

# Self-management for chronically ill older people

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RIJKSUNIVERSITEIT GRONINGEN

# Self-management for chronically ill older people

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# 1

## General introduction

## 1.1 Background

The Dutch population is ageing, and it is estimated that in 2025, 20.1% of the Dutch population will be 65 years of age or older [1]. Many older people experience health problems. Moreover, they are often confronted with one or more chronic diseases, i.e. comorbidity [2]. In 2000, 70% of people aged 65 and over in the Netherlands suffered from a long-term illness, and in 2002, people aged 65 years and over in the Netherlands had, on average, 1.48 diseases [3]. The most common chronic diseases among older people in the Netherlands are cardiovascular diseases, diabetes, lung diseases, neurological diseases, and diseases of the locomotive apparatus [3]. It is expected that the number of diseases that mainly occur at a higher age, such as coronary heart diseases, heart failure, stroke, dementia, lung diseases, and diabetes, will increase between 1994 and 2015 [4].

The impact of chronic conditions on health is substantial, it varies according to condition, and, for most conditions, it involves all aspects of functioning and well-being [5-10]. Chronic diseases may lead to severe and immediate disability, as well as progressive disability that slowly decreases the ability of older people to care for themselves [11].

Comorbidity is associated with an increase in the costs and the utilization of health services [2;12]. In the Netherlands, 42% of the health care budget is spent on patients of 65 years of age and older [4]. It is expected that in the period from 1994 to 2015, health care utilization will increase as a result of demographic developments, among which the increasing number of older people [4]. Hospitalization is expected to increase by 26%, visits to outpatient clinics by 19%, pharmaceutical use by 27%, expenditures on aids (such as walking aids, hearing aids, etc.) by 30%, home care by 30%, and district nursing by 26%.

The current focus of the health care system in the Netherlands is mainly on acute care and on cure, with treatment usually aimed at correcting biological abnormalities and preventing overall deterioration [13-15]. The care that is provided is often fragmented, because for each disease patients usually see a different medical specialist. Health care is thus physician-centered, and the physician is the expert. However, chronically ill patients have to cope with their disease on a day-to-day basis and are, therefore, on their own for most of the time. Moreover, in general, patients with chronic diseases do not only have biomedical problems, but also psychosocial and societal problems, to which the current health care system pays relatively little attention. Therefore, chronically ill patients might need a more patient-centered approach, in which the patient is the expert with regard to his or her own health care.

Given a certain discrepancy between the focus of the health care system and the specific needs of chronically ill older patients, there is a need for additional means of delivering care. These additional means may include developing new therapies, building more nursing homes, stimulating volunteer aid, or developing new technologies with regard to housing or care. However, most of these means are rather costly, and mainly focus on the physical aspect of a chronic disease. Furthermore, the active involvement of the patient in these issues is usually minimal. It seems, however, important to enhance the active involvement of chronically ill patients in their own health care, because they themselves are responsible for the daily management of their disease. Older patients, in particular, are often less actively involved in the management of their disease, because they might perceive their chronic disease as part of the aging process and therefore do not take action. Moreover, older people have many years of experience with a medical system in which the professional was usually regarded as the expert and the patient only passively adhered to treatment prescriptions and was therefore not actively involved.

One way to promote a more active involvement of older people with chronic diseases in their own health care is to offer them self-management programs that teach them how to manage their chronic disease. Given the impact of a chronic disease on various aspects of life, it is important that these self-management programs not only focus on the physical aspects of the chronic condition, but also on the psychosocial and societal aspects.

Self-management programs do not only provide information, but also teach patients to follow the advice of their clinicians at home and how to cope with the physical and psychosocial impairment a chronic disease may cause in daily life. Many types of interventions have been developed for the management of chronic diseases, such as face-to-face counseling, group sessions, telephone care, interactive computer interventions, postal interventions, and health care policies [16;17].

A great deal of research work has been carried out to investigate the effects of self-management approaches and patient education on chronic disease. Studies carried out by Cooper et al. [18], Barlow et al. [17], and Newman et al. [19] show that there is evidence that patients benefit from self-management and patient education interventions. However, the reported effects vary. In the literature reviewed by Cooper et al. [18] effects were largest for knowledge about diet, exercise and/or stress management and smallest for self-care activities and psychological outcomes such as depression, anxiety, and emotional adjustment to diabetes. In their study, Barlow et al. concluded that

“self-management approaches can provide benefits for participants particularly in terms of knowledge, performance of self-management behavior, self-efficacy, and aspects of health status” (p. 183, [17]). These benefits are over and above what is already being achieved with medical treatment, because patients generally continue to take their medicine while taking part in self-management programs. Data from arthritis patient education studies suggest that, in addition to a 20-50% improvement resulting from arthritis care, including the use of medication, a further 15-30% improvement in symptoms can be obtained through education interventions [20].

The word “self-management” is attached to many health promotion and patient education programs [21]. Wetzels and colleagues [22] refer to self-management as “patient behavior that keeps illness under control and minimizes its effect on health and quality of life”(p. 918). According to Barlow and colleagues [17], “self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life.” (p. 178). Corbin and Strauss [23;24] have suggested that living with a chronic disease involves three types of tasks: (a) medical management, such as taking medication; (b) role management, i.e. maintaining everyday life, chores and family responsibilities; and (c) emotional management, i.e. coping with the emotional consequences of having a chronic condition. Apart from these core self-management tasks, core self-management skills can also be defined. These are: problem-solving, decision-making, resource utilization, partnership with health professionals, action-planning, and self-tailoring [21;24]. In conclusion, self-management programs should not only focus on the physical aspects of a chronic disease, but also on the psychosocial and societal aspects.

The majority of self-management programs are not suitable for older patients who often have more than one chronic disease, because these programs are disease-specific, i.e. they only focus on people who have one specific chronic condition. From a literature review of Barlow et al. [17], for example, it becomes clear that a great majority of the publications concerning self-management programs mainly focus on asthma, followed by diabetes and arthritis. Older patients with more than one disease would therefore have to participate in several disease-specific self-management programs, which would probably overlap. The combination of more than one chronic disease in older

patients requires self-management programs that address general management problems that are the same for different chronic conditions, such as fatigue, pain, mobility problems, feelings of anxiety or depression, etc., rather than programs that only address the problems related to one specific disease. Besides, as mentioned before, it is important that such programs address not only the physical aspects, but also the psychological and social aspects of a chronic disease, i.e. all aspects of well-being.

The concept of well-being has often been used to refer to overall life satisfaction and quality of life. In the literature the concepts of quality of life (QoL), health-related quality of life (HQoL), well-being (WB) or subjective well-being (SWB) are used, but often not, or, if so, only briefly, defined. Therefore, the exact difference between these concepts is unclear. To illustrate this, a literature review of 20 articles shows that of the five articles dealing with quality of life indicators, only one defined the concept [25]. Studies on quality of life often focus on aspects such as physical functioning, social and role functioning, mental health, subjective health perceptions, and vitality.

A chronic disease can affect several aspects of quality of life. Physical functioning (i.e. activities such as climbing stairs, washing, dressing, and lifting shopping bags), in particular, varies per chronic disease, and depends on the severity of the disease [26]. Emotions such as frustration, fear, anger, and depression are commonly experienced by a person who has a chronic disease [21]. There is also a clear association between the number of chronic diseases and the severity of these psychological symptoms [9]. Self-management programs should not only increase healthy behavior and health status, but also improve quality of life.

Participants in self-management programs are often recruited from specific populations (for instance people aged 65 and over with arthritis), the so-called intended sample. Various studies have found it difficult to include participants in self-management programs [27-34]. It has also been reported that people who do not wish to participate are usually older [28;30-32], have less education [27-29;31], are less likely to be non-smokers [29] less often use seat belts [33], have poorer physical or mental health [27-29;31;33;34], are more likely to live further away from the study location [30;32], are more likely to experience time constraints [28;32], and perceive more social support in everyday and problem situations [35]. The results with regard to gender are less consistent; some studies report that refusers are more likely to be male [28] while others report that they are more likely to be female [27;29]. Therefore, participants in self-management programs, who are the actual subjects of a study [36], seem to be a

specific selection of the intended study sample. This makes it difficult to draw any general conclusions about the effectiveness of a self-management program.

To summarize, what is needed for a population of chronically ill older patients are self-management programs that (a) focus on general management problems instead of disease-specific ones; (b) focus not only on physical aspects of the chronic disease, but more on quality of life and well-being in general. The research questions that were addressed in the present study were (1) Are there self-management programs that are suitable for older people with one or more chronic diseases, that focus not only on the physical aspects of a chronic disease, but more on quality of life and well-being in general? (2) What is the value of such programs for maintaining physical health and improving the quality of life and well-being of older patients, and for the provision of health care to such older patients?; (3) Are the actual subjects of such studies, i.e. people who agree to participate in the program, a specific selection of the intended sample?

## 1.2 Literature search

We conducted a literature search to identify self-management programs that not only enhance the health, but also the overall well-being of chronically ill older patients with comorbidity. The keywords *well-being/well-being/quality of life/QoL* in combination with *self-management program* and *older patients/elderly/elders/ older persons*, and *chronic disease/chronic illness/chronic condition*, and *comorbidity/co-morbidity* were applied to all available International Bibliography of the Social Sciences (1981-) and Silverplatter/Medline (1988-) databases running until week 1/2 of January 2006. No publications were found. When the keywords *comorbidity/co-morbidity* were left out, one article was found, but this article was disease-specific (low back pain). We then decided also to leave out the keywords *older patients/elderly/elders/older persons*, because there might be self-management programs that, although not specifically developed for older patients, could also be suitable for older patients. Ten articles were found, eight of which were excluded because they were disease-specific (four articles about lung disease, three about chronic pain, and one about heart disease). The two remaining articles described the chronic disease self-management program (CDSMP) developed by Kate Lorig and colleagues [37;38]. One article described a study on the CDSMP in a heterogeneous group of chronic disease patients (heart disease, lung disease, stroke, or arthritis) aged 40-90 years [38], and the other article described a study in which the CDSMP was compared to a disease-

specific program for patients with arthritis [37]. The CDSMP was, among other things, aimed at enhancing aspects of quality life, such as self-rated health, disability, limitations in social/role activities, energy/fatigue, physical discomfort, and psychological well-being. It seems to be very beneficial for older patients with chronic conditions in particular, because: (1) it is a general program, and not disease-specific, (2) it has been proven to be effective among older people, and (3) it is also aimed to enhance several aspects of quality of life and well-being, and not only the physical aspects of a chronic disease.

### **1.3 The Chronic Disease Self-Management Program (CDSMP)**

The CDSMP was developed by Lorig and colleagues in the Center for Patient Education Research at Stanford University (USA). Their aim was to develop and evaluate, through randomized controlled trials, a community-based self-management program that assists people in coping with a chronic disease [38-41]. In personal correspondence, Lorig wrote: “We developed the program because of the large amount of comorbidity in older people and the need to treat the person not just the disease” (September 2002). Three principal assumptions underlie the CDSMP [38]:

1. Patients with different chronic diseases have similar self-management problems and disease-related tasks.
2. Patients can learn to take responsibility for the day-to-day management of their disease(s).
3. Confident, knowledgeable patients practicing self-management will experience improved health status and will utilize fewer health care resources.

Two additional assumptions are:

4. Patient self-management education should be inexpensive and widely available.
5. Trained lay-persons with chronic conditions could effectively deliver a structured patient education program. Such lay instructors would be acceptable to both patients and health professionals.

The CDSMP is based on prior experience (Arthritis Self-Management Program, ASMP), literature review, needs assessment (by so-called “focus groups”), and the theoretical framework of self-efficacy. It includes the following components: how to develop an exercise program; cognitive symptom-management techniques; breathing exercises; nutritional change; fatigue and sleep management; use of medication; coping with the emotions of chronic illness

(fear, anger, frustration and depression); communication skills (with family, friends, and health care providers); health related problem-solving; and decision-making [39-41]. The program content has been published in a book entitled “Living a Healthy Life with Chronic Conditions”, which serves as a guide for the participants [42]. The “Chronic Disease Self-Management Leader’s Manual” is a detailed protocol that is used by the course leaders [43]. The program consists of 6 weekly sessions, each with a duration of 2½ hours. There are 10-15 participants in each training group, and pairs of trained leaders teach the program. The program is based on the self-efficacy theory, which incorporates strategies suggested by Bandura to enhance self-efficacy (for an extensive overview of this theory, see Chapter 2; [38]). Lorig et al. encourage the use of lay-persons to teach the CDSMP because as instructors they can serve as successful role models, and lay-persons provide a large pool of potential volunteers who can also teach the program [44]. Studies suggest that lay-leaders can teach (arthritis) self-management programs with results similar to those achieved by professionals [44-46]. This is important, for instance because cost reduction can become a major issue for both patients and care providers.

The National Health Service (NHS) in the United Kingdom has adopted the CDSMP as the key educational offer in its Expert Patient Program [11]. At this moment, organizations in sixteen countries outside the USA are licensed, i.e. officially approved by Stanford University, to implement the CDSMP.

The CDSMP has been subjected to several evaluations [37;38;40;41;46-50]. Most of these were not identified in our literature search because the abstracts did not include all the keywords that we used. The majority (six) took place in the United States, five among American-speaking patients, and one among Spanish-speaking patients. One study was carried out in China and two in the United Kingdom (one of these among Bangladeshi patients). Tables 1.1a-c give an overview of these studies; studies focusing on only one specific disease are not included. The study samples in these evaluations mainly involved older adults (mean age 62.2, range 48.9-78.6), and mainly concerned patients with heart disease, lung disease, diabetes, or arthritis. However, one study included only patients with chronic low back pain [49], while another included “a diversity of primary chronic diseases that have not been previously studied” (such as myalgic encephalomyelitis, polio, endometriosis, haemophilia, liver disease; [50]). In six studies the participants were assigned to an intervention group or a control group [38;40;46-49], and in all six studies the control group was a waiting-list group that received the intervention 4-6 months later. In one evaluation, the CDSMP was compared to another intervention program [37];

Table 1.1a Overview of studies of the CDSMP that have been carried out (Authors, subject characteristics, recruitment, follow-up, setting)

Author(s), year (country)	N, mean age, %male, disease	Recruitment	Follow-up	Setting
Lorig et al., 1999 [38] (USA)	952; 65.3; 35.5; lung disease (asthma, chronic bronchitis, or emphysema), heart disease (coronary artery disease or congestive heart failure), stroke, chronic arthritis	Public service announcements in the mass media, referrals from flyers left in physicians' offices and community clinics, posters at senior citizen centers, referrals from county governments employers	6 months	Multiple community sites (churches, senior and community centers, public libraries, health care facilities)
Lorig et al., 2001 [40] (USA)	683; 65.3; 34.6; heart disease, lung disease, stroke, arthritis	Public service announcements, talks to community groups, notices in clinics	1 and 2 years	Community sites such as senior centers, churches, and medical centers
Lorig et al., 2001 [41] (USA)	613; 62.2; 27; one or more chronic disease	By physicians or case managers, and through announcements in waiting rooms and in health plan newsletters; letters to high utilizers	1 year	Health education departments of Kaiser Permanente
Lorig et al., 2003 [48] (USA)	551; 57.0; 21; heart disease, lung disease, type 2 diabetes	Community outreach to churches, community centers, and clinics	4 months	Community settings (churches, neighborhood centers, clinics)
Fu et al., 2003 [46] (China)	779; 64.0; 28.6; hypertension, heart disease (coronary or congestive heart disease), chronic lung disease (asthma, chronic bronchitis, or emphysema), arthritis, stroke, or diabetes	Public service announcements in the mass media, posters at community senior centers, flyers left in community clinics, interpersonal persuasion	6 months	Community site

Table 1.1b Overview of studies of the CDSMP that have been carried out (Authors, design, measurements, analysis)

Author(s), year (country)	Design	Measurements	Analysis
Lorig et al., 1999 [38] (USA)	Randomized controlled trial (wait-list control)	Previously tested self-administered questionnaires [51]	Analysis of covariance (controlled for baseline value of the study variable, as well as age, sex, education, and marital status) Two-way analyses of variance to determine if the intervention had different outcomes for those with different diseases
Lorig et al., 2001 [40] (USA)	Longitudinal design as follow-up to a randomized trial (wait-list control)	Questionnaire on chronic disease self- management study measures developed by Lorig et al. [51]	T-tests/ $\chi^2$ for differences in baseline measures Matched-pair t tests were used to test for changes between baseline and 1 or 2 years later
Lorig et al., 2001 [41] (USA)	Before-after cohort study	Questionnaire on chronic disease self- management study measures developed by Lorig et al. [51]	Paired t-test to assess changes in outcomes between baseline and 1 year
Lorig et al., 2003 [48] (USA)	Randomized controlled trial (wait-list control)	Physical activity scales (developed for ASMP study); Communication, health status: scales developed for the CDSMP study[51]; Health care utilization: self-report; 4-item self- efficacy scale	Analysis of covariance (controlled for age, gender, education, acculturation, number of chronic conditions Paired t-tests to determine whether changes between baseline and 1 year differed from zero)
Fu et al., 2003 [46] (China)	Randomized controlled trial (wait-list control)	Chinese version of the questionnaire on chronic disease self-management study measures developed by Lorig et al. [51]	Mann-Whitney U-test (compare baseline) Analysis of covariance (controlled for baseline value that differed between the groups at baseline: age; sex; education; marital status; follow-up time, baseline number of minutes per week of stretching and strengthening exercise, cognitive symptom- management practice, communication with medical doctor, and disability).

Table 1.1c Overview of studies of the CDSMP (Authors, variables/results, *P*-values as reported in the articles; Cohen's *d* calculated on reported scores, i.e. mainly difference scores)

Author(s), year (country)	Variables/Results (sign. improvements in italics)	<i>P</i> -values	Effect sizes (Cohen's <i>d</i> )
Lorig et al., 1999 [38] (USA)	<b>Self-management behavior</b>		
	<i>Stretching &amp; strengthening exercise</i>	.005	.14
	<i>Aerobic exercise</i>	.0003	.20
	<i>Cognitive symptom mgmt.</i>	.0001	.41
	<i>Communication w/MD</i>	.006	.16
	<b>Health status</b>		
	<i>Self-rated health</i>	.02	.16
	<i>Disability</i>	.002	.15
	<i>Social/Role activities limitations</i>	.0007	.17
	Pain/physical discomfort	.27	.02
	Psychological well-being	.10	.07
	<i>Energy/fatigue</i>	.003	.16
	<i>Health distress</i>	.001	.17
	Shortness of breath	.56	.05
	<b>Health service utilization</b>		
	MD & ER visits	.11	.04
<i>Number of hospital stays</i>	.047	.02	
<i>Nights in hospital</i>	.01	.14	
Lorig et al., 2001 [40] (USA)	<i>Self-efficacy manage chronic disease</i>	.0001	-.14
	<b>Health status</b>		
	Self-rated health	.268	.06
	<i>Disability</i>	.025	-.06
	Social/role activities limitations	.995	0
	Energy/fatigue	.165	-.05

Table 1.1c (Continued)

Author(s), year (country)	Variables/Results (sign. improvements in italics)	P-values	Effect sizes (Cohen's d)
Lorig et al., 2001 (continued)	<i>Health distress</i>	.0001	.18
	<b>Health service utilization</b>		
Lorig et al., 2001 [41] (USA)	<i>MD &amp; ER visits</i>	.006	.13
	Times hospitalized	.737	.02
	Days in hospital	.535	.03
	<b>Self-efficacy</b>	≤.001	-
	<b>Self-management behavior</b>		
	<i>Aerobic exercise</i>	.01	-
	<i>Range-of-motion exercise</i>	≤.001	-
	<i>Cognitive symptom-management</i>	≤.001	-
	<i>Communication with physician</i>	≤.001	-
	<b>Health status</b>		
	Disability	.77	-
	<i>Health distress</i>	≤.001	-
	<i>Social/role activity limitation</i>	≤.001	-
	<i>Illness intrusiveness</i>	≤.001	-
	<i>Fatigue</i>	.002	-
	<i>Shortness of breath</i>	.003	-
	<i>Pain</i>	.03	-
Self-rated health	.20	-	
<i>Depression</i>	≤.001	-	
<b>Health service utilization</b>			
Physician visits	.19	-	
<i>ER visits</i>	≤.05	-	
Hospitalizations	.14	-	
Days in hospital	.12	-	

Table 1.1c (Continued)

Author(s), year (country)	Variables/Results (sign. improvements in italics)	P-values	Effect sizes (Cohen's d)
Lorig et al., 2003 [48] (USA)	<b>Self-efficacy</b>	.0006	.28
	<b>Health status</b>		
	<i>Self-reported health</i>	<.0001	.40
	<i>Health distress</i>	<.0001	.42
	<i>Fatigue</i>	.002	.24
	<i>Pain/physical discomfort</i>	.016	.20
	<i>Role function</i>	.002	.23
	<b>Self-management behavior</b>		
	<i>Exercise</i>	.001	.21
	<i>Communication with physician</i>	<.0001	.30
	<i>Mental stress management</i>	<.0001	.50
	Currently use tobacco	.997	.03
	<b>Health service utilization</b>		
	<i>Physician visits</i>	.057	.17
<i>ER visits</i>	.005	.27	
Hospital stays	.481	-.03	
Fu et al., 2003 [46] (China)	<b>Self-efficacy</b>		
	Managing symptoms	.001	.29
	<i>Managing disease in general</i>	.001	.24
	<b>Self-management behavior</b>		
	Stretching/strengthening exercise	.07	-.02
	<i>Aerobic exercise</i>	.01	.16
	<i>Cognitive symptom-management</i>	.005	.38
Communication with medical doctor	.89	-.06	

Table 1.1c (Continued)

Author(s), year (country)	Variables/Results (sign. improvements in italics)	P-values	Effect sizes (Cohen's d)
Fu et al., 2003 (continued)	<b>Health status</b>		
	<i>Self-rated health</i>	.001	.33
	Energy	.93	-.03
	<i>Health distress</i>	.001	.22
	<i>Fatigue</i>	.03	.17
	<i>Shortness of breath</i>	.01	.14
	<i>Pain</i>	.02	.17
	<i>Disability</i>	.005	.27
	Illness intrusiveness	.06	.06
	<i>Depression</i>	.004	.10
	<i>Social/role activity limitation</i>	.046	.15
	<b>Health service utilization</b>		
	Physician visits	.72	.02
	ER visits	.44	.01
	<i>Hospital stays</i>	.04	.17
Nights in hospital	.40	.12	

two studies had a pre-test/post-test design [41;50]. Most evaluations covered a period of 4-6 months, except for two studies which covered a period of 12 months [40;41].

These evaluations of the CDSMP differ with regard to the measurement of the outcome variables. Self-efficacy, for example, was measured differently across the evaluations, varying from more general self-efficacy (“perceived self-efficacy to manage different aspects of one’s health and functioning”; [40]) to more specific self-efficacy (“self-efficacy for exercise, cognitive symptom-management, and communication with physician health care providers”; [41]). In one of the studies self-efficacy was not measured at all [38]. The components of health status also differed. Although self-rated health, pain/physical discomfort, energy/fatigue, social/role limitations, and health distress were measured in almost all evaluations, anxiety and psychological/emotional well-being were measured in only two. Some studies measured visits to physicians and the emergency department, whereas other studies did not.

Tables 1.2a-c give an overview of the *p*-values reported in the various studies. We also computed effect sizes, based on the reported data. Therefore, most of the effect sizes were computed on difference scores. Furthermore, for each outcome variable it was summarized how many studies showed an effect size  $\geq .25$ . The effects on most of these outcomes are small to moderate.

In almost all of the CDSMP studies, the participants were recruited through public announcements. Therefore, nothing is known about the patients who did not apply for participation. As a consequence, it is difficult to say anything about possible differences between participants and non-participants. Based on studies of self-management interventions, however, it might be assumed that the participants are, indeed, a selection. Furthermore, in none of the CDSMP studies gave detailed information about the recruitment process, for instance whether it was difficult to recruit participants, or the most effective method of recruitment, for example, flyers or posters.

It can be concluded that the CDSMP is the only self-management program that focuses on people with one or more chronic diseases, in order to stimulate them to become more actively involved in the management of their own health and enable them to take care of themselves. As this program has already been implemented in many countries, it would also be a candidate intervention to supplement the health care that is provided for people with one or more chronic diseases in the Netherlands. However, the various evaluations are difficult to compare, and this makes it difficult to draw any general conclusions about the effectiveness of the CDSMP. Therefore, before implementing the program in the



Table 1.2a Overview of the effect sizes (and *P*-values) of the various variables in the studies of the CDSMP

Variable	Lorig et al., 1999 [38]	Lorig et al., 2001 [40]	Lorig et al., 2001 [41]	Lorig et al., 2003 [48]	Fu et al., 2003 [46]	Number of studies that showed improvement (i.e. ES $\geq .25$ )/total number of studies in which this variable was studied	Number of studies that showed significant <i>p</i> -values ( $p \leq .05$ )/total number of studies in which this variable was studied
<b>Self-efficacy</b>	-		- ( $\leq .001$ )	.28 (.0006)		1/1	2/2
- Self-efficacy to manage chronic disease		.14 (.0001)				0/1	1/1
- Managing symptoms					.29 (.001)	1/1	1/1
- Managing disease in general					.24 (.001)	1/1	1/1
<b>Health behavior</b>							
Stretching & strengthening exercise	.14 (.005)				-.02 (.07)	0/2	1/2
Aerobic exercise	.20 (.0003)		-.01 (.01)		.16 (.01)	0/2	3/3
Cognitive symptom mgmt.	.41 (.0001)		-.01 ( $\leq .001$ )		.38 (.005)	2/2	3/3
Communication	.16 (.006)		-.01 ( $\leq .001$ )	.30 (<.0001)	-.06 (.89)	1/3	3/4
Range-of-motion exercise			-.01 ( $\leq .001$ )			-	1/1
Exercise				.21 (.001)		0/1	1/1
Mental stress management				.50 (<.0001)		1/1	1/1
Currently use tobacco				.03 (.997)		0/1	0/1

Table 1.2b (continued)

Variable	Lorig et al., 1999 [38]	Lorig et al., 2001 [40]	Lorig et al., 2001 [41]	Lorig et al., 2003 [48]	Fu et al., 2003 [46]	Number of studies that showed improvement (i.e. ES $\geq .25$ )/total number of studies in which this variable was studied	Number of studies that showed significant $p$ -values ( $p \leq .05$ )/ total number of studies in which this variable was studied
<b>Health status</b>							
Self-rated health	.16 (.02)	.06 (.268)	- (.20)	.40 (<.0001)	.33 (.001)	2/4	3/5
Disability	.15 (.002)	-.06 (.025)	- (.77)		.27 (.005)	1/3	3/4
Social/Role activities limitations	.17 (.007)	0 (.995)	- ( $\leq .001$ )	.23 (.002)	.15 (.046)	0/4	4/5
Pain/physical discomfort	.02 (.27)		- (.03)/-	.20 (.016)	.16 (.02)	0/3	3/4
Psychological well-being	.07 (.10)					0/1	0/1
Energy/fatigue	.16 (.003)	-.05 (.165)	- (.002)	-.24 (.002)	-.03(.93)/.17 (.03)	0/4	3/5
Health distress	.17 (.001)	.18 (.0001)	- ( $\leq .001$ )	.42 (<.0001)	.22 (.001)	1/4	5/5
Shortness of breath	.05 (.56)		- (.003)		.14 (.01)	0/2	2/3
Illness intrusiveness			- ( $\leq .001$ )		.06 (.06)	0/1	1/2
Depression			- ( $\leq .001$ )		.10 (.004)	0/1	2/2

Table 1.2c (continued)

Variable	Lorig et al., 1999 [38]	Lorig et al., 2001 [40]	Lorig et al., 2001 [41]	Lorig et al., 2003 [48]	Fu et al., 2003 [46]	Number of studies that showed improvement (i.e. ES $\geq .25$ )/total number of studies in which this variable was studied	Number of studies that showed significant $p$ -values ( $p \leq .05$ )/total number of studies in which this variable was studied
<b>Health service utilization</b>							
MD & ER visits	.04 (.11)	.13 (.006)				0/2	1/2
Number of hospital stays	.02 (.047)	.02 (.737)	-.14	-.03 (.481)	.17 (.04)	0/4	2/5
Nights in hospital	.14 (.01)				.12 (.40)	0/2	1/2
Physician visits			-.19	.17 (.057)	.02 (.72)	0/2	0/3
Emergency department visits			-( $\leq .05$ )	.27 (.005)	.01 (.44)	1/2	2/3
Days in hospital		.03 (.535)	-.12			0/1	0/2



Netherlands, it is necessary to investigate its usefulness and effectiveness in a systematic way. This is done in the present thesis.

The aim of the study presented in this thesis is threefold. First, to study the short-term and longer term effects of the CDSMP on self-management behavior, health, and health care utilization in a clinical sample of older people with one or more chronic diseases in the Netherlands. Secondly, to study the working mechanisms of the CDSMP, and the effect of the CDSMP on quality of life and well-being. Thirdly, to investigate whether the actual subjects in this study on the effects of the CDSMP, i.e. people who agree to participate, are a specific selection of the intended sample.

## **1.4 Outline of the dissertation**

*Chapter 2* starts with an outline of the theoretical background of the CDSMP, i.e. the self-efficacy theory. Some theoretical problems with regard to the self-efficacy theory in relation to the CDSMP are explained, and an additional theory, which could partly solve these problems, is discussed: the theory of self-management of well-being (SMW). The chapter ends with an overview of the research questions that were addressed in the study presented in this thesis, and the main hypotheses.

*Chapter 3* describes the methods used in the study, the recruitment strategy, the sample characteristics, the measurements, and the intervention, which consists of an adaptation of the CDSMP to the Dutch situation, called “GRIP op lijf en leven”. The following three chapters present sub-studies evaluating this intervention.

*Chapter 4* presents the first study, an evaluation of the short-term and longer term effects of the CDSMP among chronically ill older people in the Netherlands. Knowing from previous studies that the CDSMP can have positive effects on self-efficacy, self-management behavior, and health status, we expected to find positive effects in our sample of patients, aged 59 or older, with one or more chronic diseases.

*Chapter 5* presents the second study, which focuses on the effect of the CDSMP on self-management abilities other than self-efficacy, and investigates whether the CDSMP improves subjective well-being.

*Chapter 6* presents the third study, which focuses on the effects of the CDSMP on health care utilization.

*Chapter 7* described another study, comparing patients who refused to

participate (refusers) and patients who agreed to participate (participants), after they had been invited to participate in the self-management intervention.

*Chapter 8* describes the participants' experiences with the program, subjectively evaluated in several ways and at various moments. With possible future implementation in mind, this chapter has been written in Dutch.

Finally, *Chapter 9* contains a general discussion of the main results and the implications of these findings. The thesis ends by a summary of the results.

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# 2

## **Theory and hypotheses**

## 2.1 Introduction

In the previous chapter it became clear that the Chronic Disease Self-Management Program (CDSMP) developed by Lorig et al. is the only self-management program that applies to (older) people with one or more chronic diseases, and that it has the aim to improve or sustain general well-being, in addition to health outcomes. Several evaluations have shown that the CDSMP can be effective in improving health status and self-management behavior, and also in decreasing health care utilization. The underlying mechanism explaining these effects is assumed to be self-efficacy, which is defined as “beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments” ([1], p.3). The CDSMP incorporates strategies to enhance self-efficacy and, by doing so, to enhance self-management behavior and health-related outcomes. Figure 2.1 shows this process in a diagram.



Figure 2.1 Relationship between self-efficacy, self-management behavior, health status, and health care utilization

Insights into the relevance of the self-efficacy theory for this type of program were gained during the development of the Arthritis Self-Management Program (ASMP), on which the CDSMP is based. The ASMP is a low-cost, community-based patient education program for people with arthritis, which aims to change behavior and health status, and to reduce health care utilization. The ASMP was designed with “bits and pieces taken from theory, past practice, and good intentions” ([2], p. 356). The underlying assumption was that changes in health behavior would result in changes in health status. However, from evaluations of the ASMP this relationship appeared to be weak to non-existent [3]. In a qualitative study that was performed to find an explanation, the participants stated that they had more feelings of control after participating in the ASMP [4]. In order to operationalize this concept of control, Lorig and colleagues studied theories of locus of control, learned helplessness, coherence/congruence, stress and coping, and self-efficacy [2;5]. They rejected

the theory of locus of control, because they had used the health locus of control scale in their first study, and had found that the ASMP had no effect. The theory of learned helplessness was rejected because there were no available instruments to measure this concept [2]. In later studies, however, a questionnaire was used to measure learned helplessness. It appeared that learned helplessness correlated with self-efficacy, but was not highly associated with the observed changes in health status. The coherence theory was rejected because this theory suggests that a sense of coherence is a trait, and thus cannot easily be changed. In later studies a coherence scale was used, but no changes were found. In a study focusing on the role of coping in determining the health status of older people with osteoarthritis, it was found that coping was of limited value in predicting health status, so therefore this theory was also rejected. However, the self-efficacy theory seemed to be promising, for three reasons. First of all, this theory is belief and behavior-specific. Therefore, only the beliefs about a specific behavior have to change, and not an entire psychological structure such as, for example, a sense of coherence. Secondly, in several studies the self-efficacy theory had been shown to be highly predictive of future health behavior and health status, for example with regard to pain experience and management, and successful recovery from myocardial infarction [6]. Thirdly, the self-efficacy theory incorporates specific methods by which efficacy can be enhanced, such as skills mastery, modeling, re-interpretation of physiological symptoms, and persuasion [2].

