Susanne van Hooft

# BETWEEN EXPECTATIONS AND REALITY

Self-management support in nursing practice and nurse education

### **Between Expectations and Reality**

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Susanne Maria van Hooft

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## Self-management support in nursing practice and nurse education

### Tussen verwachtingen en realiteit

Zelfmanagementondersteuning in de verpleegkundige praktijk en in de verpleegkundige opleiding

### Proefschrift

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Overige leden:	Prof.dr. P.L. Meurs
	Prof.dr. M.J. Schuurmans
	Prof.dr. M. van Dijk
Copromotoren:	Dr. A.L. van Staa
	Dr. J. Dwarswaard

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### INTRODUCTION

Emily was a woman with multiple chronicle conditions, including diabetes, cancer, bad legs, and bad vision. She had become used to living with the treatment regimen and the disabilities inherent to the diseases, and had integrated these into her life. She had developed several routines that helped her during the day. Because of her multiple conditions, she had many hospital visits and different physicians to attend to. With some, the relationship was good, but there were also physicians she did not like. One of the latter once asked her which treatment she preferred. This question quite upset her, because deciding on treatments was supposed to be his job. How could she know what was best for her? Still, Emily had high expectations of an outpatient clinic visit. To her, this was the opportunity to tell professionals how she felt. So, she always wanted to tell her story first. This took some time and was not always to the point, so not all the physicians or nurses were inclined to let her do the talking. She did not particularly like those either.

Although Emily did not wish to choose between treatments, she held her own opinion about the effectiveness of the medications she got. Once, when she became very sick and believed that the medication only had made things worse, she told the physician: "You may as well give them to your own wife, but I will not take them anymore." One of the diabetes complications was losing eyesight. It became more difficult to walk to the grocery shop by herself. But for her, one of the biggest problems was not being able to make jigsaw puzzles anymore. The days seemed to last forever.

Once, when she was in hospital a nurse wanted to send her home because in-patient treatment was no longer necessary. When the nurse asked if she would manage at home on her own, Emily replied that she would. Of course she said she would manage! Just as she had managed before, during her entire life. But what she did not mention was that, because of her near-blindness, she was not able to cook anymore. She also didn't tell the nurse she was dizzy all the time, so she did not feel safe about climbing the stairs of her home. And, most of all, she didn't tell her that she was frightened. Frightened that some horrible things would occur, like vomiting the whole day. She was afraid to have immense pain and, above all, she was afraid to die.

Emily was my mother in law. She died last year, after suffering from multiple conditions for over twenty-five years. In the lessons or presentations I give on self-management, I often mention her as an example of someone living with chronic conditions. Because, on the one hand, she was a remarkable – one of a kind – woman; often she knew exactly what she wanted and expressed her opinions without hesitations. On the other hand, she was a perfect example of the complexity of a life with multiple chronic conditions. People are not one-dimensional. If one has a strong opinion on a certain issue, this does not necessarily mean that one has strong opinions on other subjects.

### Living with a chronic condition

As Emily's story illustrated, certain tasks need to be fulfilled in order to integrate chronic conditions into one's life. This point has also been extensively discussed in the literature (e.g. Corbin & Strauss, 1985; Lorig & Holman, 2003; Schulman-Green et al., 2012). All the tasks related to coping with a chronic condition can be regarded as self-management. Some of these tasks are general for all people confronted with unexpected life events: managing emotions, trying to maintain a positive self-image, relating to family members and friends, and preparing for an uncertain future. But there are also adaptive tasks that are specific to people confronted with a chronic condition: managing symptoms, managing treatment and forming relationships with healthcare providers (Moos & Holahan, 2007). The view on self-management as a broad concept is reflected in the definition we use in the NURSE-CC research program:

"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established." (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002 p. 178) As this definition implies, living with a chronic condition requires continuously adapting to situations that arise due to the condition. Obviously, it is not sufficient to take medication and adhere to lifestyle advices. The tasks Emily had to fulfil in order to maintain an acceptable way of life involved work on 'illness', 'everyday life', as well as 'biographical' work (Corbin & Strauss, 1985; Schulman-Green et al., 2012). The illness domain refers to tasks related to medical issues, such as taking medicines, preventing exacerbations, and learning to interpret warning signs of complications. The everyday life domain involves coping strategies to adapt the condition into one's life. That is, adapting to activities that are attainable. Emily had given up on cooking by herself, so she used pre-prepared meals she only had to heat instead. The biographical domain concerns, for example, accepting the change in life perspective after a diagnosis is given and giving a new meaning to one's life. For Emily it meant she had to accept not being able to see her grandchildren getting married. It also meant accepting that she would only be able to enjoy birthday parties for a limited time, because she was too tired afterwards. All the tasks concerning living with a chronic condition require planning and coordination, which is described as 'articulation work' (Corbin & Strauss, 1985). This contains planning and coordination of practical tasks; planning and coordination between the everyday life, the illness work and the biographical work; and, planning and coordination between the available resources. Emily had to take medication out of the medication box before she could take it, and she had to check whether it was the right medication (articulation of tasks). Emily also planned her hospital visits at times she did not have any social activities, and not

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the other way around! (articulation of lines of work). And, Emily had to make sure that the taxi would arrive on time so she could visit the outpatient clinic and that one of her children would come with her (articulation of available resources).

Accomplishing these tasks requires certain skills. Lorig & Holman (2003) distinguish six self-management skills needed to overcome the challenges. The first is problem solving, comprising the recognition of a problem, determination of its cause and reflection on possible solutions. The next is *decision makina* about everyday issues with regard to living with a chronic condition. For example, about how to interpret certain symptoms and subsequently decide what actions are required. The third self-management skill is resource utilization, which involves the use of supporting resources such as family or the internet. The fourth skill is the formation of a *partnership with health care professionals*. Patients have to inform their doctors and nurses about their symptoms and worries. They also have to ask questions and even have to ask for further explanation if the information given is not clear to them. The fifth skill is taking action, which includes changing health behaviour. The final skill that can be distinguished is self-tailoring. This involves the internalisation of information and knowledge to one's own situation. Many people with chronic conditions manage to cope with their condition by themselves (van Houtum, Rijken, Heijmans & Groenewegen, 2015). At some point however, some may need support from health care professionals in fulfilling their self-management tasks, i.e. self-management support.

While Emily tried to be as independent as possible in daily life, she still received support from family, neighbours, friends and health care providers. From health care providers she needed different kinds of support at several points in time. Sometimes she just wanted information about the cause of the symptoms, or she needed someone explaining the consequences of certain decisions. She also needed someone who repeated and rephrased the information given. For her, it was important that someone listened to her worries, and asked more about her personal life and concerns. Luckily, someone did; when her vision became limited, a home care nurse recommended listening to audio books. That gave Emily more comfort than any medication against dizziness could have done.

So, when she was to be discharged from the hospital, and the nurse asked if she could manage at home, without further information the nurse would have sent her home. What Emily needed at that time was a nurse who was interested in her and in her specific situation, and who could oversee the consequences of being chronically ill and living alone. Emily was fortunate that a family member expressed her worries and needs for her. Based on that, she was admitted to a nursing home.

People may need support regarding information about the chronic condition, training of skills and strategies, increasing self-efficacy, i.e. all the skills and tasks mentioned earlier required for managing a chronic condition (Lorig & Holman, 2003; Moos & Holahan, 2007; Schulman-Green et al., 2012). Support needs differ through time and phases in the process of being chronically ill. The needs may vary per individual, but also across the different illness stages; someone who has been recently diagnosed with a chronic condition requires a different coping behaviour than someone who has been diagnosed with this same condition a number of years ago (Moos & Holahan, 2007; van Houtum, Rijken, Heijmans & Groenewegen, 2013; van Houtum et al., 2015). A study amongst chronically ill patients showed that patients mostly needed support in coping with the consequences of living with a chronic condition (Heijmans, Spreeuwenberg & Rijken, 2010). Though patients need support in everyday life and biographical work, this aspect is often not sufficiently addressed in contacts with health care professionals (Satink et al., 2013).

### Self-management support as an assignment for the nursing profession

More than other health care professionals, nurses are considered to be eminently suited to support people with chronic conditions (Alleyne, Hancock, & Hughes, 2011; Lukewich, Mann, VanDenKerkhof, & Tranmer, 2015; van Houtum, Heijmans, Rijken, & Groenewegen, 2016). They are regarded as thrustworthy and they have been trained to maintain a person-centred approach in their care activities (Alleyne et al., 2011; Jonsdottir, 2013). Patients' self-management activities involve partnering with health care professionals, decision making and tailoring advices to one's own situation. This implies that nurses should partner with patients and hold a holistic view on nursing. Nurses should support patients with activities they are not able to do by themselves, in a way that they themselves would perform these activities. In order to do so, nurses should hold an interest in the patients' lives and motivations and accept that patients make their own choices (Grypdonck, 1996; Pool, Mostert, & Schumacher, 2004). Many nurses have learned to work according to the self-care deficit nursing theory of Orem, which in its origin is person-centred. In contrast to 'nursing care', the perspective of self-care comes from the person whom it concerns (Denyes, Orem, & Bekel, 2001). The self-care theory also implies active patient participation, for Orem already described the importance of patients taking more responsibility for their own health (Orem, Taylor, & Renpenning, 1995). Patients are regarded as active, powerful and unique agents (Taylor & Renpenning, 2011). Other nursing theories advocate a holistic and a person-centred approach as well: e.g. Roy's adaptation model, Roger's theory, Newman's Health Care System model (Papathanasiou, Sklavou, & Kourkouta, 2013).

In the new Dutch professional profiles of nurses, self-management support is mentioned as a key feature of nursing; nursing interventions should aim at 'increasing patients' self-management' (Schuurmans, Lambregts, Grotendorst & Van Merwijk, 2012). Not only the nursing profession, but also other actors in the health care context have emphasized the importance of encouraging patients' self-management. Self-manage

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ment has gained growing attention because of the increasing prevalence of people with chronic conditions, due to modern technology and higher living standards (Hoeymans et al., 2014; Westerlaken, 2013; WHO, 2005).

Although nurses play an important role in self-management support, it is not clear what kind of role this should be. Self-management is a contested concept, because it has a variety of definitions and is interpreted in many different ways, by many different stake-holders (Koch, Jenkin, & Kralik, 2004; Jonsdottir, 2013; Sattoe, Bal, van Staa & Bal, 2015). Nurses' role in self-management support is shaped and can be altered by these different stake-holders and interpretations (Barker, Reynolds, & Ward, 1995).

In policy documents, self-management is regarded as one of the means to reduce the growing health care expenditure which comes with the increase of chronic conditions (Henkemans, Molema, Franck & Otten, 2010; Kaljouw & van Vliet, 2015; RVZ, 2010a, 2010b). Self-management is expected to facilitate patients to monitor their condition themselves, and to seek for solutions in their own social network above professional help (Besseling, van Ewijk, & van der Horst, 2013; Esmeijer, van der Klauw, Bakker, Kotterink & Mooij, 2014; RVZ, 2010c). For some time now, there have been pleas to incorporate self-management in the definition of health, which was recently repeated by Huber et al. (2011) as 'the ability to adapt and to self-manage'. This view on health also represents a new view on the role of patients. Patients are more and more encouraged to actively participate in their own health care process and be involved in shared decision making (RVZ, 2010c; Udlis, 2011).

Many health care professionals regard self-management predominantly as a means to increase adherence (Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011; Sadler, Wolfe, & McKevitt, 2014). The role of nurses then would be to monitor and instruct patients to achieve these outcomes.

Due to patient emancipation, which started in the 1960s, the patients' voices are now more recognized (Kendall et al., 2011). The position of the patients is strengthened by (Dutch) law in which is stated that patients should be informed, should be offered choices, and should receive care of good quality (WBGO and WKKGZ). According to this interpretation, the focus of self-management support lies on all the aspects of the patients' lives. Nurses are required to address all the three domains of Corbin and Straus, implying paying attention to more than the medical and physiological aspects of the chronic condition (Corbin & Strauss, 1985). Giving patients the right to make their own choices concerning their health and to actively participate in medical decision making influences the relationship between patients and nurses. The relationship evolves towards a relationship based more on partnership than on a paternalistic relationship (RVZ, 2010c).

Thus, various stake holders such as people with chronic conditions, health care providers, and policy makers use self-management as a means to various ends. This unclarity of the concept of self-management may lead to confusion about the nurses' role in self-management support.

