Evaluation of the chronic disease self-management program (CDSMP) among chronically ill older people in the Netherlands

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Available online 13 March 2007

Abstract

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 program that have been carried out in the United States and China, positive effects were found on self-management behaviour and health status. However, the program 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 program among chronically ill older people in the Netherlands. 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). Demographic data and data on self-efficacy, self-management behaviour and health status were collected at three measurement moments (baseline, after 6 weeks, and after 6 months). The patients who participated rated the program with a mean of 8.5 points (range 0–10), and only one dropped out. However, our study did not yield any evidence for the effectiveness of the CDSMP on self-efficacy, self-management behaviour or health status of older patients in the Netherlands. Because the patients who participated were very enthusiastic, which was also indicated by very high mean attendance (5.6 out of 6 sessions) and only one dropout, it seems too early to conclude that the program is not beneficial for these patients.

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Keywords: Self management; Elderly; Chronic disease; Randomized trial; The Netherlands

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 (Westert, Satariano, Schellevis, & van den Bos, 2001). 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 (Baanders, Calsbeek, Spreeuwenberg, & Rijken, 2003; Gijsen et al., 2001; Heijmans, Rijken, Schellevis, & van den Bos, 2003; Kempen, Jelicic, & Ormel, 1997; Kempen, Ormel,

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Brilman, & Relyveld, 1997; Ormel, Kempen, Brilman, & Van Sonderen, 1996; Stewart, Greenfield, Hays, Wells, Rogers et al., 1989). Chronic diseases may lead to disabilities, which can have a negative effect on the ability of older people to care for themselves (Fried & Guralnik, 1997).

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 behaviour 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 for (older) people with more than one chronic disease.

The CDSMP has been evaluated in the United States and in China (Fu, Fu, McGowan, Shen, Zhu et al., 2003; Lorig, Ritter, Stewart, Sobel, Brown et al., 2001; Lorig, K.R., et al., 1999; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The study samples in these evaluations mainly involved older adults (mean age 64.2, range 40–90), and mainly concerned patients with heart disease, lung disease, diabetes, or arthritis. In all evaluations, except for one, self-efficacy was measured. Other outcome measures were self-management behaviour, health status, and health care utilization. However, there was no standard measurement of outcome variables such as self-efficacy and health status. The CDSMP has been found to be effective in maintaining and improving these abovementioned outcomes, although not consistently so in all studies. The effect sizes of most of these outcomes were small to moderate. 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 program can have positive effects on self-efficacy, self-management behaviour, and health status, we expect to find positive effects in our sample of patients aged 59 and older with one or more chronic diseases.

Methods

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

Participants

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: being aged 59 or older; having 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. In addition to having a heart disease, lung disease, arthritis, or diabetes, patients could also have other (minor) diseases such as eczema or an allergy. The majority of the patients had a minor disease as well.

Informed consent was obtained from patients who were eligible and willing to participate in the study. Each time informed consent was obtained from thirty patients, which took about four months, they were sent a baseline questionnaire. After the patients returned the questionnaire, they were randomised: within each diagnostic group, i.e., disease group, participants were assigned either to the intervention group or the control group. In this way, six consecutive blocks of about thirty people with various diseases were formed during the inclusion period, with equal numbers in the intervention group and the control group. When participants knew each other beforehand, they were randomised together, so that both of them were either in the intervention or in the control group; this avoided contamination. 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.

Intervention

The program consisted of 6 weekly sessions of each $2\frac{1}{2}$-h long, 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 (Lorig, Gonzalez, & Laurent, 1999). For practical reasons, and because a study carried out by Lorig and colleagues showed that lay-taught and professional-taught courses only differed with regard to increase of knowledge (Lorig et al., 1986) all courses were led by the primary investigator (HE), who is a masters-level psychologist and educated as a CDSMP Master Trainer at Stanford University. In this way it was taken care that the detailed manual was followed very strictly throughout all the different groups. The primary investigator led the courses with a peer leader or other Master Trainer (psychologist, PhD). The program is based on the self-efficacy theory (Bandura, 1997). Self-efficacy refers to confidence in one's abilities to adopt specific behaviour, which is a key factor in behaviour change and health functioning (O'Leary, 1985). The program incorporates strategies to enhance self-efficacy: weekly action-planning and feedback, participants modelling behaviour and problem-solving for each other, re-interpretation of symptoms, group problem-solving, and individual decision-making (Lorig, K. R., et al., 1999). The course includes: exercise; cognitive symptom-management techniques; information on nutrition; fatigue-management; use of medication; managing emotions; communication; problem-solving; decision-making (Lorig, González, & Laurent, 1997). The participants received a Dutch translation of "Living a Healthy Life with Chronic Conditions", a patient book that is used in the course, and can also be used by patients as a reference book (Lorig et al., 2000). In the translation of the patient book only a minor cultural adjustment was made, namely with regard to advance directives. We did this because the situation in the Netherlands regarding this topic differs from the American one.