## **2.2. Self-efficacy theory**

According to Bandura, who developed the self-efficacy theory, cognitive processes play an important role in the acquisition and retention of new behavior [7]. If people think that a certain behavior will lead to a certain outcome, they will adopt that behavior, but only if they consider themselves able to do so. Perceived self-efficacy influences the choice of behavior and settings, and it also influences how much effort will be spent on a given behavior and how long this effort will be maintained [1]. Bandura makes the following distinction between efficacy beliefs and outcome expectations [1;7]: perceived self-efficacy is a judgment of one's ability to organize and execute given types of performances, and outcome expectations are a judgment of the consequence of such performances [1]. However, self-efficacy can, in itself, produce benefits [1]. Enhanced self-efficacy does not depend on a specific situation, but can be generalized to other situations, provided that the activities are similar [1].

There are four ways to enhance self-efficacy: performance mastery, modeling, persuasion, and physical reframing [1;8]. Performance mastery is based on personal experiences. If a person experiences success in adopting a certain behavior, self-efficacy will be enhanced and this behavior will be adopted more frequently. This is the most important source of efficacy information, because it gives direct information about (in)ability to perform successfully. Consequently, repeated failure undermines the feeling of confidence. Modeling refers to the fact that people learn more and try harder when they are motivated by seeing other people, whom they perceive to be like themselves, managing circumstances similar to their own. Models and modeling are more effective if both the model and the behavior are perceived as relevant by the participant. It must be clear that it is the performance of the model that leads to the results of that behavior. Persuasion means giving someone the idea that (s)he can successfully adopt a certain behavior. “People who are persuaded verbally that they possess the capabilities to master given activities are likely to mobilize greater effort and sustain it than if they harbor self-doubts and dwell on personal deficiencies when problems arise” ([1], p. 101; [8], p. 302). Physical reframing is based on the assumption that people judge their capabilities with regard to certain behavior on the basis of beliefs and information about physiological symptoms. People tend to attribute physiological symptoms to a cause. Sometimes these symptoms are misinterpreted. For example, arousal can be experienced as a sign of fear, whereas it may be a sign of physical effort. Incorrect beliefs about a cause may lead to inappropriate thoughts about one’s own capabilities, which may lead to inappropriate behavior. However, positive mood during performing certain behavior enhances self-efficacy. Therefore, physical reframing is directed at reducing stress reactions and negative emotions, and at correcting misinterpretations.

A sense of personal efficacy can influence health in two ways [8]. First, biological systems are influenced by beliefs in the capability to cope with stressors. It has been reported that patients who believe that they can do something about their physical condition are less depressed and less stressed [8]. For example, a study carried out by O’Leary et al. [9] showed that enhanced self-efficacy reduced inflammation in patients with arthritis. Secondly, efficacy beliefs influence the choice and performance of health habits, and this consequently affects health status and functioning [8].

Applying the self-efficacy theory to patients with chronic illnesses, it is assumed that their self-efficacy for coping with the disease and its consequences might have been reduced, due to the usually unpredictable and variable course

of a chronic disease. This may lead to anxiety and depression, which, in turn, may increase their perceptions of pain, and reduce their efforts to cope with the consequences of the disease or to engage in daily activities [10]. As a consequence, their health status will further deteriorate, for example because of reduced immune function and heightened susceptibility to disease, as a consequence of the activation of stress-related hormones [8]. Therefore, not only specific knowledge and skills are required to cope with the challenges posed by chronic diseases, but also belief in one's ability to use those skills in realistic contexts and belief that the use of the skills will produce the desired outcomes [11]. Thus, if self-efficacy can be enhanced in patients with chronic illnesses, then the risk of a downward spiral could perhaps be reversed: feelings of control might be enhanced, anxiety and depression might decrease, pain might decrease, etc. Therefore, in an intervention supporting patients with chronic diseases a central position should be given to self-efficacy.

### *2.2.1 Application of the self-efficacy theory in the CDSMP by Lorig et al.*

Lorig et al. define self-efficacy as: "Confidence in one's ability to manage different aspects of one's health functioning" ([12], p. 257). Four strategies to enhance self-efficacy are incorporated in the CDSMP, i.e. performance mastery, modeling, persuasion, and physical reframing. Performance mastery is incorporated by means of writing a contract at the end of each session, the so-called 'action plan' [2]. In this contract the participants formulate a goal with regard to self-management behavior (for example, exercise or healthy eating), which they intend to accomplish during the following week. This goal is something that a participant wants to achieve, and is not dictated by what is taught. After formulating the contract, the participant has to state how confident (s)he is, i.e. how much self-efficacy (s)he has, that (s)he will execute the action plan. This is to assess whether the goal is realistic and attainable. If the level of confidence is below 7 (on a 1-10 scale), the contract is renegotiated by the leaders until a higher level of confidence is achieved. After a week the participants report whether or not they have accomplished their action plan, and any possible problems that might have arisen are solved. This is called feedback, which is an integral part of skills mastery. The action plan is very important, because social support and guidance during the early stages of personal change and maintenance increase long-term success [13].

The CDSMP includes three ways of modeling. First of all, it is preferable to appoint at least one leader who also has a chronic disease, which means that this

leader shares the problems of living with a chronic condition and knows what (s)he is talking about. Secondly, the participants can serve as models for each other. Thirdly, the patient book “Living a healthy life with chronic conditions” includes drawings and examples of people as models [14].

Persuasion is incorporated in two ways. Participants are encouraged to adjust their action plan every week in order to achieve a little bit more than in the preceding week. Hearing other participants making and adjusting their action plans and achieving their goals also is a type of persuasion.

One way in which the CDSMP attempts to apply physical reframing and to change certain beliefs about symptoms is to teach participants that the symptoms they experience are not only due to their disease, but that there can be several causes. This is done during small lectures included in the course, and by providing information in the patient book. Another way to change inappropriate judgments about certain behavior is to teach the participants self-talk, i.e. changing negative thoughts about the disease and self-help behavior into more positive thoughts.

### *2.2.2 Test of the self-efficacy theory with regard to the CDSMP by Lorig et al.*

The role of self-efficacy has been studied mainly in relationship to the ASMP, but in studies of the CDSMP the mediating effect of self-efficacy has not been studied. As part of the development of an arthritis self-efficacy scale, it was not only found that there is an association between perceived self-efficacy and both present and future health status, but also that improvement in self-efficacy is associated with improvement in health status [15]. With regard to the ASMP, Lorig and colleagues studied the relationship between self-efficacy, self-management behavior, and health status [5]. One finding from that study was that the ASMP created changes in self-efficacy (i.e., self-efficacy for managing pain, for managing other symptoms such as fatigue and depression, and for function), changes in self-management behavior (i.e., exercise, cognitive pain management techniques, managing other symptoms), and changes in health status (i.e., pain, depression, and disability). When investigating the correlation between changes in self-efficacy, exercise, and pain, the researchers concluded that changes in pain were associated more with changes in self-efficacy than with changes in exercise [5]. The researchers also concluded that changes in self-efficacy were not affected by changes in exercise or the use of cognitive pain management techniques. They also compared health education designed to enhance self-efficacy with health education designed to increase self-management behavior, and found that health education designed to enhance self-

efficacy resulted in larger improvements in pain, disability, and depression which were twice as great as the improvements resulting from health education designed only to increase self-management behavior.

The CDSMP focuses only on whether or not the program enhanced self-efficacy. The relationship between self-efficacy and other outcome variables was not studied, possibly because this had already been investigated in the ASMP studies [12;16]. However one study investigated the extent to which initial levels and 6-month changes in self-efficacy predict subsequent health care utilization [17]. It was found that both baseline self-efficacy and improvement in self-efficacy were accompanied by reductions in health care utilization after one year. In studies of the CDSMP, the only thing that was mentioned about the self-efficacy theory was that “self-efficacy has been shown a common pathway through which psychosocial programs affect outcomes” ([12], p. 257; [17], p. 1219). Reference has been made to Bandura’s “Self-efficacy: the exercise of control” [1], but how this ‘pathway’ works, i.e. how self-efficacy affects the related outcomes, is not mentioned in the articles. Moreover, the order in which the outcome measures are presented differs, i.e., health status, health care utilization, and perceived self-efficacy [16] and health status, health behavior, self-efficacy, and health care utilization [12]. Since self-efficacy is thought to be the working mechanism, it might be assumed that the first, i.e. primary, outcome measure would be self-efficacy. However, both studies carried out by Lorig et al. confirm that the CDSMP enhances self-efficacy, health status and health care utilization [12;16].

There seem to be some theoretical problems with regard to the CDSMP. First of all, the way the mechanisms are actually based on the self-efficacy theory in the CDSMP was not studied extensively, and the concepts used were explained only briefly. For example, self-efficacy is conceptualized in a rather general way, i.e. “confidence in one’s ability to manage different aspects of one’s health functioning”. What these ‘different aspects’ are, and what ‘health functioning’ means is not explained. This might relate to one of the methodological problems mentioned in Chapter 1, i.e., the use of different outcome variables in the different studies. Furthermore, it is not clear from the studies carried out by Lorig et al. whether there are specific behaviors for which self-efficacy should be enhanced. It seems that the self-efficacy theory was used in a rather general way, based on the mere assumption that enhanced self-efficacy leads to better health outcomes. It might, therefore, be questioned whether self-efficacy is the only working mechanism in the CDSMP.

To summarize, it seems that in addition to the problems that are encountered

in deriving a general conclusion about the effectiveness of the CDSMP, as mentioned in Chapter 1, there are also theoretical problems. The hypothesized role of self-efficacy in the CDSMP, i.e. the relationship between self-efficacy and the other outcome variables, was not assessed. Moreover, although the effect of the CDSMP on various aspects of health-related quality of life was studied, its effect on overall subjective well-being has not yet been studied. Therefore, before implementing the CDSMP in the Netherlands, we need not only to investigate its usefulness and effectiveness, but also to obtain more insight into the pathway(s) through which self-efficacy enhances the main outcome measures, to answer the question of whether there are other working mechanisms in addition to self-efficacy, and to investigate whether the CDSMP enhances overall well-being. For this we need a theory that specifies other mechanisms in addition to self-efficacy, and that also specifies pathways through which these mechanisms enhance overall well-being. The theory of self-management of well-being (SMW) seems suitable for this purpose.

### **2.3 Theory of self-management of well-being (SMW)**

The theory of SMW is based on a theory of successful ageing which, in turn, is based on the Social Production Function (SPF) theory relating to how people realize and maintain well-being [18;19]. According to the SPF theory, overall well-being consists two dimensions: physical and social well-being. Both dimensions can be achieved through the attainment of goals. For physical well-being these goals are stimulation and comfort [18;20;21]. Stimulation refers to activities that produce arousal, including mental and sensory stimulation and physical effort, and comfort refers to the absence of thirst, hunger, pain, fatigue, etc. For social well-being these goals are status, behavioral confirmation, and affection. Status refers to a feeling of being ‘better than’ many others in the eyes of relevant others and oneself. Behavioral confirmation is defined as positive feedback on behavior (the feeling of having done “the right thing”) by others and oneself. Affection includes love, friendship and emotional support, from others and oneself.

The theory of SMW assumes that people do not only need “external” resources to achieve the dimensions of well-being (e.g., a friend for affection or a comfortable house for comfort), but also “internal” resources, i.e. self-management abilities, which enable them to manage their external resources adequately. The theory of SMW explicitly specifies six core self-management abilities (SMAs) that are indirectly needed to achieve both the physical and the

social dimensions of well-being and, in turn, overall well-being. The six self-management abilities are: *self-efficacy beliefs* (i.e., feeling competent about being able to ‘produce’ well-being); having a *positive frame of mind* (i.e., a positive perspective with regard to future resources for well-being); *taking the initiative* (i.e., being agentic with regard to resources needed for the realization of dimensions of well-being); *investment behavior* (i.e. to provide reserves and to obtain future resources); taking care of a *multifunctionality* of resources and activities in order to achieve different dimensions of well-being at the same time; and achieving and maintaining a *variety* in resources (i.e., having more than one resource or ability to achieve a specific dimension of well-being). The self-management abilities are assumed to be interdependent and mutually reinforcing. Note that in the SMW theory, self-efficacy is especially related to achieving the main dimensions of well-being, whereas self-efficacy in the CDSMP is related to any behavior. Participants in the CDSMP can choose their own goals, i.e., specific behavior, which they might want to improve. However, it can not automatically be assumed y that the goals people select will, indeed, contribute to their well-being, because selecting the “right” goals, i.e., those that will enhance well-being, is not part of the intervention. Furthermore, the SMW theory specifies how self-efficacy and the other self-management abilities enhance overall well-being, namely through the enhancement of dimensions of physical and social well-being (Figure 2.2).

<b>Dimensions of well-being →</b> <b>Self-management abilities ↓</b>	<b>Comfort</b>	<b>Stimulation</b>	<b>Affection</b>	<b>Behavioral confirmation</b>	<b>Status</b>
<b>Self-efficacy beliefs</b>					
<b>Positive frame of mind</b>					
<b>Taking initiatives</b>					
<b>Investment behavior</b>					
<b>Multifunctionality</b>					
<b>Variety</b>					

Figure 2.2 The matrix of self-management abilities and dimensions of well-being (derived from Steverink, Lindenberg & Slaets, [19])

SMAs are undermined by losses that many people experience with increasing age. These losses concern several domains of functioning, and might result in a decline in subjective well-being, adverse health outcomes,

disproportional health care utilization, or depression [22]. How well people adapt to these losses depends on the availability of both external resources and SMAs. SMAs are important for the optimal management of the external resources, i.e., direct means to achieve the five dimensions of well-being, i.e., to ensure that the external resources do not decline but stay stable, or even improve. Research shows that SMAs in general and most of the individual SMAs can be enhanced in (frail) older people in the short-term and partly in the long-term by SMA interventions and well-being [22-24].

Analyzing the content of the CDSMP based on the theory of SMW suggests that in addition to self-efficacy, the other abilities may also be enhanced by the CDSMP. For instance: (a) Positive frame of mind: one of the cognitive symptom-management techniques is “positive self-talk”, in which participants learn to change negative thoughts into positive ones. Frame of mind is also influenced by social comparison. For example, seeing that someone in the group has more physical limitations than you have, can make you feel better (b) Taking initiatives: participants are encouraged to be proactive, to do the things they want to do and can do. One important way in which this is done is by making an action plan (c) Investment behavior: as the title of the patient book “Living a healthy life with chronic conditions” already says, the core of the CDSMP is trying to lead as normal a life as possible, despite a chronic disease [14]. Participants are, for example, encouraged to invest in health behavior such as exercise and healthy eating (d) Multifunctionality: in the CDSMP there is emphasis on combining business with pleasure. For example, when you walk for exercise you can do this with a friend, so walking serves two goals: a physical and a social goal (e) Variety: participants are encouraged to search for multiple ways to achieve their goals. In sum, the various SMAs might be enhanced by the specific self-management behavior taught in the CDSMP. That the CDSMP enhances self-efficacy has already been shown in previous studies of the CDSMP.

The self-management behavior taught in the CDSMP might also act as a direct mean to achieve the five dimensions of well-being. With regard to exercise, for example, stimulation could result directly from participating in the program, comfort might be improved as a consequence of decreasing symptoms, effective communication with family and friends might have a positive influence on the social well-being dimensions, being among fellow sufferers might enhance affection, and participants might gain status by the way in which they deal with (certain aspects of) their chronic disease and can confirm each other’s (self-management) behavior.

Based on the above-mentioned theoretical considerations, and on the available evidence with regard to the effectiveness of the CDSMP, the following three hypotheses are formulated (for older people with one or more chronic diseases in the Netherlands, compared to controls):

1. Participation in the CDSMP will increase self-efficacy, self-management behavior, and health status, in the short term and in the longer term.
2. The CDSMP will increase self-management abilities and well-being in the short term and in the longer term.
3. Participation in the CDSMP will decrease health care utilization in the longer term.

As mentioned in Chapter 1, most of the studies of the CDSMP provide very little information about the patients who refused participation. However, based on self-management intervention studies it might be assumed that the participants were a specific selection of an intended sample. Therefore, a fourth hypothesis is formulated:

4. The actual participants in our study on the effects of the CDSMP, i.e., people who agreed to participate, are a specific selection of the intended sample.

In Chapter 4, 5, 6 and 7 these hypotheses will be empirically tested. First of all, Chapter 3 describes the design of the study, the sample and all the measurements.

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# 3

## Methods

## **3.1 Introduction**

This chapter describes the methods used in the studies reported in this thesis. First of all, the sample size, the recruitment strategy, the enrollment process, and the characteristics of the participants are described. This is followed by an overview of the measurements and the questionnaires that were used. Subsequently, information is given about the intervention and the leaders, and the analyses are discussed.

## **3.2 Patients**

### *3.2.1 Sample size*

We originally aimed to include 200 participants, 100 of whom could be randomized to the intervention group, and 100 to the control group. We allowed for 20-30% drop-out, so that 150 of the 200 would complete the study, with 75 patients in the intervention group and 75 in the control group. This group size of 75 was based on the following power analysis for completed cases. The aim was to have a standardized effect of approximately 0.5, a power of 80%, and an  $\alpha = 0.05$  (one-tailed). These were reasonable parameters for this kind of research, and they jointly yielded a group size of 75 patients in each group.

### *3.2.2 Recruitment*

In the period between May 2003 and May 2004 patients were recruited on four wards of the Internal Medicine outpatient clinic at the University Medical Center Groningen, through announcements in the media, and various patient association magazines. The eligibility criteria were: age 59 or older; angina pectoris or heart failure, COPD or asthma, or arthritis, or diabetes; ability to communicate adequately in the Dutch language; experiencing problems in coping with the disease; ability to attend a six-week course. Patients with a life-expectancy of less than one year, or currently attending a disease-specific self-management program, or participating in another study, or who were permanent residents of a nursing home were excluded from the study. Patients with other diseases, in addition to the above-mentioned ones, for example hypertension, were also eligible for participation.

On the day before the consultations with a physician were planned, all medical files of patients with an appointment were screened to identify patients who met the above-mentioned criteria. If a patient was eligible, a green leaflet

was placed in the file, so that during the consultation the physician would see the leaflet indicating that the patient was eligible for the study. After the consultation, the physician asked the patient if (s)he had enough time to answer a few questions concerning a study investigating the influence of a chronic disease on daily life. If a patient agreed, the physician informed the medical secretary, who informed the primary researcher (i.e., Henrike Elzen). Subsequently the patient was invited to have a short conversation with the primary researcher, during which the researcher used the Groningen Frailty Indicator (GFI) to collect data on several domains of functioning [1;2]. The GFI is a short, easy-to-administer 15-item screening instrument to assess level of frailty, which will be described in more detail in the Measurement section. At the end of this conversation the patients who were, indeed, eligible at this stage were invited to participate in a study investigating the effects of Lorig et al.'s Chronic Disease Self-Management Program (CDSMP) on older people with one or more chronic diseases in the Netherlands. Patients who agreed to participate were told that they should keep in mind that they would be randomly assigned to an intervention group or a control group.

Of the 616 patients who were eligible for participation based on their medical file, 124 (20.1%) were not further assessed, because the physician did not consider the patient to be eligible for the study, or the patient had no time, or the patient did not keep the appointment (Figure 3.1). Of the 492 patients who were screened, 217 were recruited through the Rheumatology ward (44.1%), 147 through the Endocrinology ward (29.9%), 121 through the Lung Disease ward (24.6%), and 7 through the General Internal Medicine ward (1.4%). Of these patients, 131 (26.6%) had not been invited to participate during the initial conversation, mainly because the patient's (n=100) physical condition seemed to be either too bad or too good. This assessment was based on the patient's self-rated score for their health status, the answers they gave to other questions on the GFI (indicating that they did not experience any problems in daily life), or the fact that the patient appeared to be very weak. Other reasons were: cognitive impairment (n=8); impaired vision or hearing (n=5); personality characteristics, such as being too talkative, because of which the patient was not considered to be suitable for participation in a group (n=5); living in a nursing home (n=3); inability to communicate adequately in Dutch (n=2); admission to a hospital or rehabilitation center (n=5); participating in another study (n=2); or recently discharged from a psychiatric hospital (n=1).

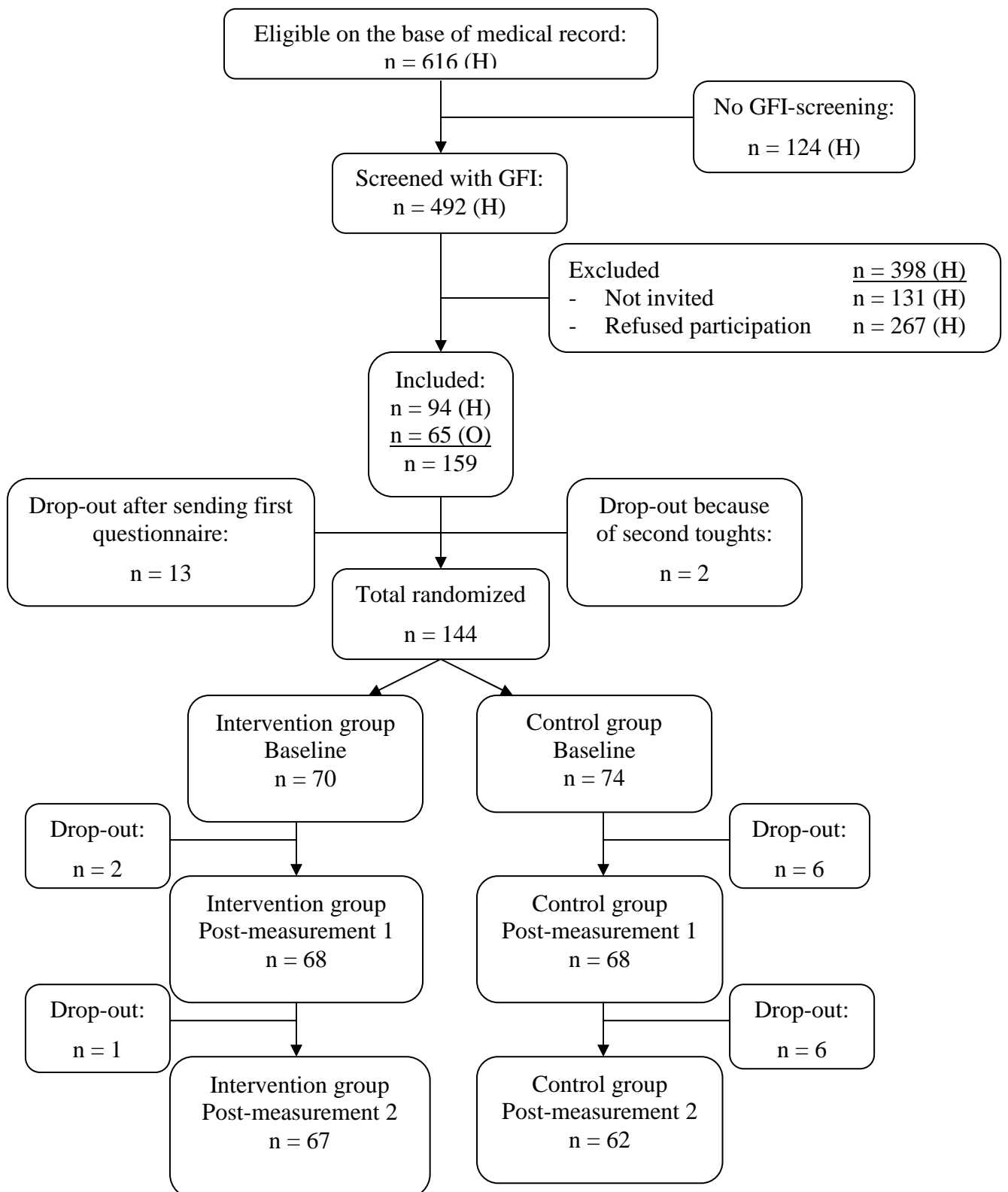


Figure 3.1 Enrolment procedure (H = hospital and O = other ways of recruitment)

Of the 361 patients who were invited, 267 refused participation (74.0%), and 80% gave their reasons for non-participation (n=218). The main reasons were: no time to attend a six-week course (19.3%), long travel distance to course location (19.3%), transportation problems (12.4%), no need to attend a course (10.1%), participation in a course would be too strenuous (7.8%; see also Chapter 7 for characteristics of the refusers).

Patients who agreed to participate, were given an information brochure and an informed consent form to take home. The primary investigator then contacted them by telephone two days later, allowing them some time for consideration. If they were still willing to participate, they were asked to sign the informed consent form and send it back. In this way, a total of 94 patients were recruited for the study.

Due to the low response rate in the wards of the outpatient clinic, other methods were used to recruit additional patients, namely announcements in local and national newspapers, announcements via local and national radio stations, an announcement in a Dutch health insurance company magazine, leaflets distributed to all residential care homes in the city of Groningen, announcements in patient association magazines and meetings (Dutch Diabetes Association, and the regional branches of the Arthritis Association and the Asthma Association). In this way, another 65 patients were recruited (see Table 3.1).

Each time about twenty-five patients returned their informed consent forms, a baseline questionnaire was sent to these patients. After they had returned this questionnaire, these twenty-five participants were randomized: within each diagnostic group participants were assigned either to the intervention or the control group. After three randomization moments, it appeared that the control group was bigger than the intervention group, so in order to eliminate this difference it was decided to randomize people with a probability of 2/3 to the fourth and fifth intervention group. The sixth group was randomized in the order in which the questionnaires were returned, i.e. the first eight were assigned to the intervention group. The sixth group also contained four people from the first control group but these four people were excluded from the analyses of the sixth group. In this way, six consecutive blocks of approximately twenty-five people with various diseases were formed during the inclusion period, half of whom were in the intervention group and half in the control group. The intervention group participated in the CDSMP and the control group received care-as-usual. After the last measurement, the control group was also offered the patient information book that was used in the intervention.

Table 3.1 Other methods of recruitment, and the number of people recruited per method

<b>Time period</b>	<b>Method of recruitment</b>	<b>N</b>
November '03	Distribution of flyers during a regional Asthma-manifestation in Groningen	1
January '04	Interview for a column in "Het Parool" (Dutch national newspaper)	0
	Interview in "Dagblad van het Noorden" (Dutch regional newspaper)	0
	Interview in "De Ochtenden" (program on the national radio)	0
	Interview in "Friesch Dagblad" (Dutch regional newspaper)	0
	Telephone interview on radio Delfzicht (local radio station)	0
	Announcement in a regional magazine of the Dutch Arthritis Association	8
March '04	Telephone interview on radio Veendam (local radio station)	0
	Presentation at a regional meeting of the Dutch Arthritis Association	0
	Interview in "Trouw" (Dutch national newspaper)	5
	Announcement in the national magazine of a Dutch health insurance company ("Health")	0
April '04	Interview on radio "Noord" (regional radio station)	12
	Presentation at a regional meeting of the Dutch Asthma Association	4
May '04	Announcement in the national magazine of the Dutch Diabetes Association	16
	Distribution of flyers in local residential care homes	5
September '04	Poster at a local rehabilitation sports center	3
	Presentation at a regional meeting of the Dutch Diabetes Association	4
October '04	Presentation at a regional meeting of the Dutch Asthma Patients Association	5
	Announcement in the national magazine of the Dutch Heart Disease Association	2
	Letters to regional contact persons for the Dutch Heart Foundation	0
<b>Total</b>		<b>65</b>

A total of 159 patients were included in the study. After giving informed consent two patients dropped out because they had second thoughts, and another 13 dropped out after receiving the baseline questionnaire (without completing it), mainly for physical reasons.

Eight patients did not complete the first post-intervention questionnaire. Two patients withdrew from the study after randomization: a couple that had been assigned to the intervention group, but the husband had subsequently suffered a heart attack. Six patients in the control group did not return the first post-intervention questionnaire: one patient had died, one wrote to say that the study did not meet her expectations, and four gave no specific reason. Five of the drop-outs had diabetes, two had arthritis, and one had a lung disease. The

eight drop-outs did not differ significantly from the other participants at baseline.

Seven patients (six in the control group and one in the intervention group) did not complete the second post-intervention questionnaire (T2). Of the six drop-outs in the control group, one had developed a brain tumor and was unable to complete the questionnaire, one had died, and four patients gave no specific reason. One patient in the intervention group did not complete the questionnaire because she no longer thought it was of any use. Of these seven drop-outs, four had diabetes, two had a lung disease, and one had a heart disease. Compared to the patients who completed the second post-intervention questionnaire, the drop-outs returned their questionnaire significantly later at T1 ( $Z=-3.269$ ,  $p=.001$ ) and had a significantly lower score for the physical functioning component of the RAND-36 ( $Z=-2.546$ ,  $p=.011$ ). The drop-outs also had a significantly lower score for exercise ( $Z=-2.695$ ,  $p=.007$ ), but a significantly higher score for cognitive symptom-management ( $Z=-2.138$ ,  $p=.033$ ) at the first post-intervention measurement.

Table 3.2 presents the characteristics of the participants. Of the 144 patients who were randomized, 48.6% ( $n=70$ ) were assigned to the intervention group and 51.4% ( $n=74$ ) to the control group. No differences between the groups were found at baseline with regard to any patient characteristics or measurement scales, confirming the random allocation to the intervention.

### **3.3 Measurements**

Data were collected through self-administered questionnaires that were mailed to the patients three weeks before the program started (T0), immediately after the program had finished (T1, six weeks after baseline), and six months after the end of a course (T2). The patients had one to three weeks to complete and return the questionnaire. A research assistant, who was unaware of the patient's randomization status, checked the returned questionnaires for completeness. If questions or pages were missing, either a copy was sent to the patient with a request for completion of the questionnaire, or the patient was interviewed by telephone. Although they returned the questionnaire, it appeared that two patients had not been able to complete the questionnaire by themselves, probably due to a low education level, so they were helped by a research assistant who visited them at home.

The baseline questionnaire was returned within, on average, 11.4 days (range 2-60). Patients in the intervention group returned their questionnaire

significantly faster at baseline than patients in the control group (average 8.8 days and 14.0 days, respectively;  $t=-2.967$ ,  $p=.004$ ). The first post-intervention questionnaire was also returned within, on average, 11.4 days (range 2-48), and again the patients in the intervention group returned their questionnaire significantly faster than the patients in the control group (average 9.3 days and 13.4 days, respectively;  $t=-2.531$ ,  $p=.013$ ). The last questionnaire (T2) was returned later than the first two questionnaires, namely after, on average, 14.9 days (range 2-162). No significant difference was found between the intervention group and the control group.

Table 3.2 Patient characteristics

Characteristics	Intervention group	Control group	P-value
N	70	74	
Mean age (SD)	68.5	68.5	.978
Range	59-84	59-87	
Gender			.935
Male (%)	37.1	36.5	
Partner (%)	67.1	56.8	.498
Disease			.496
Diabetes (%)	35.7	32.4	
Lung disease (%)	31.4	23.0	
Arthritis (%)	28.6	37.8	
Heart disease (%)	4.3	6.8	
Recruitment			.071
Hospital (%)	48.6	63.5	
Other (%)	51.4	36.5	

### 3.3.1 Measures

*Demographic variables.* The demographic data included date of birth, gender, marital status and primary chronic condition.

*Self-efficacy.* When we started collecting the data, it was uncertain which of the Lorig et al. self-efficacy scales for the CDSMP would be the most appropriate, because different scales had been used in studies of the CDSMP. In the first studies behavior-specific self-efficacy questionnaires were used, as described in Lorig et al.'s "Outcome measures for health education and other health care

interventions” [3]. An example of an item on these questionnaires is “How confident are you that you can do an aerobic exercise such as walking, swimming, or cycling three or four times each week?” In Lorig et al.’s “Sample questionnaire for the chronic disease self-management program”, however, the questions concerning self-efficacy are less behavior-specific. For example “How confident are you that you can do things other than just taking medication to reduce the effects of your illness on your everyday life?” In personal correspondence, Kate Lorig explained why this other self-efficacy scale was introduced: “the SE scale was revised to reflect the belief that one could do some behavior to lessen the major symptom groups—this is the frame of the new scale—since it is not clear that any specific behavior is related to any specific outcome, we decided that in the spirit of self-management we would not specify behavior but let people self-tailor. What we are really asking is can you do something.” Moreover, at the start of our study there was no available psychometric data on the more general questionnaire. Therefore, we decided to use a more general self-efficacy questionnaire that has also been validated in the Netherlands, namely the General Self-Efficacy Scale (GSES-16; [4]). The GSES-16 measures general expectations of self-efficacy. An example of an item is “When I make plans, I will execute them successfully”. This instrument consists of 16 questions ( $\alpha = .81$ ), scored on a 5-point Likert scale on the dimension agree/disagree, a higher score indicating a higher level of self-efficacy.

*Self-management abilities (SMA).* Self-management abilities were measured with the Self-Management Ability Scale (SMAS-30, [5]). This is a self-report questionnaire for measuring SMA in older people. It measures SMA as an overall concept of abilities systematically linked to dimensions of well-being, as described in the theory of self-management of well-being (SMW) and Lindenberg’s Social Production Function (SPF) theory [6;7]. The SMAS-30 consists of six sub-scales (the six self-management abilities), with five items for every sub-scale ( $\alpha = .89$ ). Some sub-scales are scored on a 5-point Likert scale, and some on a 6-point Likert scale. An example of an item in the sub-scale “taking initiative”, that is related to affection is: “How often do you take the initiative to get in touch with people who are dear to you?” An item in the sub-scale “variety”, which is related to stimulation, is: “How many hobbies or activities do you have on a regular basis?” However, “having a positive frame of mind” is an ability that is not directly related to specific dimensions of well-being, because it is considered to be a more general cognitive frame.