### Self-management in nursing practice and in nurse education

Apart from a lack of consensus on the concept of self-management, it is not clear how nurses could support patients' self-management process. It is not self-evident what nurses should do or stop doing when they are expected to support patients' selfmanagement. Literature offers no clear answer to the guestion which interventions are successful. Self-management support interventions are often complex interventions, because they consist of multiple, interacting components (Campbell et al., 2000). These components include e.g. the underlying theory of the intervention, characteristics of the nurse who carries out the intervention, or the means used for the intervention (Clark, 2013). Therefore, the effectiveness of interventions is often difficult to determine, since many of these interacting factors are of influence on the success of the patients' self-management (Bonell, Fletcher, Morton, Lorenc & Moore, 2012; Coster & Norman, 2009). Self-management interventions often involve patient education, but patient education alone does not guarantee successful self-management skills (Barlow et al., 2010; Coster & Norman, 2009). Patients may also need other kinds of support in acquiring skills related to problem solving, decision making, action-taking, resource utilization, partnering with health care professionals, or tailoring information; i.e. the skills required for adequate self-management (Lorig & Holman, 2003).

Recently, a new framework for the education for Bachelor of Nursing was developed (LOOV, 2015), based on the new Dutch professional profile of nurses (Schuurmans et al., 2012). Just as in the professional profiles, self-management is described as one of the key features of the nursing profession. It is also stated that, with the current developments in health care, nurses need competencies regarding the use of technology, quality improvement, and holding a broad perspective on health care (Kaljouw & van Vliet, 2015; RVZ, 2010c; WHO, 2005). This implies that nurse education should revise its curriculum in order to prepare nurse students sufficiently for these new challenges (Westerlaken, 2013). By this, reflection on the current status of self-management support in nursing education has become a matter of urgency. So far, nurses' competencies for self-management support have only been described in a broad way, as 'supporting self-management', or 'partnering with patients' (WHO 2005). Furthermore, the competencies are either not specifically described for nurses (Lawn et al., 2009; Pols, 2009), or described only for a specific group of nurses, e.g diabetes specialists nurses (NDF, 2013). A clear set of essential competencies for self-management support could facilitate nurses to knowing what to do and it could facilitate nurse education knowing what to teach.

In short, self-management is an assignment for nurses that receives increasing attention. At the same time, self-management is a contested concept, lacking a uniform and well-accepted definition. As a consequence, the required competencies of nurses for self-management support are rather vague and unclear; the interventions are complex and it is not evident which of them work and for whom in which context. The role that nurses should play in self-management support is therefore not evident . Moreover, the current curriculum has to adapt the new educational framework in which selfmanagement support is one of the central themes. But it is not yet clear what is currently being taught about self-management support in nurse education. This thesis intends to illuminate some of these unclarities and add to our understanding of self-management support by nurses and the ways in which competencies for self-management support might be introduced in nursing education.

### The main question in this thesis is:

What is the role of nurses in self-management support, what competencies are needed to fulfill this role, and how does the Dutch Bachelor of Nursing education prepare nurses for these competencies?

In this thesis, the research question is explored in three parts: the nurses' role in selfmanagement support, competencies for self-management support, and teaching on self-management support. Below, these themes are introduced through a presentation of the lay-out of the thesis.

### **THIS THESIS**

### Thesis outline and methodological approach (Figure 1)

### PART I Nurses' role in supporting patient self-management

PART I contains two chapters about the nurses' role in supporting patient self-management. It is not yet clear what the perspectives of nurses with regard to self-management support are.

Besides, because of the variety of aims, it is also not always apparent what nurse-led self-management interventions achieve. The aim of the studies of PART I therefore is to explore the role of nurses in self-management support (what is expected of nurses and how do they perceive their own role in the self-management process?).

Chapter 2 describes the perspectives nurses have about self-management. These are derived from a Q-methodological study with 39 nurses from a variety of settings. The Q-methodology was developed to study peoples' attitudes towards a certain topic. Participants are to sort statements concerning the specific topic. The gathered sorts then

are analysed with a by-person factor analysis, which reveals distinctive perspectives on this topic.

The realist review of 38 studies in Chapter 3 provides an overview of mechanisms in self-management interventions. This type of review was developed to determine what works for whom. It tries to explain why interventions do or do not work, rather than evaluate the interventions by its outcomes.

The research questions in this part of the thesis are:

- 1. What are the distinct perspectives of nurses towards self-management support in chronic care? (Chapter 2)
- 2. How do nurse-led interventions for supporting self-management of outpatients with chronic conditions work and in what contexts do they work successfully? (Chapter 3)



### CONCLUSION & GENERAL DISCUSSION

Figure 1. Thesis outline and methodological approach

### PART II Nurse competencies for self-management support

Self-management support requires specific competencies of nurses, especially with regard to partnering with patients. Until now these competencies are not well-defined. The aim of the studies in PART II is to identify the essential competencies for self-management support and whether nurses believe they master these competencies.

The development of the SEPSS (Self-Efficacy and Performance in Self-management Support), a questionnaire with the essential competencies for self-management support, is described in Chapter 4. The validation of this instrument involved 472 (Belgium and Dutch) nurses from a variety of settings, and 51 nurse students from Belgium. Chapter 5 describes the results of the cross-sectional study with a self-reported questionnaire about factors that influence self-management support behaviour of nurses. In this study 347 nurses from a university hospital participated.

The research questions for this part of the thesis are:

- 3. What are the essential competencies for self-management support, and how can nurses' behaviour and their perceived capacity with regard to these competencies validly and reliably be measured? (Chapter 4)
- 4. What is nurses' self-reported behaviour with regard to self-management support, and what factors influence this behaviour? (Chapter 5)

### PART III Teaching self-management support

PART III involves Bachelor of Nurses education in the Netherlands. Nurse education is expected to adjust its curriculum to the demand in current health care where supporting patient self-management is an important feature. It is unclear how nurse education prepares its students in supporting patient self-management. The aim of the study in PART III is to explore how self-management support is being taught in Dutch universities of applied sciences for Bachelor of Nursing. This lead to the research question:

5. What is the intended, the taught, and the received curriculum with regard to selfmanagement support in Dutch Bachelor of Nursing education? (Chapter 6)

Chapter 6 provides insight in how and when self-management support is being taught in the curricula of four Universities of Applied Sciences in the Netherlands. The curriculum scan involved screening of the learning objectives for the presence of the essential competencies for self-management support. In addition, we held individual and group interviews with teachers, (assistant) professors, and managers (with a total of 39 participants). Also, 238 fourth-year nurse students of these four universities completed a questionnaire about self-management support.

The thesis concludes with the results of the studies, methodological considerations and a general discussion about the role of nurses in self-management support.

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Nurses' role in self-management support





### Chapter 2

Four perspectives on self-management support by nurses for people with chronic conditions: a Q-methodological study

Susanne M. van Hooft, Jolanda Dwarswaard, Susan Jedeloo, Roland Bal & AnneLoes van Staa

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### ABSTRACT

### Background

Self-management support is a major task of nurses in chronic care. Several conceptualizations on what self-management support encompasses are described in the literature. However, nurses' attitudes and perceptions related to self-management support are not known.

### Objective

To reveal distinctive perspectives of nurses towards self-management support in chronic care.

### **Design and methods**

A Q-methodological study was conducted in which nurses rank-ordered 37 statements on self-management support. Thereafter they motivated their ranking in semi-structured interviews.

### Participants and setting

A purposive sample of 39 Dutch nurses with a variety of educational levels, age, and from different healthcare settings was invited by e-mail to participate in the study. Thirty-nine nurses (aged 21-54) eventually participated. The nurses worked in the following settings: hospital (n=11, 28%), home-care (n=14, 36%), mental health care (n=7, 17%), elderly care (n=6, 15%) and general practice (n=1, 3%).

### Results

Four distinct perspectives on the goals for self-management support were identified: the Coach, the Clinician, the Gatekeeper and the Educator perspective. The Coach nurse focuses on the patient's daily life activities, whereas the nurses of the Clinician type aim to achieve adherence to treatment. The goal of self-management support from the Gatekeeper perspective is to reduce health care costs. Finally, the Educator nurse focuses on instructing patients in managing the illness.

### Conclusions

The changing role of chronic patients with regard to self-management asks for a new understanding of nurses' supportive tasks. Nurses appear to have dissimilar perceptions of what self-management support entails. These distinct perceptions reflect different patient realities and demand that nurses are capable of reflexivity and sensitivity to patient needs. Different perspectives towards self-management support also call for diverse competencies and consequently, also for adaptation of educational nursing programs.

### What is already known about the topic?

Self-management support requires a major effort from nurses as they play a key role in care for people with chronic conditions.

Studies on health care professionals' attitudes or beliefs towards self-management revealed that health care professionals are not comfortable with patients making independent choices based on their patient expertise.

### What this paper adds

This paper reveals four perspectives towards self-management support of patients with chronic conditions: the Coach perspective, the Clinician perspective, the Gate-keeper perspective and the Educator perspective.

The perspectives differ with regard to the understanding of the patients' and the nurses' role, the characterization of the nurse-patient relationship, and to the goal of self-management support.

### BACKGROUND

The academic debate on the concept of self-management support in health care has paid scant attention to nurses' perceptions towards self-management support (Jonsdottir, 2013; Udlis, 2011; Wilkinson & Whitehead, 2009), although these perceptions may influence the type of support they will provide (Anderson and Funnell, 2005). It is essential therefore that these perceptions are taken into account, whilst appreciating that perceptions may differ, dependent on the goal pursued. Improving chronic patients' self-management skills is aimed at reducing health care expenditure, improving quality of life of the patient, or helping health care professionals in controlling therapy compliance (Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011; Redman, 2007). The literature presents a variety of definitions of self-management (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Jonsdottir, 2013). As it presents a holistic and patient-centred view on self-management, we have adopted the definition by Barlow et al. (2002, p. 178): "Self-management refers to the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established". Assessing nurses' understanding of their role and tasks in self-management support requires a broad exploration of the concept of self-management. Schulman-Green et al. (2012) identified three categories of self-management processes from the perspective of the chronically ill: Focusing on illness needs, activating resources, and living with a chronic illness. 'Focusing on illness needs' refers to all kind of tasks related with medical topics such as learning about the illness, taking medicines and management of symptoms. 'Activating resources' refers to different resources such as healthcare and social support. 'Living with a chronic illness' encompasses processes related to daily life, such as activities of daily living, housekeeping or occupational work. Coping with the emotions of adjusting one's life to a chronic illness also falls under this category. Much earlier, Corbin and Strauss (1985) had made a guite similar distinction, in terms of 'illness work', 'everyday life work', and 'biographical work', brought together under the overarching concept of 'articulation work', enabling choice between the other types and distribution of work across actors. 'Illness work', then, is comparable with the 'illness needs' as described by Schulman-Green et al. (2012) while 'everyday life work' and 'biographical work' match 'living with a chronic illness'. Distinguishing between patient tasks is important to identify areas on which people with a chronic disease might need support, and thereby defines the nursing role in self-management support. This approach expands the role of health care professionals in self-management (Coleman & Newton, 2005; Lorig & Holman, 2003). Informing a patient about the illness and thereby solely addressing patients' 'illness needs' is no longer sufficient; patients' coping skills and ability to activate resources must also be addressed (Coleman & Newton, 2005; Elissen et al., 2013).

Nurses are assigned a major role in self-management support because they are expected to understand how living with a chronic disease would impact the daily life of patients (Alleyne, Hancock & Hughes, 2011). This expectation has implications for nurses working in chronic care. Not only do they need to acquire new competencies (WHO, 2005), they also must accommodate a shift from 'feeling responsible for' towards 'feeling responsible to', implying a shift in the relationship between the nurse and the patient towards shared decision making (Jonsdottir, 2013; Wilkinson & Whitehead, 2009).

Several studies have investigated health care professionals' attitudes or beliefs towards specific aspects of self-management. Aasen, Kvangarsnes, & Heggen (2012) identified three kinds of nurses' perceptions of participation in end-of-life decisions of relatives of patients: paternalism, participation, and independent decision-making. Thorne, Ternulf Nyhlin, & Paterson (2000) and Wilson et al. (2006) addressed nurses' attitudes towards patient expertise. Both groups concluded that health professionals were not comfortable in dealing with expert patients or relatives. Another study found that physicians generally preferred patients to follow their medical advice and had reservations towards patients making their own independent choices (Hibbard, Collins, Mahony & Baker, 2010). Other studies showed that health care professionals acknowledged they needed additional skills for self-management support (Jones, Livingstone, & Hawkes, 2013; Mikkonen & Hynynen, 2012). Still, perceptions of nurses working in diverse health care settings on the concept of self-management support as a whole have not yet been systematically studied. In this paper we report the findings of a Q-methodological study which aimed to reveal different nurse perspectives on self-management support.

