions.

### **Part I: Self-control as a facilitator for sustainable employment of workers with chronic conditions**

**Chapter 2** focused on exploring the concept self-control in the context of work. A qualitative synthesis, showed us four elements of self-control, describing behaviors that aid workers with chronic conditions with staying at work: 1) disclosure, 2) finding a healthy balance, 3) requesting work accommodations and support, and 4) management of symptoms and limitations in the workplace. In addition to these elements, the influence of and interaction with the work, social and health care environment on the exertion of self-control were identified, within the context of the local or national policy and legislative system. Moreover, the findings illustrated that especially the work environment is of importance for the level of self-control at work, as the work environment interacts with all four elements of self-control.

### **Part II: Perspectives on staying at work and supporting workers with chronic conditions**

In **chapter 3**, the lived experiences of workers with chronic conditions were explored and existing barriers, facilitators and possible support needs for staying at work were identified. Four focus groups were conducted with 30 workers with one or more chronic conditions, who were successful in staying at work, either as employee or as (partially) self-employed worker. Disclosure and expressing one's needs were considered important facilitators for staying at work. Furthermore, several environmental facilitators were identified, including employer support. Next to this, workers described environmental barriers in the work environment, the health care system and service provision, e.g., manager and co-worker's lack of knowledge of working with a chronic condition, a lack of focus on work



in the course of treatment for a chronic condition, dissatisfaction with OPs' support, and the absence of support for self-employed workers. It was stated that the provided support should be available to all workers, and be proactive and tailored to the workers' specific support needs. These findings endorsed the importance of self-control behaviors and emphasized the influence of the work environment, providing valuable input for the development of the organizational-level intervention.

In addition to the perspectives of workers with chronic conditions, **chapter 4** aimed to explore the current practices of OPs and organizational representatives (i.e. supervisors and human resources managers), identifying both barriers to offering support and opportunities for improvement. Focus groups were conducted with both self-employed OPs and OPs employed through external occupational health services or within an in-house occupational health services department. Moreover, semi-structured interviews were held with organizational representatives of various organizations. Participants identified several barriers to offer support, including barriers at the organizational level (e.g. negative organizational attitudes towards employees with chronic conditions), the employee level (e.g. employees' reluctance to collaborate with employers in dealing with work-related problems), and in the collaboration between OPs and organizational representatives. In addition, OPs and organizational representatives described barriers in occupational health care, such as a lack of OPs' visibility and lack of utilization of OPs' support. Opportunities to optimize support included a shared responsibility of all stakeholders involved, actively anchoring prevention of work-related problems in policy and practice, and a more pronounced role of the medical health care sector in preventing work-related problems. These findings show the influence of different domains (e.g. work environment, occupational health care) on supporting workers with chronic conditions and preventing work-related problems. Furthermore, findings illustrate the complex interaction between these different domains.

### **Part III: Development and evaluation of an organizational-level intervention to create a supportive work environment**

Intervention Mapping (IM) was used for the development of the organizational-level intervention, which was described in **chapter 5**. IM is a stepwise protocol used for planning and developing effective behavioral and environmental change interventions. In step 1, a needs assessment was conducted to define the problem and explore perspectives of all stakeholders involved (i.e. workers with chronic conditions, OPs and organizational representatives). Program outcomes and performance objectives of workers with chronic conditions and OPs were

specified in step 2. In step 3, appropriate methods and practical applications were chosen. Step 4 describes the actual development of the intervention. The scope of this organizational-level intervention was to create a supportive environment for workers with chronic conditions and to develop an organizational policy with the use of the Participatory Approach (PA) at the organizational level. The intervention consisted of 1) a training for OPs to act as process leader and guide organizations with creating a supportive work environment; 2) a practical assignment in which OPs had to apply the PA; and 3) a peer-review meeting to share experiences with applying the PA among OPs. Step 5 delineates the implemented of the intervention in a pilot study with OPs putting their acquired knowledge and skills into practice within one of their organizations.