All sub-scale scores are transformed to a 100-point scale, with the sum of the items of the sub-scales as the sub-scale score and the average of the six sub-scales as the total SMA score. The higher the score, the higher the SMA. Cronbach's alpha of the overall scale was .89, and between .65 and .83 for the sub-scales.

*Self-management behavior.* Since there were no official Dutch equivalents of the Lorig et al. measures with regard to self-management behavior, i.e., frequency of exercise, cognitive symptom-management, and communication with a physician, we decided to use the Lorig et al. scales, slightly adapted for cultural differences [3]. The frequency of four different types of exercise was measured (walking, swimming, cycling and other types of exercise), with a translated and adapted version of the Lorig et al. "physical activities" [3]. We did not include the questions about frequency of 'stretching and strengthening exercises', 'aerobic exercise with equipment (such as a stair master, a health rider, etc.)', and 'other aerobic exercise' because we assumed that our older respondents would not be familiar with these exercises. The frequency of exercise refers to the number of minutes spent on exercise each week.

Cognitive symptom-management was measured with a translated and adapted version of the Lorig et al. "Coping with symptoms" [3]. The adaptation concerns two statements: 'try to feel distant from the discomfort and pretend that it is not part of your body' and 'don't think of it as discomfort but as some other sensation, such as a warm, numb feeling'. These two questions were left out, because it was assumed that our respondents would not have been familiar with these techniques. The adapted scale consists of five items ( $\alpha = .71$ ), asking whether participants, when feeling depressed or experiencing pain or other symptoms, used techniques such as distraction, breathing exercises, guided imagery, progressive muscle relaxation, or positive thinking. This is scored on a 6-point Likert scale on the dimension never/always, a higher score indicating more use of cognitive symptom-management techniques. Cognitive symptom-management was only measured at the post-intervention measurement moments, because it was assumed that these questions would only be understood after the patients had heard about this subject during the course.

Communication with a physician was measured with a Dutch translation of the Lorig et al. "Communication with a physician"[3]. The scale contains three items, asking whether participants, when visiting a physician, prepare a list with questions to ask their doctor, ask questions about things they want to know and things they do not understand about the treatment, and discuss any personal

problems that may be related to the illness. This is scored on a 6-point Likert scale on the dimension never/always. The score is the mean of the three items. Cronbach's alpha was .65, a higher score indicating better communication with a physician.

*Well-being.* In this study, overall well-being was measured by means of both positive and negative indicators. The 15-item version of the SPF-Index Level Scale (SPF-IL) was used to measure overall well-being [8]. The SPF-IL is a multidimensional instrument that measures five dimensions of well-being (affection, behavioral confirmation, status, comfort, and stimulation). The short version consists of 15 items, with three positive items per goal. An example of a question about affection is: "Do people pay attention to you?" Scoring is on a 4-point Likert scale on the dimension always/never, with the sum of the items of the sub-scales as the sub-scale score and the sum score of all sub-scales as the total score. A higher score implies greater well-being. Cronbach's alpha of the overall scale was .80, and between .68 and .81 for the sub-scales.

Depression was measured with the 10-Item Geriatric Depression Scale (GDS-10; [9]). The GDS-10 consists of ten items, which are scored either yes or no. For seven of the questions the answer "yes" gives a positive score indicating depression; in the remaining three the answer "no" scores positively. An example of a question is: "Do you have the feeling that your life is empty?" The scores are summed to give a total of 0-10, the higher the score, the greater the depression. Cronbach's alpha of the scale was .76.

Positive and negative affect were measured with a short version of the Positive and Negative Affect Schedule (PANAS; [10;11]). This version consists of 5 positive and 5 negative adjectives, scored on a 5-point Likert scale on the dimension not at all/very much. An example of a question with regard to positive affect is "How often do you feel inspired?"; an example of negative affect is "How often do you feel nervous?" The higher the score of the sub-scale, the higher the positive or negative affect. A reliability analysis showed that the internal consistency of the positive affect scale was rather low ( $\alpha=.63$ ). Leaving out the item "feeling excited", because it has an ambiguous meaning in Dutch, increased the reliability ( $\alpha=.70$ ). Therefore, we used the four-item version of the positive affect scale. Cronbach's alpha for the negative affect scale was .88.

*Health status.* Health status was measured with the RAND 36-item Health Survey [12]. This scale consists of 36 questions and covers eight domains

(physical functioning; social functioning; role function (physical problems); role function (emotional problems); mental health; vitality; pain; and general health perception). In order to reduce the number of statistical comparisons, and therefore the inflation of the probability of type I error due to multiple testing, we used only the physical and mental component summary scales of the Dutch version of the RAND 36-item Health Survey [12;13]. The physical component is a composite of the sub-scales for physical functioning, role limitations (physical problems), bodily pain, and general health. The internal consistency of this overall scale was  $\alpha=.77$ . The mental component is a composite of the sub-scales for vitality, social functioning, role limitations (emotional problems), and mental health. Cronbach's alpha of the overall mental scale is .72. The higher the score for both scales, the better the physical and mental health condition. Health status was measured at all three measurement moments.

*Frailty.* The Groningen Frailty Indicator (GFI) was used to measure frailty on both physical and psychosocial domains [1;2]. The GFI is a short, easy-to-administer 15-item screening instrument to assess level of frailty ( $KR-20 = .62$ ). The GFI relates to four domains of functioning: physical (mobility, physical fitness, vision, hearing, nourishment, and morbidity), cognitive (memory), social (emotional isolation), and psychosocial (depressed mood and feelings of anxiety). Every item is scored either 0 (no problems) or 1 (problems), and the scores are then summed. The sum scores range from 0 (not frail) to 15 (very frail).

*Health care utilization.* To measure health care utilization we used the Lorig et al. "Medical Care" [3], supplemented with questions from Bos et al. [14]. The Lorig et al. questionnaire asks how many times in the previous six months a person has visited one or more physicians, and the emergency department of a hospital. It also asks about hospital admission, and duration of hospitalization. Based on Bos et al., the patients were asked how many times in the previous six months they had visited a general practitioner (GP), a medical specialist, a physical therapist, or a social worker, and how many times in the previous six months they had made use of home care or unpaid volunteers. They were also asked if they had been admitted to any other institution, apart from a hospital (i.e., a nursing home, a rehabilitation center, a psychiatric hospital, or other institution), and how many days they had stayed there.

### **3.4 Intervention**

The Chronic Disease Self-Management Program (CDSMP), developed by Lorig et al., consists of six weekly sessions, each with a duration of 2½ hours.

Appendix 1 gives an overview of the content of each session. The program is led by two leaders who adhere to a detailed manual [15]. During the first session the participants receive “Living a Healthy Life with Chronic Conditions”, a patient book that is used during the course and can also be used by the patients as a reference book [16]. The program includes: adoption of exercise programs; use of cognitive symptom-management techniques, such as guided relaxation and distraction; nutritional change; fatigue and sleep management; use of medication and community resources; managing the emotions of fear, anger and depression; training in communication with health professionals and others; health-related problem-solving; and decision-making. The program incorporates strategies that are known to enhance a sense of personal efficacy. These include guided mastery of skills through weekly action-planning and feedback of progress, modeling of self-management behavior and problem-solving strategies by participants for one another, social persuasion through group support and guidance for individual self-management efforts, re-interpretation of symptoms by giving many possible causes for each symptom as well as several different management techniques, group problem-solving, and individual decision-making [17].

In the study reported in this thesis, there were 10-15 participants aged 59 years and older with mixed diagnoses in each course group. The participants received a Dutch translation of “Living a Healthy Life with Chronic Conditions” (second edition). Some minor adjustments had been made in this book, mainly based on cultural considerations. Chapter 12 (Making your wishes known: advance directives for health care) was adapted, by use was made of information from the website of “Right to Die-NL” (NVVE in Dutch). In Chapter 13 (Healthy eating) the food guides were left out, because the units used in the guides differ from Dutch units. In Chapter 14 (Medication) the information about buying medication without a prescription was left out, because in the Netherlands this is very unusual. In consultation with a rheumatologist, Chapter 17 (Understanding Arthritis) was adapted, except for the part on “management of chronic arthritis”. A distinction was made between arthritis and rheumatoid arthritis, and the detailed information about medication was left out. Finally, Chapter 19 (Planning for the future: fears and reality) was adapted to the Dutch

situation, especially the parts about finding care in the home and outside the home. The part “will I have enough money to pay for my care” was left out.

In the course manual only a few adjustments were made. From the second group onwards, during the introduction to session one, we also asked the participants to tell something funny or special about themselves. We did this because we noticed in the first group that when the participants only talked about their disease and disease-related problems, the atmosphere became charged with emotion. Also in the first group we noticed that the participants did not make a copy of the action plan for themselves, i.e., they did not write it down and so they forgot to stick to it. Therefore, copied the action plan every week for every participant. In the third session, five more minutes were spent on the topic ‘advance directives’ and five minutes less on healthy eating. From the fourth session onwards the action plan was dealt with at the end and not, as the manual prescribes, at the beginning of the session, because in the first three sessions the action plans were also formulated at the end of the session.

The CDSMP was given the Dutch name “GRIP op lijf en leven”, which can be translated as “Grip on your body and your life”. GRIP is an acronym for Groningen Intervention Program, a program that comprises several interventions and studies, in all different formats. All interventions are either called “Grip op het leven” or have a similar title containing the word GRIP.

### **3.5 Leaders**

For practical reasons, and because a study performed by Lorig et al. showed that there are hardly any differences between lay-taught and professional-taught courses, all courses were had at least one professional leader [18]. Each course had two leaders who followed a detailed CDSMP manual [17]. In our study, all courses were led by the primary investigator (HE), who is an MA psychologist and trained as a CDSMP Master Trainer at Stanford University (27 hours), and a peer leader or other Master Trainer (psychologist, PhD).

The first course group had two Master Trainers. Three groups were led with peer leader A, and two with peer leader B (who was also a psychologist in training). All the leaders were women, three of whom had one or more chronic diseases themselves, and one had a significant other with chronic diseases. Three of the leaders were younger than the participants, ranging in age from 30-50 years. Peer leader B, however, was 62 at the time of the study. In accordance with the study, both peer leaders A and B had received individual training for at least 20 hours based on the Master Trainer manual. Although peer leader A had

amply experience in teaching groups, she did not have experience in adhering to a detailed manual. Peer leader B was inexperienced with regard to both aspects. During the study it became clear that it was important that the peer leaders had already accepted their own disease(s). Otherwise there is a chance that a leader takes on a participant role instead of teaching, as happened to leader B during the first session. For example, she participated in a discussion instead of leading it, and she added her own experiences to the information contained in the lectures.

In most other published studies of the CDSMP, very little information is given about the leaders. Often, it is only stated that there were two lay leaders in the program, one or both of whom were suffering from a chronic condition themselves [19-21]. Some studies reported that the leaders received 20 hours of training, or stated how many of the leaders were health professionals [19;22-24]. No other characteristics of these leaders are mentioned, such as gender or age. However, in their study, Lorig et al. reported that their 87 leaders ranged in age from 21-80 years, and that 82% of them were 40 years of age and over.

### **3.6 Analyses**

Specific analyses are described in each chapter separately. In general, *t*-tests, Chi-square tests, and Mann-Whitney tests were performed to compare the demographic characteristics and the baseline scores in the intervention group and the control group. Between-group analyses of covariance (ANCOVA) were performed to compare the intervention group with the control group. Treatment group (intervention/control) was used as the independent variable. Baseline score and gender were used as covariates, and block (1-6) was used as a factor. Correlations of the baseline scores and both post-intervention measurement scores for the various outcome variables ranged from .31 to .83. Because we also wanted to control for the severity of the disease, baseline physical functioning and type of disease were both used as control variables. Since only a few people had a heart disease (n=8), and a heart disease in this older population is often due to diabetes, heart condition was combined with diabetes. Thus, type of disease was represented by two dummy variables, one for arthritis and one for lung disease. Preliminary checks were made to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, or reliable measurement of the covariates. In view of the directionality of the research hypotheses, i.e., the results for the experimental group were expected to be better than for the control group, one-

tailed tests were performed. The level of significance was  $\alpha=0.05$ . The analyses were performed in SPSS 12.0.2 [25].

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# 4

## **Evaluation of the Chronic Disease Self-Management Program (CDSMP) among chronically ill older people in the Netherlands. A randomized controlled clinical trial**

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Submitted

## **Abstract**

### **Background and Aims**

Many chronically ill older patients in the Netherlands have a combination of more than one chronic disease. There is therefore a need for self-management programs that address general management problems, rather than the problems related to a specific disease. The Chronic Disease Self-Management Program (CDSMP) seems to be very suitable for this purpose. In evaluations of the CDSMP that have been carried out in the United States and China, positive effects were found on self-management behavior and health status. However, the CDSMP has not yet been evaluated in the Netherlands. Therefore, the aim of this study was to evaluate the short-term and longer-term effects of the CDSMP among chronically ill older people in the Netherlands.

### **Methods**

One hundred and thirty-nine people aged 59 or older, with a lung disease, a heart disease, diabetes, or arthritis were randomly assigned to an intervention group (CDSMP) or a control group (care-as-usual). We collected demographic data and data on self-efficacy, self-management behavior and health status at three measurement moments (baseline, after 6 weeks, and after 6 months).

### **Results**

The patients who participated in the program were very enthusiastic about the intervention, and there were very few drop-outs. However, our study did not yield any evidence for the effectiveness of the CDSMP on self-efficacy, self-management behavior, or health status of older patients in the Netherlands.

### **Conclusions**

The patients who participated in the program were very enthusiastic about the intervention, and only one dropped out. However, our study did not yield any evidence for the effectiveness of the CDSMP on self-efficacy, self-management behavior, or health status of older patients in the Netherlands.

## 4.1 Introduction

It may be questioned whether the current Dutch medical care system, with its main focus on acute care and cure, is sufficiently responsive to chronically ill patients who often will have no hope of recovery, but have to cope with an incurable long-term disease. As in other Western societies, the number of chronically ill older people in the Netherlands is increasing. Older people are often not only confronted with a chronic disease, but also with comorbidity [1]. The impact of chronic conditions on health is substantial, it varies according to condition, and it usually affects all aspects of functioning and well-being [2-8]. Chronic diseases may lead to disabilities, which can have a negative effect on the ability of older people to care for themselves [9].

This increase in the number of older people with chronic conditions implies a need for new means of delivering care, and teaching patients self-management behavior to cope with their disease could be an element in these new means. However, because many older patients have a combination of more than one chronic disease, there is a need for self-management programs that focus less on the problems related to one specific disease, and more on general management problems that are the same for patients with different chronic conditions, such as fatigue, pain, anxiety, etc. One program that meets these criteria is the Chronic Disease Self-Management Program (CDSMP), which was developed by Lorig and co-workers at Stanford University in America. To our knowledge, it is the only self-management program that for (older) people with more than one chronic disease. The CDSMP has been evaluated in the United States and in China, and has been found to be effective in maintaining and improving self-management behavior and health status, although not consistently so in all studies [10-13]. However, there is no standard measurement of outcome variables such as self-efficacy and health status. The CDSMP has not yet been evaluated in the Netherlands.

The aim of the present study was to evaluate the short-term and longer-term effects of the CDSMP among chronically ill older people in the Netherlands. Knowing from previous studies that the CDSMP can have positive effects on self-efficacy, self-management behavior, and health status, we expect to find positive effects in our sample of patients aged 59 and older with one or more chronic diseases.

## **4.2 Methods**

The procedures, research risks, and associated safeguards for this study were approved by the Independent Review Board of the University Medical Center Groningen.

### *4.2.1 Subjects*

In the period between May 2003 and May 2004, patients attending the Internal Medicine outpatient clinic at the University Medical Center in Groningen were personally invited to participate in the study. Participants were also recruited through announcements in the media and in the magazines of various patient associations. Eligibility criteria were: age 59 or older; angina pectoris or heart failure, COPD or asthma, or arthritis, or diabetes; ability to communicate adequately in Dutch; availability to attend a six-week course. Patients with a life-expectancy of less than one year, or already attending a disease-specific self-management program, or participating in another study, or who were permanent residents of a nursing home were excluded from the study. Patients with other diseases in addition to a heart disease, lung disease, arthritis, or diabetes were also eligible for participation.

Informed consent was obtained from patients who were eligible and willing to participate in the study. Each time informed consent was obtained from twenty-five patients, which took about four months, they were sent a baseline questionnaire. After the patients returned the questionnaire they were randomized: within each diagnostic group (i.e., disease group) the participants were assigned either to the intervention group or the control group. In this way, six consecutive blocks of about twenty-five people with various diseases were formed during the inclusion period, with equal numbers in the intervention group and the control group. The intervention group received the CDSMP, and the control group received care-as-usual. After the last measurement, the control group also received the patient book that was used in the intervention.

### *4.2.2. Intervention*

The program consisted of 6 weekly sessions, each with a duration of 2½ hours at the University Medical Center in Groningen. There were 10-13 participants in each training group with two leaders who adhered to a detailed manual [14]. For practical reasons, and because a study carried out by Lorig et al. showed that there were hardly any differences between lay-taught and professional-taught courses [15], all courses were led by the primary investigator (HE), who is an

MA psychologist and educated as a CDSMP Master Trainer at Stanford University, and a peer leader or other Master Trainer (psychologist, PhD). The program is based on the self-efficacy theory [16]. Self-efficacy refers to people's beliefs in their abilities to adopt specific behavior, which is a key factor in behavior change and health functioning [17]. The program incorporates strategies to enhance self-efficacy: weekly action-planning and feedback, participants modeling behavior and problem-solving for each other, re-interpretation of symptoms, group problem-solving, and individual decision-making [12]. The participants received a Dutch translation of "Living a Healthy Life with Chronic Conditions", a patient book that is used in the program, and can also be used by patients as a reference book [18]. In the translation of the course manual and the patient book, only a few minor cultural adjustments were made, namely with regard to advance directives.

#### 4.2.3 Measures

Data were collected through self-administered questionnaires that were mailed to the patients three weeks before the course started (T0), immediately after the course had finished (T1), and six months after the end of the course (T2). The data included date of birth and gender, marital status, and primary chronic condition. Outcome measures were self-efficacy, self-management behavior, and health status.

*Self-efficacy.* Self-efficacy was measured with a Dutch version of the General Self-Efficacy Scale (GSES-16; [19]. The GSES-16 consists of 16 questions ( $\alpha = .81$ ), scored on a 5-point Likert scale of the dimension agree/disagree, a higher score indicating a higher level of self-efficacy. Self-efficacy was measured at all three measurement moments.

*Self-management behavior.* Measures of self-management behavior included frequency of exercise, cognitive symptom-management, and communication with a physician. We used measurement scales developed by Lorig et al., which were slightly adapted to account for cultural differences [20]. The frequency of four different types of exercise were measured (walking, swimming, cycling and other types of exercise), with a translated and adapted version of the Lorig et al. "physical activities" [20]. We did not include the questions about frequency of 'stretching and strengthening exercises', 'aerobic exercise with equipment (such as a stair master, a health rider, etc.)', and 'other aerobic exercise' because we assumed that our older respondents would not be familiar with these exercises.

The frequency of exercise refers to the total number of minutes spent on exercise each week, and this was measured at all three measurement moments.

Cognitive symptom-management was measured with a translated and adapted version of the Lorig et al. “Coping with symptoms” [20]. Two questions were left out: ‘When you are feeling down in the dumps, feeling pain or having other unpleasant symptoms, how often do you try to feel distant from the discomfort and pretend that it is not part of your body’ and ‘When (...) don’t think of it as discomfort but as some other sensation, such as a warm, numb feeling’, because it was expected that our respondents would not be familiar with these descriptions. The adapted scale consists of five items ( $\alpha = .71$ ) and measures whether participants, when feeling depressed or experiencing pain or other symptoms, used techniques such as distraction, breathing exercises, guided imagery, progressive muscle relaxation, or positive thinking. This is scored on a 6-point Likert scale of the dimension never/always, a higher score indicating more use of cognitive symptom-management techniques. Cognitive symptom-management was only measured at the post-intervention measurement moments, because it was expected that our older respondents would not have been familiar with these techniques at baseline.

Communication with a physician was measured with a Dutch translation of the Lorig et al. “Communication with physician” [20]. The scale contains three items, asking whether participants, when visiting a physician, prepare a list with questions, ask questions about things they want to know or do not understand, and discuss personal problems. This is scored on a 6-point Likert scale of the dimension never/always. The score is the mean of the three items. The internal consistency was  $\alpha=.65$ . A higher score indicates better communication with a physician. Communication was measured at all three measurement moments.

*Health status.* Health status was measured with the RAND-36 [21]. In order to reduce the number of statistical comparisons, only the physical and mental component summary scales of the Dutch version of the RAND 36-item Health Survey were used [21;22]. The physical component is a composite of the sub-scales physical functioning, role limitations (physical problem), bodily pain, and general health. The internal consistency of this overall scale was  $\alpha=.77$ . The mental component is a composite of the sub-scales vitality, social functioning, role limitations (emotional problem), and mental health. The internal consistency of the overall mental scale was  $\alpha=.72$ . The higher the score on both scales, the better the physical and mental health condition. Health status was measured at all three measurement moments.

#### *4.2.4 Statistical Analyses*

First, *t*-tests, Chi-square tests and Mann-Whitney tests were performed to compare the demographic characteristics and the baseline scores of the intervention group and the control group. One-way between-groups analyses of covariance (ANCOVA) were then performed to compare the intervention group with the control group.

Baseline score and gender were used as covariates, and block (1-6) was used as a factor. Because the severity of the disease might have influenced the results, baseline physical functioning and type of disease were used as control variables. Since only a few people had a heart disease ( $n=8$ ), and a heart disease in this older population is often caused by diabetes, heart condition was combined with diabetes. Thus, type of disease was represented by two dummy variables, one for arthritis and one for lung disease. Preliminary checks were made to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, or reliable measurement of the covariates. Correlations of the baseline scores and both post-intervention measurement scores of the various outcome variables ranged from 0.55 to 0.80.

In view of the directionality of the research hypotheses, i.e., the results for the experimental group were expected to be better than for the control group, one-tailed tests were carried out. The level of significance was  $\alpha=0.05$ . The analyses were performed in SPSS 12.0.2.[23].

### **4.3 Results**

#### *4.3.1 Subjects*

Of the 361 patients who were personally invited to participate in the outpatient clinic, 94 (26%) agreed to participate. Another 50 were recruited through public announcements. Of the 144 patients who were included in the study, 136 completed the first post-intervention measurement (T1). Of these, 50% ( $n=68$ ) had been assigned to the intervention group. As shown in Table 4.1, no significant differences in the basic patient characteristics were found at baseline between the intervention and the control group. No group differences were found on any of the measurement scales (not shown in Table 1).

Table 4.1 Patient characteristics

Variable	Intervention			Control			P- value*
	N (%)	M (SD)	range	N (%)	M (SD)	range	
N	68			68			
Age		68.2 (6.0)	59-84		68.5 (6.6)	59-87	.775
Gender							1.0
Male	25 (36.8)			25 (36.8)			
Partner	45 (66.2)			40 (58.8)			.376
Disease							.375
Diabetes	23 (33.8)			21 (30.9)			
Lung disease	22 (32.4)			16 (23.5)			
Arthritis	20 (29.4)			26 (38.2)			
Heart disease	3 (4.4)			5 (7.4)			

\* P-value of t-tests, Chi-square tests, or Mann-Whitney test

Figure 4.1 is a flow diagram of the drop-out of participants. As can be seen, relatively few patients dropped out after inclusion. Of the eight patients who did not complete the first post-intervention questionnaire, two withdrew from the study after randomization. This concerned a couple that had been assigned to the intervention group, and the husband had suffered a heart attack. Six patients in the control group did not return the first post-intervention questionnaire: one patient had died, one wrote to say that the study did not meet her expectations, and four gave no specific reason. Five of the drop-outs had diabetes, two had arthritis, and one had a lung disease. The eight drop-outs did not differ significantly from the other participants at baseline.

Seven patients (six in control group and one in the intervention group) did not complete the second post-intervention questionnaire, leaving 129 participants in the study (67 in the intervention group and 62 in the control group). Of the six drop-outs in the control group, one had developed a brain tumor and was unable to complete the questionnaire, one had died, and four persons gave no specific reason. One patient in the intervention group did not complete the questionnaire because she no longer thought it was of any use. Of these seven drop-outs, four had diabetes, two had a lung disease, and one had a heart disease. At T1 these drop-outs had returned their questionnaire significantly later than the other participants ( $Z=-3.269$ ,  $p=.001$ ), and had a significantly lower score for the physical functioning component of the RAND-36 ( $Z=-2.546$ ,  $p=.011$ ). The drop-outs also had a significantly lower score for exercise ( $Z=-2.695$ ,  $p=.007$ ), but a

significantly higher score for cognitive symptom-management ( $Z=-2.138$ ,  $p=.033$ ).

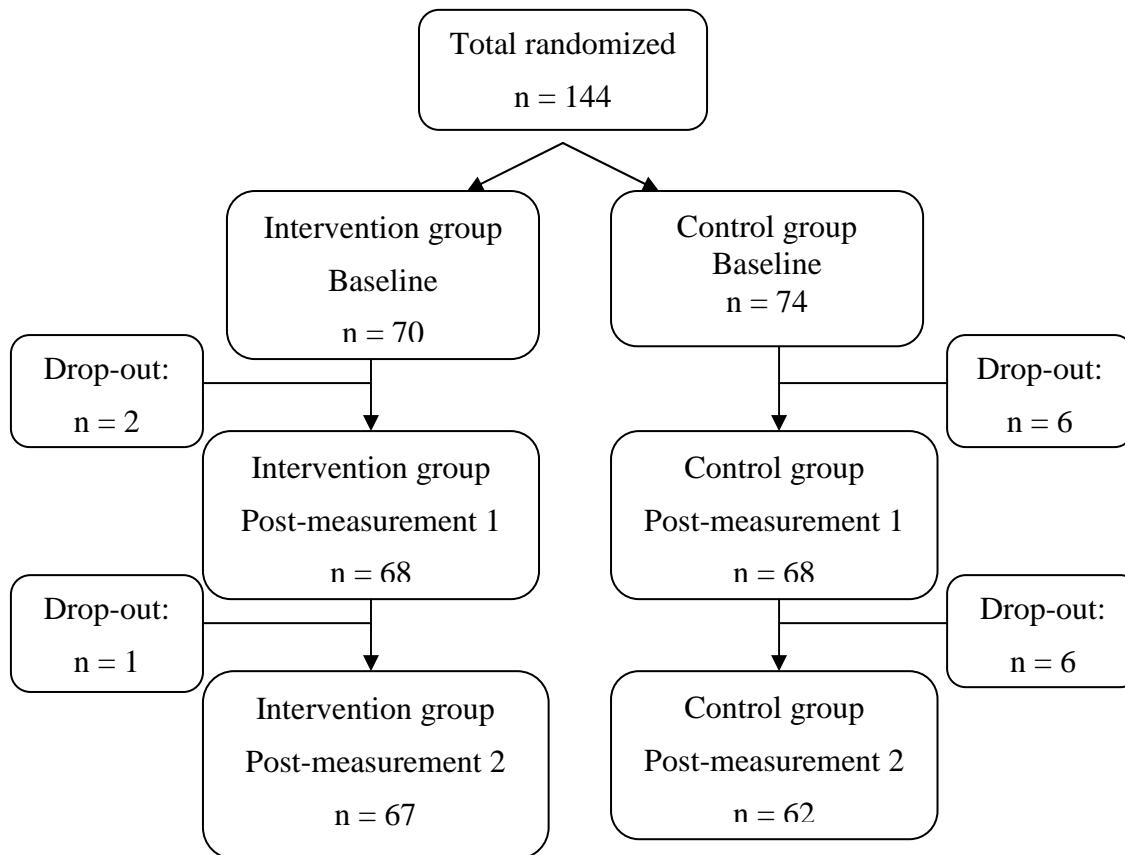


Figure 4.1 Enrolment procedure (H = hospital and O = other ways of recruitment)

#### 4.3.2 Subjective evaluation of the intervention

The participants in the intervention group attended, on average, 5.6 of the 6 course meetings. All the participants finished the course, except for one patient, who dropped out after four sessions because of transportation problems. The patients in the intervention group were also asked, by means of a short questionnaire, to evaluate the intervention (Table 4.2). In general, the participants were very enthusiastic about the course and the associated patient book. The course was scored with an average of 8.5 points (scale 0-10). As shown in Table 2, most of the participants indicated that they enjoyed the course, and that they thought that it was useful. The majority of the participants thought that the patient book was clearly written, and read it on a regular basis. They were satisfied about the way in which the course was prepared and taught, and they were also content with the length of the meetings, the size of the group,

and the meeting rooms. However, about 25% of the participants found that the course was strenuous.

In the questionnaire, some space was left for remarks. Some remarks were made, most of which were positive. One patient stated that she had become more self-confident by participating, and another found that participation had helped her to accept her disease. There were also a few critical remarks. Some patients thought that the course included too much information, and one patient even suggested adding two more sessions to the course.

Table 4.2 Subjective evaluation made by patients in the intervention group (percentage of patients who gave a certain answer; n=70)

<b>Question</b>	<b>Agree</b>	<b>Slightly agree</b>	<b>Neither agree nor disagree</b>	<b>Slightly disagree</b>	<b>Disagree</b>
I enjoyed participating in the course	88.6	7.1	1.4	2.9	-
Participating in the course was useful	75.7	17.1	4.3	2.9	-
The patient book was clearly written	94.3	4.3	1.4	-	-
I read the patient book on a regular basis	67.1	24.3	4.3	1.4	2.9
Participating in the course was strenuous	5.7	25.7	17.1	4.3	47.1
The length of the meetings was good	81.4	14.3	4.3	-	-
I had enough opportunities to speak	87.1	10.0	2.9	-	-
The size of the group was good	97.1	2.9	-	-	-
The leaders prepared the meetings well	97.1	2.9	-	-	-
I liked the way the course was taught	94.3	5.7	-	-	-
The meeting rooms were easily accessible	75.7	14.3	5.7	2.9	1.4
The meeting rooms were pleasant	72.9	17.1	7.1	1.4	1.4

### 4.3.3 Self-efficacy

Table 4.3 shows the baseline, 6-week, and 6-month scores for self-efficacy, self-management behavior, and the two composite scales for health status, i.e., physical status and mental status. After adjusting for the covariates and factor mentioned earlier, there were no significant differences in self-efficacy between the intervention group and the control group at T1 [ $t(124)=1.37, p=.09, \text{partial } \eta^2=.02$ ] or at T2 [ $t(117)=1.55, p=.06, \text{partial } \eta^2=.02$ ].

### 4.3.4 Self-management behavior

No significant differences in exercise were found between the intervention group and the control group at T1 [ $t(122)=-1.58, p=.06, \text{partial } \eta^2=.02$ ] or at T2 [ $t(110)=-.08, p=.47, \text{partial } \eta^2=.00$ ].

Because there was no baseline measurement of cognitive symptom-management, the baseline score could not be used as a covariate. No significant differences in cognitive symptom-management were found between the intervention group and the control group at T1 [ $t(124)=-1.42, p=.08, \text{partial } \eta^2=.02$ ] or at T2 [ $t(117)=-1.09, p=.14, \text{partial } \eta^2=.01$ ].

There were also no significant differences in communication with a physician, between the intervention group and the control group at T1 [ $t(124)=-.298, p=.38, \text{partial } \eta^2=.001$ ] or at T2 [ $t(117)=-.05, p=.48, \text{partial } \eta^2=.00$ ].

### 4.3.5 Health status

With regard to the physical component summary scale, no significant differences were found between the intervention group and the control group at T1 [ $t(124)=-.55, p=.29, \text{partial } \eta^2=.002$ ] or at T2 [ $t(115)=-.137, p=.45, \text{partial } \eta^2=.00$ ]. There were also no significant differences in the mental component summary scale at T1 [ $t(124)=.39, p=.35, \text{partial } \eta^2=.001$ ] or at T2 [ $t(115)=-.11, p=.46, \text{partial } \eta^2=.00$ ].