### **METHODS**

### Q-methodology

Q-methodology was developed by Stephenson in the 1930s to study values and beliefs of people (Stephenson, 1935). Q-methodology has proved to be an adequate method to reveal nurses' perspectives on issues relevant for nursing practice (Akhtar-Danesh et al., 2008). Other Q-methodological studies have investigated preferences of chronically ill adolescents (Jedeloo et al., 2010), addressed childhood obesity (Akhtar-Danesh et al., 2011), or explored attitudes of chronically ill patients regarding self-management (Dickerson et al., 2011; Kim et al., 2006; Stenner et al., 2000).

In Q-methodological studies, data are gathered in the form of Q-sorts. A Q-sort is a collection of statements, or any other sort of item, which are sorted by the participants according to a subjective dimension such as "agree most" versus "disagree most". By sort-

ing the statements, the viewpoint of the person on the issue is constructed. The Q-sort is pre-prepared by the researcher on the basis of statements about the subject from a variety of sources (Watts & Stenner, 2012).

Collected Q-sorts are compared and contrasted through by-person factor analyses. That is, the factor analysis seeks to find groups of persons who have rank-ordered the statements in a similar way, whereas 'normal' factor analysis seeks to find correlation between items (Watts & Stenner, 2012). Shared values are clustered and interpreted, resulting in the delineation of factors or profiles of shared attitudes towards the topic investigated. The percentage of variance explained demonstrates how much of the full range of meaning and variability in the study has been captured (Watts & Stenner, 2012).

Q-methodology does not provide information about the distribution of these viewpoints among the study population, nor does it reveal the association of viewpoints with personal characteristics (Cross, 2005). This Q-methodological study was conducted in four sequential steps, described in the next sections.

### Step 1. Statements

The first step of a Q-methodological study is the design of the collection of representative statements. These statements should cover all the relevant ground on a subject (Watts & Stenner, 2012), and might be collected from interviews, newspapers, talk shows (Brown, 1993) or websites. In this study, we started with an unstructured approach of creating the statements (Watts & Stenner, 2012). A broad range of opinions on selfmanagement support was selected via websites of stakeholders, policy documents and journal articles. In addition, information was extracted from transcriptions of qualitative interviews with nurses about their perceived tasks in self-management support from another study by our research group. In total 242 statements on self-management support were collected. Three researchers (SH, JD & SJ) made a first selection by sorting out duplicates. This resulted in a set of 71 statements. We ensured the balance and representativeness of this set by comparing the statements using the Five A's cycle model (Glasgow, Davis, Funnell & Beck, 2003; Whitlock, Orleans, Pender, & Allan, 2002) and the Chronic Care Model (Wagner et al., 2001). The 'Five-A's cycle' is a framework with a counselling approach, entailing a series of sequential steps (Assess, Advise, Agree, Assist, and Arrange). This approach emphasizes collaborative goal setting, patient skill building to overcome barriers, self-monitoring, personalized feedback, and systematic links to community recourses (Glasgow et al., 2003; Whitehead, 2003). The Chronic Care Model contains all aspects the patient and the health care professional may encounter in their collaborative process of self-management (Wagner et al., 2001).

Supplementary to the use of these theoretical frameworks, content validity was also assessed by consulting other researchers engaged in self-management, experts from the national nursing organization and expert nurses (n=8). When there was disagree-

ment on a statement; we kept the statement in the set (Akhtar-Danesh et al., 2008). This procedure resulted in a preliminary set of 37 statements for use in a pilot study to test face validity. In this pilot study, four participants of different age and educational level sorted the statements and were interviewed afterwards to elicit opinions on the phrasing of the statements. They were also given the opportunity to add statements or themes to the set, but refrained from doing so. Then, a final revision was performed: two statements were rephrased because they were considered ambiguous. The final set of statements contained 37 statements (Table 1).

		Factor arrays			
		Coach	Clinician	Gatekeeper	Educator
1.	You should stimulate every patient to become a good 'self-manager'	1	1	-2*	2
2.	It is necessary to monitor the patient to prevent worsening of health status	-1	1	-1	1
3.	You have to give attention to the skills a patient needs in order to manage his condition	1°	2°	1°	2°
4.	You should give the patient the liberty to choose for not being treated	0	0	3*	-1
5.	You need to offer solutions for problems the patient encounters	-2	1#	0#	-3
6.	You should collaborate with the patient based on partnership	2*	0	0	3*
7.	You are allowed to intertwine your own goals with the goals of the patient	-1	0	0	-1
8.	You should always provide options for the patient	0°	1°	0°	2°
9.	Self-management support is teamwork	1	3#	-1*	2
10.	Self-management support is difficult	-2#	0	0	0
11.	You should not refrain from giving unsolicited advice to the patient	-1	1	2#	0
12.	You have to set goals together with the patient	2°	2°	1°	3°
13.	Self-management is nothing new	0°	-1°	1°	-1°
14.	Self-management support mainly is a matter of patient education	-1	-1	-1	1#
15.	You have to intensify the support of the patient who makes an unhealthy choice	0°	0°	0°	0°
16.	You must unconditionally accept the choice of the patient, even if this deviates from your perception of good care	0	-2	-2	-1
17.	As a health professional you are responsible if the patient is not faring well	-1	-3	-3	-1
18.	The patient's experience is as valuable as my professional knowledge	2	0	1	-1

#### Table 1. List of statements with composite factor scores.

### Table 1. List of statements with composite factor scores. (continued)

		Factor arrays			
		Coach	Clinician	Gatekeeper	Educator
19.	You should only support the patient if he asks for it	-1	-1	-2	-3
20.	Self-management should contribute to affordability of health care	0	0	3*	0
21.	Self-management support is only feasible if we reorganize health care	1	-1	0	-2
22.	You make people dependent on health care by using self-management tools	-3#	0*	-2	-2
23.	Care at a distance can replace the physical presence of health care professionals	1	-2	1	-2
24.	Self-management support is time-consuming for the health care professional	-3*	-1	-2	0
25.	You have to let the patient decide what to discuss during contact moments	0	0	-3#	-1
26.	Good self-management support should lead to lesser need of professional health care	0	-2*	2	1
27.	Self-management support should achieve that the patient is better able to integrate his disease into his life	3	2	0	1
28.	In stimulating self-management you should give priority to the patient's life goals rather than the treatment goals	2#	-1	-1	0
29.	The ultimate goal of self-management is adherence to treatment	-2	3*	-1	0#
30.	Good self-management support requires other knowledge and skills than those health care professionals are being taught now	1	1	0	-1
31.	The patient's social environment is key to successful self-management	0	0	-2	0
32.	Modern technology should be used to support self- management	1°	0°	0°	0°
33.	An individual health care plan is essential for successful self-management	3°	2°	2°	1°
34.	You should always be available to the patient	0	1	-1	-2
35.	The health care professional should have a limited role in self-management support.	-2	-2	0	0
36.	Self-management should be discussed in each contact with the patient	0	-1#	2#	0
37.	Self-management requires you to interfere in the patient's private life	-1	-3*	0	0

Note: "-3" indicates that nurses with that perspective on (weighted) average disagree most with that statement; "3" indicates nurses holding that perspective on (weighted) average agree most with that statement (rank-ordered at extreme left/ right in Fig. 1, respectively).

# Distinguishing statements for a factor are indicated (p<.05).

\* Distinguishing statements for a factor are indicated (p<.01).

° Consensus statements - those that do not distinguish between any pair of factors

### Step 2. Participants

The purpose of a Q-methodological study is to identify different opinions on a topic, instead of generalization (Akhtar-Danesh et al., 2008). A limited sample is sufficient, therefore, as long as this sample holds a maximum variation of opinions (Watts & Stenner, 2012). We invited a purposive sample of 49 registered nurses, representing a diversity of education, age, areas of nursing, work experience and gender (Table 2). Participants were recruited from our professional network in the Rotterdam - the Hague area, and invited to participate in the study by e-mail. Recruitment was with the snowball method: participants who completed the Q-sorting were asked to suggest other nurses whom they expected to have a different opinion on self-management.

		e	eper	r	ded	(%)
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HC setting						
Hospital	3	2	1	2	3	11 (28)
Home-care	6	1		2	5	14 (36)
Mental health care	1	2	1	2	1	7 (17)
Elderly care	2	1	1		2	6 (15)
General Practice				1		1 (3)
Education						
Master Advanced Nursing Practice (level 7)	2	1		2	1	6 (15)
Bachelor of Nursing program (level 5)	8	2	2	3	8	23 (59)
Basic nursing degree (level 4)	2	3	1	2	2	10 (26)
Age group						
≤30	5	3	1	2	3	14 (36)
31-40	1	1		3	2	7 (17)
41-50	2	1	1	2	4	10 (26)
≥51	4	1	1		2	8 (21)
Gender						
Male		2	2	1		5 (13)
Female	12	4	1	6	11	34 (87)

 Table 2. Distribution of participants significantly loading on perspectives by health care setting, education, age group and gender (n=39).

### Step 3. Sorting the statements

The statements were printed on separate cards with random numbers. The participants were asked to read the statements carefully and then sort them in three piles: agree, disagree, or neutral. Thereafter, they sorted the statements even more precisely on a

Q-sort table with a forced-choice frequency distribution (Figure 1) on a range from '- 3 agree least' until '+3, agree most'. This forced participants to make choices about which is more and which is less important to them. Next, participants in face-to-face interviews explained their motivations for the choice of the statements sorted on -3 and +3, and at random about other statements. The interviews lasted between 10 and 65 minutes and were recorded and transcribed ad verbatim.



Figure 1. Forced-choice frequency distribution in Q-sort

### Step 4. Analysis

The individual Q-sorts were subjected to a by-person factor analysis (centroid factor analysis with varimax rotation), using PQMethod version 2.33 (Schmolck, 2002). Q-sorts that loaded significantly on a particular factor did so because they had similar sorting patterns. This might suggest shared viewpoints towards self-management support. These Q-sorts had correlations of at least 0.6 on any one factor and no more than 0.4 on any other factor (Jordan et al., 2005). The correlation was calculated by weighted averaging (Watts & Stenner, 2012). In the factor analysis phase, these shared viewpoints were integrated into one single average Q-sort, a factor array. The factor arrays formed the basis of the different factor interpretations. The goal of factor interpretation is to fully understand and explain the shared viewpoint of the participants whose Q-sort was captured by the factor. The significant statements form the basis of the interpretation but do not fully explain the factors. Participants may agree or disagree with a statement for different reasons. Thus, the explanations derived from all the Q-sorts that loaded significantly on the particular factor are used for these interpretations. Based on a Q-set
Four perspectives on self-management support

of 37 statements and p<.01, the factor loading of a Q-sort must be equal to or higher than .42 (Watts & Stenner, 2012). The factor loadings and the interview data served as input for the description of the perspectives on self-management support.

# **Ethical considerations**

All nurses received written information about the study and gave their verbal informed consent. The nurses volunteered and did not receive a reward in return for their participation.

# RESULTS

# Response

Of the 49 nurses who were invited, thirty-nine eventually participated. Four declined because of lack of time, and six did not respond to the e-mail message, not even after a reminder.

Data were collected in March-June 2013. Table 2 shows the characteristics of the participants as well as the distribution of the distinct perspectives among them.

# Analysis

By-person factor analysis of Q-sorts with correlations of at least .6 on any one factor and no more than 0.4 on any other factor revealed a four factor solution, indicating four distinct perspectives on self-management support. According to this criterion eleven Q-sorts loaded strongly on one factor but not on the others. These Q-sorts helped to determine the four factor solution. More participants loaded significantly (>.42) on each separate perspective (these are the so-called exemplars: the Coach n=12, the Clinician n=6, the Gatekeeper n=3, the Educator n=7). Each factor explained 7 to 16% of the variance, 45% in total. Correlation between the factor arrays ranged from low (r=.18) to moderate (r=.46). The lowest correlation was between the Clinician perspective and the Gatekeeper perspective, indicating that these two perspectives were the most distinct. The highest correlation was between the Coach perspective and the Educator perspective, indicating that these two perspective and the Educator perspective, indicating that these two perspective and the Educator perspective, indicating that these two perspective and the Educator perspective, indicating that these two perspective and the Educator perspective, indicating that these two perspective and the Educator perspective, indicating that these two perspectives have the most in common.