**Chapter 6** aimed to evaluate the pilot implementation of the intervention (step 6 of the IM protocol), including a process evaluation and feasibility study, and to explore similarities and differences between organizations when applying the PA at the organizational level. A qualitative research design was used, with semi-structured interviews being conducted with OPs and stakeholders within their organizations. Convincing organizations to create a supportive work environment appeared to be the first challenge, with three out of 12 organizations willing to apply the PA. Reasons for not participating included, organizations not having a sense of urgency to prevent work-related problems and having other priorities. OPs ease of making contact with the designated stakeholder and having a say in policy setting facilitated the recruitment of organizations. Of the three participating organizations, organizations (A) generally applied the PA according to protocol, in contrast to the other two organizations (B and C), where dose delivered, dose received and/or fidelity were poor. Overall, organizations were positive about using the PA as a method to improve support for workers with chronic conditions. However, not being able to attend meetings or to express one's opinion hampered the process of the PA, while the availability of driving forces (e.g. human resources managers) facilitated the process of applying the PA. The process leader role increased OPs' visibility, however, opinions differed on the suitability of OPs as process leaders.

The general discussion, **chapter 7**, summarizes the findings of each individual chapter and reflects upon the methods used in this thesis. In a broader sense, the barriers to prevention, including preventive support, within organizations, occupational health care and curative health care are considered, followed by recommendations for research, policy and practice.





Qualitative research is aimed at understanding people's experiences, behaviors and interactions, using an interpretative and inductive approach. As self-control is a concept which evolves around human behavior, exploring self-control and its interaction with the work environment has resulted in a thesis consisting of studies using solely qualitative research. Although there are drawbacks to qualitative research, different strategies were used to counteract these, including triangulation, respondent validation and researcher reflectivity. A strengths of this thesis is the participation of patients (i.e. workers with chronic conditions) in research. Workers were included in the project at different times and in different ways.

Prevention in organizations and in occupational health care is difficult due to current legislation. The lack of prevention within organizations can be traced back to employers' significant financial responsibility in case of sickness absence of employees. In addition, employers are able to select aquired services from OPs and occupational health services. The emphasis of offered services by OPs and occupational health services lies with reducing sickness absence, due to OPs responsibility in guiding sickness absence and the high demand for these kinds of services from organizations. The shortage of OPs and OPs' position outside the health care system further hamper prevention. To increase prevention within organizations and occupational health care, legislative change is needed.







## Samenvatting

Werken is belangrijk; het zorgt voor sociale contacten en de mogelijkheid om een bijdrage te kunnen leveren aan de maatschappij. Werken met een chronische ziekte kan echter uitdagend zijn; lichamelijke en/of psychische beperkingen kunnen het werk belemmeren. De komende jaren zal het aantal werkenden met een chronische ziekte verder stijgen. Dit komt onder andere door de stijging van de pensioenleeftijd, verbeterde medische zorg en een ongezondere leefstijl. Als werkenden met een chronische ziekte eenmaal zijn uitgevallen uit het arbeidsproces, dan is het terugkeren naar werk vaak lastig. Het is daarom van groot belang om ziekteverzuim te voorkomen (preventie) en om ervoor te zorgen dat werkenden met een chronische ziekte op een gezonde en prettige manier aan het werk kunnen blijven (duurzame inzetbaarheid).

Er zijn inmiddels al veel verschillende factoren bekend die werkenden met een chronische ziekte kunnen helpen om aan het werk te blijven, één daarvan is zelfredzaamheid. Bij zelfredzaamheid gaat het om het vermogen om je aan (nieuwe) uitdagende situaties aan te passen. Een hogere mate van zelfredzaamheid bevordert het welzijn en de gezondheid van werkenden en helpt op deze manier bij het kunnen blijven werken. Echter, niet iedereen is even zelfredzaam. De werkomgeving is van invloed op de mate van zelfredzaamheid. Het creëren van een ondersteunende werkomgeving, waarin werkenden met een chronische ziekte (meer) zelfredzaam kunnen zijn, kan ziekteverzuim voorkomen.