Table 4.3 Baseline, 6-week, and 6-month scores in the intervention group and the control group for self-efficacy, self-management behavior and health status, and the effect sizes (Cohen's *d*)

Variable	Baseline (T0)		6-weeks (T1)		6-months (T2)		Effect sizes	
	Intervention	Control	Intervention	Control	Intervention	Control	T1	T2
N	68	68	68	68	67	62		
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	Cohen's d (95% CI)	Cohen's d (95% CI)
Self-efficacy	57.5 (10.6)	56.4 (10.9)	57.1 (10.8)	58.0 (11.2)	56.6 (10.8)	58.4 (12.2)	-.08 (-.41, .25)	-.16 (-.49, .17)
Self-management behavior								
Exercise	170.6 (112.5)	160.8 (118.8)	192.5 (116.9)	170.7 (117.5)	191.0 (119.7)	182.5 (121.4)	.19 (-.15, .53)	.07 (-.26, .40)
Cognitive symptom- management	-	-	2.1 (0.9)	1.9 (1.0)	2.0 (0.9)	1.8 (0.9)	.21 (-.01, .55)	.22 (-.01, .56)
Communication	2.2 (1.1)	2.6 (1.3)	2.4 (1.2)	2.5 (1.3)	2.6 (1.3)	2.8 (1.2)	-.08 (-.41, .25)	-.16 (-.49, .17)
Health status								
Physical component	35.4 (10.9)	36.8 (10.5)	36.3 (10.5)	35.3 (10.6)	35.0 (10.0)	35.8 (11.1)	.10 (-.23, .43)	-.08 (-.41, .25)
Mental component	46.8 (10.1)	48.0 (9.9)	47.4 (10.6)	48.0 (9.5)	45.8 (10.5)	46.6 (12.6)	-.06 (-.39, .27)	-.07 (-.26, .40)



#### 4.4 Discussion

In this study we evaluated the short-term and longer-term effects of the CDSMP among chronically ill older people in the Netherlands. Based on studies carried out in other countries, we expected to find at least some effects of the CDSMP on self-efficacy, self-management behavior and health status. The patients in the intervention group were very enthusiastic about the program, and drop-out was low. However, with regard to the core variables in this study, no short-term or longer-term differences were found between the intervention group and the control group. It should be noted that in almost all of the other studies in which the CDSMP was evaluated only *p*-values were reported, without the effect sizes. When computed, the effect sizes in those studies appear to be quite small (0.02-0.50), and comparable to the effect sizes found in our study. This indicates that the present study, although not supporting any effects, is not a contradiction of earlier findings.

The fact that we did not find any significant effects may, however, be an important result, because our study seems to be one of the first to find no significant effects at all of the CDSMP. As Rosenthal has stated, it is very difficult to get articles reporting no significant effects accepted for publication: "...the probability of publication is increased by the statistical significance of the results so that published studies may not be representative of the studies conducted (page 128; [24])". This implies that also the non-significant results of the present study are important and informative.

Nevertheless, how can it be explained that we did not find any significant effects? First of all, there could be a cultural explanation. It could be that the CDSMP, which was developed in the USA, is basically not appropriate for the cultural background and ways of coping with chronic diseases in our study population. What contradicts this argument is that, as became clear when we translated the program into Dutch, we only had to make a few minor cultural adjustments, namely with regard to advance directives. Moreover, the participants in our study made only a few critical remarks about the content of the course. In fact, these remarks concerned topics that were not included (for example sexuality) instead of topics that were unsuitable or redundant. Thus, in our opinion, the cultural differences are so small that these are unlikely to have influenced our results. Nevertheless, future research is needed to support our findings and to exclude a possible cultural reason for the absence of effects of the program.

A second explanation might be that our patients already had a high baseline level of self-efficacy and health status, causing ceiling-effects. The participants



were expected to make their own way to the hospital on six occasions, since no transportation was provided. This may have demanded a certain level of (physical) functioning, which could have caused a ceiling-effect, indicating that the participants already had a high level of functioning and there was therefore little room for improvement. There may have been a ceiling-effect with regard to self-management knowledge, i.e., because the participants already knew a lot of the information that was taught in the course, because in the Netherlands chronically ill patients do not usually only see a physician, but also a specialized nurse who gives them a lot of information about various aspects of self-management.

A third possible explanation for not finding any significant effects of the program may be the fact that we did not use all of the questionnaires that were used in the other CDSMP evaluation studies. For two of the core outcomes, self-efficacy and health status, we used different measurement instruments. We decided to do so for two reasons. First, we wanted to be able to compare our study results with the results of other self-management studies, both in the Netherlands and abroad. Therefore, we needed to apply widely used and commonly accepted measurement instruments with sound psychometric properties. The second reason was that at the moment when we started to collect the data it was uncertain which of the Lorig et al. self-efficacy scales that were used in former CDSMP studies would be the most appropriate. Therefore, we decided to use a general scale for self-efficacy that is widely used in health-related research. However, as became clear during the study, “general” self-efficacy might have been a too broad concept to measure the specific self-efficacy beliefs of patients with chronic diseases. In order to obtain more insight into this possible problem, as a post hoc procedure after the end of the official data-collection we asked our study participants to complete the most recent self-efficacy questionnaire that Lorig et al. had used (the 6-item scale “Confidence about doing things”,  $\alpha = .93$ ). It was expected that due to participation in the course the intervention group would score higher on this specific self-efficacy measure than the control group. Fifty-six participants in the intervention group were compared to 50 in the control group. However, no significant differences were found between the two [ $t(94)=1.197$ ,  $p=.12$ , partial  $\eta^2 = .02$ ], indicating that our choice of self-efficacy measure did not necessarily caused the lack of effects. We doubt that our measurement of health status contributed to the lack of effects, because the RAND-36 is a commonly used, reliable, and valid questionnaire.



A fourth explanation might be that with regard to some of the variables in this study, the control group improved, though not significantly more than the intervention group. It was expected that the control group would remain stable or deteriorate on most outcomes. The improvement in the control group might have been due to the fact that there was a selective drop-out between T1 and T2. Most of these drop-outs were patients in the control group who had a lower level of physical functioning. Therefore, the controls who still participated at T2 might have been patients whose physical functioning was better, making it harder to find differences between the intervention group and the control group. The improvement in the control group might also have been caused by a Hawthorne effect, i.e., participating in a study and filling in a questionnaire three times might have caused patients in the control group to feel better [25]. The improvement in the control group could also have been caused by reactivity of measurement, i.e., patients in the control group became more conscious of the self-management behavior associated with a chronic disease by filling in the questionnaires. As a consequence, they might have adopted such behavior more often, and this also might have led to an improvement in other variables [25]. An additional explanation could be that the patients in the control group received care-as-usual, while in a great majority of the other CDSMP studies there was a waiting-list control group. In other words, the controls in our study knew that filling in the questionnaires was all that they could expect, whereas people in a waiting-list control group might think that they would forfeit participation in the course if they improved too much.

A fifth explanation could be that some of our patients were selected from the files of physicians in an outpatient clinic, and subsequently personally invited to participate by one of the researchers, while in most of the other CDSMP studies the patients were recruited through public announcements. It is possible that patients who took the initiative to apply for participation were more motivated than patients who participated because they were invited. However, when comparing our participants from an outpatient clinic with participants who applied on their own initiative, no differences were found in any patient characteristics or outcome variables.

Finally, an explanation that never can be excluded, especially for this rather small sample, is chance. It should be remembered that non-significance does not mean evidence for equality of the intervention and the control groups, but merely the lack of convincing evidence for the intervention group to be better than the control group. This is in line with the fact that the estimated effect sizes found in this study were in line with effect sizes that were inferred from earlier



studies with bigger samples that did find significant results.

Some limitations of our study should be mentioned. First, due to difficulties we encountered in recruiting patients for this study, the target of 200 participants was not reached. However, the achieved sample size ( $n = 144$ ) is large enough to give 80% power to detect a medium difference between two independent sample means when calculated with one-tailed tests and  $\alpha = .05$  [26]. The number of participants in the other CDSMP studies ranged from 430 to 683, so our sample size is clearly smaller, but otherwise our sample is comparable to that of other studies with regard to age, gender and marital status.

A second limitation could be the measurement moments chosen for this study (i.e., six weeks and six months after the end of the course). Other CDSMP studies had measurement moments ranging from six months to two years. It is possible that a period of six months was too short for the program to be effective and to observe improvements in this sample of chronically ill older patients in the Netherlands. It might also be too short a period to detect a response shift, i.e., a change in internal standards for a chronic disease. Future research should take this into consideration.

In conclusion, our study did not yield any evidence for the effectiveness of the CDSMP in chronically ill older patients in the Netherlands. Because the patients in the intervention group were very enthusiastic about the course, which was also indicated by a very high participation rate and very low drop-out, it seems too early to conclude that the program is not beneficial for these patients. Future research should concentrate on the further evaluation of the CDSMP.



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# 5

## **Is self-efficacy the only self-management ability that is addressed in the Chronic Disease Self-Management Program?**

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Submitted

## **Abstract**

### **Background and Aims**

In a Dutch study of the CDSMP among chronically ill older people no effects were found on self-efficacy, health behavior or health status. Positive subjective evaluations made by the participants might, however, indicate that other general self-management skills or abilities were addressed, and this may have positively influenced subjective well-being. This study investigates whether the CDSMP addresses other self-management skills, in addition to self-efficacy, and whether these skills affect the subjective well-being of chronically ill older people in the Netherlands.

### **Methods**

From 136 participants, aged 59 or older and with a chronic disease, data were collected on demographic characteristics, self-management abilities, and subjective well-being.

### **Results**

No effectiveness of the CDSMP was found on any other self-management abilities than self-efficacy, or on subjective well-being.

### **Conclusions**

It is possible that the content of the intervention was too implicit with regard to these other self-management abilities. It might also be that we included patients who had little room for improvement.

## 5.1 Introduction

It has been widely acknowledged that a chronic disease usually affects all aspects of functioning and well-being [1-13]. Because the number of chronically ill older people in the Netherlands, as in other Western societies, is increasing, the number of older people experiencing such disease-related problems will also increase [14;15].

The current focus of the Dutch health care system is on acute care and on cure, and therefore treatment is usually aimed at correcting biological abnormalities and preventing overall deterioration [16-18]. It may, however, be questioned whether this system is sufficiently responsive to chronically ill patients who have complex and continuing needs. Moreover, the number of chronically ill older people is increasing while cut-backs in health care are also increasing, so there is a growing burden on the health care system [19].

Self-management programs can be an important addition to the care that is currently provided for chronically ill patients, because these programs also focus on other aspects of functioning and well-being, and not only on the physical aspects. Moreover, these programs are cost-effective, because they stimulate patients to manage their disease themselves as much as possible. As a consequence, the burden on the health care system may decrease.

An example of a self-management program that focuses on the management of other aspects of functioning and well-being, in addition to the physical aspects, is the Chronic Disease Self-Management Program (CDSMP), developed by Lorig et al., which is already well-known and has been implemented in many countries [20-23]. The CDSMP is based on the self-efficacy theory, and incorporates the following strategies that are known to enhance a sense of personal efficacy: guided mastery of skills through weekly action-planning and feedback of progress; participants modeling behavior and problem-solving for each other; social persuasion through group support and guidance for individual self-management efforts; re-interpretation of symptoms by giving many possible causes for each symptom as well as several different management techniques; group problem-solving; and individual decision-making. The program includes: exercise; use of cognitive symptom-management techniques; information on nutrition; fatigue-management; information on the use of medication; management of emotions; communication; problem-solving; and decision-making [24].

In evaluations of the CDSMP that have been carried out in the USA and China, the program has been found to be effective in maintaining and improving

self-efficacy, self-management behavior, and health status, while decreasing health care utilization, although this was not consistently found in all studies [20-22]. However, in a Dutch replication study among chronically ill older people no effects were found [25]. This is strange, but the results of previous studies were not unambiguous. Nevertheless, the subjective evaluations made by the people in the intervention group were very positive, and their rate of attendance was high. The participants stated that they knew better how to (self-) manage their disease, and that they “felt better”. Knowing better how to (self-) manage a disease seems to indicate better self-management skills or abilities. This is enhanced by the fact that the CDSMP is unique in that it is not disease-specific, but aimed at more general aspects of living with a chronic disease. It is therefore possible that, in addition to self-efficacy, other general self-management skills or abilities were addressed in the program, but that these were not measured in the replication study. Participants in the CDSMP also stated that they “felt better”. It might therefore also be possible that the CDSMP adds something to what could be called “subjective well-being”. Moreover, it may be that knowing better how to (self-) manage a disease leads to enhanced subjective well-being.

The main aim of the present study was to investigate whether the CDSMP possibly enhances self-management abilities other than self-efficacy, and whether it improves subjective well-being, and also to study the relationship between those two in a sample of people aged 59 or older in the Netherlands with one or more chronic diseases. The short-term and longer-term effects were studied, comparing an experimental group with a control group.

### *5.1.1 Theoretical background*

In order to find out whether and, if so, how the CDSMP may lead to enhanced self-management abilities and subjective well-being, there is a need for a theory that specifies which self-management abilities are needed to achieve well-being, and how well-being is achieved. A theory that meets these criteria is the theory of self-management of well-being (SMW; [26]). This theory specifies not only the self-management abilities that are needed to achieve well-being, but also the pathways through which these abilities lead to well-being. The SMW theory is based on the Social Production Function theory (SPF), a theory about how people achieve and maintain overall well-being [27]. To summarize, according to the SPF theory, overall well-being is achieved through physical and social well-being, which again can be achieved through the attainment of lower-order goals, i.e., physical well-being through stimulation and comfort, and social well-

being through status, behavioral stimulation and affection [27-29]. The SMW theory assumes that people not only need external resources to “produce” the dimensions of well-being (e.g., a friend for affection or a comfortable house for comfort), but also “internal” resources, i.e., self-management abilities, by which they are able to manage their external resources adequately. People who have to face a chronic illness or age-related losses, may become at risk of losing important external resources for their physical and social well-being [30;31]. Therefore, for these people it becomes especially important that they have adequate self-management abilities to maintain their external resources in the best possible way.

The SMW theory specifies six key self-management abilities (SMAs) that are needed for the adequate management of resources for both the physical and social dimensions of well-being and, thus, for overall well-being. The six SMAs are: *self-efficacy beliefs*, i.e., feeling competent about being able to ‘produce’ the dimensions of well-being; *having a positive frame of mind*, i.e., a positive perspective with regard to future resources for well-being; *taking the initiative*, i.e., being instrumental in obtaining the resources needed to achieve the dimensions of well-being; *investment behavior*, i.e., providing reserves and obtaining future resources; taking care of a *multifunctionality* of resources and activities in order to achieve different dimensions of well-being at the same time; and achieving and maintaining a *variety* of resources, i.e., having more than one resource or ability to achieve a specific dimension of well-being. Note that the self-management abilities are explicitly linked to the five dimensions of well-being as specified in the SPF theory. Research has shown that SMA, in general, and also most of the individual SMAs can be enhanced in physically and/or socially frail older people in the short-term and the long-term by SMA interventions, and that this has a positive influence on overall well-being [30-32].

When analyzing the content of the CDSMP according to the SMW theory, it may be assumed that the CDSMP enhances all of the six SMAs. In addition to self-efficacy, the other SMAs could be enhanced by the CDSMP as follows: (a) having positive frame of mind: one of the cognitive symptom-management techniques is “positive self-talk”, so the participants learn to change their negative thoughts into positive ones; (b) taking the initiative: participants are encouraged to be proactive, to do the things they want to do and can do; (c) investment behavior: as the title of the patient book “Living a healthy life with chronic conditions” already says, the core of the message of the CDSMP is trying to lead as normal a life as possible, despite a chronic disease (for

example, participants are encouraged to invest in healthy behavior, such as exercise and healthy eating); (d) multifunctionality: in the CDSMP there is emphasis on combining business with pleasure (for example, when you walk for exercise you can do this with a friend, so walking serves two goals: a physical and a social goal); (e) variety: participants are encouraged to search for multiple ways in which to achieve their goals.

Based on these considerations, we expect that the CDSMP will enhance not only self-efficacy, but possibly all six SMAs. Although no effect on self-efficacy was found in the Dutch CDSMP replication study [25], it is possible that an effect on self-efficacy could be found if a different questionnaire was used.

## **5.2 Methods**

The procedures, research risks, and associated safeguards for this study were approved by the Independent Review Board of the University Medical Center Groningen.

### *5.2.1 Subjects*

In the period between May 2003 and May 2004, patients attending the Internal Medicine outpatient clinic at the University Medical Center in Groningen were personally invited to participate in the study. Participants were also recruited through announcements in the media and in the magazines of various patient associations. Eligibility criteria were: age 59 or older; angina pectoris or heart failure, COPD or asthma, or arthritis, or diabetes; ability to communicate adequately in Dutch; availability to attend a six-week course. Patients with a life-expectancy of less than one year, or already attending a disease-specific self-management program, or participating in another study, or who were permanent residents of a nursing home were excluded from the study. Patients with other diseases in addition to a heart disease, lung disease, arthritis, or diabetes were also eligible for participation.

Informed consent was obtained from patients who were eligible and willing to participate in the study. Each time informed consent was obtained from twenty-five patients, which took about four months, they were sent a baseline questionnaire. After the patients returned the questionnaire they were randomized: within each diagnostic group (i.e., disease group) the participants were assigned either to the intervention group or the control group. In this way, six consecutive blocks of about twenty-five people with various diseases were

formed during the inclusion period, with equal numbers in the intervention group and the control group. The intervention group received the CDSMP, and the control group received care-as-usual. After the last measurement, the control group also received the patient book that was used in the intervention.

### *5.2.2. Intervention*

The program consisted of 6 weekly sessions, each with a duration of 2½ hours, at the University Medical Center in Groningen. There were 10-13 participants in each training group with two leaders who adhered to a detailed manual [33]. For practical reasons, and because a study carried out by Lorig et al. showed that there were hardly any differences between lay-taught and professional-taught courses [34], all courses were led by the primary investigator (HE), who is an MA psychologist and educated as a CDSMP Master Trainer at Stanford University, and a peer leader or other Master Trainer (psychologist, PhD). The program is based on the self-efficacy theory [35]. Self-efficacy refers to people's beliefs in their abilities to adopt specific behavior, which is a key factor in behavior change and health functioning [36]. The program incorporates strategies to enhance self-efficacy: weekly action-planning and feedback, participants modeling behavior and problem-solving for each other, re-interpretation of symptoms, group problem-solving, and individual decision-making [22]. The participants received a Dutch translation of "Living a Healthy Life with Chronic Conditions", a patient book that is used in the program, and can also be used by patients as a reference book [24]. In the translation of the course manual and the patient book, only a few minor cultural adjustments were made, namely with regard to advance directives.

### *5.2.3 Measures*

Data were collected through self-administered questionnaires that were mailed to the patients three weeks before the course started (T0), immediately after the course had finished (T1), and six months after the end of the course (T2). The data included gender and age, marital status and primary disease.

*Self-management abilities (SMAs).* Self-management abilities were measured with the Self-Management Ability Scale (SMAS-S; [37]). The SMA-S is a self-report questionnaire that measures SMAs in older people, and consists of six sub-scales (i.e., the six SMAs), with five items for every sub-scale. It measures SMA as an overall concept of abilities systematically linked to dimensions of well-being, as described in Lindenberg's Social Production

Function (SPF) theory [27]. An example of an item in the sub-scale “taking initiative” which is related to affection is: “How often do you take the initiative to get in touch with people who are dear to you?” An item in the sub-scale “variety” which is related to stimulation is: “How many hobbies or activities are you involved in on a regular basis?” However, “having a positive frame of mind” is not directly related to specific dimensions of well-being, because it is considered to be a more general cognitive frame. All sub-scale scores are transformed to a 100-point scale, with the sum of the items of the sub-scales as the sub-scale score, and the average of the six sub-scales as the total SMA score. A higher total SMA score indicates higher SMAs. The internal consistency was 0.89 for the overall scale, and 0.65-0.83 for the sub-scales.

*Well-being.* In this study overall well-being was measured by means of both positive and negative indicators. The 15-item version of the SPF-Index Level Scale (SPF-IL) was used to measure overall well-being [38]. The SPF-IL is a multidimensional instrument that measures the five goals (i.e., affection, behavioral confirmation, status, comfort, and stimulation) that enable people to achieve well-being. The short-version consists of 15 items, three per goal, scored on a 4-point Likert scale of the dimension always/never. The sum of the items of the sub-scales is the sub-scale score and the sum score of all sub-scales is the total score. A higher score indicated greater well-being. The internal consistency was 0.80 for the overall scale, and 0.68-0.81 for the sub-scales.

Positive and negative affect were measured with a short version of the Positive and Negative Affect Schedule (PANAS; [39;40]). This version consists of 5 positive and 5 negative adjectives, scored on a 5-point Likert scale of the dimension not at all/very much, a higher sub-scale score indicating a greater positive or negative affect. A reliability analysis showed that the internal consistency for the positive affect scale was rather low ( $\alpha=0.63$ ). Leaving out one item (i.e., “feeling excited”) increased the reliability ( $\alpha=0.70$ ). The internal consistency for the negative affect scale was 0.88.

Depression was measured with the 10-Item Geriatric Depression Scale (GDS-10; [41]). The GDS-10 consists of 10 items, which are scored either yes or no. For seven of the questions a “yes” answer is a positive score, indicating depression; in the remaining three a “no” answer is positive. The scores are summed to give a total of 0-10, a higher total score indicating more depression. The internal consistency of the scale was 0.76.

#### *5.2.4 Statistical Analyses*

For comparisons between the intervention group and the control group at baseline, *t*-tests were used for continuous variables, such as age, and Pearson's Chi-square tests were used for dichotomous variables, such as gender. To compare the two groups with regard to disease Mann-Whitney tests were used.

One-way between-group analyses of covariance (ANCOVA) were made to compare the intervention with the control group. Treatment group (intervention/control) was used as the independent variable, block was used as a factor, and gender as a covariate. We also wanted to control for the severity of the disease, so both baseline physical functioning (as measured with the RAND-36, see [42]) and type of disease were used as control variables. Because there were only a few people who had a heart disease ( $n=8$ ), and a heart disease in this older population is often due to diabetes, heart disease was combined with diabetes. Thus, type of disease was represented by two dummy variables, one for arthritis and one for lung disease. Preliminary checks were made to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, or reliable measurement of the covariates. Correlations of the baseline scores and both post-intervention measurement scores for the various outcome variables ranged from 0.45 to 0.83.

In view of the directionality of the research hypotheses, i.e., better results for the experimental group than for the control group, one-tailed tests were carried out. The level of significance was  $\alpha=0.05$ . Analyses were performed in SPSS 12.0.2 [43].

### **5.3 Results**

#### *5.3.1 Subjects*

Of the 136 patients who completed the first post-intervention measurement, 50% ( $n=68$ ) were in the intervention group. No significant differences were found at baseline with regard to any of the patient characteristics, confirming the random allocation to intervention.

#### *5.3.2 Self-management abilities*

Table 5.1 shows baseline, 6-week, and 6-month scores in the intervention group and the control group for SMAs and well-being. At baseline, a significant



Table 5.1 Baseline, 6-week, and 6-month scores in the intervention group and the control group, the effect size of the two post-intervention measurements)

Variable	Baseline		6-weeks		6-months	
	Intervention 68	Control 68	Intervention 68	Control 68	Intervention 67	Control 62
N	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Self-management abilities	61.0 (11.7)	63.6 (10.8)	62.3 (11.1)	63.3 (12.2)	60.6 (11.9)	63.3 (11.7)
Self-efficacy	72.7 (13.6)	74.4 (11.8)	74.0 (13.4)	72.8 (13.1)	72.5 (15.0)	75.6 (14.4)
Positive frame of mind	57.4 (17.6)	66.8 (15.6)	59.0 (17.0)	64.2 (15.7)	57.8 (17.3)	62.8 (14.6)
Taking initiative	53.4 (16.6)	55.1 (13.6)	54.5 (15.4)	54.1 (15.7)	53.0 (16.1)	56.0 (14.4)
Investment	58.0 (13.2)	59.7 (13.1)	60.8 (12.1)	61.7 (14.4)	58.5 (16.7)	59.0 (15.2)
Multifunctionality	72.9 (18.7)	72.1 (20.9)	71.8 (18.4)	72.1 (22.4)	69.9 (20.8)	72.5 (18.6)
Variety	51.5 (16.5)	53.5 (16.4)	53.6 (16.2)	55.2 (16.7)	52.2 (15.8)	54.5 (17.2)
Well-being (SPF-IL)	23.5 (5.7)	23.4 (6.4)	23.9 (6.0)	24.2 (6.7)	22.2 (6.0)	24.9 (6.1)
Stimulation	5.4 (1.8)	5.5 (1.9)	5.5 (1.8)	5.8 (1.7)	5.2 (1.8)	5.6 (1.9)
Comfort	3.3 (2.1)	3.3 (2.0)	3.5 (2.1)	3.3 (2.1)	3.0 (2.0)	3.5 (2.1)
Status	3.2 (2.0)	3.1 (1.9)	3.2 (1.9)	3.4 (2.0)	3.0 (1.9)	3.4 (1.6)
Behavioral confirmation	6.2 (1.7)	6.0 (1.8)	6.1 (1.8)	6.0 (1.6)	5.8 (1.7)	6.4 (1.7)
Affection	5.4 (2.1)	5.5 (2.0)	5.6 (1.9)	5.6 (2.2)	5.2 (1.8)	5.8 (1.8)
GDS	2.7 (2.3)	2.7 (2.5)	2.5 (2.5)	2.5 (2.4)	2.7 (2.4)	2.6 (2.4)
PANAS positive affect	13.7 (1.9)	13.8 (2.9)	14.1 (2.7)	14.3 (2.5)	13.6 (3.0)	13.9 (2.9)
PANAS negative affect	11.5 (3.5)	11.8 (4.3)	11.1 (3.6)	11.1 (4.3)	11.5 (4.1)	11.5 (4.6)



difference was found with regard to positive frame of mind, in favor of the control group ( $t=-3.30$ ,  $p=0.001$ ). With respect to all variables, the 15 patients who were lost to follow-up at six-months were similar to those who remained in the study.

After adjusting for the covariates and factor mentioned earlier, no significant differences were found with regard to the mean total SMA-S score between the intervention group and the control group at T1 [ $t(124)=-0.32$ ,  $p=0.38$ , partial  $\eta^2=0.001$ ] or at T2 [ $t(116)=0.17$ ,  $p=0.43$ , partial  $\eta^2=0.000$ ]. There were also no significant differences with regard to the separate sub-scales.

### 5.3.3 Well-being

No significant difference in the total SPF-IL score was found between the intervention group and the control group at T1 [ $t(122)=0.68$ ,  $p=0.25$ , partial  $\eta^2=0.004$ ] or at T2 [ $t(114)=3.74$ ,  $p=0.00$ , partial  $\eta^2=0.109$ ]. There were no significant differences in the positive affect scale of the PANAS between the intervention group and the control group at T1 [ $t(124)=0.267$ ,  $p=0.40$ , partial  $\eta^2=0.001$ ] or at T2 [ $t(115)=0.78$ ,  $p=0.22$ , partial  $\eta^2=0.005$ ], and also no differences in the negative affect scale of the PANAS at T1 [ $t(124)=-0.46$ ,  $p=0.33$ , partial  $\eta^2=0.002$ ] or at T2 [ $t(117)=-0.26$ ,  $p=0.40$ , partial  $\eta^2=0.001$ ]. There were also no significant differences in the depression score (GDS-10) between the intervention group and the control group at T1 [ $t(123)=1.27$ ,  $p=0.10$ , partial  $\eta^2=0.013$ ] or at T2 [ $t(117)=0.28$ ,  $p=0.39$ , partial  $\eta^2=0.001$ ].

## 5.4 Discussion

In this study we evaluated the short-term and longer-term effects of the Chronic Disease Self-Management Program on self-management abilities and subjective well-being of chronically ill older people in the Netherlands. In an earlier study no effects were found on self-efficacy, which was the core theoretical basis of the program, or on self-management behavior and health status, even though the participants stated that they knew better how to (self-)manage their disease and that they “felt better” after participating. Therefore, in this study we investigated whether other self-management abilities were triggered by the program, leading to positive feelings and better subjective well-being. Based on the theory of self-management of well-being (SMW) the content of the CDSMP was analyzed in terms of other self-management abilities, in addition to self-efficacy. These other self-management abilities were: having a positive



frame of mind, taking the initiative, investment, ensuring multifunctionality, and taking care of variety. We expected to find positive effects on these self-management abilities, and subsequently on the indicators of subjective well-being, both in the short-term and the longer-term.

The results showed that no short-term or longer-term differences were found between the intervention group and the control group in any of the self-management abilities or the indicators of well-being, i.e., overall well-being, positive and negative affect, and depression. The intervention group did not significantly improve or deteriorate on these outcomes, compared to the control group.

How, then, can it be explained that, also in this study, we not only found no effects on self-efficacy, but also no effects on self-management abilities or subjective well-being? Let us first consider the self-management abilities. First of all, of course, the CDSMP was not explicitly designed to enhance any other self-management abilities than self-efficacy, although its content does seem to address these other abilities throughout the program. This may have caused the lack of effects. Three other self-management interventions that did focus explicitly on these self-management abilities, including self-efficacy, were found to have significant effects [30-32]. In those interventions the self-management abilities were not only measured as outcomes, but they were also explicitly addressed in the content of the intervention. Thus, the way in which the other abilities were addressed in the CDSMP may be too implicit.

A second explanation for the lack of effects with regard to self-management abilities could be that the intervention group and the control group differed significantly at baseline with regard to having a positive frame of mind, i.e., the control group had a significantly higher score for this ability, which could possibly have been the reason for the initial differences between the two groups. Controlling for this variable, however, did not change the results of the analyses.

A third explanation might be that our patients did not have many problems with regard to their self-management abilities. They may therefore have had little room for improvement, i.e., causing ceiling effects. A comparison of the present sample with a random sample of the general population of older people aged 65 years and older in the Netherlands (N=1338; [37]) underscores this possibility: our patients had similar scores on all six self-management abilities at baseline.

How can it be explained that we also found no effects on the various different indicators of well-being, even though the patients were very positive about the program? One explanation might be that, although the CDSMP aims



to teach patients self-management behavior, and thus also to improve their health and well-being, the way in which the CDSMP does this is not explicitly aimed at enhancing well-being. This becomes especially visible when considering the way in which the CDSMP teaches the patients to set and achieve goals. They are allowed to choose their own personal goals, assuming that the goals that they select will, indeed, contribute to their well-being, but whether or not they select the “right” goals, i.e., goals that enhance their well-being, is not assessed in the intervention. However, in the interventions based on the theory of SMW the self-management abilities are explicitly related to physical and social dimensions of well-being, and the patients were encouraged to select goals that directly addressed these dimensions of well-being.

A second explanation for the lack of effects on well-being might be that the baseline levels of overall well-being, positive affect, and negative affect in our patients were, again, not lower than those in a random sample of the general population of people aged 65 years or older in the Netherlands (respectively N=1338; [37] and N=439; [44]). With regard to overall well-being and positive affect this might possibly, again, have caused ceiling-effects, whereas with regard to negative affect there might have been a floor-effect. The fact that no differences were found in the scores for depression could also indicate the possibility of a floor-effect.

Some limitations of our study should be mentioned. First, we applied a self-management theory and a self-management measurement to an intervention that was not based on either. Although the intervention seemed to be in line with many aspects of this theory, and could thus help to shed more light on the working mechanisms of the CDSMP, the fit between the two is not optimal. Future studies should search for other abilities than those investigated here.

Secondly, it appears that we included chronically ill patients who, contrary to our expectations, did not experience many problems with regard to the outcome variables, as could be seen from the relatively high baseline levels. Consequently, there was little room for improvement. Although we applied clear inclusion and exclusion criteria, it might have been better to select patients who had more problems in managing their chronic disease(s). For example, as suggested in a study carried out by Fried et al. [45], it is better to select patients who do not just have one or more chronic diseases, but who are also frail and/or disabled, because the combination of frailty and/or disablement and comorbidity is much more of a problem than “only” comorbidity. The intervention might have been more effective for such patients, so future research should take this into consideration.



## **5.5 Conclusions**

Although the patients who participated in the CDSMP stated that they knew better how to (self-) manage their disease, and that they “felt better” after participating, our study yielded no evidence for the effectiveness of the CDSMP on self-management abilities other than self-efficacy, or on subjective well-being. It is possible that the content of the intervention was too implicit with regard to these other self-management abilities, or that there are other self-management abilities in addition to those investigated in the present study. It is also possible that “feeling better” relates to other outcome variables than those measured in this study. Finally, it might also be that the patients who were included in the study had little room for improvement.



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# 6

## **The effect of a self-management intervention on health care utilization in a sample of chronically ill older people in the Netherlands**

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## **Abstract**

### **Background and Aims**

The combination of an increasing number of chronically ill patients and increasing cutbacks in health care will result in a growing burden on the Dutch health care system. The Chronic Disease Self-Management Program (CDSMP) has been found to have a positive effect on health care utilization in the USA. The aim of the present study was to evaluate the effect of the CDSMP on health care utilization among chronically ill older people in the Netherlands.

### **Methods**

129 people aged 59 or older, with a lung disease, a heart disease, diabetes, or arthritis were randomly assigned to an intervention group (CDSMP) or a control group (care-as-usual). We collected demographic data and data on health care utilization (visits to a general practitioner, visits to a medical specialist, total visits to a physician, visits to a physical therapist, visits to a social worker, help from home care, help from unpaid volunteers, admission to hospital or to other institution).

### **Results**

A significant difference was found between the intervention and the control group with regard to home care utilization, but this effect could not be attributed to the intervention. No differences were found between the intervention and control group with regard to use of the other health services.

### **Conclusions**

In this study we found no convincing evidence for a decrease in health care utilization as a result of the CDSMP. More research is needed to investigate more thoroughly the long-term effectiveness of the CDSMP in decreasing health care utilization in the Netherlands.

## 6.1 Introduction

In the Netherlands, 42% of the health care budget is spent on patients who are 65 years of age and older [1]. Older people are often confronted with one or more chronic diseases (i.e., comorbidity; [2]). In 2002, people aged 65 years and older in the Netherlands had, on average, 1.48 diseases [3], comorbidity being associated with an increase in both the costs and the utilization of health services [1;2]. Since the Dutch population is aging, the number of chronically ill patients will also increase, and this, in combination with increasing cut-backs in health care, will result in a growing burden on the health care system [4].