Table 1 presents the list of the statements with the factor arrays. Seventeen of the 37 statements showed significant differences between the factors (p<.05). These 17 statements formed the basis of the interpretation of the factors, complemented with the qualitative analysis which was conducted in three steps. In the first step, the transcripts of the interviews were read carefully and summarized to acquire an overview of the participants' perspectives about self-management. Then patterns were explored among

the participants loading significantly on one factor. Finally, their argumentation with regard to the distinguishing statements was used for the factor interpretation.

In the next sections, the four perspectives will be described.

#### The Coach perspective

'It is the patient's life. He is the one who has to deal with his own chronic condition for 24 hours a day, seven days a week. [...] These people already do a lot when it comes to managing their condition. One cannot say that they do too little or nothing at all. One just can't.'

We named this perspective the Coach perspective because nurses who adhere to this view see it as their main goal to support patients in incorporating their chronic condition into their lives. Self-management is regarded as a natural part of patients' life (3; *numbers in brackets referring to Q-sort statements in Table 1*) and subsequently, self-management support is seen as a self-evident, natural task for nurses (27, 2). Supporting self-management is not regarded as time-consuming (24) or as a difficult task (10). Still, self-management support requires different skills and attitudes than nurses have learned thus far (30): nurses should learn to keep their own opinion to themselves, to refrain from giving unsolicited advice and rather not come up with solutions (5, 11). Using self-management tools will not make patients more dependent on health care (22).

Nurses with the Coach perspective have a holistic view and focus on the abilities and needs of the patient. One participant stated: 'Good self-management support is only possible if you look at the holistic person, if you open up all your senses and look at what this person needs.'

Nurses within the Coach perspective consider the patient as an expert in living with the particular chronic condition (18). More than in the other three perspectives, patients should co-decide what will be discussed with healthcare professionals and are regarded as a partner (6, 25). These nurses also think that patients' needs should be leading in health care (28), requiring the reorganization of health care (21).

Twelve participants loaded significantly on this factor. These were all women, with different educational level (level 4, 5 and Master Advanced Nursing Practice). Ages varied from 21 to 54 years. They worked in hospitals, home care, mental health care, and institutionalized elderly care.

#### The Clinician perspective

'Adherence is the starting point. This is the prerequisite for patients to be discharged.'

In this perspective, which we named the Clinician perspective, self-management support is teamwork (9), and foremost a means to foster adherence (29). Yet, self-management itself is not a regular topic of conversation with the patient (36). Self-management does not need to lead to less professional support (26). The nurses who adhere to this

perspective consider it important to regularly monitor the condition of their patients (2); monitoring is easily accomplished via direct contact between the patient and the nurse (23). Therefore, the patient should be facilitated to contact the nurse at all times (34). The patient-nurse relationship is a goal-oriented relationship in this perspective. The personal life of the patient is beyond the scope of the nurse (37), and personal (life) goals of the patient are secondary to medical goals (28). One participant commented: *'What would be the advantage of interfering with the personal lives of patients?'* 

These nurses believe that solely providing education or information is not sufficient; they should also propose recommendations and solutions for problems the patient encounters (11, 5, 14). The patient is not always considered capable of making the best choices and thus nurses cannot always accept patient choices (16), but need to direct the patient towards better choices in terms of adherence. One participant commented: 'There are some boundaries within which the patient has to stay in order to secure safety. For that reason, sometimes you have to take the lead and give them options for choices they don't want to make at all.'

According to this perspective, the professional knowledge of the nurse is valued higher than the expertise of the patient (18), as one participant stated: '*Not all experiences are good experiences*.'

Six participants loaded significantly on this factor. These were four women and two men, with different types of education. Ages varied from 21 to 53 years. They worked in the hospital setting, home care, mental health care, and elderly care.

# The Gatekeeper perspective

'As a nurse you have a societal function. You have to defend general interests in health care, and health care should remain affordable for a lot of people.'

In this perspective, which we named the Gatekeeper perspective, the goal of selfmanagement is to reduce public expenditure (20). The nurse takes the lead and determines which topics will be discussed with the patient (25). A participant expressed: '*As a professional you have a broader view.* [...] You have to discuss topics the patient does not bring up himself.' More than in the other three perspectives, it is important to promote self-management during each contact with the patient, so as to stimulate the patient to become more independent of health care (26, 36). The nurse with the Gatekeeper perspective also proposes solutions and recommendations for problems the patient encounters (5, 11). A participant commented on this: 'It is part of being a good health care professional to act when you notice a conflict between the choice of a patient and the 'healthy' choice.' Nevertheless, the patient has the right not to be treated (4) and the nurse does not feel responsible if the patient does not do well (17). One participant explained: 'The nurse is responsible for giving advice and possible solutions. Not for the outcome of these.' Self-management is not necessarily something in which the whole team is involved (9). Unlike the nurses with other perspectives, the nurse who adheres to this perspective feels that not every patient should be stimulated to become a good self-manager of his chronic condition (1).

Three participants loaded significantly on this factor. These were one woman and two men, with different types of educational level. Ages varied from 28 to 53 years. They worked in the hospital setting, mental health care, and elderly care.

#### The Educator perspective

'You want the patient to do it himself. You practice together if it is necessary and you then inform him once again.'

From the Educator perspective, collaboration with the patient is an essential aspect of self-management (6, 12). The goal of self-management is not necessarily adherence (29); the patient is considered to be a good self-manager when he is capable to act in unexpected situations related to his chronic condition. While in the Coach perspective the focus lies on maintaining a good life, the Educator believes the illness itself is the leading factor. The role of the nurse is important (35); the nurse takes the initiative to support the patient (19) and professional knowledge is valued higher than patient experience (18). One participant explained why: 'Sometimes, ignorance plays a part. As a health professional it is my duty to support patients and especially to give information, even when the patient does not ask for it.' Providing health education (14) is an important skill for nurses to enable the patient to manage his condition. Sometimes the nurse has to monitor the patient's clinical condition (2), for which she believes physical contact is required (23). Self-management support is sometimes perceived as difficult (10) and, more than in other perspectives, time-consuming (24). In this regard, a participant stated: 'Sometimes, it is difficult. You can't have a partnership with everyone [...] You are inclined to come up with solutions yourself, but you have to let them think for themselves to come up with something they feel content with.'

Unexpected situations that bear on the chronic condition should be managed by the patient himself, rather than resorting to contacting the health care professional (34). One participant commented: 'You have to make sure someone is capable of managing himself, which is my goal. Then you don't have to be available at all times [...] He should not call saying: "I have this or that, what should I do now?" He has to <u>know</u> what to do.'

Seven participants loaded significantly on this factor. These were six women and one man, with different types of educational level. Ages varied from 26 to 50 years. They worked in the hospital setting, mental health care, and elderly care.

#### Consensus about self-management support

Consensus (i.e. number of statistically non-significant difference in ranking statements between any pair of perspectives; p>.05) was found on seven statements. In all four

perspectives, self-management is not something new (13) and it is important to pay attention to the skills a patient needs to manage his condition (3). Nurses are expected to collaborate with patients through developing goals together, use an individual health care record, and give the patients options of choices (8, 12, 33). The participants were neutral about the statement suggesting to increase support when a patient makes an unhealthy choice and the one about the use of modern technology (15, 32). It is worth mentioning that statistical consensus does not necessarily imply agreement between participants about a statement. For instance, attitudes on the purpose of an individual health care record so that the team knew what was agreed with the patient, while the Coach nurse emphasized the individualized aspects of the health care record.

## DISCUSSION

This study revealed four distinct perspectives of nurses on self-management support. Self-management support seems to be an obvious task for nurses (Alleyne et al., 2011); it has a central position in the Dutch new general nursing competencies (Lambregts &Grotendorst, 2012). Consistent with the current debate in the literature (Bodenheimer et al., 2002; Jonsdottir, 2013; Kendall et al., 2011), we could conclude that nurses hold different interpretations of self-management support. Main differences between the perspectives were related to the goal of self-management support, the role of the nurse and the role of the patient (Table 3). The goal of self-management support from the Coach perspective is to help the patient to incorporate the disease into his life. In the Clinician perspective adherence is the most important goal, as a means to gain control over the disease (Yen et al., 2011). The disease also has a central position in the perception of nurses with the Educator perspective, who focus on teaching their patients problem solving skills. In contrast, the Clinician nurse places an emphasis on providing solutions for problems patients may encounter. The goal of self-management support in the Gatekeeper perspective is quite different from that in the other three perspectives; namely to reduce costs and support rational decision making. Although gatekeeper behaviour was also found in a study about healthcare professionals' attitudes towards patient expertise (Anderson & Funnell, 2005; Thorne et al., 2000), the present finding that nurses may assume a gatekeeper role is new in the context of self-management support. Nurses with the Clinician and the Educator perspectives placed professional knowledge above patient experiences, which is in line with other studies that revealed that health care professionals had difficulty acknowledging patient expertise as valuable factor in the care of patients with chronic conditions (Thorne et al., 2000; Wilson et al., 2006). Rather, they relied on their own professional knowledge and even tended to share this

Characteristic			
Perspective	Patient role	Nurse role	Goal of self-management support
Coach	expert	following	incorporate chronic condition in life
Clinician	compliant	prescriptive	patient adherence good clinical patient outcomes
Gatekeeper	independent	in the lead	reduction of health care costs
Educator	active student	teaching	live with chronic condition good clinical patient outcomes

<b>Table 5.</b> Main characteristics of the four perspectiv	able 3.	Та	<b>3.</b> Mair	i characteristics	of the f	four pe	erspective	S.
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knowledge if patients did not comply with therapy, even when lack of knowledge was not the issue (Thorne et al., 2000). Both the Clinician nurse and the Educator nurse aim at good clinical patient outcomes and believe that regular monitoring is important. This is consistent with a study by Elissen et al. (2013) on self-management in practice, which, however, also showed nuances of perceptions on the importance of monitoring.

Attitudes of nurses towards self-management and the consequential perspectives are in part defined by the type of patients they care for (Barlow et al., 2002). Psychiatric patients might require a different approach to self-management support than frail elderly people (Haslbeck et al., 2012; Lucock et al., 2011). In our study however, the different health care settings were evenly distributed among the four perspectives, suggesting that we have captured beliefs and attitudes rather than tasks opinions. Nevertheless, further research should determine the prevalence and distribution of the perspectives in a larger, representative sample of the wider population of nurses.

We observed strong contrasts between some perspectives in their strengths and pitfalls. One strength of the Coach perspective is the broad scope, whereas the Clinician perspective has a focus on good clinical outcomes. Encouraging patients' independence is a strength of the Gatekeeper perspective, whereas the strength of the Educator perspective lies in attention to the patient's coping skills. Despite the strong contrasts between some perspectives, nurses will not fit exclusively into one perspective. Most nurses will have one dominant perspective complemented with one or more secondary perspectives. In short, we cannot recommend one particular perspective on selfmanagement support. Furthermore, patients benefit from support from nurses who are able to move between different approaches (Hostick & McClelland, 2002). Sometimes they need coaching; in other situations education or a clinician approach may be more suitable. It will be difficult, therefore, to describe all-purpose nursing competencies for self-management support. Moreover, nurses must have the capability to reflect on their own perspective towards self-management support and, if necessary, act according to one of their secondary perspectives to the benefit of the patient.

#### Self-management support perspectives in healthcare

The relevance of the identification of four different perspectives on self-management support could go beyond nurse professionalism. Although we did not perform a systematic search, we found similar perspectives in self-management literature. The Coach perspective seems to fit best with the patient-centeredness approaches described by Glasgow et al. (2003) and the Chronic Care Model (Wagner et al., 2001), due to the esteem for patient expertise and autonomy. Moreover, the health care professional in this perspective addresses all three categories of self-management processes from the perspective of the patient described by Schulman-Green et al. (2012). The focus of the Gatekeeper is described in literature as 'self-management as cost-cutting mechanism' (Kendall et al., 2011), which strategy is in line with the Dutch governmental perspective (VWS, 2008).