Vanuit de Nederlandse overheid wordt er steeds meer nadruk gelegd op het belang van preventie, zowel binnen organisaties als binnen de bedrijfsgezondheidszorg; de zorg die zich bezig houdt met de gezondheid van werkenden (waaronder bedrijfsartsen). Zowel werkgevers als bedrijfsartsen hebben de verantwoordelijkheid om ziekteverzuim onder werkenden met een chronische ziekte te voorkomen. Op dit moment is het echter zo, dat bedrijfsartsen het grootste deel van hun tijd besteden aan het begeleiden van terugkeer naar werk. Zij houden zich nog weinig bezig met preventie. Bedrijfsartsen kunnen echter een belangrijke rol spelen bij het versterken van zelfredzaamheid van werkenden met een chronische ziekte. Dit kunnen zij doen door organisaties te begeleiden bij het creëren van een ondersteunende werkomgeving. Dit is een mooi voorbeeld van hoe preventie er uit kan zien.

Het doel van dit proefschrift was om een aanpak op organisatieniveau te ontwikkelen die moet bijdragen aan meer ondersteuning voor werkenden met een chronische ziekte in een organisatie. En om vervolgens deze aanpak ook te implementeren en te evalueren in de praktijk. De aanpak heeft tot doel om de zelfredzaamheid van werkenden met een chronische ziekte te versterken, om zo ziekteverzuim te voorkomen. Bedrijfsartsen spelen een belangrijke rol in deze aanpak; ze begeleiden organisaties bij het creëren van een ondersteunende werkomgeving.

De doelstellingen van dit proefschrift waren:

1. Het verkennen en definiëren van zelfredzaamheid in het werk vanuit het perspectief van werkenden met een chronische ziekte. En ook om inzicht te krijgen in omgevingsfactoren die van invloed zijn op de mate van zelfredzaamheid.
2. Het krijgen van inzicht in de belemmerende en bevorderende factoren voor werkenden met een chronische ziekte om aan het werk te blijven. En daarbij om inzicht te verkrijgen in de behoeften aan ondersteuning. Daarnaast het identificeren van belemmerende factoren voor het bieden van ondersteuning vanuit het perspectief van bedrijfsartsen en werkgevers. En het verkennen van de kansen voor verbetering van deze ondersteuning.
3. Het ontwikkelen en evalueren van een aanpak op organisatieniveau waarin bedrijfsartsen organisaties begeleiden bij het creëren van een ondersteunende werkomgeving voor werkenden met een chronische ziekte.

### **Deel I: Zelfredzaamheid als een bevorderende factor om aan het werk te blijven**

**Hoofdstuk 2** is erop gericht om het concept zelfredzaamheid in het werk te verkennen en te definiëren. Literatuuronderzoek toonde ons vier elementen van zelfredzaamheid: 1) openheid, 2) vinden van de juiste balans, 3) vragen om aanpassingen en ondersteuning, en 4) managen van de ziekte op de werkvloer. Deze vier elementen kunnen werkenden met een chronische ziekte helpen om aan het werk te blijven. Daarbij liet deze studie ook zien dat zowel de werkomgeving, de sociale omgeving, als de gezondheidszorg van invloed zijn op de mate van zelfredzaamheid. Daarnaast speelt ook de nationale wet- en regelgeving een rol. Een belangrijke bevinding was dat met name de werkomgeving van groot belang is voor de mate van zelfredzaamheid van werkenden met een chronische ziekte.



## Deel II: Perspectieven ten aanzien van aan het werk blijven en het ondersteunen van werkenden met een chronische ziekte

In **hoofdstuk 3** worden de ervaringen van werkenden met een chronische ziekte om aan het werk blijven verkend. We zijn daarvoor in gesprek gegaan met werkenden met één of meerdere chronische ziekten. Deze werkenden zijn erin geslaagd om aan het werk te blijven, hetzij als werknemer, hetzij als (gedeeltelijk) zelfstandig ondernemer. Aan de hand van deze gesprekken hebben we de door hen ervaren belemmerende en bevorderende factoren om aan het werk te blijven in kaart gebracht, met daarbij de ervaren behoeften aan ondersteuning. Openheid en het duidelijk maken van behoeften werden daarbij beschouwd als belangrijke factoren. Bovendien werden verschillende bevorderende factoren vanuit de omgeving geïdentificeerd, waaronder ondersteuning vanuit de werkgever. Daarnaast beschreven werkenden belemmerende factoren in de werkomgeving, de bedrijfsgezondheidszorg en de reguliere gezondheidszorg (zorg geleverd door huisartsen en medisch specialisten): 1) een gebrek aan kennis bij leidinggevenden en collega's over werken met een chronische ziekte, 2) te weinig aandacht voor werk tijdens de behandeling van de chronische ziekte, 3) ontevredenheid over de ondersteuning van de bedrijfsarts, en 4) het ontbreken van ondersteuning (door bijvoorbeeld een bedrijfsarts) voor zelfstandig ondernemers. Er werd gesteld dat de geboden ondersteuning beschikbaar moet zijn voor alle werkenden en afgestemd op de specifieke ondersteuningsbehoeften van de werkenden. Deze bevindingen onderschrijven het belang van zelfredzaamheid en benadrukken de invloed van de werkomgeving, wat waardevolle input leverde voor de ontwikkeling van de aanpak.