Recently, the role of the chronically ill patient has been changing from a passive, care-receiving role, to a more active, self-regulating role. In this development, self-management programs play an important role, and from the literature it becomes clear that such programs can reduce health care utilization [5-17]. Multiple studies of self-management programs have demonstrated a significant reduction in visits to physicians [5-11;16;17], visits to a clinic [12], visits to hospital emergency departments [13;17], number of hospital admissions [11;17;18], duration of hospitalization [11], and total ambulatory visits [14;15].

One of the self-management programs that has been found to have a positive effect on health care utilization is the Chronic Disease Self-Management Program (CDSMP; [18-20]). In a study carried out by Lorig et al. the treatment group had fewer hospital admissions and spent fewer nights in hospital [18]. In other studies carried out by Lorig et al., the participants made significantly fewer visits to physicians and to emergency departments, during the one and two-year follow-up periods [19;20]. A Chinese study of the CDSMP also showed a significant reduction in the number of hospital admissions, and a study of the CDSMP among Hispanic patients showed a significant reduction in visits to an emergency department [21;22]. Although the above-mentioned studies show significant effects of the CDSMP on health care utilization, these effects were not consistently found in all studies of the CDSMP.

The effect of the CDSMP on health care utilization had already been evaluated in the United States and in China, but not in the Netherlands. Therefore, the aim of the present study was to evaluate the effect of the CDSMP on health care utilization among chronically ill older people in the Netherlands. Knowing from previous studies that the CDSMP can have positive effects on health care utilization, i.e., a decrease in health care utilization, we expected to find at least some effects in our sample of patients aged 59 or older with one or more chronic diseases.

## **6.2 Methods**

The procedures, research risks, and associated safeguards for this study were approved by the Independent Review Board of the University Medical Center Groningen.

### *6.2.1 Subjects*

In the period between May 2003 and May 2004, patients attending the Internal Medicine outpatient clinic at the University Medical Center in Groningen were personally invited to participate in the study. Participants were also recruited through announcements in the media and in the magazines of various patient associations. Eligibility criteria were: age 59 or older; angina pectoris or heart failure, COPD or asthma, or arthritis, or diabetes; ability to communicate adequately in Dutch; availability to attend a six-week course. Patients with a life-expectancy of less than one year, or already attending a disease-specific self-management program, or participating in another study, or who were permanent residents of a nursing home were excluded from the study. Patients with diseases in addition to a heart disease, lung disease, arthritis, or diabetes were also eligible for participation.

Informed consent was obtained from patients who were eligible and willing to participate in the study. Each time informed consent was obtained from twenty-five patients they were sent a baseline questionnaire, which took about four months. After the patients returned the questionnaire, they were randomized: within each diagnostic group, i.e., disease group, the participants were assigned either to the intervention group or the control group. In this way, six consecutive blocks of about twenty-five people with various diseases were formed during the inclusion period, with equal numbers in the intervention group and the control group. The intervention group received the CDSMP, and the control group received care-as-usual. After the last measurement, the control group also received the patient book that was used in the intervention.

### *6.2.2 Intervention*

The program consisted of 6 weekly sessions, each with a duration of 2½ hours, at the University Medical Center in Groningen. There were 10-13 participants in each training group, with two leaders who adhered to a detailed manual [23]. For practical reasons, and because a study carried out by Lorig et al. showed that there were hardly any differences between lay-taught and professional-taught courses [24], all courses were led by the primary investigator (HE), who is an

MA psychologist and educated as a CDSMP Master Trainer at Stanford University, and a peer leader or other Master Trainer (psychologist, PhD). The program is based on the self-efficacy theory [25]. Self-efficacy refers to people's beliefs in their abilities to adopt specific behavior, which is a key factor in behavior change and health functioning [26]. The program incorporates strategies to enhance self-efficacy: weekly action-planning and feedback, participants modeling behavior and problem-solving for each other, re-interpretation of symptoms, group problem-solving, and individual decision-making [18]. The program includes: exercise; cognitive symptom-management techniques; information on nutrition; fatigue-management; use of medication; managing emotions; communication; problem-solving; decision-making [27]. The participants received a Dutch translation of "Living a Healthy Life with Chronic Conditions", a patient book that is used in the program, and can also be used by patients as a reference book [28]. In the translation of the course manual and the patient book, only a few minor cultural adjustments were made, namely with regard to advance directives.

### *6.2.3 Measures*

Data were collected through self-administered questionnaires that were mailed to the patients three weeks before the course started (T0), immediately after the course had finished (T1), and six months after the end of a course (T2). The data included gender and age, marital status and primary condition.

*Health care utilization.* The Lorig et al. "Medical Care" questionnaire [29] was used for the measurement of health care utilization, supplemented with questions from Bos et al. [30]. In the questionnaire of Lorig et al., the participants were asked how many times in the past six months they had visited one or more physicians, and the emergency department of a hospital. They were also asked whether they had been admitted to a hospital, and, if so, how many days they had been hospitalized. In the Bos et al. questions that were included they were asked how many times in the past six months they had visited a general practitioner (GP), a medical specialist, a physical therapist, or a social worker. They were also asked how many times in the past six months they had received home care or help from unpaid volunteers. In addition, the participants were asked if they had been admitted to any other institution, apart from a hospital (i.e., nursing home, rehabilitation center, psychiatric hospital, or any other institution), and for how many days they had been admitted.

#### *6.2.4 Statistical Analyses*

Baseline differences between the intervention group and the control group were tested with *t* tests for continuous variables, Pearson's Chi-square tests for dichotomous variables such as gender and health care utilization (yes/no), and Mann-Whitney tests for disease.

Between-group analyses of covariance (ANCOVA) were performed to compare the intervention group with the control group with regard to the number of visits to the different health services. Treatment group (intervention/control) was used as the independent variable. Baseline score and gender were used as covariates, and block (of about twenty-five people, each with various diseases) was used as a factor. Correlations of the baseline scores and both post-intervention measurement scores on the outcome variables ranged from .31 to .67. Because the severity of the disease might have influenced the results, baseline physical functioning (measured with the RAND-36, see [31]) and type of disease were used as control variables. Since only a few people had a heart disease ( $n=8$ ), and a heart disease in this older population is often caused by diabetes, heart disease was combined with diabetes. Thus, type of disease was represented by two dummy variables, one for arthritis and one for lung disease. Preliminary checks were made to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, or reliable measurement of the covariates. In view of the directionality of the research hypotheses, i.e., expecting less health care utilization in the intervention group compared to the control group, one-tailed tests were carried out. The level of significance was  $\alpha=0.05$ , and all analyses were performed in SPSS 12.0.2 [32].

### **6.3 Results**

#### *6.3.1 Subjects*

Of the original sample of 144 patients, 129 (89.6%) completed the second post-intervention measurement. Of these, 67 (52%) were in the intervention group. No differences were found at baseline with regard to any of the patient characteristics, confirming the random allocation to treatment. The characteristics of the 15 patients who were lost to follow-up at six-months were similar to those of the patients who remained in the study with respect to demographic variables.

### 6.3.2 Health care utilization

Table 6.1 shows the number (percentages) of people who made use of the different health care services, at baseline and at 6 months. No significant differences were found between the intervention group and the control group, either at baseline or at 6 months. Because some health care services had been visited or used by only ten people or less at all measurement points, we excluded these services from further analyses. This concerned the social worker, the unpaid volunteer, the emergency department, and admission to a nursing home, rehabilitation center, psychiatric hospital, or other institution.

Table 6.2 presents the mean number of visits (SD, range) to the different health services in the intervention group and the control group at baseline and at 6 months. After adjusting for the covariates and the factor mentioned earlier, no significant differences were found between the intervention group and the control group with regard to number of visits to a GP [ $t(113)=.424, p=.336$ , partial  $\eta^2=.002$ ], number of visits to a medical specialist [ $t(115)=-.759, p=.225$ , partial  $\eta^2=.005$ ], total visits to a physician [ $t(113)=.247, p=.403$ , partial  $\eta^2=.001$ ], number of visits to a physical therapist [ $t(116)=.424, p=.336$ , partial  $\eta^2=.002$ ], and number of days hospitalized [ $t(117)=.559, p=.289$ , partial  $\eta^2=.003$ ]. With regard to home care utilization, a weak but significant difference was found between the intervention group and the control group [ $t(115)=1.716, p=.045$ , partial  $\eta^2=.025$ ]. The data showed that for the majority in both the intervention group (74%) and the control group (71%) there was no change in home care utilization, but that the significant difference was due to the combination of a decrease in utilization in the intervention group and an increase in the control group. The decrease in the intervention group was due to two people, who, at baseline, needed home care temporarily, one after rehabilitation and the other because of a broken shoulder. The increase in health care utilization in the control group was due to three patients who had a hip-operation, and therefore needed home care at T2. This difference between the intervention group and the control group with regard to home care utilization was therefore due to acute medical incidents, and not to ways of coping with a chronic disease.



Table 6.1 Percentages of people in the intervention and the control group using the different health services at baseline and at 6 months ( $p$ -values for  $\chi^2$ -tests)

Variable	Baseline			Six months		
	Intervention 67	Control 62		Intervention 67	Control 62	
<i>N</i>	N (%)	N (%)	<i>P</i> -value	N (%)	N (%)	<i>P</i> -value
General practitioner	53 (79.1)	54 (87.1)	.228	60 (89.6)	54 (87.1)	.664
Medical specialist	59 (88.1)	52 (83.9)	.493	59 (88.1)	53 (85.5)	.666
Total visits to a physician	64 (95.5)	61 (98.4)	.348	66 (98.5)	58 (93.5)	.145
Physical therapist	20 (29.9)	21 (33.9)	.624	23 (34.3)	17 (27.4)	.397
Social worker	6 (9.0)	4 (6.5)	.595	4 (6.0)	3 (4.8)	.777
Home care	20 (29.9)	20 (32.3)	.768	15 (22.4)	16 (26.2)	.612
Unpaid volunteer	3 (4.5)	3 (4.8)	.922	3 (4.5)	4 (6.5)	.621
Visits to emergency department	5 (7.5)	5 (8.1)	.898	7 (10.4)	5 (8.1)	.642
Hospital	12 (17.9)	7 (11.3)	.289	9 (13.4)	12 (19.4)	.363
Nursing home	-	1 (1.6)	.297	1 (1.5)	-	.334
Rehabilitation center	1 (1.5)	-	.334	-	2 (3.2)	.138
Psychiatric hospital	-	-	-	-	-	-
Other institution	-	-	-	-	-	-



Table 6.2 Mean number of visits (SD, range) in the intervention and the control group at baseline and at 6 months (*p*-values of t-tests)

	Baseline					Six months				
	Intervention 67		Control 62		<i>P</i>	Intervention 67		Control 62		<i>P</i> -value
<i>N</i>	M (SD)	range	M (SD)	range		M (SD)	range	M (SD)	range	
<b>Variable</b>	M (SD)	range	M (SD)	range	<i>P</i>	M (SD)	range	M (SD)	range	<i>P</i> -value
General practitioner	3.0 (2.9)	0-15	4.2 (4.9)	0-24	.082	3.1 (2.3)	0-12	4.1 (5.1)	0-26	.133
Medical specialist	2.8 (2.2)	0-10	2.2 (2.7)	0-19	.125	2.7 (2.8)	0-15	2.2 (1.7)	0-7	.200
Total visits to a physician	5.8 (3.9)	0-17	6.4 (5.7)	0-26	.482	5.8 (4.3)	0-24	6.3 (5.9)	0-29	.575
Physical therapist	6.3 (13.0)	0-52	7.4 (14.5)	0-52	.659	5.6 (11.6)	0-52	5.3 (11.8)	0-52	.861
Home care	11.3 (29.3)	0-182	11.6 (30.0)	0-182	.966	8.7 (24.7)	0-160	15.5 (41.9)	0-194	.261
Hospital admission	0.2 (0.6)	0-2	0.1 (0.3)	0-1	.081	0.2 (0.3)	0-1	0.3 (0.6)	0-3	.381
Duration of hospitalization (days)	1.3 (4.6)	0-33	0.4 (1.4)	0-7	.104	1.1 (4.4)	0-25	1.2 (2.8)	0-13	.828



In order to check whether the results might have been influenced by outliers, we decided to categorize the health care utilization. We used the categories described by Westert et al. [2], which are ordinal i.e., the first category relates to the lowest level of health care utilization, and the last category to the highest level, as follows :

1. No services used
2. Primary Care (GP and home care and/or physiotherapist; minimum of two types)
3. Medical Care (GP or medical specialist)
4. Clinical Care (GP and/or medical specialist and/or hospitalization; minimum of two types)
5. Comprehensive Care (GP and/or home care and/or physiotherapist and/or medical specialist and/or hospitalization; minimum of three types).

Table 6.3 shows the percentage of people with a higher, lower and similar level of health care utilization at six months, compared to baseline. No significant differences were found between the intervention group and the control group. This result does not confirm our expectations that health care utilization in the intervention group would decrease.

Table 6.3 Percentage of people (N) with a higher, lower and similar level of health care utilization at 6 months, compared to baseline

	<b>Intervention</b>	<b>Control</b>
Lower (difference <0)	15% (10)	2% (16)
Similar (difference =0)	61% (41)	59% (36)
Higher (difference >1)	24% (16)	15% (9)

## 6.4 Discussion

In this study we evaluated the effects of the CDSMP on health care utilization among chronically ill older people in the Netherlands. Based on studies carried out in other countries, we expected to find a decrease in health care utilization in the longer term. A significant difference was found between the intervention group and the control group with regard to home care utilization, but qualitative inspection of the data showed that this effect could not be attributed to the intervention. No effects were found with regard to visits to a GP, visits to a medical specialist, total visits to a physician, visits to a physical therapist, or number of days hospitalized.



One possible explanation for finding almost no effects, in contrast to the findings in the USA, is that the USA has a different health care system and a different health insurance policy. For example, in the Netherlands, the GP acts as gatekeeper to the health care system, and patients must be referred by a GP to all other health care services. It is therefore possible that the number of visits to a GP is relatively high in our study population.

In order to know whether the lack of effects with regard to the number of visits to the different health care services might have been caused by our specific study sample, health care utilization in our sample was compared to that in a sample of chronically ill patients aged 45 years and older in the Netherlands [3], and to the samples in previous studies of the CDSMP [18;20-22;33]. Compared to other chronically ill people in the Netherlands, the patients in our study did not differ very much with regard to visits to most of the health care services, but they visited a physical therapist less often, and were less often admitted to a hospital. Compared to the (mainly American) samples in other studies of the CDSMP, our sample was similar in health care utilization. Therefore, the lack of effects was probably not due to floor or ceiling effects.

Our study has some limitations. First, the follow-up period in our study was six months. However, a great majority of the studies investigating the effect of self-management programs on health care utilization had follow-up periods of one to three years. It could be that the period of six months in our study was too short to bring about a reduction in health care utilization, but unfortunately, measuring the effects of the CDSMP after 12 months was beyond the scope of this study. Therefore, an important recommendation for future research on the effects of the CDSMP on health care utilization is to include a follow-up period of at least one year.

Secondly, our results might be influenced by the way in which some aspects of health care utilization were measured. Certain health care services might have overlapped each other, for instance receiving physical therapy during admission in a nursing home. It might therefore be questioned whether our measurement methods were sensitive enough to measure these separate aspects of health care utilization.

Thirdly, we collected data through self-report, over a period of six months, and this can be quite a long period in which to recall all health care utilization, especially in an older population. In a study carried out by Ritter et al. [34], also with an older study population, a tendency towards under-reporting of visits to a physician was found, and also a tendency towards over-reporting of visits to an emergency department. This problem might be overcome, for example, by using



a monthly questionnaire, by asking participants to keep a diary of their health care utilization, or by checking the medical records.

To summarize, in this study we found no convincing evidence for a decrease in health care utilization as a result of the CDSMP. More research is needed to investigate more thoroughly the long-term effectiveness of the CDSMP in decreasing health care utilization in the Netherlands.



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# 7

## **Do older patients who refuse to participate in a self-management intervention in the Netherlands differ from older patients who agreed to participate?**

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Submitted

## **Abstract**

### **Background and Aims**

Refusal of patients to participate in an intervention program is an important problem in clinical trials but, in general, researchers devote relatively little attention to it. In this article a comparison is made between patients who agreed to participate in a self-management intervention (participants) and those who refused (refusers) after having been personally invited. Compared to other studies of refusers, in the present study a considerable amount of information was obtained from the refusers with regard to their personal characteristics and their reasons to refuse, because all potential participants were invited personally.

### **Methods**

Older patients from a Dutch outpatient clinic were invited to participate in a self-management intervention, and their characteristics were assessed. Demographic data were collected, as well as data on physical and social functioning. People who refused to participate were asked to give their reasons to refuse.

### **Results**

Of the 361 patients who were invited to participate, 267 (74%) refused participation. These refusers were more restricted in their mobility, lived further away from the location of the intervention and more often had a partner compared to the participants. No differences were found in level of education, age, or gender. The main reasons given by the respondents for refusing participation were lack of time, travel distance, and transportation problems.

### **Conclusions**

As in many studies, the refusal rate in this study is high, and seems to be related to physical mobility, travel distance, and social support. These findings can be used to make the recruitment process more effective, for example by offering transportation to the location of the intervention.

## 7.1 Introduction

Refusal of patients to participate in an intervention program is an important problem in clinical trials [1-3]. Many researchers have to deal with this problem, but relatively few devote explicit attention to it. Retaining a low number of participants can, among other things, threaten the statistical power of the study. If we know beforehand which patients are more likely to refuse participation, measures can be taken to encourage their participation. Why is it that so many patients who are potential participants refuse to participate in what are often well developed interventions? Are patients who refuse to participate in a self-management intervention different from the patients who agreed to participate?

As the number of older people with chronic conditions increases, the number of (randomized) clinical trials in which older participants are involved will probably also increase. These trials often concern intervention studies, aimed at evaluating self-management programs, and the demands made on participants in self-management evaluation studies are, in general, relatively large. For example, patients have to travel to a hospital on several occasions, to meet with other patients in group sessions. For many patients this may, indeed, be a burden, but we still know relatively little about which patients refuse and how they differ from participants.

Most of the literature on older patients who refuse participation concerns health promotion intervention studies. In this literature, two definitions are used for older people who do not want to participate, namely refusers [4] and non-participants [4-7]. From the literature it is also clear that people who do not want to participate are usually older [5;6;8-10], have a lower level of education [4;5;7;9], show less health- or protection-related behavior such as use of seat belts or owning smoking alarms [11], are more likely to smoke [7], have a lower level of physical or mental health [4;5;7;9;11;12], are more likely to live further away from the study location [6;8;10], are more likely to experience time constraints [5;10], and perceive more social support in everyday and problem situations [13]. The results with regard to gender are less consistent. Some studies found that refusers are more likely to be male [5], others found that they were more likely to be female [4;7] while others again found that there was no difference [6].

This article aims to add to this literature by comparing patients who refused to participate (refusers) and patients who agreed to participate (participants), after they had been invited to participate in a self-management intervention program. Because all the patients were invited personally, we were able to

gather a considerable amount of information with regard to characteristics and reasons to refuse participation.

As said before, the demands of participating in a self-management intervention are rather high. With regard to the self-management intervention described in this chapter, participation required willingness to travel to a hospital on six occasions, once a week, to meet with 10 to 15 other patients in group sessions with a duration of two and a half hours. Therefore, we first expected that people with more physical problems, such as mobility problems, or more chronic diseases, would be more likely to refuse participation. Secondly, we asked the participants to come to the location of the intervention themselves, without providing transportation. Therefore, we expected that people who lived further away would be more likely to refuse participation, because they needed more time to travel. Thirdly, during the recruitment we asked people if they would like to participate in a “course”. Therefore, because a course implies education and learning, we expected that people with a low level of education would be more likely to refuse participation, because they might be deterred by this educational aspect. Fourthly, the self-management intervention for which the patients in this study were recruited was a group intervention, and being with a group of fellow-sufferers can be a source of social support. Therefore, we expected that people who experienced a lack of support would be more likely to participate, and that people who receive enough social support will refuse participation more often. We had no expectations with regard to age, because people over 60 are rather heterogeneous with regard to physical resources and other resources: age itself is not the best predictor of functioning [14]. We also had no specific expectations with regard to gender, since we had no reason to expect to find differences between men and women in their willingness to participate in a self-management intervention. However, we did compare the groups with regard to both age and gender.

## **7.2 Methods**

The procedures, research risks, and associated safeguards for this study were approved by the Independent Review Board of the University Medical Center Groningen.

### *7.2.1 Subjects*

In the period from May 2003 to May 2004, potential participants were invited to participate in a self-management intervention program. This intervention

consisted of six weekly meetings in groups of 10-15 patients [15]. Potential participants were selected on the basis of their medical records and personally invited in four wards of the Internal Medicine outpatient clinic at the University Medical Center Groningen, i.e., General Internal Medicine, Rheumatology, Endocrinology, and Lung Diseases. Eligibility criteria were: age 59 or older; a heart disease (angina pectoris or heart failure), or a lung disease (COPD or asthma), or arthritis, or diabetes, because these are the most common chronic diseases among older people; ability to communicate adequately in Dutch; experiencing problems with regard to ways of coping with their disease; physically able to attend a six-week course. Patients with a life-expectancy of less than one year, or already attending a disease-specific self-management program, or participating in another study, or who were permanent residents of a nursing home, were excluded. Patients with other diseases in addition to a heart disease, lung disease, arthritis, or diabetes were also eligible for participation.

### *7.2.2 Procedure*

During the patient's visit to one of the four wards of the hospital, his/her physician was notified by means of a small note in the medical record that this patient was considered to be eligible for the self-management intervention, and thus eligible to be invited to participate by the primary researcher (HE). The physician then only asked the patient if (s)he had time, after the appointment, to answer some questions asked by a researcher. If the patient gave verbal consent, a short interview took place with the primary researcher. During this interview, the Groningen Frailty Indicator (GFI) questions were asked to collect as much information as possible about all patients, i.e., including the refusers [14;16]. The GFI is a short, easy-to-administer 15-item instrument that assesses four domains of functioning: basic functions (3 items), physical functioning (7 items), social functioning (3 items), and psychological functioning (2 items). Because not all eligibility criteria could be derived from the medical records, for instance whether or not the patient was experiencing problems in coping with his or her disease, or whether the patient was physically able to attend a six-week course, this information was obtained during the interview. At the end of this interview, if the patient was considered to be eligible, (s)he was invited to participate in a study on the effects of a self-management program for chronically ill older people. The patients were given information about the content of the program, for instance how to deal with fatigue or communicate with a physician, and the procedure of the study was explained, i.e., that the

participants would be randomly assigned to an intervention or a control group, and that they would have to fill in questionnaires on three occasions. Patients who refused to participate were asked, by means of an open-ended question, to give their reason. These reasons were categorized later on in the study.

### 7.2.3 Measures

In order to test our hypotheses, we used the relevant items of the GFI, i.e., those concerning physical functioning and social functioning. These items are shown in Table 7.1.

Table 7.1 Items of the Groningen Frailty Indicator (GFI) concerning physical and social functioning

<b>Physical functioning</b>	
<i>Mobility</i>	
Are you able to carry out these tasks single-handed without any help? (The use of aids such as a walking stick, walking frame, or wheelchair, is considered as independent)	
1	Shopping
2	walking around outside (around the house or to the neighbors)
3	dressing and undressing
4	going to the toilet
<i>Physical fitness</i>	
5	What score do you give yourself for physical fitness? (scale 0 to 10)
<i>Comorbidity</i>	
6	Do you take 4 or more different types of medicine?
<b>Social functioning</b>	
7	Do you sometimes experience an emptiness around you?
8	Do you sometimes miss people around you?
9	Do you sometimes have the feeling of being left alone?
Scoring:	
Question 1 – 4:	independent = 0; dependent = 1
Question 6:	no = 0; yes = 1
Question 7-9:	no = 0; sometimes and yes = 1

Each item is scored either zero (no problems) or one (problems), except for physical fitness, which has a score ranging from 0-10. The four mobility items together form a sub-scale, which yields an overall mobility score, and the three social items form a sub-scale, which yields an overall social functioning score. The data included the variables travel distance (kms), level of education (with five categories from 1=elementary to 5=university), and having a partner (yes/no). The latter variable was also used as an indicator for social support. Data on age and gender was also collected.

#### *7.3.4 Statistical Analyses*

First, the refusers and participants were compared by means of bivariate analyses. *T*-tests were used for continuous variables, such as age. The variables partner and gender, and the 1-item variables of the GFI were analyzed with Pearson's Chi-square test or Fischer's Exact test. Mann-Whitney tests were used to compare the two groups with regard to travel distance and level of education. Secondly, logistic regression analysis was used to predict refusal of participation. All analyses were performed in SPSS 12.0.2. [17].

### **7.3 Results**

#### *7.3.1 Subjects*

Of the 492 patients who had the short interview with the primary investigator, 131 (26.6%) were not considered to be eligible for the self-management intervention, and were therefore not invited to participate (Figure 7.1). The most important reasons for non-eligibility were that the patient did not experience problems in coping with the disease (n=83), or that the patient was physically unable to attend a six-week course (n=17). Other reasons were: living in a nursing home (n=3); inability to communicate adequately in Dutch (n=2); admission to a hospital or rehabilitation center (n=5); or participating in another study (n=2). During the recruitment process it became clear that certain other patients were also not eligible for participation: patients who were cognitively impaired (n=8), patients with severely impaired vision or hearing (n=5), patients with certain personality characteristics, such as being too talkative, which made them unsuitable for group sessions (n=5), and patients who had recently been discharged from a psychiatric hospital (n=1).

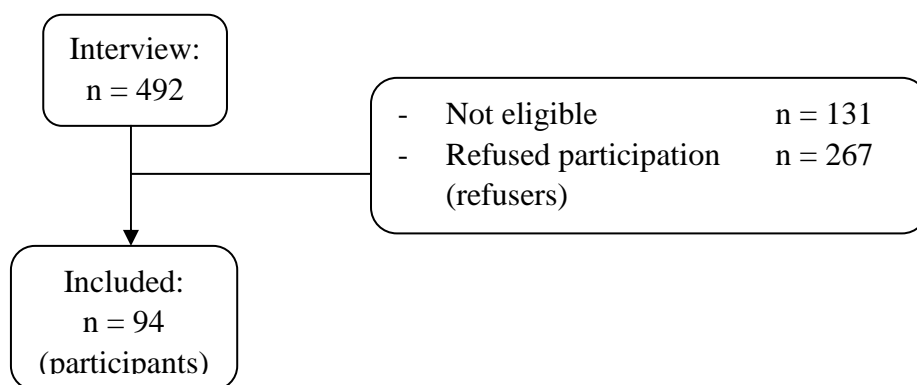


Figure 7.1 Enrolment procedure

Table 7.2 presents the characteristics of the refusers and the participants with regard to physical functioning, travel distance, level of education, partner status, social functioning, age, and gender.

Of the 361 patients who were invited, 267 refused participation (74.0%). With regard to physical functioning, there was only a significant difference in mobility between the two groups. Refusers had significantly more problems relating to mobility than the participants. No differences were found with regard to physical fitness or comorbidity. The finding concerning physical fitness is unexpected, because the refusers and the participants differed in their mobility problems.

A difference was found with regard to travel distance, i.e., refusers lived significantly further away. No statistically significant differences were found between refusers and participants with regard to education. It should be noted that the level of education of only a relatively small number of patients was known, namely 73 refusers and 72 participants. With regard to marital status significantly more refusers than participants had a partner. No differences were found with regard to social functioning, and there were also no differences between refusers and participants with regard to age or gender.

To summarize, our expectations with regard to physical problems were partly confirmed, i.e., refusers had more problems with mobility than the participants, but there were no differences in physical fitness or comorbidity. Our expectation with regard to travel distance was confirmed, i.e., refusers lived further away than the participants. However, our expectation with regard to education, was not confirmed, i.e., refusers did not have a lower level of education than the participants, and our expectation with regard to social support was only partly confirmed, i.e., more refusers had a partner.

Table 7.2 Characteristics of refusers and participants

Characteristics	Refusers				Participants				P-value*
	N	M	SD	Range	N	M	SD	Range	
	267				94				
	% (N)				% (N)				
<i>Physical functioning</i>									
Mobility score		0.44	0.71	0-3		0.17	0.41	0-2	0.000 <sup>  </sup>
Physical fitness score		6.1	1.53	1-10		6.1	1.30	0-8	0.977
Comorbidity <sup>‡</sup>	77.2 (206)				81.9 (77)				0.335
Travel distance (km)									0.031
<= 10 <sup>‡</sup>	33.3 (89)				45.7 (43)				
>10 - <= 20 <sup>‡</sup>	23.6 (63)				18.1 (17)				
>20 - <= 30 <sup>‡</sup>	9.7 (26)				11.7 (11)				
>30 - <= 40 <sup>‡</sup>	13.9 (37)				13.8 (13)				
> 40 <sup>‡</sup>	19.5 (52)				10.6 (10)				
Education <sup>†</sup> (N)	73				72				0.106
Elementary <sup>‡</sup>	1.4 (1)				5.6 (4)				
Primary <sup>‡</sup>	19.2 (14)				30.6 (22)				
Secondary <sup>‡</sup>	68.5 (50)				51.4 (37)				
Tertiary <sup>‡</sup>	8.2 (6)				12.5 (9)				
University <sup>‡</sup>	2.7 (2)				-				
Partner (%)	85.2 (225) <sup>§</sup>				64.9 (61)				0.000 <sup>  </sup>
Social functioning		.96	1.09	0-3		1.17	1.18	0-3	.109
Age		69.0	6.22	59-86		68.6	5.71	60-87	0.589
Gender									0.769
Male	39.0 (104)				37.2 (35)				

\* P-value of t-tests, Chi-square tests, or Mann-Whitney test

† Classification based on Statistics Netherlands (CBS, 2005)

‡ Given are percentages of people (N)

§ n = 264

|| sign  $\alpha = .05$  (2-tailed)

However, no differences were found in social functioning. We did not have any specific expectations with regard to age or gender, but no differences were found.

In order to know which of all the measured variables predict refusal of participation, a binary logistic regression analysis was performed (Table 7.3). All variables were included, with (non-)participation as the dependent variable. Because the level of education of only a relatively small number of patients was known, this variable was excluded from the analysis. The analysis showed that mobility ( $B=-1.006$ ,  $p=0.000$ ) and having a partner ( $B=-1.127$ ,  $p=0.000$ ) were

significantly related to participation. Travel distance was not a significant predictor in this analysis.

Table 7.3 Binary logistic regression

	<b>B</b>	<b>S.E.</b>	<b>Wald</b>	<b>df</b>	<b>Sig.</b>	<b>Exp(B).</b>
Mobility score	-1.006	.288	12.207	1	.000	.366
Physical fitness score	-.066	.094	.492	1	.483	.936
Comorbidity	.532	.332	2.578	1	.108	1.703
Travel distance	-.124	.089	1.962	1	.161	.883
Partner	-1.127	.314	12.888	1	.000	.324
Social functioning	.050	.120	.173	1	.677	1.051
Age	-.026	.022	1.375	1	.241	.974
Gender	-.175	.276	.401	1	.527	.804
Constant	2.218	1.724	1.656	1	1.986	9.192

### 7.3.2 Reasons for refusing participation

Eighty percent of the refusers gave a reason for refusing participation (n=218). The main were: no time to attend a six-week course (19.3%), travel distance too far (19.3%), transportation problems (12.4%), no need to attend a course (10.1%), and attending a course is too strenuous (7.8%). So, two main groups of refusers could be distinguished: those who had no time to attend a six-week course (n=42), and those who lived too far away from the course location (n=42). Because we were curious about the characteristics of these two groups, we performed some explorative analyses. First, we compared the two groups with regard to all variables. It appeared that the refusers who “lived too far away” did, indeed, live further away from the course location ( $Z=-5.141$ ,  $p=0.000$ ), but more of them had a partner ( $\chi^2=4.100$ ,  $p=0.043$ ), and more of them were female ( $\chi^2=6.039$ ,  $p=0.014$ ), compared to the refusers who “had no time”. Each of the groups was also, separately, compared to the participants. The refusers who “lived too far away” lived further away, and more of them had a partner, compared to the participants (respectively  $Z=-6.028$ ,  $p=0.000$  and  $\chi^2=13.583$ ,  $p=0.000$ ), but no differences were found between the refusers who “had no time” and the participants.

## 7.4 Discussion

The aim of this study was to compare the patients who refused participation in a self-management intervention with the patients who agreed to participate. We collected demographic data, as well as data on physical and social functioning from all patients who were invited to participate in the intervention. We assumed that, on average, refusers would have more physical problems, live further away, have a lower level of education, and receive more social support. We had no specific expectation with regard to age and gender.

As is the case in many studies, the 74.0% rate of non-participation in this study was high, but it was even higher than in most intervention studies with an older study population, in which it varies from 7 to 50% [1;4-6;9]. However, it was comparable to the rate of non-participation in the study carried out by Chang et al. [10], which concerned a 15-week relaxation response intervention, in which 65% of the screened patients refused participation. It is not quite clear why the rate of non-participation in our study was so high. One possible explanation might be that the recruitment strategy differed from that of most other studies, especially with regard to the way in which patients were invited to participate (usually by telephone or by letter in other studies), and the fact that the patients were only invited to participate once (usually more than once in most studies). Besides, in our study, potential participants first were approached by their physician. In other studies, potential participants often first receive a letter signed by their physician, and were then contacted by a researcher. On the other hand, however, a lower rate of non-participation could have been expected because the recruitment strategy in this study concerned a time and effort-consuming face-to-face procedure.