In the Educator perspective, the role of the nurse is congruent to the way self-management education is described in the competencies for diabetic care in the Netherlands and the definition of self-management of the Dutch Health Care Insurance Board (CVZ, 2010; NDF, 2011). Health education is focused on the illness itself (Coleman & Newton, 2005) and a broader focus of the nurse is required only when life interferes with the therapy (Elissen et al., 2013). The Clinician perspective is referred to in other studies as the 'medical model' or as 'traditional care' (Bodenheimer et al., 2002; Koch et al., 2004).

It would be interesting to further systematically study this, as findings could help clarify underlying tensions in the definition of, research into, and policy with regard to self-management and self-management support.

Although this study focused on nurses' perceptions, self-management support is a multidisciplinary assignment. Nurses in chronic care should collaborate with other providers and these professionals also need to re-evaluate the focus of the relationship with their patients (Jones et al., 2013; Visse, Teunissen, Peters, Widdershoven & Abma, 2010). It would be fascinating to examine whether other professionals hold similar perspectives and therefore we intend to replicate this study in a sample of Dutch physiotherapists.

## Strengths and limitations of the study

A strength of our study is that we gathered additional motivations of the nurses, in addition to the Q-sort. Few Q-methodological articles pay attention to the use of qualitative data in the analysis of the factors. However, in this study the qualitative data was essential in interpreting the factor scores. For example, given the high correlation between the Coach and the Educator perspectives, it is clear that both attach importance to paying attention to aspects of living with a chronic disease. Nevertheless, they emphasize different aspects and define their relation with the patient differently. This was not directly visible in the quantitative data. Q-methodological studies often pay little attention to how statements are developed and by which criteria, and how representative a set of statements is (Kim et al., 2006; Morecroft et al., 2006; Shabila et al., 2014). This is remarkable since the statements shape the scope of the participants and provide crucial input for the results. In our study, we tried to capture all elements of self-management support by using two theoretical frameworks. To enhance content validity, experts in self-management commented on the statements. Face validity was tested in a pilot and participants were asked to remark on the statements and point out missing topics. Also, the analysis of the interviews did not indicate that relevant elements were missing. We feel that the statements encompassed a broad view on self-management support which led participants to express dissimilar views on the subject.

We used purposive sampling, inviting representatives from different age groups, education and health care settings, and asked nurses to recruit others with a different perspective on self-management support than their own. Consequently, we had a diversity of participants, which is likely to have contributed to the identification of four distinctive perspectives on self-management support. However, it is possible we did not capture all the existing attitudes of nurses towards self-management support.

All participants worked in the Rotterdam-the Hague area, in the Netherlands. Nurses from other geographical areas or from other countries could well have a different attitude towards self-management. A Q-study, however, is not intended to generate general findings about the prevalence and distribution of attitudes (Akhtar-Danesh et al., 2008). However, it might be interesting to learn if and how specific nurse characteristics, such as age or health care setting, are associated with specific perspectives. As a next step therefore we will conduct a survey among a larger, nation-wide sample of nurses.

## **Practice implications**

The relevance of having identified these four perspectives towards self-management support lies in knowing the strengths and main characteristics of each perspective. Since different situations and patients demand different kinds of attitudes, nurses should be able to incorporate some aspects of all the perspectives in daily practice. It may be difficult however, to judge what perspective is required when. That poses a new challenge on nurse education. Nurse education and nursing practice could use these perspectives also to reflect on the nursing competencies.

## CONCLUSION

This study has revealed four distinct nurses' perspectives towards self-management support: the Coach, the Clinician, the Gatekeeper, and the Educator perspective. Each has

its own strengths and limitations, and therefore it is not possible to select a preferred one. While nurses will act from one dominant perspective, they should be aware that their work environment and the patient's preferences may require them to act from a secondary perspective. Nurses should therefore be able to switch between the four perspectives. Critical reflection on one's own perspective and interpretation of the approach required in a certain situation seems to be a key competency for adequate selfmanagement support. Each perspective requires distinct competencies from nurses, and nurse education should equip nurses to fulfill the different roles defined by the four perspectives.

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# Chapter 3

A realist review: what do nurse-led selfmanagement interventions achieve for outpatients with a chronic condition?

Susanne M. van Hooft, Janet M.J. Been-Dahmen, Erwin Ista, AnneLoes van Staa & Hennie R. Boeije

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# ABSTRACT

### Aim

The aim of this study was to examine how nurse-led interventions that support selfmanagement of outpatients with chronic conditions work and in what contexts they work successfully.

## Background

Self-management could be directed at goals such as quality of life, adherence, or patients' empowerment. Self-management support is an increasingly important task of nurses. Many nurse-led interventions have been developed but it is not clear how these actually help improve patients' self-management capabilities.

## Design

Realist review

## Data Sources

Primary research studies on self-management support interventions conducted by nurses from January 2000 until March 2015 were retrieved from all relevant databases. The studies had a before/after design and used qualitative and quantitative methods.

## **Review Methods**

For each study we described how the intervention was supposed to improve selfmanagement and compared this with the empirical evidence. Next, we described the Context-Mechanism-Outcome strings for each separate study, explored patterns and integrated the findings.

## Results

Thirty-eight papers were included, evaluating 35 interventions concerning a diversity of conditions. Seven different context-mechanism-outcome strings were identified. Interventions focusing on patients' intrinsic processes were most successful. Least successful were interventions only providing education aimed at patient behaviour change. Various contexts can influence the success of the interventions: involvement of relatives, target group (i.e. chronic condition, motivation, being recently diagnosed or not), involvement of fellow patients and intervention group homogeneity or heterogeneity.

## Conclusion

Successful interventions focus on patients' intrinsic processes (i.e. motivation or selfefficacy). This would guide nurses to decide what self-management support intervention they can best use in their specific setting and patient group.

## Why is this research or review needed?

The growing population of people with chronic conditions and the simultaneous increase of healthcare expenditures would benefit from effective self-management support.

Self-management support is a core activity of nurses in outpatient settings. They are expected to know how a chronic condition impacts a patient's life and are therefore eminently suited to coach patients.

The effective elements of nurse-led self-management interventions and the optimal circumstances have yet to be determined.

## What are the key findings (what does it add to knowledge)?

Seven mechanism-outcome strings of interventions were identified. Nurse-led interventions focusing on patients' intrinsic motivation and self-efficacy were most successful.

Least successful were interventions providing solely education aimed at changing patients' behaviour.

Contexts that influence the effectiveness of an intervention are family involvement, type of condition, patient's motivation, recently diagnosed or not, peer support and intervention group homogeneity or heterogeneity.

# How should the findings be used to influence policy/practice/research/education?

The influence of contexts on the effectiveness of an intervention should be taken into consideration when choosing or developing a self-management support intervention.

Development of self-management support interventions should be based on theoretical concepts and proper selection of outcomes.

## INTRODUCTION

The growing population of people with chronic conditions and the simultaneous increase of healthcare expenditures require effective interventions (WHO, 2005). Self-management is seen as a means to several ends: to improve patients' lifestyle or patients' adherence, to increase quality of life, or to empower patients (Jonsdottir, 2013; Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011; Wilkinson & Whitehead, 2009). A much-used definition of self-management is: 'the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established' (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). This definition implies that self-management is not only a matter of medical or symptom management, but also of incorporating disease in one's life. This is important because people often struggle with the social meaning of the chronic condition (Atkin et al. 2010) and have to deal with practical consequences of the condition and the treatment in daily life. Self-management requires an active role of patients, since it implies a responsibility for *self* managing the condition (Lorig & Holman, 2003).

## Background

Although self-management is a task for the patients themselves, they may need support. Self-management support (SMS) requires a multidisciplinary approach (Wagner et al., 2001), but in practice is often provided by outpatient clinic nurses. Self-management support is a core activity of outpatient nurses (Elissen et al., 2013). They are expected to have insight into the impact of a chronic condition on a patient's life and are therefore designated to coach patients in their self-management (Alleyne, Hancock & Hughes, 2011; Elissen et al., 2013; Schenk & Hartley, 2002).

Many self-management interventions are composed of multiple, interacting components and can therefore be regarded as complex (Campbell et al., 2000). Possible components are for instance the means of providing the content of the intervention, the theory on which it is built, the professionals executing the intervention and clinical guidelines (Clark, 2013). Added to this complexity is the fact that different factors may influence the patient's self-management and consequently it is to be expected that there is no one-size-fits-all intervention that works for all patients and for all patient groups (Bonell et al., 2012; Coster & Norman, 2009).

Although several recent reviews proved that certain self-management interventions were useful, it is not clear to what components success can be ascribed, for whom these interventions work and in what circumstances (Jones, Lekhak, Kaewluang, & Napatsawan,

2014; Radhakrishnan, 2012; Tu et al., 2015). Reviews often examine one specific type of intervention or one specific chronic condition (Bonner et al., 2014; Kuo et al., 2014; Song et al., 2014). Besides, not all of these reviews are aimed at interventions specifically conducted by nurses (Bentsen et al., 2012; Bonner et al., 2014; Radhakrishnan, 2012). Furthermore, the realist review methodology was developed precisely to examine what works for whom and why; on which theoretical assumptions interventions are based, how they are supposed to work and why they work or do not work in certain circumstances. A realist review provides explanatory rather than evaluative results, which is an added value of the evidence provided by traditional reviews. So realist reviews are also suitable for topics on which there is a certain amount of evidence (e.g. Kane et al., 2010; Kousoulis et al., 2014).

This is why the methodology is suitable for reviewing complex interventions aimed at people with different and often multiple conditions.

# THE REVIEW

## Aim

The objective of this realist review was to examine how nurse-led interventions that support self-management of outpatients with chronic conditions work and in what contexts they work successfully.

# Design

The theory-driven realist review methodology can synthesize a diversity of evidence about the effectiveness of interventions in real life settings (Pawson & Tilley, 1997; Pawson et al. 2004; Pope et al., 2007). Underlying theories and assumptions of an intervention are tested and give insight into how and why complex interventions do or do not work in a specific context (Pawson et al., 2004; Pawson et al., 2005). In other words, a realist review identifies the pathways successful interventions follow (Pawson et al., 2004). An essential element is the description of a mechanism: defined as a reaction triggered by the intervention in a certain context and that leads to a certain outcome (Kane et al., 2010). The contexts, mechanisms and outcomes of an intervention are the cornerstones of a realist review. Linking these three elements leads to the so called 'context-mechanism-outcome strings' (CMOs), which articulate the interaction between the intervention, the context where the intervention is applied and the mechanisms that are set in motion by this interaction – leading up to an outcome (Pawson et al., 2005). In contrast to the traditional systematic reviews, the realist review methodology allows to include a variety of study designs, not only Randomized Clinical Trials. Whilst

conducting a realist review is an iterative process, the review was conducted according to sequential steps (Pawson et al., 2005) (Table 1).

Step		Sur	nmary of approach
1.	Clarifying the scope of the review		The objective of this realist review was determined. The scope involves nurse-led interventions for self-management support of outpatients with chronic conditions.
2.	Determining the search strategy and	•	A search strategy was developed (Box 1). Only studies using a comparison between 'standard care' and self-management support interventions (e.g. RCT, before-after design and qualitative and quantitative methods) were included. Inclusion criteria were: self-management support interventions with a prominent role for nurses, outpatient clinic setting, adults with chronic
			condition, evaluation study, and written in the English language. Studies were excluded if results were not measured at a patient level, if the setting was a palliative care, primary care, or psychiatric care.
3.	Ensuring proper article selection and appraisal of evidence		According to the realist review approach, studies were selected based on rigor and relevance. In addition studies quality appraisal occurred with appropriate instruments (one for qualitative and one for quantitative studies).
4.	Extracting of data		Data extraction forms were used to organize data. Information was obtained about: a) design of the study, b) characteristics of the intervention, and c) the underlying theory (either implicitly or explicitly mentioned).
5.	Synthesis of findings and drawing conclusions		Synthesis of the findings: underling theories were compared with the empirical evidence. The Context- Mechanism-Outcome (CMO) for each separate study was described, and patterns in the CMOs were explored. Conclusions were drawn about in what works for whom, in what circumstances.

