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Self-management for chronically ill older people

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General discussion

9.1 Introduction

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

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

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

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

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

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

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

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

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

9.2 Main findings

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

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

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

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

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

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

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

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

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

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

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

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

9.3 Methodological considerations

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

9.3.1 Recruitment

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

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

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

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

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

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

9.3.2 Sample size

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

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

9.3.3 Course leaders

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

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

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

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

9.3.4 Measurements

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

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

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

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

9.4 Theoretical and conceptual considerations

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

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

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

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

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

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

9.4.2 Cultural differences

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

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

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

9.5 Conclusions

9.5.1 Scientific implications

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

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

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

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

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

9.5.1 Practical implications

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

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

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

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

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

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

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

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

9.6 References

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