In accordance with our expectations, differences were found between refusers and participants with regard to physical functioning. This finding is also in accordance with the findings of Van Heuvelen et al. [13], who reported that the participants in their study were functionally and physically more active. It could, however, be that especially these people with mobility problems could have benefited most from the program. No differences were found in physical fitness or comorbidity. With regard to physical fitness, this is remarkable, because there was a difference in mobility problems. Apparently, physical fitness was assessed on the basis of something other than mobility. An explanation for finding no difference with regard to comorbidity might be that we included patients aged 59 or older with one or more chronic diseases. In this population of chronically ill older patients comorbidity is very common, as is

illustrated by our data, which show that, on average 79% of the patients experienced comorbidity.

Also in accordance with our expectations, the two groups differed with regard to travel distance. Therefore, one way to make the recruitment process more successful could be to have more than one course location, so that patients can participate in a self-management intervention closer to their home. Contrary to our expectations, no differences were found between refusers and participants with regard to level of education. However, a significant difference was found with regard to one aspect of social support, i.e., more of the refusers had a partner, compared to the participants. This finding also seems to be in accordance with the findings of Van Heuvelen et al. [13], who reported that the participants in their study perceived less social support. As expected, it seems that a partner can provide social support in coping with a chronic disease, which implies that there is less need to participate in a self-management program [18]. With regard to the social functioning scale no differences were found. It might, however, be that the items of this scale are more related to social loneliness, whereas not having a partner more relates to emotional loneliness [19;20]. A logistic regression analysis showed that, of all the variables, mobility and having a partner had a unique association with (non-) participation.

The main reasons given by the respondents for refusing participation were no time to attend a six-week course, travel distance too far, transportation problems, no need to attend a course, and attending a course is too strenuous. When comparing the two main groups of refusers, i.e., “having no time” and “living too far away”, the latter group did, indeed, live further away from the course location, more of them had a partner, and more of them were female. This supports what was observed during the interviews, namely that women frequently mentioned that they depended on their husband for transportation, because they themselves did not have a driver’s license. These women might have refused participation because they did not want to burden their husband with driving them to the course location for six consecutive weeks. This potential problem could be solved by providing some kind of meeting or activity for the husbands while the women attend the course. No differences were found between the participants and the refusers who “had no time”. The refusers who “lived too far away” did, indeed, live further away, but also more of them had a partner, compared to the participants. Again, future studies could provide more than one course location, closer to the homes of the participants, or could offer transportation.

Some limitations of our study should be mentioned. First, although we included quite a number and variety of variables in order to distinguish refusers from participants, we did not gather information about motivational or psychological reasons for (non-)participation. However, these reasons could be related to the variables measured in our study. Future research should take this into consideration. Secondly, a question that arises from our results is why do certain patients participate in the intervention even though they would be expected to refuse participation because, for example, they have mobility or transportation problems. This should be investigated in future research.

## **7.5 Conclusions**

As in many studies, the rate of non-participation in this study was high. Refusal in this study seemed to be related to physical mobility, to travel distance, and to social support. As a consequence, the participants who were included in our self-management intervention were only a selection of the target population. In future self-management intervention studies the above-mentioned characteristics of refusers should be taken into account, for example by offering transportation or providing some kind of activity for the partners of people who are unable to drive themselves.

## 7.6 References

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# 8

## **Subjective experiences of participants of the “Grip op lijf en leven” course**

## **Subjective experiences of participants of the “Grip op lijf en leven” course**

This chapter describes the course participants’ subjective experiences with the “Grip op lijf en leven” course, which were collected in several ways and at various moments. In general, the participants were very enthusiastic about the program and the patient book. This is supported by the fact that the participants graded the program with, on average, an 8.5 on a 1-10 scale, the fact that on average 5.6 of the 6 course meetings were attended, and that only one patient of the 70 dropped out.

Most participants said they had learned something from the program, although some participants preferred to have had the program at the beginning of their illness period when more of the topics were new to them. Some participants preferred eight instead of six meetings to discuss the contents of the course. For other participants the two-hour sessions were too long because they became stiff from sitting so long.

Most participants were pleased with the contents of the program. There were only a few critical remarks with regard to the way it was taught (for example, that people would have liked to have more time to exchange experiences) and the contents (for example, that people missed the topic “sexuality”). Participants enjoyed the action planning. They became motivated and activated to reach goals, and experienced that they were able to do more than they had thought. With regard to the patient book, the participants were also satisfied, although for some participants the book was too heavy. However, one of them provided us with some very practical tips to create a more practical and manageable book, such as providing the relevant chapters at the session in which they are discussed.

Participants were very enthusiastic about the fact that people with different chronic diseases participated in the same group. They discovered that the problems were the same despite the different diseases, which enhanced the feeling of being among fellow sufferers. Some participants told that they became more resigned to their own situation by hearing others talk about their disease. For some participants, however, hearing stories of fellow sufferers was confronting, because it could be their future. Two of the six groups became so close that they continued to meet after the course had finished.

The participants were very satisfied with the way the course was taught, which can be contributed to the very structured manual, but also to the leaders. Participants very much appreciated the fact that all, except one, of the leaders of the program had a chronic disease themselves. However, during the course it became clear that it is important that peer leaders teaching the course have

accepted their disease, for otherwise there is a chance that they fall back into a participant's role.

Although most participants were content about the rooms and the location the courses were given, some participants had some critical remarks. Especially the reachability of the rooms seems important, i.e. the distance between the entrance of the building and the room. In this study, this distance was about 300 meters, which was too far for some participants.

Summarizing, the chronically ill older people who participated in the course "Grip op lijf en leven" were very enthusiastic about the program, and provided us with useful suggestions to improve the course.

With possible future implementation in mind, the rest of this chapter is written in Dutch.

## 8.1 Introductie

De ervaringen van de deelnemers aan de cursus “Grip op lijf en leven” zijn op verschillende manieren en verschillende momenten geïnventariseerd. Ten eerste werd de cursisten aan het eind van de vijfde bijeenkomst, als onderdeel van de cursus, gevraagd een (fictieve) brief te schrijven aan hun arts of andere behandelaar over hun ervaringen in de cursus. In de eerste groepen werd deze opdracht gebracht als vrijblijvend. Daardoor gaven er echter relatief weinig cursisten gehoor aan. Toen in de loop van het onderzoek bleek dat het erg zinvol was om de cursisten een dergelijke brief te laten schrijven, werd de opdracht anders geformuleerd, waardoor het minder vrijblijvend werd, echter nog steeds niet verplicht.

Ten tweede vond aan het eind van de zesde en tevens laatste bijeenkomst als onderdeel van de cursus een evaluatie plaats waarin de cursisten werd gevraagd hoe ze de cursus hadden ervaren. Voor de mensen die een brief hebben geschreven bestond dan de gelegenheid deze brief voor te lezen en/of in te leveren. Uiteindelijk hebben 30 mensen een dergelijke brief geschreven.

Ten derde kregen de cursisten tegelijk met de eerste nameting, direct na de cursus, een evaluatieformulier waarin aan de hand van een aantal stellingen verschillende aspecten van de cursus werden geëvalueerd (Appendix 3). In deze evaluatie werd ook gevraagd de cursus te waarderen met een cijfer (1-10), en was er ruimte voor op- en aanmerkingen. Alle cursisten, op één na, hebben het evaluatieformulier ingevuld (n=69).

Ten vierde werd in de tweede nameting, een half jaar na de cursus, gevraagd of de cursisten nog contact hadden met medecursisten en zo ja, met wie. Daarnaast werd gevraagd of de cursisten nog wel eens in het cursusboek lazen en of ze nog wel eens oefeningen uit het boek deden. In deze nameting werd de cursisten ook gevraagd of ze bereid waren mee te doen aan een (telefonisch) interview over hun bevindingen in de cursus. Wegens logistieke redenen zijn alleen de deelnemers van groep 1 en 2 geïnterviewd. Van de twaalf deelnemers van groep 1 waren er elf bereid deel te nemen aan het interview. Echter, één mevrouw werd niet geïnterviewd omdat ze een bekende was van de interviewer, één deelnemer bleek in de tussentijd te zijn overleden en één deelnemer lag in het ziekenhuis. Van de dertien deelnemers van groep 2 wilden negen meedoen. Deze zijn ook allen geïnterviewd. Uiteindelijk zijn er dus 17 mensen geïnterviewd. Binnen het huidige onderzoek zijn enkele gegevens uit dit interview opgenomen, maar er was echter geen gelegenheid meer de andere (kwalitatieve) data van deze interviews te analyseren.

In dit hoofdstuk wordt achtereenvolgens een algemene evaluatie van de cursus beschreven, evenals de evaluatie van de inhoud van de cursus, het boek dat bij de cursus hoort, de cursusgroep, de cursusleiding en de cursusruimtes. Het hoofdstuk wordt afgesloten met een samenvatting en discussie.

## 8.2 Algemeen

De cursus bestaat uit zes bijeenkomsten van twee tot tweeënhalf uur. Iedere bijeenkomst is opgebouwd uit vijf tot zeven activiteiten, variërend in duur van 5 tot 40 minuten (Appendix 2). Halverwege iedere bijeenkomst is er een pauze van 20 minuten. De cursus is opgebouwd uit verschillende werkvormen, namelijk lezingen (het geven van informatie), discussies (uitwisselen van ideeën), brainstormen (vergaren van ideeën), demonstraties/oefeningen (zoals ontspanningstechnieken) en rollenspelen. De cursus vraagt een actieve rol van de deelnemers. Belangrijk is dat de deelnemers onderling uitwisselen hoe ze met bepaalde dingen omgaan, zodat ze van elkaar kunnen leren.

### 8.2.1 Telefonisch interview

In het telefonisch interview (n=17) werd gevraagd naar de reden waarom mensen hebben meegedaan aan het onderzoek c.q. de cursus. Als belangrijkste reden om mee te doen noemden zeven deelnemers het opdoen van praktische kennis. Vier mensen noemden lotgenotencontact als belangrijkste reden. *“Tussen mijn medemensen te zitten die ook ziek zijn en dan over en weer gegevens uitwisselen, hoe vergaat die dat.”* Drie mensen deden mee omdat ze werden gevraagd door hun behandelend arts. De overige drie geïnterviewden noemden andere redenen.

Op de vraag “zou u een vriend of kennis aanraden deze cursus te volgen en, zo ja, waarom?” antwoorden 15 deelnemers positief. Men noemde onder andere als reden: *“Dan krijgen ze wat zelfvertrouwen, en kunnen ze er beter tegen.”* en *“Ja, omdat het toch iets bijdraagt. Je krijgt iets positiefs mee, je staat sterker en je krijgt toch wel steun.”*. Eén persoon antwoordde: *“Dat weet ik niet, lijkt me wat te vergezocht. Nee, dat zou ik niet zomaar doen.”* Een ander zei: *“Ik zou het wel noemen, maar aanraden? Om te zeggen, nou jongens, daar word je een stuk beter van of zoiets, nee, nee dat niet.”* De twee andere deelnemers antwoorden dat ze het niet direct zouden aanraden, omdat ze er zelf niet erg veel aan gehad hadden.

### 8.2.2 Evaluatie

Uit de presentielijst, die tijdens de cursus is bijgehouden, bleek dat de deelnemers (n=70) gemiddeld 5,6 van de 6 bijeenkomsten bezochten. Eén deelnemer is na de vierde bijeenkomst gestopt met de cursus, vanwege problemen met vervoer. Door middel van het schriftelijke evaluatieformulier zijn aan de hand van vijf stellingen enkele algemene aspecten van de cursus beoordeeld (Tabel 8.1).

De meeste deelnemers (89%) vonden de cursus leuk om te doen, en 76% van de mensen heeft ook het gevoel iets aan de cursus te hebben gehad. De gemiddelde waardering was een 8,5; variërend van een 8,1 tot een 8,7.

Tabel 8.1 Evaluatie algemene aspecten cursus (n=69; percentages)

	Wel mee eens	Enigszins mee eens	Niet mee eens/ Niet mee oneens	Enigszins mee oneens	Niet mee eens
Ik vond de cursus leuk om te doen	89	7	1	3	-
Ik heb het gevoel dat ik iets aan de cursus heb gehad	76	17	4	3	-
Ik vond de cursus inspannend	6	26	17	4	47
Ik vond de duur van de bijeenkomsten goed	82	14	4	-	-
Ik had het idee dat ik voldoende de mogelijkheid had om aan het woord te komen tijdens de bijeenkomsten	87	10	-	3	-

Hoewel de meeste mensen (81%) de duur van de bijeenkomst goed vonden, waren er toch enkele opmerkingen over de duur van de bijeenkomsten en de lengte van de cursus:

*“Deze cursus had voor mij wel langer mogen duren. Je leert elkaar beter kennen en ik denk dat het praten, als ook elkaar iets vertellen over je ziekte, over je gevoelens, dat het nog soepeler was gegaan als er een paar weken bij waren gekomen. Niet ieder praat gelijk over zijn ziekte of gevoelens. Dat heb ik wel gemerkt. Ook ik zelf heb daar een probleem mee.” (vrouw, 61, evaluatieformulier)*

*“De sessies plm 2-2,5 uur vond ik behoorlijk lang, bij mij gaf dat een behoorlijke stijfheid na het zitten.” (vrouw, 72, brief)*

*“Ik zou deze cursus met nóg twee middagen willen verlengen, zodat er meer tijd beschikbaar blijft voor alle onderwerpen. Soms ging het iets te vlug naar mijn mening. Onze incasseringsvermogen is minder naarmate je ouder wordt.” (vrouw, 70, brief)*

*“Het was voor mij prettig geweest bijvoorbeeld eens in de veertien dagen. Dan had ik meer tijd om er aan te werken zodat het van mij zelf wordt.” (man, 74, brief en evaluatieformulier)*

Enkele deelnemers noemden dat ze twee uur aaneengesloten zitten te lang vonden. Echter, aan het begin van de eerste bijeenkomst is te kennen gegeven dat mensen vrij waren tijdens de bijeenkomsten te gaan staan of te gaan lopen, of bijvoorbeeld naar het toilet te gaan, als hier behoefte aan was. Dit gebeurde echter vrij weinig. Wat ook gebeurde, is dat men tijdens de pauze op de plek bleef zitten, in plaats van even de benen te strekken.

Bij het werven van deelnemers is geen rekening gehouden met de duur van de aandoening. Enkele deelnemers hadden echter een opmerking over het moment van aanbieden:

*“Deze cursus is vooral geschikt voor patiënten die in een beginfase zitten met een chronische aandoening (steeds meer moeten inleveren). Het neemt (een stuk) onzekerheid weg en daarnaast geeft het mij inzicht. Je leert om met je ziek zijn om te gaan. Het luisteren naar je lichaam. (...) Voor ieder chronische patiënt die in een beginfase zit zou deze cursus van zeer belang zijn.” (man, 74, brief en evaluatieformulier)*

*“Het is fantastisch wat ik allemaal heb geleerd. Vroeger had je dit soort dingen niet, terwijl ik al 22 jaar deze aandoening heb.” (vrouw, 69, mondeling).*

*“Het lijkt me prettig om wat vlugger na je ziek worden (1 à 2 jaar) deze cursus te doen. Dan weet je nog niets en ben je zoekende. Na zo’n 15 à 20 jaar heb je al een hoop verwerkt, en loopt alles zo’n beetje, al dan niet goed.” (vrouw, 72, evaluatieformulier)*

*“Ikzelf, iemand die deze chronische aandoening pas heeft, vond het erg nuttig om in dit stadium van het hebben van een chronische aandoening de cursus te volgen.” (vrouw, 59, mondeling)*

### **8.3 Inhoud van de cursus**

In appendix 2 wordt een overzicht gegeven van de onderwerpen die in de verschillende bijeenkomsten aan de orde komen. Centraal in de cursus staat het opstellen en uitvoeren van een haalbaar actieplan. Dit actieplan heeft betrekking op een bepaald doel dat men de komende week wil bereiken. Aan het eind van iedere bijeenkomst stellen de cursisten een actieplan op. Nadat een actieplan is opgesteld, geeft de cursist door middel van een cijfer aan hoeveel vertrouwen hij/zij heeft dat het plan zal worden uitgevoerd (0=geen vertrouwen, 10=alle vertrouwen dat het plan zal worden uitgevoerd). De cursisten vertellen de week daarop of ze hun doel hebben bereikt. In de cursus wordt de nadruk gelegd op het opstellen van actieplannen met betrekking tot lichaamsbeweging. Het belangrijkste van een actieplan is echter dat het iets is dat de cursist wil doen, en niet iets dat moet. Enkele voorbeelden van actieplannen, zoals deze door deelnemers aan de cursus zijn geformuleerd:

*“Ik ga de komende week drie keer ’s middags gedurende vijftien minuten ontspanningsoefeningen doen m.b.v. een cassettebandje. Ik heb daarin een vertrouwen van een zeven.” (vrouw, 69 jaar)*

*“Ik ga de komende week vier keer ’s avonds geen (hartige) tussendoortjes meer eten en ik heb daarin een vertrouwen van een acht.” (vrouw, 61 jaar)*

*“Ik ga de komende week op zes dagen drie keer ’s ochtends de trap op en af lopen. Ik heb daarin een vertrouwen van een acht.” (vrouw, 65 jaar)*

#### **8.3.1 Evaluatie**

Tijdens de verschillende evaluaties werden er diverse opmerkingen over het actieplan gemaakt, waaronder de volgende:

*“Jezelf een taak stellen, door middel van een actieplan, is erg belangrijk want anders komt het er niet van. Je raakt gauw in een sleur, en door*

*middel van het actieplan doe je dingen waar je anders niet aan toe komt. Ik zal er ook zeker mee door gaan.” (man, 62, mondeling)*

*“Vooral de actieplannen stimuleerde mij door te zetten en verder te gaan, ook na de cursus. Ik ga nu zeker vaker om 23.00 uur naar bed, alsmede bijna iedere avond 20 min lopen voor het slapen gaan. Mijn echtgenoot doet met alles mee, dat is gezelliger.” (vrouw, 70, brief)*

*“Van actieplannen ben ik niet zo gecharmeerd. Mijn agenda staat (gelukkig) vrij vol. Met dingen die afgesproken zijn en dus gewoon moeten gebeuren. Aan daarnaast nog actieplannen heb ik niet zo'n behoefte. De bedoeling ervan begrijp ik overigens wel.” (man, 71, brief)*

*“Steeds een nieuw actieplan maken, waar in deze cursus op gehamerd werd, zal ik volhouden. Dat is een goede stok achter de deur en maakt je actiever. En je beseft, dat je meer kan dan je denkt.” (vrouw, 70, brief)*

*“De wekelijkse actieplannen werden zoveel mogelijk gehaald, ik ging aan de slag. Ik heb er van geleerd “dat je zelf er wat aan kunt doen!” (vrouw, 64, brief)*

Over de inhoud en de opzet van de cursus de volgende opmerkingen:

*“Ik mis het onderdeel seksualiteit: tegen welke problemen loop je aan, omgang met partner. Hier zouden we misschien iets over kunnen leren, bijv. brainstormen. Alleen al horen dat anderen die problemen ook hebben, zou al helpen. Ik heb het gevoel dat dit onderwerp is overgeslagen.” (vrouw, 69, mondelinge evaluatie)*

*“Ik zou wel graag wat meer beweging tijdens de cursus willen, en meer tijd om iets over onszelf te zeggen. Daartoe zou de stof meer verdeeld kunnen worden, bijvoorbeeld over acht bijeenkomsten. Het delen met elkaar vind ik erg belangrijk. (...) Er wordt te veel verteld door de docentes en te weinig geoefend (b.v. in samenspraak en lichaams oefeningen) door de cursisten. Mensen werden ook stijf van het zitten. En luisteren is niet zo vormend als meedoen.” (vrouw, 60, brief)*

*“Ik zou graag meer ruimte willen om met elkaar te praten. Ik vind het lotgenotencontact heel belangrijk, en dat heb ik hier gevonden. Dat kan ik ook wel bij een patiëntenvereniging vinden, maar dan heb je daar alleen maar mensen met reuma.” (vrouw, 72, mondeling)*

*“In de cursus kwamen veel creatieve manieren aan de orde om met een chronische aandoening om te gaan. Actieplannen: zelf maken en er aan houden, ik leefde voor de cursus van dag tot dag. Ik vond de handreikingen omtrent het onthouden van medicijnen zinvol, ikzelf vergeet ze ook wel eens in te nemen. Ik heb geleerd te ontbijten, en daardoor ook met meer regelmaat mijn medicijnen in te nemen. (...) Voor een “rommelig”, “overactief” mens als ik ben zijn de actieplannen een leidraad om naar te gaan leven. Om wat rustiger te gaan worden.” (vrouw, 62, mondeling en brief)*

#### **8.4 Het boek “GRIP op lijf en leven: zelfmanagement van verschillende chronische aandoeningen”**

Alle cursisten ontvingen tijdens de eerste bijeenkomst een Nederlandse vertaling van de tweede editie van “Living a Healthy Life with Chronic Conditions” [1]. Dit boek telt 380 pagina’s en is opgebouwd uit 20 hoofdstukken (Appendix 4). Het boek dient als naslagwerk, en is dus geen cursusboek in de strikte zin. De cursisten wordt gevraagd het boek iedere bijeenkomst mee te nemen. Aan het eind van elke bijeenkomst worden de hoofdstukken en paginanummers van de onderdelen die in die bijeenkomst aan de orde zijn geweest doorgegeven, zodat de cursisten het thuis nog eens rustig kunnen nalezen.

##### *8.4.1 Evaluatie*

Op de vraag “ik vind het cursusboek duidelijk” antwoordde de meerderheid “wel mee eens” (94%; Tabel 8.2). Ook op de vraag “ik heb het cursusboek regelmatig ingekeken” antwoordde de meerderheid (67%) “wel mee eens”. Na een half jaar las 58% procent nog wel eens in het cursusboek en deed 45% nog wel eens oefeningen uit het boek.

Tabel 8.2 Evaluatie van het cursusboek (n=69; percentages)

	Wel mee eens	Enigszins mee eens	Niet mee eens/ Niet mee oneens	Enigszins mee oneens	Niet mee eens
Ik vind het cursusboek duidelijk	94	4	2	-	-
Ik heb het cursusboek regelmatig ingekeken	67	24	4	2	3

Over het cursusboek zijn enkele opmerkingen gemaakt:

*“Er is nogal wat informatie verstrekt middels het cursusboek. Hierbij was de cursusleiding verduidelijkend. (...) Ik denk dat mensen met een chronische aandoening, die dit pas hebben, of die hun beperkingen (nog) niet de baas zijn, of onder de knie hebben, veel aan dit cursusboek kunnen hebben. Wel is het nodig om dan gebruik te kunnen maken van iemand die een en ander kan verduidelijken.” (man, 74, brief)*

*“Het cursus boek “Grip op lijf en leven” vind ik goed. (...) Eigenlijk zou het voor iedere, in dat boek beschreven, patiënt verplichte literatuur moeten zijn. Of dat het in ieder geval bij de huisarts of specialist tegen inkoopprijs te verkrijgen moet zijn. Ook het trefwoorden register vind ik goed, misschien kan het nog iets uitgebreider. Bijv. het woord “puffjes” kwam ik niet tegen.” (man, 67, brief)*

*“Ik vind het boek te dik, te zwaar, te onhandelbaar. Ik krijg er pijn van in mijn handen en polsen. Misschien kan het opgedeeld worden in drie exemplaren. Dan zou ik ook graag horen per bijeenkomst of het boek moet worden meegenomen. Ik zou graag per bijeenkomst horen wat er de volgende bijeenkomst wordt behandeld en wat ik daar eventueel over kan lezen in het boek. Dan kan ik mijn opmerkingen en vragen meenemen. Nu kregen wij op de bijeenkomst tijdens het behandelen van de stof te horen in welke hoofdstukken we het konden nalezen.(...) Er zou een werkschrift voor de cursisten kunnen worden ontwikkeld, met daarin het aantal actieplannen en iets meer in aantal, met de huiswerkopgaven per bijeenkomst. Cursisten kunnen dan zelf kiezen of ze wel of niet zich willen voorbereiden. Met pagina’s waarop feedback gegeven kan worden, zowel*

*op de eigen bevindingen per week van de cursisten alsook op het cursusgebeuren. Blanco pagina's voor aantekeningen. Informatiepagina's zoals b.v.: hoe stel je een probleem vast, positief denken, communicatie, voorbeeld medicijnenlijst, voorbeeld euthanasieverklaring, enz, enz. Zodat het een handig werkschrift is, wat je graag bij je hebt en waarin je je eigen aantekeningen en opmerkingen van lotgenoten en docentes bijhoudt. Dan wordt het grote cursusboek meer een naslagwerk.” (vrouw, 60, brief)*

## 8.5 De cursusgroep

Het is de bedoeling dat de cursus wordt gegeven aan groepen van tien tot vijftien cursisten. In dit onderzoek bestonden de groepen uit gemiddeld elf cursisten (variërend van acht tot dertien), met verschillende chronische aandoeningen. Het ging hierbij om mensen van 59 jaar en ouder met een longaandoening (COPD of astma, 31,4%), een hartaandoening (angina pectoris of hartfalen, 4,3%), diabetes (35,7%), of reumatoïde artritis of artrose (28,6%). De gemiddelde leeftijd was 68,5 (variërend van 59 tot 84 jaar). Drieënzestig procent van de deelnemers was vrouw. De verdeling man/vrouw verschilde per groep; in sommige groepen zaten er slechts twee mannen en acht vrouwen, in andere groepen zaten bijna evenveel mannen als vrouwen.

### 8.5.1 Evaluatie

Op de vraag “ik vond de grootte van de groep goed” antwoordde de meerderheid “wel mee eens” (97%; Tabel 8.3).

Tabel 8.3 Evaluatie groepsgrootte (n=69; percentages)

	Wel mee eens	Enigszins mee eens	Niet mee eens/ Niet mee oneens	Enigszins mee oneens	Niet mee eens
Ik vond de grootte van de groep goed	97	3	-	-	-

In de tweede nameting gaf 28% nog steeds aan contact te hebben met medecursisten. Aan het eind van iedere cursus werd toegezegd dat als de groep nog eens bij elkaar zou willen komen, er vanuit het Universitair Medisch Centrum Groningen daarvoor een ruimte beschikbaar zou kunnen worden gesteld. Zeven cursisten van groep 3 hebben hier gebruik van gemaakt en kwamen een aantal keren bijeen. Deelnemers van groep 5 zijn een half jaar na de laatste bijeenkomst nog een keer samen geweest, waarbij is besloten vaker bij elkaar te komen. De mensen die aangaven nog steeds contact te hebben met medecursisten waren dus vooral deelnemers uit groep 3 en groep 5.

De cursus “Grip op lijf en leven” is niet aandoeningspecifiek, maar richt zich op de gemeenschappelijke problemen van het hebben van een chronische aandoening. Er zitten dus mensen met verschillende chronische aandoeningen in de groep. Dit is door de meeste deelnemers als zeer positief ervaren:

*“Ik zou niet graag met alleen 18 personen willen zitten over COPD. Want dan heb je het de hele cursus, de hele 6 weken, niks anders over dan over COPD”. (man, 69, interview)*

*“Ik vond het geweldig, je kon hier alles kwijt, zoals woede en emoties. Je kon hier jezelf zijn omdat je bij mensen bent die hetzelfde hebben.” (vrouw, 67, mondeling)*

*“Het voelde verruimend, bevestigend en confronterend om met een aantal mensen, allemaal met een of meerdere chronische aandoening(en), samen te komen o.l.v. ervaringsdeskundige docentes. Het verruimende aspect ontstaat doordat ieder haar of zijn verhaal kan houden in alle openheid, want we zijn onder gelijken. Hier zou m.i. meer ruimte voor kunnen zijn, elke bijeenkomst. Dit geeft de cursisten meer inzicht in hun situatie. Het bevestigende aspect wordt o.a. bepaald door de docentes en medecursisten wanneer ze de klachten en opmerkingen bij elkaar herkennen en dit ook met zoveel woorden duidelijk maken. Dit geeft zelfvertrouwen door herkenning en ruimte voor meer grip op het zelfmanagement van het dagelijkse leven. (...) Het is confronterend voor mij dat de meeste medecursisten meer pijn en hinder ondervinden van hun aandoening(en) dan ik op dit moment. Dit zou mijn voorland kunnen zijn. En de herkenning van de pijn en de eenzaamheid, dit heeft mij ook menigmaal ontroerd.” (vrouw, 60, brief)*

## 8.6 Cursusleiding

De cursus wordt gegeven door twee cursusleiders, die gebruik maken van een gestructureerd protocol. Hoewel er vanuit de VS de voorkeur gegeven wordt aan twee zogenaamde “peer leaders”, d.w.z. ervaringsdeskundigen, is dat in het kader van dit onderzoek niet gebeurd. Alle cursussen werden geleid door de primaire onderzoeker, Henrike Elzen. Zij is aan de Stanford Universiteit door Kate Lorig en collega’s opgeleid tot Master Trainer. Dit houdt in dat ze gecertificeerd is om de cursus te geven, maar ook om mensen op te leiden zodat die de cursus kunnen geven. De eerste groep werd gegeven samen met een andere Master Trainer, drie groepen met peer leader A en twee groepen met peer leader B. Alle cursusleiders waren jonger dan de cursisten (30-50 jaar), behalve peer leader B, die 62 jaar was. Alle vier cursusleiders waren vrouw, van wie er drie zelf ook een chronische aandoening hadden.

Hoewel het de bedoeling is dat cursusleiders in groepen worden getraind, gebeurde de training in het kader van dit onderzoek individueel. Peer leader A had ruimschoots ervaring met het geven van groepen, maar niet met het volgen van een gedetailleerd protocol. Peer leader B was onervaren. Voor beide leiders bleek het soms moeilijk zich strikt aan het protocol te houden, onder andere omdat ze een andere mening hadden over het onderwerp of over de manier waarop het werd gebracht. Verder bleek het belangrijk dat de peer leaders hun eigen aandoening al in grote mate hebben geaccepteerd, omdat anders de kans bestaat dat ze tijdens de cursus terug vallen in een deelnemersrol, wat gebeurde met peer leader B tijdens de eerste bijeenkomst. Ze deed bijvoorbeeld mee met de discussies, in plaats van deze te leiden. Ook paste ze in een enkel geval de inhoud van bepaalde lezingen aan haar eigen ervaringen aan. Dit heeft trouwens geen verdere consequenties gehad voor de groep.

### 8.6.1 Evaluatie

Zowel op de vraag “de cursusleiding was goed voorbereid” als op de vraag “ik vond de manier waarop de cursus werd gegeven prettig” antwoordde de meerderheid “wel mee eens” (respectievelijk 97% en 94%; Tabel 8.4).

Tabel 8.4 Evaluatie cursusleiding (n=69; percentages)

	Wel mee eens	Enigszins mee eens	Niet mee eens/ Niet mee oneens	Enigszins mee oneens	Niet mee eens
De cursusleiding was goed voorbereid	97	3	-	-	-
Ik vond de manier waarop de cursus werd gegeven prettig	94	6	-	-	-

Enkele opmerkingen over de cursusleiding:

*“De stof werd eenvoudig gegeven. Begrijpbaar voor iedereen.” (vrouw, 67, evaluatieformulier)*

*“De docenten behandelen de onderwerpen op een duidelijke manier en zijn alert op vragen en suggesties.” (vrouw, 80, brief)*

*“De leiding was prettig en begripvol. Medische vragen waren door jullie als psychologen niet te beantwoorden. Maar dat wisten we van te voren. Ik heb daarom tijdens de cursus besloten lid te worden van een reumapatiëntenvereniging.” (vrouw, 70, brief)*

*“Bij het behandelen van veel onderwerpen werd soms te veel uit het boek of dictaat voorgelezen. Ook het voorlezen van de flap-over vond ik overbodig.” (man, 67, brief)*

*“De cursus werd op prettige wijze gepresenteerd. Om binnen de beschikbare tijd iedereen aan het woord te laten (soms afbreken) is een kunst op zich. “ (vrouw, 65, brief)*

## 8.7 Cursusruimtes

De cursus werd, in het kader van het onderzoek, gegeven in het onderwijscentrum van het Universitair Medisch Centrum Groningen (UMCG). Het onderwijscentrum bevond zich op de tweede etage en was bereikbaar via lift en trap, ongeveer tien minuten lopen van de hoofdingang. Voor mensen die

moeilijk ter been waren, was vervoer door middel van een rolstoel of trolley mogelijk. De eerste bijeenkomst werd de groep opgehaald bij de hoofdingang, daarna werd van de cursisten verwacht dat ze zelfstandig, dat wil zeggen individueel of met de hele groep, naar de cursusruimte kwamen.

De ruimtes in het onderwijscentrum zijn neutrale cursusruimtes, voorzien van tafels, stoelen, en diverse media zoals overhead en beamer. Daarnaast is iedere ruimte voorzien van een whiteboard en flap-over. Voor de cursus zijn schema's nodig, geschreven op een flap-over. Deze schema's werden iedere bijeenkomst opgehangen. Aan het begin van de bijeenkomst was er koffie en thee, halverwege koffie/thee en cake. Omdat er op een gegeven moment klachten kwamen over de harde stoelen, werd er gezorgd voor twee (zachtere) bureaustoelen. Hiervan werd in drie groepen gebruik gemaakt.