Table 1. Steps in the realist review based on Mogre et al. (2014) and Yardley et al. (2015)

# Search methods

The Embase, Medline OvidSP, CINAHL, Web-of-science, PsychINFO, OvidSP, Cochrane central and PubMed Databases were searched from January 2000 until March 2015 for nurse-led SMS intervention studies. Various search terms for self-management, evaluation, chronic disease and nurses were used (Supplement 1). The scope of our search was deliberately broad because many self-management support needs are not disease-specific but generic in nature. They are mostly dependent on patients' subjective health perceptions and the availability of social support (Dwarswaard, Bakker, van Staa & Boeije, 2015; van Houtum, Rijken, Heijmans, & Groenewegen, 2013).

# Search outcome

The search yielded almost 4,000 references. After removing duplicates, we screened 3022 abstracts, of which 314 full texts articles were assessed for eligibility (Figure 1). The exclusion of articles which did not meet the inclusion and exclusion criteria reduced the number of studies to 38.



Figure 1. Flowchart of studies from identification to inclusion

# **Quality appraisal**

Methodological quality of the qualitative studies was assessed with the Qualitative research review guidelines - RATS (Clark, 2003). Methodological quality of RCTs was assessed with the Cochrane 'Risk of bias' tool (Higgins et al., 2011). Other quantitative studies were assessed with the rating system of Anderson and Sharpe (1991) adapted by Huis et al. (2012) (Supplement 2). In realist reviews, however, eligibility of studies is based on rigor and relevance for the objective of the review rather than on the established quality (Pawson et al., 2004).

# **Data abstraction**

Titles, abstracts and subject headings of the retrieved citations were screened for relevance and full-texts of potentially eligible studies were evaluated. In case of doubt, a third reviewer was consulted. Inclusion criteria were: SMS interventions with a prominent role for nurses, outpatient clinic setting, evaluation study, adults with chronic condition and written in the English language. 'Evaluation study' was defined as a study comparing 'standard care' with SMS interventions (e.g. RCT, before-after) design and/ or using qualitative evaluation. Studies were excluded if results were not measured at a patient level, if the setting was palliative care, primary care, or psychiatric care. These exclusion criteria were chosen because the interventions should be targeted at people with somatic chronic conditions in an outpatient hospital setting.

# **Synthesis**

First, the full texts of included studies were reviewed and data were extracted. Information was obtained about: A. design of the study, B. characteristics of the intervention and C. the underlying theory. If theoretical assumptions were not provided, the corresponding author was contacted. Reporting effectiveness evidence, including estimates of precision, is not always done in realist reviews, although there are some examples of realist reviews that do (Hoare et al., 2012; Leeman et al., 2010). We also decided to report these effect sizes to enhance interpretation of the studies. If possible, effect sizes with the bias-corrected effect size Hedges (G) were calculated (Fritz, Morris, & Richler, 2012) (Supplement 3).

The research team reached consensus about the extraction and interpretation of the data in several rounds. A study's underlying theory, either implicitly or explicitly mentioned, was compared with the empirical evidence reported in the study. The CMO for each separate study was described and patterns in the CMOs were explored to explain what interventions worked in what settings.

## RESULTS

We included 35 different intervention studies reported in 38 papers. Two interventions were evaluated qualitatively, one was a mixed methods case-study, the other 32 interventions were evaluated with a quantitative design (of which 21 were RCTs). The 35 studies included a total of 3,490 patients, representing a diversity of chronic conditions (Table 2; a more comprehensive table with statistical outcomes is provided in Supplement 3). Most interventions contained educational and counselling components; some involved physical exercises. Often, interventions were provided in group sessions, sometimes combined with individual sessions. Only few studies described a self-monitoring intervention.

## **Underlying theories**

A study's underlying theory not always corresponded with the theory found in the empirical evidence. Therefore we distinguish two types below: espoused theories (the theory mentioned as base for the interventions) and theories-in-use (how interventions had actually worked) (Argyris, 1976).

#### Espoused theories

Based on the espoused theory we distinguished five categories of interventions, addressing respectively: (i) knowledge; (ii) behavioural change; (iii) coping; (iv) motivation; and (v) self-efficacy. (i) Thirteen studies involved interventions with an emphasis on knowledge gain through the provision of education – with the (often tacit) assumption that education would lead to the desired behavioural change; (ii) Six interventions aimed at changing the patient's lifestyle and thus at behavioural change; (iii) Nine stud-

Author(s); year of publication; country	Intervention characteristics	Design	Patient group characteristics (n; diagnosis)						
Akyil & Ergüney (2012), Turkey	Education Individual	Quasi experimental design with control group	n=65 Chronic Obstructive Pulmonary Disease (COPD)						
Bakan & Akyol (2007), Turkey	Counselling Group & individual Self-monitoring Family involvement	RCT	n= 43 Chronic Heart Failure (CHF)						
Balk et al. (2008), The Netherlands	Education Individual Self-monitoring	RCT	n=214 CHF						
Carrieri-Kohlman et al. (2005), USA	Education Individual Physical exercises	Prospective, randomized single- blind trial	n=103 COPD						
Choi & Lee (2012), Korea	Education Counselling Group & individual	RCT	n=61 Chronic Kidney Disease (CKD)						
Donesky et al. (2013), USA	Education Individual Physical exercises	RCT	n=115 COPD						
Gonzalez et al. (2014), USA	Education Individual	Single-group before after design	n=30 Venous ulcers						
Goossens et al. (2014), Belgium	Education Individual	Descriptive, cross- sectional study	n=317 Congenital heart disease (CHD)						
Grilo et al. (2015), USA	Education Counselling Individual Self-monitoring	Pilot clinical trial	n=28 Uncontrolled hypertension and comorbid Diabetes Mellitus (DM) type 2						
Hagberth et al. (2008), Sweden	Education Group	Qualitative descriptive study	n=13 Asthma						
Howden et al. (2015), Australia	Education Counselling Individual Physical exercise	RCT	n=83 CKD						
Huang et al. (2008), Taiwan	Education Individual Self-monitoring Family involvement	RCT	n=148 Asthma						
Jiang & He (2012), China	Education Counselling Individual	RCT	n=96 COPD						
Kara & Asti (2003), Turkey	Education Groups & individual Physical exercises Family involvement	RCT	n=60 COPD						
Kaşıkçı (2010), Turkey	Education Individual Physical exercises	Case-study	n=1 COPD						

 Table 2. Overview of selected studies (in alphabetical order by first author)

Author(s); year of publication; country	Intervention characteristics	Design	Patient group characteristics (n; diagnosis)						
Lee et al. (2014), South Korea	Counselling Individual	RCT	n=151 COPD						
Lindskov et al. (2007), Sweden	Education Individual Groups for family	Naturalistic non- randomized waiting list controlled trial	n=48 Parkinson's Disease						
van der Meer et al. (2009), The Netherlands	Education Groups Telemonitoring	RCT	n=200 Asthma						
Monninkhof et al. (2003), The Netherlands	Education Exercises Groups Family involvement	RCT	n=248 COPD						
Moriyama et al. (2009), Japan	Education Counselling Individual Self-monitoring Family involved	RCT	n=65 DM type 2						
van Os-Medendorp et al. (2007a), The Netherlands	Education Counselling Individual	Mixed-methods	n=65 Chronic pruritic skin disease						
Van Os-Medendorp et al. (2007b), The Netherlands	Education Counselling Individual	RCT	n=65 Chronic pruritic skin disease						
Otsu & Moriyama (2011), Japan	Education Counselling Individual Self-monitoring Family involvement	RCT	n=102 CHF						
Otsu & Moriyama (2012), Japan	Education Counselling Individual Self-monitoring Family involvement	RCT	n=94 CHF						
Ronning et.al. (2013), Sweden	Education Counselling Individual	Single group before- after design	n=55 Congenitally malformed hearts						
Rootmensen et al. (2008), The Netherlands	Education Individual	RCT	n=191 COPD						
Sarian et al. (2012), Canada	Education Groups Family involvement	Single group before after test	n=10 Peritoneal dialysis patients						
Scheurs et al. (2003), The Netherlands	Education Counselling Groups	Single group before- after design	n=83 Asthma, DM, and CHF						
Smeulders et al. 2010a/b), The Netherlands	Education Groups	RCT	n=317 Congestive heart failure						

Table 2. Overview of selected studies (in alphabetical order by first author) (continued)

Author(s); year of publication; country	Intervention characteristics	Design	Patient group characteristics (n; diagnosis)						
Trappenburg et al. (2008), The Netherlands	Education Individual Telemonitoring	Non randomized controlled multicenter study	n=115 COPD						
Tsay et al. (2005), Taiwan	Education Counselling Groups	RCT	n=57 End-stage renal disease						
Williams et al. (2012), Australia	Education Counselling	RCT	n=78 CKD, DM, and cardiovascular disease						
Wilson et al. (2008), Ireland	Education Counselling Individual & groups	RCT	n=91 COPD						
Yildiz & Kurcer (2012), Turkey	Education Counselling Individual	Single-group before- after design	n=84 CKD						
Yu et al. (2014), China	Education Individual Family involvement	Non-randomized controlled trial	n=84 COPD						
Zoffman & Kirkevold (2012), Denmark	Counselling Individual	Qualitative evaluation study	n=50 DM type 1						
Zoffman & Lauritzen (2006), Denmark	Counselling Group	RCT	n=30 DM type 1						

Table 2. Overview of selected studies (in alphabetical order by first author) (continued)

ies aimed at coping with the symptoms of the chronic condition. The focus lies primarily on re-interpretation of symptoms and dealing with stress; (iv) Two studies involved interventions aimed at increasing the patient's motivation (v) Six interventions focus on self-efficacy. The espoused theories are described in Box 1.

#### Theories in use: contexts, mechanisms and outcomes

We found three different mechanisms in the interventions: increase patients' knowledge, patients' skills enhancement and increase patients' motivation. Three different outcomes of the interventions were identified: behavioural change, increase of coping and increase of self-efficacy.

On the basis of the theory-in-use we identified seven different strings that linked the mechanisms and the outcomes (Figure 2). For instance, regarding an intervention aimed at explaining the risks of certain behaviour (knowledge) it is assumed that patients will effectively change their behaviour after learning about the risks. In certain contexts the aim could be realized. The CMO-strings we identified by comparing all studies are described below and presented in Supplement 4.

Knowledge	
Theory of constructivism (Bodner, 1986)	Rönning et al.( 2011)
Chronic Care Model (Wagner, 2001)	Grilo et al. (2015), Sarian et al. (2012)
Orem's theory of self-care (Orem, 1983)	Gonzales (2014)
No theory mentioned	Balk et al. (2008), Goossens et al. (2014), Howden et al.(2015), Huang et al. (2009), Lindskov et al. (2007), van der Meer et al. (2009), Rootmensen et al. (2008), Trappenburg et al. (2008), Yildiz & Kurcer (2012)
Behaviour change	
Theory of cognitive behaviour (Lindeman, 1989)	Otsu & Moriyama (2011), Otsu & Moriyama (2012), Moriyama et al. (2009)
Theory of Planned Behaviour (Ajzen, 1991)	Wilson et al. (2008)
Health Belief Model (Becker & Maiman, 1975)	Williams et al. ( 2012)
Trans-theoretical model of stages of change (Prochaska et al., 1985)	Wilson et al. (2008), Zoffmann & Lauritzen (2006)
No theory mentioned	Choi & Lee (2012)
Coping	
Vifladt & Hopen model (Vifladt & Hopen, 2004)	Hagberth et al. (2008)
Self-Regulation Model (Leventhal et al., 2003)	Schreurs et al.( 2003)
Pro-active coping theory	Schreurs et al.( 2003)
Transactional Model of Stress and Coping (Lazarus, 1993)	Jiang & He (2012), van Os-Medendorp et al. (2007a), van Os-Medendorp <i>et al.</i> (2007b), Tsay et al. (2005)
Roy's Adaptation Model (Whittemore & Roy, 2002)	Akyil & Ergüney (2012), Bakan & Akyol (2007)
No theory mentioned	Lee et al. (2014), Monninkhof et al. (2003)
Motivation	
Self-determination theory (Zoffmann, 2004).	Zoffmann & Lauritzen (2006), Zoffmann & Kirkevold (2012)
Self-efficacy	
Social Cognitive Theory (Bandura, 1991)	Carrieri-Kohlman et al. (2005), Donesky et al. (2013), Kara & Aşti (2004), Kaşikçi (2010), Smeulders et al. (2010a), Smeulders et al. (2010b), Yu et al. (2014)

Box 1. Espoused theories: Underlying theories within the categories of interventions

# String A Knowledge leads to behavioural change

Interventions that follow this string are based either on the espoused theories emphasizing knowledge and cognition (Balk et al., 2008; Gonzalez, 2014; Goossens et al., 2014; Grilo et al., 2015; Howden et al., 2014; Huang et al., 2009; van der Meer et al., 2009; Rootmensen et al., 2008; Rönning et al., 2011; Trappenburg et al., 2008; Yıldız & Kurcer, 2012; Yu et al., 2014), on the one aiming at behavioural change (Choi & Lee, 2012; Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Wilson et al., 2008), or on the one aiming at self-efficacy (Yu et al., 2014). Education was offered about the disease, its symptoms, medication and the importance of adherence. Also, (self-)



Figure 2. A to G: strings between Mechanisms and Outcomes

monitoring was applied to provide patients feedback about their knowledge gain and behavioural change (Balk et al., 2008; Grilo et al., 2015; Huang et al., 2009; Moriyama et al., 2009; Otsu & Moriyama, 2011, Otsu & Moriyama, 2012; Trappenburg et al., 2008). In one intervention, the patients' families were involved (Moriyama et al., 2009).