In aanvulling op de perspectieven van werkenden met een chronische ziekte in hoofdstuk 3, is **hoofdstuk 4** erop gericht om de perspectieven van bedrijfsartsen en werkgevers te verkennen. Hiervoor hebben we gesproken met bedrijfsartsen (zowel zelfstandig werkend of werkend bij een arbodienst) en met leidinggevenden en HR-managers van verschillende organisaties. De huidige gang van zaken met de bijbehorende belemmerende factoren omtrent het (preventief) ondersteunen van werkenden met een chronische ziekte werden in kaart gebracht. Ook werden er kansen voor verbetering van de ondersteuning geïdentificeerd. Verschillende belemmerende factoren voor het bieden van ondersteuning kwamen naar voren, waaronder belemmerende factoren op organisatieniveau (zoals een negatieve houding van de organisatie ten aanzien van werkenden met een chronische ziekte), op werknemersniveau (onwil van werknemers om samen met de werkgever de problemen op het werk aan te pakken), en in de samenwerking tussen bedrijfsartsen en werkgevers. Daarnaast werden er verscheidene belemmerende factoren in de

bedrijfsgezondheidszorg beschreven, zoals 1) een gebrek aan zichtbaarheid van bedrijfsartsen en 2) het gebrek aan tijd bij bedrijfsartsen om zich te focussen op preventie. Volgens bedrijfsartsen en werkgevers kan de ondersteuning van werkenden met een chronische ziekte wel verbeterd worden. Het is dan echter nodig dat alle belanghebbenden (zoals werkgevers, werknemers en bedrijfsartsen) hun verantwoordelijkheid nemen. Daarbij moet preventie verankerd worden in beleid, zowel binnen organisaties als de bedrijfsgezondheidszorg. In aanvulling daarop kan de reguliere gezondheidszorg een grotere rol spelen bij preventie. Zo kunnen huisartsen en medisch specialisten meer aandacht besteden aan werk tijdens het behandeltraject en meer samenwerken met de bedrijfsgezondheidszorg. Deze bevindingen laten zien dat bij het ondersteunen van werkenden met een chronische ziekte er meerdere belanghebbenden betrokken zijn, namelijk vanuit de werkomgeving, de bedrijfs- en reguliere gezondheidszorg.

### **Deel III: Ontwikkeling en evaluatie van een aanpak op organisatieniveau: het creëren van een ondersteunende werkomgeving**

In dit proefschrift hebben we een aanpak ontwikkeld. Hoe we dit hebben aangepakt staat beschreven in **hoofdstuk 5**. De eerste stap in de ontwikkeling van de aanpak bestond uit het verkennen van de perspectieven en een behoeftepeiling onder alle belanghebbenden, om zo het probleem te kunnen definiëren. Vervolgens zijn er doelstellingen opgesteld en werden geschikte methoden (zoals, gezamenlijk verkennen van huidige belemmeringen rondom zelfredzaam in de organisatie en het bedenken van oplossingen hiervoor) gekozen om deze doelstellingen te behalen. De aanpak had tot doel het creëren van een ondersteunende werkomgeving voor werkenden met een chronische ziekte en het opstellen van een organisatiebeleid. De Participatieve Aanpak (PA) op organisatieniveau werd hierbij als methode ingezet. De aanpak bestond uit 1) een training voor bedrijfsartsen waarin ze leren hoe ze als procesbegeleider een organisatie kunnen begeleiden bij de stappen van de PA om zo een ondersteunende werkomgeving te creëren, 2) een praktijkopdracht waarbij bedrijfsartsen de PA daadwerkelijk toepassen, en 3) een bijeenkomst waarin bedrijfsartsen hun ervaringen met het toepassen van de PA onderling met elkaar delen. Hoofdstuk 5 wordt afgesloten met een schets van het implementatieproces in een pilotstudie, waarbij bedrijfsartsen hun opgedane kennis en vaardigheden in de praktijk brengen binnen één van hun organisaties.