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). This means that the control group participants were only contacted at these moments. The data included date of birth and gender, marital status, and primary chronic condition. Outcome measures were self-efficacy, self-management behaviour, and health status. An evaluation measure was given to intervention participants only.

Self-efficacy

Self-efficacy was measured with a Dutch version of the General Self-Efficacy Scale (GSES-16; Bosscher & Smit, 1998). This scale, measuring general self-efficacy, was chosen because at the start of the study this was the only scale that was known to have good psychometric properties. 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 behaviour

Measures of self-management behaviour included frequency of exercise, cognitive symptom-management, and communication with a physician. We used measurement scales developed by Lorig and colleagues, which were slightly adapted to account for cultural differences (Lorig et al., 1996). 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" (Lorig et al., 1996). 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. (1996) "Coping with symptoms". 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 rated on a 6-point Likert scale with the endpoints 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 be familiar with these techniques at baseline.

Communication with a physician was measured with a Dutch translation of the Lorig et al. (1996) "Communication with physician". 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 rated on a 6-point Likert scale using the endpoints never/always. The score is the mean of the three items ($\alpha = .65$). 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 (Zee & Sanderman, 1993). 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 (Ware Jr, Kosinski, & Keller, 1994; Zee & Sanderman, 1993). The physical component is a composite of the sub-scales physical functioning, role limitations (physical problem), bodily pain, and general health ($\alpha = .77$). The mental component is a composite of the sub-scales vitality, social functioning, role limitations (emotional problem), and mental health ($\alpha = .72$). The higher the score on both scales, the better the physical and mental health condition. Health status was measured at all three measurement moments.

Analyses

Data were checked twice for their accuracy after being entered into SPSS. First, *t*-tests, Chi-square tests and Mann-Whitney tests were performed to compare the demographic characteristics and the baseline scores of the intervention 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 varied 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 significance level was $\alpha = 0.05$. The analyses were performed in SPSS 12.0.2 (version 12.0.1, Chicago, SPSS Inc., 2004).

Results

Description of sample

Of the 361 patients who were personally invited to participate in the outpatient clinic, 94 (26%) agreed to participate. We analysed the non-participants and found that they were more restricted in their mobility, lived further away from the location of the intervention and had a partner more often, compared to the participants (Elzen, Slaets, Snijders, & Steverink, 2007, submitted). No differences were found in level of education, age, or gender. Another 50 participants 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 1, no significant differences in the basic patient characteristics were found at baseline. No group differences were found on any of the measurement scales.

Fig. 1 is a flow diagram of the sample and drop-outs. 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 randomisation. This concerned a couple who 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 tumour 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 ($z = -2.138$, $p = .033$).

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

Table 1
Patient characteristics

Variable	Intervention			Control			p-value[a]
	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	25 (36.8)			25 (36.8)			1.0
Male							
Partner	45 (66.2)			40 (58.8)			.376
Disease							
Diabetes	23 (33.8)			21 (30.9)			.375
Lung disease	22 (32.4)			16 (23.5)			
Arthritis	20 (29.4)			26 (38.2)			
Heart disease	3 (4.4)			5 (7.4)			
Self-efficacy		57.5 (10.6)			56.4 (10.9)		.555
Self-management behavior							
Exercise		170.6 (112.5)			160.8 (118.8)		.624
Cognitive symptom-management	—			—			—
Communication		2.2 (1.1)			2.6 (1.3)		.081
Health status							
Physical component		35.4 (10.9)			36.8 (10.5)		.897
Mental component		46.8 (10.1)			48.0 (9.9)		.751