### 8.7.1 Evaluatie

Op de vragen “de cursusruimten waren goed bereikbaar” en “de cursusruimten waren prettig” antwoordde de meerderheid “wel mee eens” (respectievelijk 76% en 73%; Tabel 8.5). Er waren slechts enkele, minder positieve, opmerkingen over de cursusruimtes:

*“De cursusruimtes waren geen probleem maar de stoelen waren niet prettig om gedurende twee uur op te zitten.” (vrouw, 61, evaluatieformulier)*

*“Met mijn reumatische aandoeningen vond ik de af te leggen afstand van de lift naar het cursuslokaal te ver c.q. te inspannend (pijnlijk) voor mijn voeten.” (vrouw, 72, brief)*

Tabel 8.5 Evaluatie cursusruimtes (n=69; percentages)

	Wel mee eens	Enigszins mee eens	Niet mee eens/ Niet mee oneens	Enigszins mee oneens	Niet mee eens
De cursusruimten waren goed bereikbaar	76	14	6	3	1
De cursusruimten waren prettig	73	17	7	2	1

## 8.8 Samenvatting en discussie

De ervaringen van deelnemers aan de cursus “Grip op lijf en leven” zijn op verschillende manieren en op verschillende momenten geëvalueerd, zowel als onderdeel van de cursus als in het kader van het onderzoek. De deelnemers waren over het algemeen zeer positief over de cursus en het bijbehorende patiëntenboek. De cursus werd gemiddeld met een achtenhalf gewaardeerd, er werden gemiddeld ruim vijf van de zes bijeenkomsten bezocht en slecht één deelnemer is voortijdig afgehaakt.

Enkele deelnemers vonden zes bijeenkomsten te weinig, en hadden liever de stof in bijvoorbeeld acht bijeenkomsten behandeld gezien. Enkele deelnemers vonden de sessies, van twee uur, te lang. Ze werden bijvoorbeeld stijf van het zitten. Deelnemers zouden meer aangespoord moeten worden tijdens de pauze even in beweging te komen, of er zouden tijdens de bijeenkomsten gezamenlijk enkele rek- en strekoefeningen kunnen worden gedaan.

De deelnemers waren tevreden over de inhoud van de cursus. Er kwamen slecht enkele opmerkingen over de werkvormen (bijvoorbeeld dat men meer ruimte wilde om te bewegen, of om ervaringen uit te wisselen) en de inhoud (bijvoorbeeld dat men het onderwerp “seksualiteit” had gemist). Veel deelnemers waren erg enthousiast over het actieplan. Het motiveerde en activeerde ze, en men ervoer dat men meer kon dan men dacht. Ook met betrekking tot het cursusboek was men zeer enthousiast, hoewel sommige deelnemers het boek erg zwaar vonden. Eén van deze deelnemers gaf een aantal praktische tips om het boek praktischer en handzamer te maken.

Veel deelnemers waren erg enthousiast over het feit dat er mensen met verschillende chronische aandoeningen in de groep zaten. Ze ontdekten dat de problemen, dat wil zeggen de gevolgen, van een chronische aandoening hetzelfde zijn, ongeacht het type aandoening. Dit versterkte het “lotgenotengevoel”. Enkele deelnemers gaven in hun evaluatie aan dat het relativerend werkte om verhalen van mensen met andere aandoeningen te horen. Voor andere deelnemers was het horen van deze verhalen confronterend, omdat het hen confronteerde met hun voorland. Twee van de zes groepen werd zo hecht dat ze ook na afloop van de cursus enkele keren bij elkaar kwamen.

De meeste deelnemers waren erg tevreden met de manier waarop de cursus werd gegeven. Het feit dat de cursus, die door drie verschillende “leidersduo’s” gegeven werd, gemiddeld gewaardeerd werd met een achtenhalf, pleit voor de kracht van het protocol. Hoe de cursus wordt gegeven, lijkt dus belangrijker dan door wie de cursus wordt gegeven. Wat tijdens de cursus naar voren kwam, is dat het belangrijk is dat de cursusleiders, indien ze zelf een chronische

aandoening hebben, deze in sterke mate geaccepteerd moeten hebben. Er bestaat anders namelijk een kans dat men tijdens het geven van de cursus vervalt in een deelnemersrol.

Hoewel de meeste mensen positief waren over de cursusruimten en de bereikbaarheid daarvan, kwamen hier toch enkele kritische opmerkingen over. Vooral een goede bereikbaarheid lijkt belangrijk, dat wil zeggen dat de loopafstand tot de cursusruimte niet te groot moet zijn. Echter, in de meeste gevallen maakte men gebruik van een rolstoel van het ziekenhuis en werd de deelnemer door een medecursist naar de cursusruimte gebracht. Een belangrijk punt is dat het goed is om, indien niet aanwezig, te zorgen voor een paar stoelen met een zachte zitting. Deelnemers kunnen natuurlijk ook zelf een kussen meebrengen, wat één cursist ook daadwerkelijk deed.

Samengevat waren de deelnemers tevreden over de cursus. Dit wordt onder andere geïllustreerd door de volgende opmerkingen:

*“Wat heeft de cursus mij gedaan? Wat heb ik bereikt? Toen ik de cursus begon was ik structureel doodmoe. Onregelmatig wandelde en fietste ik. Nu ben ik vol energie; kan alles weer aan. Het wandelen gebeurt nu dagelijks volgens vaste routine. Ik heb geleerd dat de chronische aandoeningen niet je geest en lichaam mogen beheersen. Ik heb geleerd dat ikzelf de baas ben over mijn geest en lichaam en ook over mijn aandoeningen voor zover dat mogelijk is. Ik heb voorts de verbanden gezien tussen: chronische aandoeningen en structureel bewegen; chronische aandoeningen & symptomen.(...) Ik heb ontdekt dat – als ik een actieve zelfmanager wil worden – ik ook planmatig dien te gaan bewegen; ik heb de symptomen van de aandoeningen beter leren begrijpen en de verbanden daartussen. Elke dag loop ik nu een uur een route door het dorp waar ik woon en ik heb bemerkt dat ik mijn wandeling nu loop binnen het uur. Al maandenlang heb ik niet meer gestofzuigd voor mijn vrouw, omdat ik daarna uitgeput ben. Vanmorgen heb ik gevraagd weer eens te proberen om te stofzuigen, en dat is gelukt, zonder moe te worden. Kortom: ik constateer dat hoe meer ik beweeg, hoe minder ik vermoeid ben.” (man, 73, brief)*

*“Het gaat nu geweldig goed met mij, en dit is echt te wijten aan de cursus die ik kreeg, Grip op lijf en leven. Mijn motto is geworden: Je kunt er zelf ook wat aan doen, dat het beter met je gaat.” (vrouw, 62, opmerking tweede nameting)*

## 8.9 References

- 1 Lorig K, Holman H, Laurent D, Gonzalez VM, Minor M. Living a Healthy Life with Chronic Conditions. 2<sup>nd</sup> ed. Palo Alto, CA: Bull Publishing, 2000.







# 9

## **General discussion**

## 9.1 Introduction

This thesis addresses the problems of the increasing number of chronically ill older people in an ever more costly health care system. Due to this increase there is a need for additional means of delivering care, one of which could be the active involvement of chronically ill patients in their own health care, perhaps by making them more responsible for the daily management of their disease. This could improve their health status, and may subsequently, also reduce the costs. The active involvement of patients can be enhanced through self-management programs that teach them about self-management of their chronic disease. However, due to the combination of more than one chronic disease in many older patients there is a need for self-management programs that do not only address the problems related to one specific disease, but rather address general management problems that are the same for different chronic conditions, such as fatigue, pain, mobility problems, feelings of anxiety or depression. Because a chronic disease usually has an impact on various aspects of life, it is also important that such self-management programs focus not only on the physical aspects of a chronic disease, but also on quality of life and well-being.

One program that meets these criteria is the Chronic Disease Self-Management Program (CDSMP), developed by Lorig and co-workers at Stanford University (USA). The CDSMP is a group course (10-15 participants) that consists of six weekly meetings, taught by two leaders. The CDSMP has been evaluated in the United States and in China, and has been shown to be effective in maintaining and improving aspects of self-management behavior, such as exercise and communication, and various other aspects of health, such as fatigue, health distress, and physical functioning, though not consistently so in all studies. The same results have been reported for health care utilization. Because of these inconsistent findings, and also due to differences in the study designs, these evaluations are difficult to compare, which makes it difficult to draw any general conclusions about the effectiveness of the CDSMP.

In a great majority of the CDSMP studies, the participants were recruited through public announcements. As a consequence, nothing is known about the people who did not apply for participation (non-participants). It is therefore not clear whether and, if so, how participants differed from non-participants, and whether the actual subjects were a specific selection of the intended sample. However, based on studies of self-management interventions, it might be assumed that these participants were, indeed, a selection, so it is important to study possible differences between participants and non-participants.

Therefore, before eventually implementing the program in the Netherlands, its usefulness and effectiveness must be investigated in a Dutch population. The present thesis describes such an investigation. After translating the program into Dutch, three research questions were formulated: 1) What are the short-term and longer term effects of the CDSMP in terms of self-efficacy, self-management behavior, health status, and health care utilization?; 2) What are, if any, the working mechanisms of the CDSMP, and what is the effect of the CDSMP on quality of life and well-being?; 3) Are the actual subjects of this study, i.e., people who agreed to participate in the program, a biased selection of the intended sample?

In order to obtain deeper understanding of the working mechanisms of the CDSMP, the theoretical arguments underpinning the expected effects, i.e., the self-efficacy theory, of the CDSMP were investigated. The theory postulates that enhanced self-efficacy leads to improvements in self-management behavior and health status, and a decrease in health care utilization. Although the self-efficacy theory seemed to be relevant, there were still some problems with regard to the self-efficacy theory in relation to the CDSMP. For example, the hypothesized mediating role of self-efficacy in the CDSMP had not been evaluated consistently in earlier research. Moreover, it was not questioned whether other self-management mechanisms could possibly play a role, and especially those that would enhance quality of life. Therefore, before implementing the program in the Netherlands, the following research was deemed necessary: first, to obtain more insight into the possible pathway(s) through which self-efficacy enhances health outcome measures; secondly, to investigate whether there are other working mechanisms in addition to self-efficacy; and, thirdly, to determine whether the CDSMP enhances overall quality of life and well-being. Therefore, in addition to the self-efficacy theory, we needed a theory that specifies additional self-management abilities and that postulates pathways through which self-management abilities enhance quality of life and overall well-being. The theory of self-management of well-being (SMW) seemed to be suitable for this purpose because it specifies how certain self-management abilities, including self-efficacy, enhance overall well-being.

Based on the above-mentioned theoretical considerations, the following four hypotheses were formulated (for older people with one or more chronic diseases in the Netherlands, compared to controls) and empirically tested:

1. Participation in the CDSMP will increase self-efficacy, self-management behavior, and health status in the short-term and in the longer term.

2. The CDSMP will increase self-management abilities and well-being in the short-term and in the longer term.
3. Participation in the CDSMP will decrease health care utilization in the longer term.
4. The actual subjects in our study on the effects of the CDSMP, i.e. people who agreed to participate, are a biased selection of the intended sample.

The main findings of the studies described in this thesis will now be summarized and discussed, and some methodological and conceptual/theoretical considerations will be addressed. The conclusions that have been formulated, based on the results of our study with respect to the four hypotheses will be described, and implications for policy and practice will be discussed.

## **9.2 Main findings**

After the course manual and the patient book had been translated into Dutch, patients aged 59 or older with angina pectoris or heart failure, or COPD or asthma, or arthritis, or diabetes were recruited through the Internal Medicine outpatient clinic at the University Medical Center in Groningen, through announcements in the media and in the magazines of various patient associations. Subsequently, the program, which consisted of 6 weekly sessions, each with a duration of 2½-hours, was offered to six separate groups of patients at the University Medical Center in Groningen. There were 10-13 participants in each training group with two leaders who adhered to a detailed manual.

The first three hypotheses were tested by means of a randomized controlled clinical trial. A total of 129 Dutch chronically ill older people, aged 59 and older, with COPD or asthma, angina pectoris or heart failure, or diabetes, or arthritis were included and randomly assigned to an intervention group (n=67) or a control group (n=62). The outcomes of the two groups were compared with regard to the short-term (immediately after the course) and the longer term (after six months) outcomes.

### *9.2.1 The short-term and longer term effects of the CDSMP on self-efficacy, self-management behavior, and health*

First of all, the short-term and longer term effects of the CDSMP on self-efficacy, self-management behavior and health status were studied. Data were collected by means of questionnaires that were mailed to the patients. The

results showed that the program had no effect on any of these outcome variables in either the intervention group or the control group. Nevertheless, qualitative evaluations showed that, in general, the participants were very enthusiastic about the course. This was also confirmed by the fact that participants attended, on average, 5.6 of the 6 course meetings, and scored the course was scored with an average of 8.5 points (scale 0-10). These are very positive results, so it is concluded that although no significant effects were found, the patients had more knowledge of self-management and reported positive experiences.

### *9.2.2 The short-term and longer term effects of the CDSMP on self-management abilities and overall well-being*

In order to investigate whether other self-management abilities in addition to self-efficacy, could possibly be enhanced by the CDSMP, the intervention group and the control group were also compared with regard to other abilities and overall well-being. These other self-management abilities were based on the theory of self-management of well-being (SMW) and included: having a positive frame of mind, taking initiative, invest, taking care of multifunctionality, and taking care of variety. The results of this study also showed no effects of the CDSMP, i.e., patients in the intervention group did not significantly improve or deteriorate with regard to the other self-management abilities or well-being. It is concluded that, although a great majority of the self-management abilities were addressed in the intervention, patients in the intervention group did not improve significantly compared to controls.

### *9.2.3 The longer term effects of the CDSMP on health care utilization*

In order to investigate whether participation in the CDSMP resulted in a decrease in health care utilization, the participants were asked to make an inventory of the use they had made of certain health care services in the previous six months, such as visits to a physician or the use of home care. They did this at baseline and six months after the end of the course. The intervention and the control group were compared with regard to their health care utilization. A significant difference was found between the intervention group and the control group with regard to the use of home care, but qualitative inspection of the data showed that this effect could not be attributed to the intervention. No differences were found between the intervention group and the control group with regard to visits to a general practitioner, a medical specialist, total physician visits, visits to a physical therapist, or the number of days hospitalized. More research is

needed to draw definite conclusions about the long-term effectiveness of the CDSMP in reducing health care utilization in the Netherlands.

#### *9.2.4 The difference between participants, i.e., the actual subject, in the CDSMP study, and non-participants*

The comparison between participants and non-participants is important to estimate the validity of the CDSMP in daily practice. In order to investigate whether the participants in our study, i.e., the actual subjects, were a biased selection of the intended sample, we compared patients who agreed to participate (participants) after having been invited to participate in the self-management intervention with those who refused (refusers). Of the 361 patients who were invited, 267 (74%) refused participation. As in many studies, this refusal rate was high. The comparison of participants and the refusers showed that the latter were more restricted in their mobility, lived further away from the study location, and were more likely to have a partner than the participants. No differences were found with regard to level of education, age, or gender. The main reasons for refusing participation were lack of time, travel distance, and transportation problems. In summary, the refusal rate in this study seemed to be related to physical mobility, travel distance, and the availability of social support. It can be concluded that the participants who were included in our self-management intervention were not an unbiased selection of the intended sample. To improve the validity of the CDSMP, problems with regard to mobility and travel distance of potential participants should therefore be addressed.

### **9.3 Methodological considerations**

Our study is one of the first to investigate the effects of the CDSMP among chronically ill older people in the Netherlands. As such, the present study contributes to the existing literature on CDSMP studies. However, with regard to the sub-studies described in this thesis, there are some methodological considerations that may relate to the main findings. In the following paragraphs these considerations will be addressed.

#### *9.3.1 Recruitment*

The target population of our study was chronically ill patients aged 59 or older. However, for practical reasons, our intended sample consisted of patients who visited a medical specialist in one of the outpatient clinics of the University

Medical Center Groningen in the period between May 2003 and May 2004. The actual subjects are patients from the intended patient sample who agreed to participate.

With regard to recruitment, the overall design differed slightly from the designs of the previous CDSMP studies. First of all, half of our participants were recruited personally in the outpatient clinics of a hospital, and the other half through public announcements, whereas the participants in most other studies were recruited through public announcements only. It might be assumed that participants who were recruited in the outpatient clinics had a worse physical condition, but no such differences were found with regard to any characteristics or outcome variables.

Secondly, throughout the sub-studies it became clear that we might have included relatively many patients with a relatively high baseline level of functioning, despite the fact that they had one or more chronic diseases. An important reason for this might be that the demands that were made on the participants in our study were relatively high. Participation required willingness to travel to the university hospital on six occasions once a week, to meet with 10 to 15 other patients in group sessions that lasted for two and a half hours. No transportation was provided, so the participants had to make their own way to the study location. Participation might, therefore, have demanded a certain level of (physical) functioning and/or of self-management. This baseline level of functioning might have caused ceiling or floor effects, i.e., participants either functioned well and could therefore not improve any more, or had a low level of functioning which could therefore not decrease any further. As our study on refusers showed, the participants were less restricted in their mobility, and lived closer to the course location, although they had more social needs than refusers. The actual subjects in our study were therefore probably a biased selection of the intended sample of chronically ill older people visiting the outpatient clinics between May 2003 and May 2004. However, our sample is comparable to the samples in other studies of the CDSMP with regard to age, gender, and marital status.

Finally, our control group received care-as-usual, whereas the control groups in the other studies were waiting-list groups, i.e., they did not take part in the course immediately, but after six months. These participants knew that they would participate in the course later on, whereas the patients in our control groups knew that they would only participate by completing the questionnaires. Some people in a waiting-list control group might feel the need for treatment, i.e., the intervention, and might therefore have thought that they would forfeit

participation in the course if they improved too much, so they might have had reservations in reporting any improvements.

### *9.3.2 Sample size*

A second methodological consideration concerns the sample size. We originally aimed to include 200 participants, 100 of whom could be assigned to the treatment group, and 100 to the control group. We allowed for 20-30% drop-out, so that 150 of the 200 would complete the study, with 75 patients in the intervention group and 75 in the control group. This would provide enough power.

However, as became clear during the recruitment process, it was rather difficult to include 200 patients through the outpatient clinic of the University Medical Center Groningen. Although we also used other methods of recruitment, it was still very difficult to include 200 patients in the period we had planned for recruitment. However, post-hoc power analysis showed that the realized sample size ( $n = 144$ ) was enough to give 80% power to detect a medium difference between two independent sample means when calculated with one-tailed tests and  $\alpha = .05$ . Nevertheless, our sample size is clearly smaller than the sample sizes in other CDSMP studies, which varied from 430 to 683.

### *9.3.3 Course leaders*

A third methodological consideration concerns the course leaders. For practical reasons, and because a study carried out by Lorig et al. showed that there are hardly any differences between lay-taught and professional-taught courses, our courses were taught by at least one professional [1]. All the courses were led by the primary investigator (HE), who is an MA psychologist and educated as a CDSMP Master Trainer at Stanford University, and a peer leader or other Master Trainer (psychologist, PhD). Because the leaders had to adhere to a detailed teaching manual, the risk that the primary investigator would influence the study results was considered minimal. Although it could be argued that HE would be very eager to achieve an effect through the course, it can also be argued that this should be expected of all leaders. A leader who teaches the program but who does not aim to achieve effects through the course might not be considered to be a good leader.

While teaching the program, it appeared to be difficult for both peer leaders to adhere closely to the manual, for example because they had a different opinion with regard to a certain topic, or the way in which a topic was taught.

Moreover, it appeared to be important that the peer leaders had already accepted their own disease(s), since otherwise there is a chance that a leader will take on the role of a participant while teaching the course. Being first of all a participant and sharing experiences with others, before leading a group, might have prevented this change in roles. It might also be useful to formulate criteria that can be used to recruit and include peer leaders.

In most other CDSMP studies, little information is given about the leaders with regard to age or gender. Therefore, nothing can be said about differences or resemblances between the leaders in our study and those in other studies.

### *9.3.4 Measurements*

A final methodological consideration concerns the measurements. The CDSMP has been the focus of several studies, most of which have been carried out by Lorig et al. In these studies they used different versions of questionnaires measuring self-efficacy and health status that they had developed themselves [2]. During the Master Trainers course both Master Trainers (HE and NS) received a version of Lorig et al.'s "Sample questionnaire for the chronic disease self-management program" (July 2000). In our study, however, we decided to use other instruments to measure self-efficacy and health status, for two reasons. First, when we started collecting the data it was uncertain which of the different Lorig et al.'s self-efficacy scales that had been used in former CDSMP studies would be the most appropriate. Moreover, at the start of our study there were no available psychometric results with regard to the more general questionnaire. These became available during our study period, but by that time we had already chosen a more general self-efficacy questionnaire that had also already been validated in the Netherlands, namely the General Self-Efficacy Scale (GSES-16). In a personal conversation with professor Bandura it became clear that this self-efficacy measurement instrument was too general, i.e., it measured self-efficacy in general, and not self-efficacy related to a chronic disease. This might have influenced the results, in that at baseline both the intervention and the control group gave a general answer to the questions about self-efficacy. However, at the first post-intervention measurement the intervention group possibly answered the questions about self-efficacy in relation to their chronic disease, whereas the control group gave general answers.

A second reason for not using all of the Lorig et al. questionnaires was that we wanted to be able to compare our study results with the results of other self-management studies, both in the Netherlands and abroad. Therefore, we needed

to apply widely used and commonly accepted measurement instruments with sound psychometric properties. With regard to health status, we decided to use the RAND-36, because this questionnaire has also been validated in the Netherlands. In their questionnaire, Lorig et al. combined scales from the Medical Outcome Study (MOS) with new instruments to measure health status. It should be noted, however, that the content of sub-scales of the MOS and the RAND-36 do not differ very much, so the RAND-36 can be seen as a comparable questionnaire. We also decided to use all sub-scales of the RAND-36, in accordance with the intentions of the questionnaire, whereas Lorig et al. only used a few sub-scales of the MOS.

In conclusion, in our study we used almost all of the Lorig et al. questionnaires. However, to measure self-efficacy we chose to use a different questionnaire, which might have been one reason for not finding any effect on self-efficacy.

## **9.4 Theoretical and conceptual considerations**

With regard to all the sub-studies described in this thesis there are also some theoretical and conceptual considerations that may relate to the main findings. In the following paragraphs these considerations will be addressed.

### *9.4.1 Self-efficacy theory and theory of self-management of well-being (SMW)*

In a great majority of previous studies the CDSMP was found to have positive effects on self-efficacy, which is the underlying mechanism of the program. From these studies, however, it was not clear exactly how self-efficacy relates to the other outcomes, i.e., self-management behavior and health status. The role of self-efficacy has, in fact, only been studied with regard to the Arthritis Self-Management Program (ASMP), an arthritis program, on which the CDSMP is partly based. These studies revealed that self-efficacy enhanced both self-management behavior and health status. As far as we know, the mediating role of self-efficacy in the CDSMP has not yet been assessed. Therefore, in order to obtain more insight into this role of self-efficacy in the CDSMP, we had the intention to study the mediating effect of self-efficacy on self-management behavior and health status. However, it appeared that the CDSMP also addressed other self-management abilities, and because we also wanted to achieve better understanding of other possible self-management abilities, we shed a different theoretical light on the program, based on the theory of SMW. This theory also yields hypotheses about self-management abilities and well-

being. Because we did not find evidence that the CDSMP enhanced self-efficacy, other self-management abilities, self-management behavior, health status, or well-being, the possible mediating relationship or pathways between these variables, could not be studied. However, in another intervention study with an older study population, these mediating effects with regard to self-management abilities and well-being were found [3;4]. This study was explicitly based on the theory of SMW and aimed to enhance well-being by improving self-management abilities.

Based on the results of our study, however, it seems premature to state that the self-efficacy theory and the theory of SMW are not useful with respect to the CDSMP. Our study sample already had relatively high baseline scores for self-management abilities and well-being, so they had little room for improvement. Future research should also include participants who have lower scores for baseline self-management abilities and well-being.

In their subjective evaluations, the participants stated that, due to the program, they were better able to (self-) manage their disease, and that they “felt better”, despite the fact that no positive effects were found on self-management abilities or well-being. It is therefore possible that other self-management skills or abilities than those measured in our study were addressed, such as self-regulation or proactive coping [5], and this should be investigated in future research.

#### *9.4.2 Cultural differences*

There also could be a cultural explanation for the lack of effects. The CDSMP was originally developed for a population of chronically ill patients in America. This might be reflected not only in the content of the program, but also in the teaching strategies. When translating the CDMSP into Dutch, we intended to adhere as closely as possible to the original American version, and this appeared to be very well feasible. We needed to make some minor cultural adjustments in the patient book. These mainly concerned the chapter on advance directives, because the Dutch situation is different in this respect. A few minor adjustments were also made in the disease-specific chapters, resulting in the omission of extensive descriptions of various types of medication that are acceptable in the US, but not in the Netherlands. The tables with regard to the nutritional content of certain portions of, mostly typical American, food were left out of the chapter on healthy eating. With regard to the course manual, at first no adjustments at all were made, but during the course we did make some minor adjustments. These

mainly consisted of adding certain things to the instructions, for example, asking participants if they had any questions after a lecture. Furthermore, more time ( 5 min) was spent on the topic of advance directives, whereas less time (5 min) was spent on healthy eating. No adjustments at all were made in the teaching strategies. In one other, non-American study the program was adapted substantially [6], in spite of which positive effects of the program were still found.

It can be questioned whether we might have made too few adjustments. What contradicts this, though, is that the participants in our study only made a few critical remarks with regard to the content and these mainly concerned topics that were not included, such as sexuality, and not topics that were unsuitable or redundant. No remarks were made about the teaching strategies. However, patients in the Netherlands might be better informed with regard to their chronic disease, and the health care system in the USA differs from the Dutch system with regard to the availability of good care for everyone. Perhaps the CDSMP focuses on resources and skills that are not available in usual care in the USA, but that might be provided in the Netherlands. It might, therefore, be useful to reassess the content of the course for patients in the Netherlands, preferably in focus groups of chronically ill older people, because in this way their exact needs can be assessed. As a consequence, the program can be made more sensitive to meet the requirements of these patients.

## **9.5 Conclusions**

### *9.5.1 Scientific implications*

Previous studies of the CDSMP show that the program is effective. However, there is ambiguity about the outcome variables on which the program has an effect, and the size of these effects. The studies did not show consistent effects, i.e., not all studies showed the same effects on the same outcomes, and they showed different effect sizes. Moreover, outcome variables such as self-efficacy and health status were conceptualized and measured differently across the different studies, which makes it difficult to draw any general conclusions about the effectiveness of the CDSMP on these variables. Therefore, there is a need for more studies on the effectiveness of the CDSMP, and these studies should not only replicate previous studies exactly, i.e., including the exact same outcome variables and measurements, but they should also include additional outcome measures.

In our study we did not find any effects of the CDSMP on self-efficacy, self-management behavior, health status, or health care utilization. However, we did not study the longer-term effects, i.e., after one year or more. It is possible that the participants in an intervention such as the CDSMP, which is mainly aimed at enhancing self-management behavior, need longer than six months to integrate this behavior into their daily lives. Future research should be aimed at the longer-term effects of the CDSMP in a sample of older patients in the Netherlands.

The fact that in our study we did not find any effects of the CDSMP is important, because it seems to be one of the first studies in which no significant effects at all have been found. However, publication bias might have occurred, i.e., studies reporting no effects of the CDSMP were not published. As Rosenthal has stated: "...the probability of publication is increased by the statistical significance of the results so that published studies may not be representative of the studies conducted" (page 128; [7]). This implies that the non-significant results of the present study are also important and informative.

The CDSMP has been implemented all over the world, but only a few studies have investigated the effects of the CDSMP in countries outside the USA, and even less in non-English-speaking samples. In a study that was carried out in China, the CDSMP was adapted extensively, but despite these adaptations it showed positive effects on all outcomes, i.e., self-efficacy, self-management behavior, health status, and health care utilization. Our study was the first to investigate the effects of the CDSMP in the Netherlands, and therefore indicates that more research should focus on the effects of the CDSMP in non-English-speaking countries.

In articles reporting on CDSMP studies it is often mentioned that self-efficacy is the working mechanism of the CDSMP, but very little explanation is given. How self-efficacy relates to the other outcomes is often not explained. A literature search that was aimed to achieve more clarity with regard to this working mechanism identified no studies on the exact role of self-efficacy in the CDSMP. However, there are some studies that have investigated the role of self-efficacy in the ASMP, a program on which the CDSMP is partly based, but in these studies the mediating role of self-efficacy is not very clear. Future research should focus on the role of self-efficacy, and also other possible self-management abilities, in the CDSMP.

### *9.5.1 Practical implications*

In the medical world, there is strong emphasis on evidence-based care, because this provides objective evidence for the effectiveness of a treatment. The personal experiences and perceptions of the patients are considered to be less important. Our randomized controlled trial did not show any statistically significant effects of the CDSMP, despite the fact that observations and subjective evaluations showed that the patients were very satisfied. They gave high scores to the program, the attendance rate was high and there were no drop-outs due to lack of motivation. Therefore, we can more or less promise potential participants that they will enjoy participating in the CDSMP, that they will attend almost all sessions, that they will not regret having participated, and that they will feel better afterwards.

Observations showed that focusing on common problems among the participants is an important strength of the CDSMP. By starting the course with an overview of the problems experienced by all the participants, instead of focusing on each separate disease, the focus is on what the participants have in common. This seemed to create a kind of group feeling, of being among fellow sufferers, which was also reflected in one of the most important statements that the participants made in their evaluations: “being among fellow sufferers, who understand what you’re going through”. Mainly for this reason, two of the groups continued to meet after the course had finished. This aspect of enjoying being among fellow sufferers seems to be related to the results of our study of non-participants, in which it was concluded that the participants mainly participated for social reasons. Future research could expand on outcome variables such as, for instance, social support, and also on social needs as inclusion criteria. Another important issue is that some participants indicated that they had difficulty in adapting to certain changes in their social role. For example, after having been fulfilling the role of a wife or mother who could do everything and to whom people could always make an appeal, arthritis made an end to this. However, the people in her social environment did not take her disability into account, and still made the same appeals for help, even though she informed them about her disease and the related consequences. It is therefore recommended that future studies consider the inclusion of partners or significant others as participants in the CDSMP. In fact, the CDSMP also addresses significant others.

People with different chronic diseases can participate in the CDSMP. In practice, this means that less time is needed to recruit the number of participants needed to start a group. For example, for a group of 15 participants only one or

two patients with diabetes might be needed, in addition to 13 patients with other diseases, whereas for a diabetes program 15 people with diabetes have to be recruited.

Our study also confirmed that lay-persons could be trained to teach the program. This mainly relates to the fact that the manual is user-friendly, describing in detail what has to be done, how much time this will take, and which information has to be given. Both professional and lay-leaders should be aware that they have to act more as facilitators than as lecturers. This means that they should not prescribe things, such as the choice of an action plan, but rather assist participants in making their own choices. For some leaders this may require a change of attitude. For professional leaders, whose job it is to explicitly inform patients about various aspects of their disease and to prescribe certain life-style changes, it might mean that they have to step back and let the patient be the expert. For lay-leaders, who might not have any experience with leading groups, guiding the group processes might be difficult.

One of the professional leaders in our study had a chronic disease herself, and our experience is that when a professional leader also has a chronic disease, the participants not only see the leader as a trained professional but also as an “expert by experience”. Sometimes it is easier for the participants to accept advice from a fellow sufferer than from a professional, but although having a chronic disease can be an “advantage”, this should not be a criterion for a professional leader. It may be expected that professionals are educated to empathize adequately with any patients, despite the characteristics of the patients, and this is the added value of professional leaders. From lay-leaders this cannot generally be expected, but for them it is important that they have already accepted their chronic disease(s), and this can be facilitated by first being a participant in the intervention. It should therefore be taken into account that not all lay-persons, and also not all professionals, are eligible to teach the program. It is recommended that certain criteria for a “good” leader are formulated. One criterion might be that at least one of the leaders is of the same age as the participants, so that (s)he is a peer leader in that sense. These criteria can be supported by creating a central training facility, as in the Stanford Patient Education Center. Another reason for the central training of leaders is to prevent leaders from other organizations from changing the program, as sometimes happens in practice, in order to safeguard the quality of the program.

During the second year of our study, an interview which was held with the primary researcher (HE) about the study was published in a national newspaper. Many people from different organizations all over the Netherlands responded to

this article by calling and asking if it was already possible to implement the program. In our opinion, these reactions show that there is a considerable need for programs like the CDSMP in the Netherlands. Participants in such programs will not feel disappointed...

## 9.6 References

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## **Summary**

## Summary

The population in the Netherlands is ageing, and older people are often confronted with one or more chronic diseases (comorbidity). Comorbidity is associated with an increase in both the costs and the utilization of health care services. The current focus of the health care system in the Netherlands is on acute care and on cure, with the physician as expert, and relatively little attention seems to be paid to the psychosocial and societal problems that patients with chronic diseases often have to cope with in addition to their biomedical problems. Since chronically ill patients themselves are responsible for the daily management of their disease, it seems important to encourage them to be actively involved in their own health care. This can be achieved through self-management programs. Because a chronic disease has an impact on various aspects of life, it is important that such self-management programs focus not only on the physical aspects of a chronic disease, but also on quality of life and well-being. However, due to the combination of more than one chronic disease in many older patients there is a need for self-management programs that do not only address the problems related to one specific disease, but rather address general management problems that are similar for different chronic conditions.