Hoe het implementeren van de aanpak daadwerkelijk is verlopen, inclusief de evaluatie hiervan, wordt beschreven in **hoofdstuk 6**. In deze laatste studie van dit proefschrift hebben we gekeken hoe het implementatieproces is verlopen en hebben we gekeken naar overeenkomsten en verschillen tussen de deelnemende





organisaties. Om een duidelijk beeld te krijgen van het implementatieproces, zijn wij in gesprek gegaan met de bedrijfsartsen die de training hebben gevolgd. We hebben hen gevraagd naar hun ervaringen met het in de praktijk brengen van de PA. Het overtuigen van organisaties om een ondersteunende werkomgeving te creëren bleek de eerste uitdaging te zijn, waarbij maar een kwart van de benaderde organisaties bereid was om hiermee aan de slag te gaan. Redenen om niet mee te doen waren onder meer: 1) organisaties voelen (nog) niet de urgentie om ziekteverzuim te voorkomen, en 2) organisaties hebben andere prioriteiten. Inspraak van bedrijfsartsen bij beleidsvorming vergemakkelijkt de werving van organisaties. Drie organisaties wilden wel een ondersteunende werkomgeving creëren met behulp van de PA. Naast de bedrijfsartsen, hebben we ook gesproken met belanghebbenden (o.a. werknemers, HR-managers, en leidinggevenden), die betrokken waren bij het implementeren van de aanpak in de organisatie. Van deze drie deelnemende organisaties, paste organisatie A de PA over het algemeen volgens protocol toe, in tegenstelling tot de andere twee organisaties (B en C). Er werden zowel belemmerende factoren (bijv. het niet kunnen bijwonen van bijeenkomsten of het niet durven uiten van een mening), als bevorderende factoren (HR-managers als drijvende kracht) van het implementatieproces beschreven. Alle drie de organisaties waren positief over het gebruik van de PA als methode om de ondersteuning voor werkenden met een chronische ziekte te verbeteren.

In de discussie, **hoofdstuk 7**, reflecteer ik op alle bevindingen en de methoden die in dit proefschrift zijn gebruikt. In bredere zin komen de belemmerende factoren voor preventie, binnen organisaties, bedrijfs- en de reguliere gezondheidszorg aan de orde. De discussie wordt afgesloten met aanbevelingen voor onderzoek, beleid en de praktijk.

Kwalitatief onderzoek is erop gericht om gedrag en ervaringen van mensen te onderzoeken. Aangezien gedrag een belangrijk aspect is van zelfredzaamheid, heeft het verkennen hiervan geresulteerd in een proefschrift bestaande uit uitsluitend kwalitatieve studies. Een sterk punt van dit proefschrift is de deelname van de doelgroep (d.w.z. werkenden met een chronische ziekte) aan het onderzoek. Deze werkenden werden op verschillende tijdstippen en op verschillende manieren bij het onderzoek betrokken.

De huidige wetgeving maakt preventie lastig. Eén van de aspecten die bijdraagt aan het gebrek aan preventie binnen organisaties is de grote financiële verantwoordelijkheid van werkgevers in geval van ziekteverzuim van werknemers. Tegelijkertijd kunnen werkgevers in grote mate bepalen welke diensten zij

afnemen van bedrijfsartsen en arbodiensten. Door de verantwoordelijkheid van bedrijfsartsen bij het begeleiden van ziekteverzuim en de grote vraag naar dit soort diensten vanuit organisaties, ligt de nadruk van de taken van de bedrijfsarts dan ook op het terugdringen van het ziekteverzuim. Het tekort aan bedrijfsartsen en de lastige positie van bedrijfsartsen (betaald door de organisatie) zijn extra belemmerende factoren voor preventie. Om meer aandacht te krijgen voor preventie en het aandeel aan preventieve maatregelen binnen organisaties en de bedrijfsgezondheidszorg te vergroten is verandering in wetgeving noodzakelijk.







