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## Self-management for chronically ill older people

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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.