Self-management for chronically ill older people

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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).

Dimensions of well-being ➔ **Self-management abilities ⬇**	**Comfort**	**Stimulation**	**Affection**	**Behavioral confirmation**	**Status**
Self-efficacy beliefs					
Positive frame of mind					
Taking initiatives					
Investment behavior					
Multifunctionality					
Variety					

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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