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Self-management for chronically ill older people

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

2006

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Elzen, H. A. (2006). *Self-management for chronically ill older people*. [Thesis fully internal (DIV), Rijksuniversiteit Groningen]. s.n.

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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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