Most interventions used a mixture of means (Supplement 5).

These interventions did not always lead to the desired behaviour; for example, in the context of recalcitrant smokers who lacked symptoms of dyspnoea and had little confidence that another attempt to quit smoking would be successful (Wilson et al., 2008) or in the context of food-insecure patients with uncontrolled hypertension and comorbid diabetes type 2 (Grilo et al., 2015). Interventions employing re-enforcement education were more successful, i.e. when the nurse repeated the information in the next consultations or in telephone calls and answered individual questions (Choi & Lee, 2012; Huang et al., 2009). Thus, the information was tailored to individual needs, enabling patients to relate it to their own situation.

Self-monitoring (by receiving feedback via a TV-channel or computer program about the accuracy of their answers to questions) was successful in that it stimulated learning. Thereby, patients who were recently diagnosed learned to recognize warning signs that required behaviour change (Balk et al., 2008; Huang et al., 2009). However, selfmonitoring had no added value for people who had received the diagnosis long ago.

In spite of the prominent role of education in these interventions, knowledge gain was often not measured (Gonzalez, 2014; Grilo et al., 2015; Howden et al., 2014; Lee et al., 2014; Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Trappenburg et al., 2008; Wilson et al., 2008; Yıldız & Kurcer, 2012; Yu et al., 2014). The effect evaluation of most of the studies that did measure knowledge gain showed that patients' knowledge had increased, irrespective of context and education program (Balk

et al., 2008; Choi & Lee, 2012; Goossens et al., 2014; Huang et al., 2009; Rootmensen et al., 2008). But change of behaviour was only achieved if re-enforcement and repeated education sessions were provided (Choi & Lee, 2012; Huang et al., 2009). The involvement of family did not seem to affect effectiveness.

In summary, re-enforcement education and tailored knowledge gained from answers to individual questions led to behavioural change in recently diagnosed patients. This string was less successful for target groups with little confidence in their ability to change behaviour and for patients who fail to see any effect of behavioural change on their symptoms.

## String B Knowledge leads to coping

Some interventions following this string are based on the espoused theory emphasizing knowledge and cognition (Lindskov et al., 2007; Sarian et al., 2011), but most are based on the one emphasizing coping (Akyil & Ergüney, 2013; Bakan & Akyol 2008; Hagberth et al., 2008; Jiang & He, 2012; Monninkhof et al., 2003; van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b; Schreurs et al., 2003; Tsay et al., 2005). Their common feature is teaching patients how to re-interpret the symptoms of their chronic condition. This was usually done by the nurse, but in some studies disease-related information and experiences were discussed with fellow patients and/or family (Bakan & Akyol, 2008; Hagberth et al., 2008; Sarian et al., 2011).

In many interventions patients played an active role: e.g. keeping diaries, doing homework or using a self-help manual (Supplement 5). Sharing experiences and, by doing so, learning from fellow patients helped patients feel understood and made it easier for them to adapt the knowledge to their own situation than when a professional provided information. However, patients mentioned that this was not useful for all topics (Hagberth et al., 2008).

In several interventions, information about symptoms was given by professionals, which enabled patients to re-interpret the symptoms (Akyil & Ergüney, 2013; Bakan & Akyol, 2008; Hagberth et al., 2008; Jiang & He, 2012; Monninkhof et al., 2003; van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b). Through this reinterpretation, patients were more successful in dealing with these symptoms (Akyil & Ergüney, 2013; Jiang & He, 2012; van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b). Learning from fellow patients usually made it easier to adapt the knowledge to the own situation than when a professional provided information. Some interventions consisted of goal-setting (Bakan & Akyol, 2008; Monninkhof et al., 2003, Sarian et al., 2001), or keeping a diary so as to raise awareness of how they dealt with symptoms (van Os-Medendorp et al., 2007b; Schreurs et al., 2003; Tsay et al., 2005). The latter was not always successful, because the patients participating in these interventions did not appreciate the home-work, which accompanied the diary keeping, before the consultations with the professional.

Although interventions and contexts differed, most interventions following this string seemed to improve coping strategies. Knowledge gain – the starting point of this string – was demonstrated in only two interventions (Hagberth et al., 2008; Sarian et al., 2011). The other eight studies, though, had not included this in the effect evaluation.

To sum up, interventions using this string were successful in various chronic conditions when experiences and disease-related information were shared with fellow patients or relatives and when information was personalized. This enabled patients to re-interpret the information and the symptoms – and thus to better cope with the disease. Less successful were interventions asking patients to keep a diary (Supplement 5).

## String C Knowledge leads to self-efficacy

Interventions following this string are based on the espoused theory emphasizing selfefficacy (Kara & Aşti, 2004; Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kaşıkçı, 2011; Smeulders et al., 2010a; Smeulders et al., 2010b).

Education was provided about managing day-to-day disease related problems – via telephone interviews, brochure or group sessions (Supplement 5). In some interventions patients were encouraged to share experiences with fellow patients or experienced laymen (modelling) (Kara & Aşti, 2004; Smeulders et al., 2010a; Smeulders et al., 2010b). This provided ready-to-use information and made patients feel acknowledged and more self-confident.

Two of the six studies, both in COPD patients, showed significantly increased selfefficacy (Kara & Aşti, 2004; Kaşıkçı, 2011). The other studies had either not measured the effect on self-efficacy (Carrieri-Kohlman et al., 2005; Donesky et al., 2014), or reported that patients' self-efficacy did not increase (Smeulders et al., 2010a; Smeulders et al., 2010b). Although providing and discussing knowledge was key to all interventions in this string, none of the studies described whether patients' knowledge had increased. This string was successful in the context of COPD in both individual and group counselling sessions focusing on day-to-day problems.

## String D Skills enhancement leads to behavioural change

The interventions following this string are based on the espoused theory emphasizing knowledge and cognition (Huang et al., 2009; Rootmensen et al., 2008) and on the one emphasizing behavioural change (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Wilson et al., 2008). All interventions aimed at learning 'how-to'- skills, such as inhalation (Rootmensen et al., 2008) and relaxation techniques (Wilson et al., 2008), abandoning smoking (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Rootmensen et al., 2008; Wilson et al., 2008), or alcohol use (Otsu &

Moriyama, 2011; Otsu & Moriyama, 2012), preventing exacerbation (Rootmensen et al., 2008), or using a peak flow meter for monitoring of the condition (Huang et al., 2009). Usually the nurse provided support, but sometimes also family members, who received the same instructions (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012). Other means of these interventions include check-and-correct skills, daily exercises, personal targets, record keeping and motivational interviewing.

All interventions following this string also followed string A. In one study this proved to be a successful combination, because patients learned how to monitor their asthma and received feedback about their self-management by rating the symptoms on a scale and using a peak flow meter (Huang et al., 2009). This study showed significant positive effects on both skills and change of behaviour. The other studies either not measured these outcomes (Moriyama et al., 2009), or were not entirely successful (Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Rootmensen et al., 2008; Wilson et al., 2008). For instance, this combination of strings was less successful in the context of poorly motivated patients and reluctant smokers (Moriyama et al., 2009; Wilson et al., 2008). Some interventions did not take skills achievement into account in the effect measurement, but could be regarded as successful in terms of better clinical outcomes (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012).

In short, this string was not successful in the context of poorly motivated patients, nor was the additional instruction of family members effective. However, it was successful in the context of patients with asthma, who learned to effectively monitor their condition.

## String E Skills enhancement leads to coping

All interventions following this string are based on the espoused theory emphasizing coping (Jiang & He, 2012; Lee et al., 2014; Monninkhof et al., 2003; van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b; Schreurs et al., 2003; Tsay et al., 2005). The interventions aimed to improve coping with symptoms through education on practical self-management tasks, such as peak flow monitoring, but also skills for stress reduction. Means of these interventions were diary records, instruction booklets, self-help manuals and peer groups. In two studies, skills were practiced in a group with fellow patients and this approach appeared to be successful (Schreurs et al., 2003; Tsay et al., 2005). These patients also set personal goals, kept diary records and discussed these with fellow patients. Eventually they could better cope with stress- and health-related problems caused by their chronic condition. All studies but one combined teaching skills with the provision of knowledge (via string B). In the exceptional study, when information was needed nurses referred patients to educational material they had received earlier (Lee et al., 2014). This approach was not successful. However, the combination of strings B and F seemed to be successful in improving coping strategies. In one study patients with

COPD were reminded through telephone calls to practice distraction and relaxation skills (Jiang & He, 2012). This approach considerably improved coping skills.

In sum, this string was successful if realistic goals were set and skills were practiced in either individual sessions or homogeneous patient groups.

## String F Skills enhancement leads to self-efficacy

All interventions following this string are based on the espoused theory emphasizing self-efficacy (Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kara & Aşti, 2004; Kaşıkçı, 2011; Smeulders et al., 2010a; Smeulders et al., 2010b). All interventions combined this string with string C *'Knowledge leads to self-efficacy'*. They included 'mastery experiences', 'verbal encouragement', 'modelling' and 'adverse emotional or physical arousal' (Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kara & Aşti, 2004; Kaşıkçı, 2011; Smeulders et al., 2010a; Smeulders et al., 2010b), to be achieved by supervised training, record keeping, setting personal targets, home exercise and group support. Two interventions used group-training sessions, among other things to increase patients' confidence and thus their self-efficacy (Kara & Aşti, 2004; Smeulders et al., 2010a; Smeulders et al., 2010b). Newly learned behaviour was sustained through encouragement from the healthcare professional or fellow patients and thereby improved self-efficacy (Kara & Aşti, 2004; Kaşıkçı, 2011). This approach was not successful in all studies. In one study, the effect on self-efficacy was not sustained. The researchers explained this by the short duration of the intervention (one year) (Smeulders et al., 2010a, Smeulders et al., 2010b).

Overall, this string was successful in the context of patients with COPD who received feedback from either healthcare professionals or peers and who saw other patients performing exercises.

## String G Motivation leads to behavioural change

Interventions following this string are based on the espoused theory emphasizing behavioural change (Williams et al., 2012) and the one emphasizing motivation (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012). Several interventions made use of motivational interviewing, phone calls, interpreters and personal targets (Supplement 5). In two studies involving patients with poorly controlled diabetes, patients reflected on their problems with the aid of reflection worksheets (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012). Qualitative data showed that patients became internally motivated to follow lifestyle adjustments and were more capable to integrate the chronic condition into their lives. The intervention groups showed a substantial level of behavioural change.

Another study described an intervention using culturally-adjusted information provision. An interpreter translated the messages of the nurse into the patients' own language. Although patients perceived the sessions as helpful, actual change of behaviour could not be proven (Williams et al., 2012).

This string was successful in the context of patients with poorly controlled diabetes who worked with reflection sheets (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012). Deploying interpreters in the context of culturally and linguistic diverse patient groups was less successful.

#### DISCUSSION

This realist review aimed to explore how nurse-led interventions that support selfmanagement of outpatients with chronic conditions work and in what contexts they work successfully. The theories in use were determined and accordingly, seven strings of interventions were identified.