In a literature search we found that the Chronic Disease Self-Management Program (CDSMP) developed by Lorig and colleagues was reported to be beneficial for older people with one or more chronic diseases. The results of studies show that the CDSMP can have positive effects on self-efficacy, health behavior, health status, and health care utilization. However, the different evaluations are difficult to compare, and this makes it difficult to draw any general conclusions about the effectiveness of the CDSMP.

From previous studies of the CDSMP it is not known whether the actual subjects were a specific selection of the intended sample, but based on other studies of self-management interventions it might be assumed that the participants are a biased selection of the intended sample. Therefore, before implementing the CDSMP in the Netherlands, its usefulness and effectiveness must be investigated in a systematic way, and this has been done in the studies described in the present thesis. After translating the program into Dutch, three research questions were formulated: 1) What are the short-term and longer term effects of the CDSMP in terms of self-efficacy, self-management behavior, health status, and health care utilization?; 2) What are, if any, the working mechanisms of the CDSMP, and what is the effect of the CDSMP on quality of life and well-being?; 3) Are the actual subjects in this study, i.e., people who agreed to participate, indeed, a biased selection of the intended sample?

Before describing the study, *Chapter 2* gives an overview of the theoretical background of the CDSMP. The CDSMP is based on Bandura's self-efficacy theory, and we explain why Lorig and colleagues chose this self-efficacy theory. This is followed by a definition of self-efficacy, various ways in which to enhance self-efficacy are discussed, and we explain how the self-efficacy theory can be applied to patients with chronic illnesses. Lorig et al. incorporated four strategies to enhance self-efficacy in the CDSMP, i.e., performance mastery, modeling, persuasion, and physical reframing. The mediating role of self-efficacy was mainly studied in the Arthritis Self-Management Program (ASMP), an arthritis program on which the CDSMP is partly based. However, in a study on the mediating role of self-efficacy in the CDSMP, it was found that both baseline self-efficacy and improvement in self-efficacy were accompanied by 1-year reductions in health care utilization. To summarize, enhanced self-efficacy leads to improvements in self-management behavior and health status, and a reduction in health care utilization.

Nevertheless, in addition to the earlier-mentioned methodological problems encountered in the CDSMP studies, there also seem to be theoretical problems. For example, the hypothesized mediating role of self-efficacy in the CDSMP was not evaluated consistently in earlier research. Moreover, it was not questioned whether other self-management mechanisms could possibly play a role, especially those that would enhance quality of life. Therefore, it was deemed necessary (1) to obtain more insight into the possible pathway(s) through which self-efficacy enhances health outcome measures, (2) to investigate whether there are other working mechanisms in addition to self-efficacy, and (3) to determine whether the CDSMP enhances overall quality of life and well-being. Therefore, in addition to the self-efficacy theory, we needed a theory that specifies self-management abilities other than self-efficacy, and that postulates pathways through which self-management abilities enhance quality of life and overall well-being. The theory of self-management of well-being (SMW) seemed to be suitable for this purpose, because it specifies how certain self-management abilities, including self-efficacy, enhance overall well-being. This theory specifies six self-management abilities that are needed to indirectly enhance both the physical and the social dimensions of overall well-being: self-efficacy beliefs, having a positive frame of mind, taking the initiative, investment behavior, multifunctionality; and achieving and maintaining a variety in resources. When analyzing the content of the CDSMP, based on the theory of SMW, it might be assumed that these self-management abilities will also be enhanced in the CDSMP.

Based on the above-mentioned theoretical considerations, the following four hypotheses were formulated (for older people with one or more chronic diseases in the Netherlands, compared to controls) and empirically tested:

1. Participation in the CDSMP will increase self-efficacy, self-management behavior, and health status in the short-term and in the longer term.
2. The CDSMP will increase self-management abilities and well-being in the short term and in the longer term.
3. Participation in the CDSMP will decrease health care utilization in the longer term.

and:

4. The actual subjects in this study on the effects of the CDSMP, i.e., people who agree to participate, are a selection of the intended sample.

*Chapter 3* describes the methods used in the studies reported in this thesis. First of all, the sample size, the recruitment strategy, the enrollment process, and the characteristics of the participants are described. This is followed by an overview of the measurements and the questionnaires that were used. Subsequently, the intervention is described, and, finally, the analyses applied in the studies are discussed.

The first three hypotheses were tested by means of a randomized controlled clinical trial. A total of 129 chronically ill older people, aged 59 and older, with COPD or asthma, angina pectoris or heart failure, or diabetes, or arthritis, were included and assigned to an intervention group (n=67) or a control group (n=62). The intervention group participated in the Dutch version of the CDSMP, and the two groups were compared with regard to the short term (immediately after the course) and/or longer term (after six months) outcomes.

*Chapter 4* describes our evaluation of the short-term and longer-term effects of the CDSMP among chronically ill older people in the Netherlands. This study did not yield any evidence for the effectiveness of the CDSMP on self-efficacy, self-management behavior or health status. However, because the patients who participated in the program were very enthusiastic, which was also confirmed by the very high participation rate and only one drop-out, it seems too early to conclude that the program was not beneficial for these patients.

Although no effects of the study were found on self-efficacy, health behavior or health status, the participants in the intervention group were very positive. They stated that they were more able to (self-) manage their disease, and that they “felt better”. Greater ability to (self-) manage the disease seems to indicate enhanced self-management skills or abilities. Therefore, it is possible

that, in addition to self-efficacy, other general self-management skills or abilities were addressed in the program, which may have had a more positive influence on subjective well-being than on health status. *Chapter 5* describes a study that aimed to evaluate whether the CDSMP possibly enhanced other self-management abilities, in addition to self-efficacy, and whether these abilities affected subjective well-being. The findings showed no effectiveness of the CDSMP on self-management abilities other than self-efficacy, or on subjective well-being, i.e., patients in the intervention group did not significantly improve or deteriorate with regard to these outcomes. It is possible that the content of the intervention was too implicit with regard to these other self-management abilities. It might also be that the patients who were included had a level of functioning that left little room for improvement.

The combination of an increasing number of chronically ill patients and constant cut-backs in health care resources will result in an increasing burden on the Dutch health care system. In the USA, the CDSMP has been reported to have a positive effect on health care utilization. The aim of the study described in *Chapter 6* was to evaluate the effect of the CDSMP on health care utilization among chronically ill older people in the Netherlands. In the sample described above, the intervention group and the control group were compared with regard to health care utilization, i.e., visits to a general practitioner, visits to a medical specialist, total visits to a physician, visits to a physical therapist, visits to a social worker, help from home care, help from unpaid volunteers, and number of days hospitalized. A significant difference was found between the intervention group and the control group with regard to home care utilization, but qualitative inspection of the data showed that this effect could not be attributed to the intervention. No differences were found between the two groups with regard to utilization of the other health care services. More research is needed to determine the long-term effectiveness of the CDSMP in reducing health care utilization in the Netherlands.

Patients who refuse to participate in interventions constitute an important problem in clinical trials but, in general, relatively little attention is paid to this problem. In our study, the majority of the potential participants were invited to participate personally, so we were able to gather a considerable amount of information about their characteristics, as well as reasons for refusal. In *Chapter 7* patients who agreed to participate (participants) after having been invited to participate in a self-management intervention were compared to those who refused (refusers), in order to determine whether the actual subjects are a biased selection of the intended sample. Of the 361 patients who were invited to

participate, 267 (74%) refused participation, and as in many studies, this refusal rate was high. The refusers in our study were more restricted in their mobility, lived further away from the study location, and were more likely to have a partner. No differences were found with regard to level of education, age, and gender. The main reasons for refusal were lack of time, travel distance, and transportation problems. Therefore, the high refusal rate in this study seems to be related to physical mobility, travel distance, and to social support. As a consequence, the participants who were included in our self-management intervention were a biased selection of the target population. To improve the validity of future interventions, problems with regard to mobility and travel distance should be addressed.

*Chapter 8* describes the subjective experiences of the participants, which were evaluated in several ways and at various moments. It became clear that, in general, the participants were very enthusiastic about the program and the patient book. The course was scored with an average of 8.5 points (ranging from 1 to 10), and the participants attended, on average, 5.6 of the 6 course meetings. Some critical remarks were made about the number of sessions, the length of the sessions, and the accessibility of the course location. However, the participants particularly enjoyed the action-planning and the patient book. They were very enthusiastic about people with different chronic diseases participating in the same group. During the course it became clear that it was important that the peer leaders teaching the program had accepted their disease, otherwise there is a chance that a leader will take on the role of a participant while teaching the course. It is recommended that certain criteria are formulated for the appointment of leaders. The participants also made useful suggestions to improve the course, such as providing copies of the relevant chapters at the session in which they are discussed.

*Chapter 9* presents a summary of the main findings, and the methodological, theoretical and conceptual considerations. The thesis concludes with a summary of the scientific and practical implications.

## **Samenvatting**

## **Samenvatting**

De populatie in Nederland vergrijst. Ouderen krijgen vaak te maken met één of meerdere chronische aandoeningen (co-morbiditeit, d.w.z. het hebben van meer dan één aandoening). Mensen met meer dan één aandoening maken meer gebruik van de gezondheidszorg dan mensen met één aandoening. Het gezondheidszorgsysteem in Nederland is vooral gericht op de acute zorg, waarbij de behandeling vaak gericht is op het verhelpen van fysieke problemen en het voorkomen van verdere achteruitgang. Binnen dit systeem lijkt weinig aandacht te bestaan voor de psychosociale en maatschappelijke problemen die patiënten met een chronische aandoening ervaren. Omdat patiënten zelf verantwoordelijk zijn voor de dagelijkse zorg voor hun aandoening, is het belangrijk hen daarbij actief te betrekken. Eén manier om dit te doen is met behulp van zelfmanagementinterventies. Belangrijk daarbij is dat dergelijke interventies zich niet alleen richten op de fysieke gevolgen van het hebben van een chronische aandoening, maar ook op zaken als kwaliteit van leven en welbevinden. De meest gebruikelijke interventies zijn echter aandoeningspecifiek, dat wil zeggen gericht op één aandoening. Voor ouderen met meer dan één (chronische) aandoening is een dergelijke interventie minder geschikt. Beter is een interventie gericht op meer algemene problemen die gerelateerd zijn aan het hebben van een chronische aandoening.

Uit een literatuuronderzoek bleek de “Chronic Disease Self-Management Program (CDSMP)” een geschikte interventie voor ouderen met één of meerdere chronische aandoeningen. Uit verschillende onderzoeken blijkt dat deze interventie een positief effect kan hebben op de self-efficacy (“zelfeffectiviteit”), het zelfmanagementgedrag, de gezondheidstatus en het gezondheidszorggebruik. Deze onderzoeken zijn echter moeilijk te vergelijken, waardoor er geen eenduidige conclusies kunnen worden getrokken over de effectiviteit van de interventie. In eerdere onderzoeken naar het effect van de CDSMP wordt niet duidelijk of de deelnemers aan die onderzoeken een a-selecte steekproef vormden. Op basis van andere zelfmanagementinterventiestudies kan echter verwacht worden dat de deelnemers geen a-selecte steekproef van de beoogde populatie zullen zijn. Het is daarom belangrijk dat de bruikbaarheid en effectiviteit van de CDSMP systematisch worden onderzocht voordat het in Nederland wordt geïmplementeerd. Dat onderzoek wordt in dit proefschrift beschreven. Nadat de CDSMP in het Nederlands was vertaald, werden er drie onderzoeksvragen geformuleerd: 1) wat zijn de korte en lange termijneffecten van de CDSMP in termen van self-efficacy, zelfmanagementgedrag, gezondheid en gezondheidszorggebruik bij oudere mensen met meer dan één chronische

aandoening in Nederland; 2) wat zijn werkzame mechanismen van de CDSMP, voor zover deze er zijn, en wat is het effect van de CDSMP op kwaliteit van leven en welbevinden?; 3) zijn de deelnemers aan het onderzoek een a-selecte steekproef van de beoogde populatie?

Alvorens de onderzoeken te beschrijven waarin deze vragen worden beantwoord, wordt in *hoofdstuk 2* een overzicht gegeven van de self-efficacy theorie van Bandura, waarop de CDSMP is gebaseerd. Beschreven wordt hoe Lorig en haar collega's tot de keuze van deze theorie kwamen, wat self-efficacy is en hoe deze versterkt kan worden, en hoe self-efficacy (negatief) beïnvloed kan worden door het hebben van een chronische aandoening. De vier manieren om self-efficacy te versterken, namelijk succeservaring, modeling, overreding en het herinterpreteren van symptomen, zijn door Lorig en collega's verwerkt in de CDSMP. De mediërende rol van self-efficacy is voornamelijk onderzocht in de ASMP, een reuma-interventie waarop de CDSMP gedeeltelijk is gebaseerd. Echter, uit onderzoek naar de mediërende rol van self-efficacy in de CDSMP bleek dat zowel self-efficacy op baseline niveau als een toename in self-efficacy samen hangt met een afname in gezondheidszorggebruik na één jaar.

Naast de eerder genoemde methodologische problemen blijken er echter ook theoretische problemen te bestaan. De mediërende rol van self-efficacy, bijvoorbeeld hoe de uitkomsten samenhangen met de rol van self-efficacy in de CDSMP, is niet systematisch onderzocht. Hoewel het effect van de CDSMP op verschillende aspecten van welbevinden is onderzocht, is nog geen onderzoek gedaan naar het effect van de interventie op subjectief welbevinden. Het is daarom belangrijk om meer inzicht te krijgen in de rol van self-efficacy in het bijzonder, hoe deze andere uitkomsten versterkt. Daarnaast kan worden onderzocht of er, naast self-efficacy, misschien ook andere zelfmanagementvaardigheden worden versterkt en, zo ja, welke dat dan zijn. Tot slot zou nog onderzocht moeten worden wat het effect van de CDSMP is op welbevinden. Hiervoor is er een theorie nodig die niet alleen andere zelfmanagementvaardigheden specificeert, maar ook hoe deze leiden tot een verbetering van het subjectieve welbevinden. Hiervoor kan “de theorie van zelfmanagement van welbevinden” (theory of self-management of well-being, SMW) worden gebruikt. Deze theorie definieert zes zelfmanagementvaardigheden (self-management abilities, SMAs) die nodig zijn voor het realiseren van zowel de fysieke als sociale dimensie van (algemeen) welbevinden: self-efficacy, positief perspectief, initiatief nemen, investeren, multifunctionaliteit en variëteit. Op basis van een analyse van de inhoud van de



CDSMP kan worden verondersteld dat de CDSMP deze zelfmanagementvaardigheden ook versterkt.

Op basis van bovenstaande overwegingen zijn de volgende vier hypothesen geformuleerd en empirisch getoetst (bij Nederlandse oudere chronisch zieken, in vergelijking met een controlegroep):

1. Door deelname aan de CDSMP neemt de self-efficacy, het zelfmanagementgedrag en de gezondheid toe, zowel op de korte als de lange termijn.
2. Door deelname aan de CDSMP nemen de zelfmanagementvaardigheden en subjectief welbevinden toe, zowel op de korte als lange termijn.
3. Door deelname aan de CDSMP neemt het gebruik van de gezondheidszorg af, zowel op de korte als lange termijn.

En:

4. De deelnemers aan het onderzoek zijn geen a-selecte steekproef van de beoogde populatie.

In *hoofdstuk 3* worden de methoden beschreven die zijn gebruikt om bovenstaande hypothesen te testen. Er wordt een beschrijving gegeven van de grootte van de onderzoeksgroep, de wervingsstrategie en het inclusieproces, en de kenmerken van de onderzoeksgroep. Vervolgens wordt een overzicht gegeven van de uitkomstmaten en de daarvoor gebruikte meetinstrumenten. Tot slot wordt informatie gegeven over de cursus en de cursusleiders, en worden analyses beschreven.

De eerste drie hypothesen werden getest door middel van een gerandomiseerd gecontroleerd onderzoek. Honderdnegenentwintig Nederlandse chronisch zieke ouderen van 59 jaar en ouder met COPD of astma, angina pectoris of hartfalen, of diabetes of reuma werden geïncludeerd en gerandomiseerd in een interventiegroep (n=67) en een controlegroep (n=62). De uitkomsten van beide groepen werden vergeleken op de korte termijn (direct na afloop van de cursus) en/of op de langere termijn (na zes maanden).

*Hoofdstuk 4* beschrijft het onderzoek naar de korte en lange termijneffecten van de CDSMP op self-efficacy, zelfmanagementgedrag en gezondheid bij Nederlandse oudere chronisch zieken. In ons onderzoek werden echter geen effecten gevonden van de CDSMP op deze variabelen. Omdat de deelnemers in de interventiegroep echter zeer enthousiast waren over de cursus, zoals ook blijkt uit de hoge aanwezigheid en de lage uitval, lijkt het te voorbarig om te zeggen dat de interventie niet bruikbaar is voor deze groep patiënten. Verder onderzoek zou gericht moeten zijn op verdere evaluatie van de interventie.



Hoewel we in ons eerste onderzoek geen effecten vonden op self-efficacy, zelfmanagementgedrag en gezondheid, waren de deelnemers in de interventiegroep erg positief. Na afloop noemden ze dat ze beter wisten hoe om te gaan met hun aandoening, en dat ze zich beter voelden. Het “beter weten om te gaan met” lijkt te wijzen op zelfmanagementvaardigheden. Het zou daarom kunnen zijn dat er in de cursus naast self-efficacy ook meer algemene zelfmanagementvaardigheden zijn versterkt, die eerder een positieve invloed hadden op welbevinden dan op gezondheid. In *hoofdstuk 5* wordt een onderzoek beschreven dat als doel heeft na te gaan of de CDSMP ook andere zelfmanagementvaardigheden versterkt, naast self-efficacy, en of deze van invloed zijn op het subjectief welbevinden van een groep Nederlandse chronisch zieke ouderen. Er werd echter geen effect gevonden van de CDSMP op andere zelfmanagementvaardigheden dan self-efficacy, noch op subjectief welbevinden, dat wil zeggen dat deelnemers in de interventiegroep niet significant verbeterden of verslechterden met betrekking tot deze uitkomstmaten. Het kan zijn dat in de CDSMP de andere zelfmanagementvaardigheden slechts impliciet aan de orde komen, of dat er nog andere zelfmanagementvaardigheden zijn dan door ons onderzocht. Het zou ook kunnen zijn dat wij patiënten hebben geïncludeerd die niet veel meer konden verbeteren op de gemeten aspecten.

De combinatie van een groeiend aantal chronisch zieken, en toenemende bezuinigingen in de gezondheidszorg zorgt voor een toenemende belasting van het Nederlandse gezondheidszorgsysteem. Uit onderzoek blijkt dat de “Chronic Disease Self-Management Program” (CDSMP) een positief effect kan hebben op gezondheidszorggebruik in de USA. In *hoofdstuk 6* wordt beschreven wat de effecten zijn van de CDSMP op gezondheidszorggebruik in Nederland. In dezelfde populatie als in bovengenoemde onderzoeken werden de interventie en controlegroep vergeleken met betrekking tot gezondheidszorggebruik: het aantal bezoeken aan de huisarts, de specialist, het totaal aantal bezoeken aan een arts, bezoeken aan een fysiotherapeut, bezoeken aan een maatschappelijk werker, hulp van thuiszorg, hulp van een vrijwilliger en het aantal dagen dat iemand opgenomen was geweest in een ziekenhuis of andere instelling. Er werd een significant effect gevonden met betrekking tot het gebruik van thuiszorg. Dit effect kon echter niet aan de interventie worden toegeschreven. Met betrekking tot de andere soorten gezondheidszorg werden geen verschillen gevonden. Er is meer onderzoek nodig om conclusies te kunnen trekken over het effect van de CDSMP op gezondheidszorggebruik in Nederland op de lange termijn.

Het weigeren van deelname aan onderzoeken is een veelvoorkomend probleem bij interventiestudies. Echter, weinig onderzoekers besteden hier



aandacht aan. In ons onderzoek werden patiënten persoonlijk benaderd voor deelname, waardoor er relatief veel informatie verzameld kon worden, zowel met betrekking tot (demografische) kenmerken als redenen om te weigeren. In *hoofdstuk 7* wordt een vergelijking gemaakt tussen mensen die mee wilden doen aan de cursus “GRIP op lijf en leven” (participants) en mensen die weigerden (refusers), om na te gaan of de deelnemers een a-selecte selectie waren van de beoogde populatie. Er werd informatie verzameld met betrekking tot (demografische) kenmerken van de patiënten en domeinen van functioneren. Van de 361 patiënten die gevraagd werden mee te doen, weigerden 267 (74%) deelname. Dit aantal is, net als in andere onderzoeken, hoog. De mensen in ons onderzoek die niet mee wilden doen, hadden meer problemen met de fysieke mobiliteit, woonden verder van de onderzoekslocatie en hadden vaker een partner. Er werden geen verschillen gevonden met betrekking tot opleiding, leeftijd en geslacht. De belangrijkste redenen om niet mee te doen waren gebrek aan tijd, de reisafstand en problemen met vervoer. Samengevat lijkt, in onze studie, weigering van deelname samen te hangen met de fysieke mobiliteit, afstand tot de cursuslocatie, en het hebben van meer sociale steun. Als gevolg hiervan zijn de deelnemers die in de interventie werden geïncludeerd, een selecte steekproef van onze beoogde populatie. Om de validiteit van interventies te vergroten, moet er rekening worden gehouden met problemen van potentiële deelnemers in relatie tot mobiliteit en reisafstand.

*Hoofdstuk 8* beschrijft de subjectieve ervaringen van deelnemers aan de cursus, welke op verschillende manieren en op verschillende momenten werden geïnventariseerd. De deelnemers waren over het algemeen zeer positief over de cursus en het bijbehorende patiëntenboek. De cursus werd gemiddeld met een rapportcijfer achtenhalf gewaardeerd, en er werden gemiddeld ruim vijf van de zes bijeenkomsten bezocht. Er waren enkele kritische opmerkingen met betrekking tot het aantal bijeenkomsten, de duur van de bijeenkomsten en de bereikbaarheid van de cursusruimtes. De deelnemers waren echter vooral positief over het actieplan en het patiëntenboek. Men was enthousiast over het feit dat mensen met verschillende aandoeningen in dezelfde groep zaten. Tijdens het geven van de cursus werd duidelijk dat de ervaringsdeskundigen die de cursus geven in hoge mate hun eigen aandoening geaccepteerd moeten hebben, omdat er anders een kans bestaat dat ze in een deelnemersrol vervallen. Het wordt daarom aangeraden criteria op te stellen, waaraan cursusleiders zouden moeten voldoen. De deelnemers hebben enkele nuttige tips gegeven voor het verbeteren van de cursus en het cursusmateriaal, zoals het uitdelen van



hoofdstukken van het patiëntenboek per bijeenkomst, in plaats van het hele boek in één keer).

*Hoofdstuk 9* geeft een korte samenvatting van de belangrijkste bevindingen van dit proefschrift, en enkele methodologische, theoretische en conceptuele beschouwingen. Verder worden er wetenschappelijke en praktische implicaties gegeven.

## Appendix 1

### *Content of the program*

#### **Session 1**

- Activity 1: Introduction – Identifying common problems (30 min)
- Activity 2: Workshop overview and responsibilities (10 min)
- Activity 3: Differences between acute and chronic conditions (15 min)  
Break (20 min)
- Activity 4: Introduction to cognitive symptom-management (15 min)
- Activity 5: Introduction to action plans (40 min)
- Activity 6: Closing (10 min)

#### **Session 2**

- Activity 1: Feedback/Problem-solving session (30 min)
- Activity 2: Dealing with anger, fear and frustration (30 min)  
Break (20 min)
- Activity 3: Introduction to exercise (30 min)
- Activity 4: Making an action plan (20 min)
- Activity 5: Closing (5 min)

#### **Session 3**

- Activity 1: Feedback/Problem-solving session (25 min)
- Activity 2: Better breathing (15 min)
- Activity 3: Muscle relaxation (10 min)  
Break (20 min)
- Activity 4: Fatigue management (15 min)
- Activity 5: Endurance exercise (20 min)
- Activity 6: Making an action plan (20 min)
- Activity 7: Closing (5 min)



**Session 4**

Activity 1: Feedback/Problem-solving session (15 min)

Activity 2: Healthy eating (25 min)

Activity 3: Distraction (10 min)

Break (20 min)

Activity 4: Advance directives for health care (15 min)

Activity 5: Communication skills (15 min)

Activity 6: Problem-solving (25 min)

Activity 7: Making an action plan/Closing (20 min)

**Session 5**

Activity 1: Feedback/Problem-solving session (10 min)

Activity 2: Medication usage (20 min)

Activity 3: Making informed treatment decisions (10 min)

Break (20 min)

Activity 4: Depression management (15 min)

Activity 5: Self-talk (25 min)

Activity 6: Guided imagery (20 min)

Activity 7: Making an action plan/Closing (20 min)

**Session 6**

Activity 1: Feedback/Problem-solving session (20 min)

Activity 2: Informing the health care team (15 min)

Activity 3: Working with your health care professional (20 min)

Break (20 min)

Activity 4: Looking back and planning for the future (40 min)

Activity 5: Closing (10 min)



## **Appendix 2**

### *Overzicht van de cursus*

#### **Sessie 1**

Activiteit 1: Introductie/vaststellen van gemeenschappelijke problemen (30 min)

Activiteit 2: Overzicht van de cursus en verantwoordelijkheden (10 min)

Activiteit 3: Verschillen tussen acute en chronische aandoeningen (15 min)

Pauze (20 min)

Activiteit 4: Introductie cognitieve symptomen management (15 min)

Activiteit 5: Introductie actieplan (40 min)

Activiteit 6: Afsluiting (10 min)

#### **Sessie 2**

Activiteit 1: Feedback/probleem-oplossen (30 min)

Activiteit 2: Omgaan met boosheid, angst en frustratie (30 min)

Pauze (20 min)

Activiteit 3: Introductie lichaamsbeweging (30 min)

Activiteit 5: Een actieplan maken (20 min)

Activiteit 6: Afsluiting (5 min)

#### **Sessie 3**

Activiteit 1: Feedback/probleem-oplossen (25 min)

Activiteit 2: Beter ademen (15 min)

Activiteit 3: Spierontspanning (10 min)

Pauze (20 min)

Activiteit 4: Management van vermoeidheid (15 min)

Activiteit 5: Lichaamsbeweging voor het uithoudingsvermogen (20 min)

Activiteit 6: Een actieplan maken (20 min)

Activiteit 7: Afsluiting (5 min)



#### **Sessie 4**

Activiteit 1: Feedback/probleem-oplossen (15 min)

Activiteit 2: Gezond eten (25 min)

Activiteit 3: Afleiding (10 min)

Pauze (20 min)

Activiteit 4: Wilsverklaring (15 min)

Activiteit 5: Communicatievaardigheden (15 min)

Activiteit 6: Probleem-oplossen (25 min)

Activiteit 7: Een actieplan maken/afsluiting (20 min)

#### **Sessie 5**

Activiteit 1: Feedback/probleem-oplossen (10 min)

Activiteit 2: Gebruik van medicijnen (20 min)

Activiteit 3: Beslissingen omtrent behandeling (10 min)

Pauze (20 min)

Activiteit 4: Management van somberheid (15 min)

Activiteit 5: Positief denken (25 min)

Activiteit 6: Geleide fantasie (20 min)

Activiteit 7: Een actieplan maken/afsluiting (20 min)

#### **Sessie 6**

Activiteit 1: Feedback/probleem-oplossen (20 min)

Activiteit 2: Het behandelteam informeren (15 min)

Activiteit 3: Samenwerken met uw arts (20 min)

Pauze (20 min)

Activiteit 4: Terugkijken en plannen maken voor de toekomst (40 min)

Activiteit 5: Afsluiting (10 min)



### Appendix 3

#### *Subjectieve evaluatie van de cursus (subjective evaluation of the program)*

	<b>Wel mee eens</b>	<b>Enigszins mee eens</b>	<b>Niet mee eens niet mee oneens</b>	<b>Enigszins mee oneens</b>	<b>Niet mee eens</b>
Ik vond de cursus leuk om te doen.	1	2	3	4	5
Ik heb het gevoel dat ik iets aan de cursus heb gehad.	1	2	3	4	5
Ik vond het cursusboek duidelijk.	1	2	3	4	5
Ik heb het cursusboek regelmatig ingekeken.	1	2	3	4	5
Ik vond de cursus inspannend.	1	2	3	4	5
Ik vond de duur van de bijeenkomsten goed.	1	2	3	4	5
Ik had het idee dat ik voldoende de mogelijkheid had om aan het woord te komen tijdens de bijeenkomsten.	1	2	3	4	5



	<b>Wel mee eens</b>	<b>Enigszins mee eens</b>	<b>Niet mee eens niet mee oneens</b>	<b>Enigszins mee oneens</b>	<b>Niet mee eens</b>
Ik vond de grootte van de groep goed.	1	2	3	4	5
De cursusleiding was goed voorbereid.	1	2	3	4	5
Ik vond de manier waarop de cursus werd gegeven prettig.	1	2	3	4	5
De cursusruimten waren goed bereikbaar.	1	2	3	4	5
De cursusruimten waren prettig.	1	2	3	4	5

Welk rapportcijfer zou u de cursus in zijn geheel geven (0=heel slecht, 10=uitstekend)?: \_\_\_\_\_

Indien u nog opmerkingen heeft, of dingen over de cursus kwijt wilt die in bovenstaande vragen niet aan de orde zijn geweest, kunt u dat hieronder opschrijven.

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## Appendix 4

*Overzicht van de hoofdstukken in het patiëntenboek (overview of the chapters of the patient book in Dutch)*

1. Wat is zelfmanagement?
2. Een actieve zelfmanager worden
3. Het vinden van hulpbronnen
4. Symptomen begrijpen
5. Uw gedachten gebruiken om goed met symptomen om te gaan
6. Bewegen voor uw plezier en als training
7. Oefeningen voor lenigheid en spierkracht: opwarmen en afkoelen
8. Oefeningen voor het uithoudingsvermogen: aerobicoefeningen
9. Oefentips voor specifieke chronische aandoeningen
10. Communicatie
11. Seksualiteit en intimiteit
12. Uw wensen kenbaar maken: een wilsverklaring
13. Gezonde voeding
14. Omgaan met medicijnen
15. Informatie over chronische longaandoeningen
16. Informatie over hartaandoeningen en een hoge bloeddruk
17. Informatie over reuma
18. Informatie over diabetes
19. Plannen voor de toekomst: vrees en realiteit
20. 200<sup>+</sup> nuttige tips







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Amersfoort, september 2006





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## About the author

Henrike Anje Elzen was born on February 27th, 1973 in Stadskanaal, The Netherlands. After completing High school there (1991), she studied for primary teacher (graduated 1995), and in 1996 she started the study of psychology at the University of Groningen. From 1998 up until 2002 she worked as a psychological assistant at a rehabilitation center. In June 2002, she started her PhD project at the University Medical Center Groningen, Departments of Internal Medicine and Geriatrics, and the Interuniversity Center for Social Science Theory and Methodology (ICS), University of Groningen. In August 2002, she received her Master's degree in clinical psychology, with endorsements for developmental psychology, and neuro/biopsychology. During her project, Henrike visited dr. Kate Lorig at the Stanford University (USA) one week to be trained as a Master Trainer (2002), and one month for an ICS-traineeship. She visited MD PhD Ruud Kempen at the University of Maastricht (The Netherlands), also for an ICS-traineeship. Since September 2006 she works as a teacher at the Center of Psychogerontology at the Radboud University, Nijmegen.

Henrike Anje Elzen werd geboren op 27 februari 1973 te Stadskanaal. Na de middelbare school (MAVO, diploma 1989 en HAVO, diploma 1991) doorliep ze de Pedagogische Academie voor het Basisonderwijs (PABO), welke zij in 1995 afrondde. In 1996 begon ze zowel met de studie psychologie aan de Rijksuniversiteit Groningen alsmede de LOI-opleiding tot psychologisch-pedagogisch assistent (1998). Vanaf 1998 tot en met mei 2002 werkte ze als psychologisch assistente bij het Centrum voor Revalidatie (voorheen "Revalidatiecentrum Beatrixoord") van het Universitair Medisch Centrum Groningen (UMCG). In juni 2002 begon ze met haar promotieonderzoek op de afdeling Geriatrie van het UMCG. In augustus 2002 behaalde ze haar doctoraal diploma psychologie, met als afstudeerrichting klinische psychologie en als nevenrichtingen ontwikkelingspsychologie en neuro/biopsychologie. Als AIO was ze verbonden aan de onderzoeksschool "Interuniversity Center for Social Sciences Theory and Methodology" (ICS). Tijdens haar promotieonderzoek bezocht ze dr. Kate Lorig aan de Stanford Universiteit (USA) een week in het kader van de opleiding tot Master trainer en één maand in het kader van een stage voor het ICS. Voor het ICS heeft ze ook een maand stage gelopen bij prof. dr. Ruud Kempen, verbonden aan de Universiteit van Maastricht. Sinds september 2006 is ze werkzaam als docent bij het Centrum voor Psychogerontologie van de faculteit Sociale Wetenschappen, Radboud Universiteit Nijmegen.