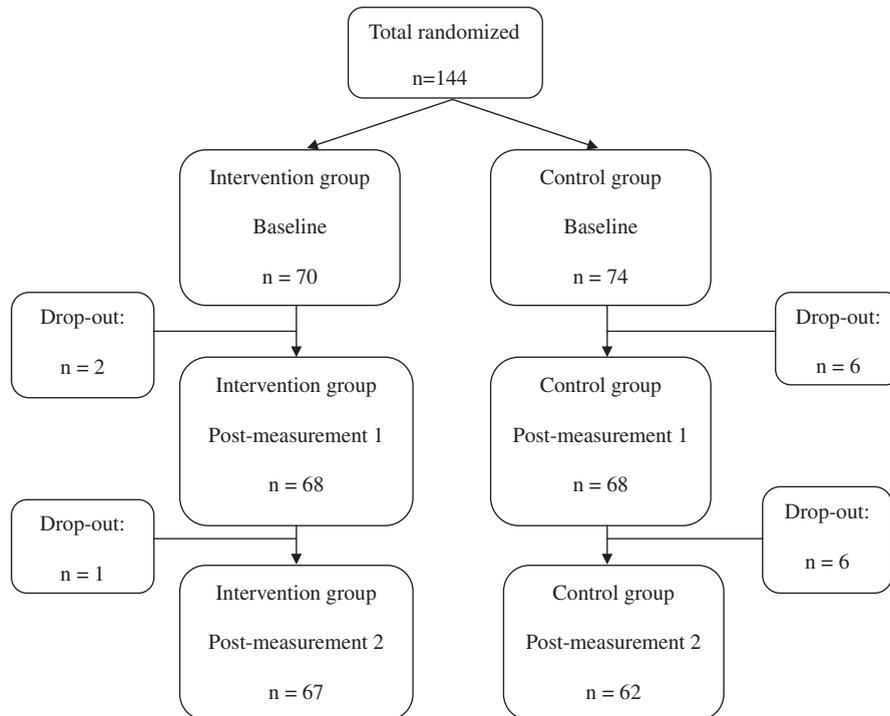[a]*P*-value of *t*-tests, χ^2-tests, or Mann-Whitney test.

Fig. 1. Flow diagram of the drop-out of participants.

12 items, to evaluate the intervention. In general, the participants were very enthusiastic about the course and the associated patient book. The course was rated with an average of 8.5 points (range 0–10). 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. For three participants the two-hour sessions were too long because they became stiff from sitting that long.

Self-efficacy

After adjusting for the covariates and factor mentioned earlier, there were no significant differences in self-efficacy between the intervention and the control group at T1 [$t(124) = 1.37$, $p = .09$, partial $\eta^2 = .02$] or at T2 [$t(117) = 1.55$, $p = .06$, partial $\eta^2 = .02$].

Self-management behaviour

No significant differences in exercise were found between the intervention and the control group at T1 [$t(122) = -1.58$, $p = .06$, partial $\eta^2 = .02$] or at T2 [$t(110) = -.08$, $p = .47$, 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 and the control group at T1 [$t(124) = -1.42$, $p = .08$, partial $\eta^2 = .02$] or at T2 [$t(117) = -1.09$, $p = .14$, partial $\eta^2 = .01$].

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

Health status

With regard to the physical component summary scale, no significant differences were found between the intervention and the control group at T1

$[t(124) = -.55, p = .29$, partial $\eta^2 = .002]$ or at T2 $[t(115) = -.137, p = .45$, partial $\eta^2 = .00]$. There were also no significant differences in the mental component summary scale at T1 $[t(124) = .39, p = .35$, partial $\eta^2 = .001]$ or at T2 $[t(115) = -.11, p = .46$, partial $\eta^2 = .00]$.

Discussion

In this study we evaluated the short-term and longer-term effects of the CDSMP among chronically ill older people in the Netherlands. The CDSMP seemed to be an innovative intervention in the Netherlands, because, to our knowledge, all models and programs for patients with chronic diseases are disease-specific. Based on studies carried out in other countries, we expected to find at least some effects of the CDSMP on self-efficacy, self-management behaviour 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 and 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.

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" (Rosenthal, 1991, p. 128). It might be that evaluations of the CDSMP showing non-significant results have not been published before.

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.

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 might 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. However, when compared to a general population, our study sample had considerably lower scores on the RAND-36 physical component summary scale. Because in previous studies done on the CDSMP the outcome variables were measured in various ways, it was difficult to compare our sample to those of other studies. There might 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. In addition, chronically ill patients in the Netherlands have relatively easy access to health care, and the quality of this care can, on average, be considered good.

A third possible explanation for not finding any significant effects of the program may be to 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 cause 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 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 (Becker, Roberts, & Voelmeck, 2003). 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 behaviour asso-

ciated with a chronic disease by filling in the questionnaires. As a consequence, they might have adopted such behaviour more often, and this might have led to an improvement in other variables as well (Becker et al., 2003). 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.

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 $\alpha = .05$ (Cohen, 1992). The number of participants in the other CDSMP studies varied from 430 to 683, so our sample size is clearly smaller, but our sample is comparable to that of other studies with regard to gender and marital status; with regard to age, our sample seems somewhat older.

A second limitation could be the measurement moments chosen for this study (i.e., six weeks and six months). 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.

Acknowledgements

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