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## About the author

Astrid was born in Eindhoven on March 30th 1979, and grew up in Heemstede, the Netherlands. She attended her secondary education at Atheneum College Hageveld in Heemstede and obtained her VWO diploma in 1997. After not being selected for the study Veterinary Medicine, she started the bachelor program Biology at the VU University Amsterdam and completed her first year (propedeuse) in 1998. That same year, she got accepted at Utrecht University and started the study Veterinary Medicine. She graduated and obtained her degree, with a specialization in small animal practice, in 2004. Soon after, she started her promising career as a veterinarian at a small animal practice in Noordwijk. However, her career as a vet came to an end in 2006, after which she decided to pursue a career change. Astrid started the premaster program in Health Sciences at the VU University Amsterdam, where she obtained her master's degree in Health Sciences one year later.

The following years, Astrid worked in education (junior lecturer and study advisor) at the Health Sciences department of the VU University Amsterdam and conducted research at the VU University Medical Center. She worked, first as a research assistant and later as junior researcher, on a project where she explored perspectives on genetic testing of maturity-onset diabetes of the young (MODY) among patients and professionals. In 2014, she chose for a change of scenery and decided to work as a study advisor at the University of Amsterdam. Because of the desire to take on a new challenge, Astrid returned and started her PhD at the Department of Public and Occupational Health at Amsterdam UMC, location VUmc in March 2017.

Aside from research activities, she continued to be engaged in teaching and guiding Health Sciences and medical students. She used her own experience to explain to students the impact of a chronic condition on work and employment. During her PhD, she collaborated with researcher from the Karolinska Institute in Sweden, to explore the distribution of types of occupations, and the relation to sickness absence and disability pension among people with MS. Astrid will continue her academic career as a postdoc researcher at the Department of Public and Occupational Health at Amsterdam UMC, location VUmc.







## List of publications

### Articles included in this thesis:

**A.R. Bosma**, C.R.L. Boot, R. Schaap, F.G. Schaafsma, J.R. Anema. Participatory Approach to create a supportive work environment for employees with chronic conditions: a pilot implementation study. Submitted to Journal of Occupational and Environmental Medicine.

**A.R. Bosma**, C.R.L. Boot, N.C. Snippen, F.G. Schaafsma, J.R. Anema. Supporting employees with chronic conditions to stay at work: perspectives of occupational health professionals and organizational representatives. BMC Public Health. 2021; doi.org/10.1186/s12889-021-10633-y.

**A.R. Bosma**, C.R.L. Boot, F.G. Schaafsma, G. Kok, J.R. Anema. Development of an intervention to create a supportive work environment for employees with a chronic condition: an Intervention Mapping approach. Journal of Occupational Rehabilitation. 2020; doi: 10.1007/s10926-020-09885-z.

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N.C. Snippen, H.J. de Vries, **A.R. Bosma**, S.J. van der Burg-Vermeulen, M. Hagedoorn, S. Brouwer. Workers' views on involving significant others in occupational health care. A focus group study among workers with a chronic disease. Disability and Rehabilitation. 2021; doi: 10.1080/09638288.2021.2011435.

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R. Schaap, F.G. Schaafsma, **A.R. Bosma**, M.A. Huysmans, C.R.L. Boot and J.R. Anema. Improving the health of workers with a low socioeconomic position: Intervention Mapping as a useful method for adaptation of the Participatory Approach. *BMC Public Health*. 2020; doi.org/10.1186/s12889-020-09028-2.

**A.R. Bosma**, C.R.L. Boot, F.G. Schaafsma, J.R. Anema. Steun de chronisch zieke werknemer. *Medisch Contact*. 2019. <https://www.medischcontact.nl/tijdschrift/medisch-contact-thema/thema-artikel/steun-de-chronisch-zieke-werknemer.htm>