Interventions that focused on patients' intrinsic processes (self-efficacy and motivation, in strings C, D and G) were the most successful ones (Carrieri-Kohlman et al., 2005; Kara & Aşti, 2004; Kaşıkçı, 2011; Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012). This focus appealed to patients' internal perceived locus of control, which is important for persistence and performance of new behaviour (Ryan et al., 1995). Overall, least successful was string A where education was assumed to lead to behavioural change. Our review demonstrates that when patients are not confident of their power to change their behaviour or if they do not immediately see positive results of their efforts, education alone will not result in behavioural change. This is in agreement with previous systematic reviews which concluded that education is not sufficient to incite behavioural change (Barlow, Cooke, Mulligan, Beck, & Newmann, 2010; Coster & Norman, 2009). Our review adds that behavioural change could be successfully achieved by re-enforcement of education, tailoring the information to the individual patient's need and by combining knowledge transfer with skills enhancement.

Various contexts were found to influence the effectiveness of interventions. Relatives were involved in the strings with knowledge as a starting point (A, B, C) and this seemed to have a surplus value, as patients felt more supported in daily life. This is in line with findings from a qualitative synthesis of patients' self-management needs, which concluded that relatives' support is essential (Dwarswaard et al., 2015). Other relevant contexts are the target group (condition, extent of motivation, recently diagnosed or not), the use of peers and group homogeneity or heterogeneity. In all strings, most interventions were developed for homogeneous groups of patients and the homogeneity mostly had a positive impact on recognition and confidence.

## **Limitations and strengths**

This review represents interventions concerning a variety of chronic conditions but is not exhaustive in this respect; e.g. rheumatic disorders are lacking. Studies on this condition were retrieved in the initial search, however, but did not meet the selection criteria. Some were not an empirical study (Faradji et al., 2012; Lagger et al., 2010,); others were outdated (Sinclair et al., 1998). It is also possible that, due to our 'nurse-led' and 'outpatient ward' criteria, we might have missed other relevant studies.

Due to the broad approach of our search strategy, many different diseases and different types of interventions were included in our review. This complicates the comparison between interventions. In van Houtum's study among a large sample of Dutch patients with different chronic conditions, self-management tasks and support needs were only partly determined by disease-related factors (2013). While the methodology of realist review has been well described (Pawson et al., 2004), realist reviews differ in the way they are executed or documented (Higgins et al., 2012; Kane et al., 2010; Wong et al., 2010). Identifying mechanisms and the corresponding contexts and outcomes, may require a long, continuous process of abductive thinking, reflection and debating (Jagosh et al., 2013). In the current review we worked cyclically to discover what each decision in the study meant for the steps yet to come. Close collaboration between all team members was beneficial for finding creative solutions as a component of abductive thinking and for reflection.

#### **Practice implications**

The insights of this review may help nurses decide what self-management support intervention they can best use in their specific setting and patient group. Preferably they should select interventions aimed at increasing patients' motivation and self-efficacy, instead of focusing solely on education. Involving peers or relatives could be helpful in achieving these goals.

Different espoused theories were found in the primary evaluation studies. In thirteen studies (34%) no clear underlying theory was mentioned but they could implicitly be linked to existing theories. To evaluate properly the mechanisms that make an intervention 'work', a clear theoretical base underlying the intervention is crucial (Clark, 2013; Pawson & Tilley, 1997). A theoretical framework provides not only suggestions of how to measure the effects but also appropriate targets for the intervention (Michie & Prestwich, 2010; van Os et al., 2004).

In complex interventions, the role of the healthcare professional is of great influence on the outcomes (Disler et al., 2012; Clark, 2013). Nurturing relationships with healthcare professionals may stimulate patient's self-efficacy to manage a chronic condition (Disler et al., 2012). Although suitable training offers resources to support patients effectively (MacDonald et al., 2008), only few authors of the reviewed papers described how healthcare professionals were trained prior to the intervention. This aspect deserves more attention in the description of the intervention in forthcoming studies.

## CONCLUSION

Until now it was not known what elements of nurse-led SMS interventions were effective. This realist review discusses some of the working elements and shows that interventions focusing on patients' intrinsic processes were most successful. It clarifies in what context nurse-led interventions in supporting self-management of outpatients with chronic conditions will be effective or not. These insights may help nurses choose the appropriate SMS intervention for their target group. The specific context (the involvement of family or relatives, the target group of chronic ill patients, the involvement of fellow patients and intervention group homogeneity or heterogeneity) should be taken into account because not all interventions work for all patients in all circumstances. When developing an intervention, using an underlying theory is recommended because this provides guidance as to what outcome the intervention should be aimed at.

#### Supplement 1. Search Strategy

(evaluation/de OR 'evaluation and follow up'/de OR 'evaluation research'/de OR 'nursing evaluation research'/ de OR 'self evaluation'/de OR 'comparative effectiveness'/de OR 'clinical effectiveness'/de OR (evaluat\* OR effectiv\*):ab,ti) AND ('self care'/de OR 'self help'/de OR 'self medication'/de OR 'health education'/de OR 'patient education'/de OR 'coping behavior'/exp OR (((self OR shared) NEAR/3 (manag\* OR care\* OR medicat\* OR efficac\*)) OR ((health OR patient\*) NEAR/3 (educat\*)) OR coping OR resilien\* OR ((psycholog\* OR behav\*) NEAR/3 (adapt\* OR adjust\*))):ab,ti) AND ('chronic disease'/de OR 'genetic and familial disorders'/ exp OR 'congenital disorder'/exp OR (((chronic\* OR longterm OR 'long term' OR 'end stage' OR endstage\* OR degenerat\* OR persisten\* OR genetic\* OR familial\* OR congenit\*) NEAR/3 (ill\* OR disease\* OR condition\* OR disorder\*))):ab,ti) AND (nursing/exp OR nurse/exp OR 'nursing staff'/de OR 'nursing education'/exp OR 'nurse attitude'/de OR 'nurse patient relationship'/de OR 'nurse training'/de OR (nurs\*):ab,ti) NOT ((child/exp OR pediatrics/exp OR (child\* OR pediatric\* OR paediatric\*):ab,ti) NOT (adult/de OR 'middle aged'/de OR aged/de OR adult\*:ab,ti))

Items of quality appraisal	Risk of Bias (RCT's) <sup>a</sup>					Quality other quantitative studies <sup>b</sup>						Quality of qualitative studies <sup>c</sup>											
Author(s); year of publication; country	Adequate sequence generation	Allocation concealment	Blinding	Incomplete data addressed	Free of selective reporting	Free of other bias	Design of study	Content (description intervention)	Sample size	Validity and reliability of instruments	Test statistics	Significance	Research question	Qualitative method	Sample & recruitment	Sample characteristics	Data collection	Procedure/ ethics	Analysis	Results: interpretation	Conclusion & discussion	Overall picture	
Akyil & Ergüney (2012), Turkey							1	1	1	1	1	1											
Bakan & Akyol (2007), Turkey	0	0	0	+	0	0																	
Balk <i>et al.</i> (2008), The Netherlands	+	+	0	0	0	-																	
Carrieri-Kohlman et al. (2005), USA							1	1	0	1	1	1											
Choi & Lee (2012), Korea	0	0	+	0	0	-																	
Donesky et al. (2013), USA	0	0	+	+	0	0																	
Gonzalez et al. (2014), USA							0	1	0	0	1	0											
Goossens et al. (2014), Belgium							0	1	0	1	1	1											
Grilo et al. (2015), USA							1	1	0	0	1	0											
Hagberth et al. (2008), Sweden													3	3	3	3	3	3	3	3	2	3	
Howden et al. (2015), Australia	+	+	0	+	0	-																	
Huang et al. (2008), Taiwan	+	+	+	+	0	0																	
Jiang & He (2012), China	0	0	+	+	0	-																	
Kara & Asti (2003), Turkey	-	-	+	+	0	0																	
Kasikci (2010), Turkey							0	1	0	1	1	0											
Lee et al. (2014), South Korea	0	0	+	+	0	0																	
Lindskov et al. (2007), Sweden							1	0	0	1	1	1											
van der Meer et al. (2009), The Netherlands	+	+	0	+	+	0																	
Monninkhof et al. (2003), The Netherlands	+	+	0	+	0	+																	
Moriyama et al. (2009), Japan	0	0	0	+	0	-																	
van Os-Medendorp et al. (2007a/2007b), The Netherlands	0	0	0	+	0	0							3	3	3	3	2	3	1	1	2	3	

## Supplement 2. Table Quality appraisal
Items of quality appraisal	Risk of Bias (RCT's) <sup>a</sup>			Quality other quantitative studies <sup>b</sup>			Quality of qualitative studies <sup>c</sup>					5 <sup>c</sup>										
Author(s); year of publication; country	Adequate sequence generation	Allocation concealment	Blinding	Incomplete data addressed	Free of selective reporting	Free of other bias	Design of study	Content (description intervention)	Sample size	Validity and reliability of instruments	Test statistics	Significance	Research question	Qualitative method	Sample & recruitment	Sample characteristics	Data collection	Procedure/ ethics	Analysis	Results: interpretation	Conclusion & discussion	Overall picture
Otsu & Moriyama (2011) & (2012), Japan	+	0	+	+	0	0																
Ronning et.al. (2013), Sweden							0	1	0	0	0	0										
Rootmensen et al. (2008), The Netherlands	+	+	+	+	0	+																
Sarian et al. (2012), Canada							0	1	0	0	0	0										
Scheurs et al. (2003), The Netherlands							0	1	0	1	1	1										
Smeulders et al. (2010a/b), The Netherlands	+	+	+	+	+	+																
Trappenburg et al. (2008), The Netherlands							1	1	0	1	1	1										
Tsay et al. (2005), Taiwan	0	0	+	+	0	0																
Williams et al. (2012), Australia	+	+	+	+	0	-																
Wilson et al. (2008), Ireland	+	+	0	+	0	0																
Yildiz & Kurcer (2012), Turkey							0	1	0	1	1	1										
Yu et al. (2014), China							1	1	0	1	1	1										
Zoffman & Kirkevold (2012), Denmark													4	4	2	4	4	4	3	3	4	4
Zoffman & Lauritzen (2006), Denmark	+	-	-	+	0	0																

Supplement 2. Table	Quality appraisal	(continued)
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<sup>a</sup> Risk of bias according to Cochrane's tool for assessing risk of bias: + = low risk of bias; - = high risk of bias; 0 = uncertain risk of bias

<sup>b</sup> Quality rating according to Huis et al. (2012) <sup>c</sup> 1= Not at all/ 2= A little/ 3= Reasonable/ 4= Very

Author(s); year of publication	Design	Theory mentioned in study	Patient group characteristics ( <i>n; diagnosis</i> )
Akyil & Ergüney (2012)	Quasi experimental design with control group	Roy's Adaptation Model	n=65 Chronic Obstructive Pulmonary Disease (COPD)
Bakan & Akyol (2007)	RCT	Roy's Adaptation Model	n= 43 Chronic Heart Failure (CHF)
Balk et al. (2008)	RCT	Not mentioned	n=214 CHF
Carrieri-Kohlman et al. (2005)	Prospective, randomized single- blind trial	Social cognitive theory	n=103 COPD
Choi & Lee (2012)	RCT	Not mentioned	n=61 Chronic Kidney Disease (CKD)

Supplement 3. Tab	le Overview of	f selected studies with	effect sizes (in a	alphabetical o	order by first aut	hor)
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Donesky et al. (2013)	RCT	Social cognitive theory	n=115 COPD
Gonzalez et al. (2014)	Single-group before after design	Orem's theory of self-care	n=30 Venous ulcers
Goossens et al. (2014)	Descriptive, cross- sectional study	Not mentioned	n=317 Congenital heart disease (CHD)
Grilo et al. (2015)	Pilot clinical trial	Chronic Care Model	n=28 Uncontrolled hypertension and comorbid Diabetes Mellitus (DM) type 2
Hagberth et al. (2008)	Qualitative descriptive study	Vifland & Hopen model	n=13 Asthma

Outcomes	Outcomes
Hedges (G)*	Hedges (G)*
- Knowledge	
- Behavioural change	- Clinical outcomes
- Skills	- Quality of Life
- Coping	Only reported / calculated if measured in the
- Self-efficacy	original study
Only reported / calculated if measured in the original	
study	
Coping Adaptation	
Physiological adaptation 4.93 (3.95 - 5.91)	
Self-concept-physical self-adaptation: 4.82 (3.86 - 5.78)	
Self-concept-personal self-adaptation: 3.78 (2.97 - 4.59)	
Role-function mode: 4.53 (3.61 - 5.45)	
Perceived social support from friends 1.16 (0.63 - 1.68)	
Perceived social support from family: 0.37 (-0.12 - 0.86)	
Coping Social Support: 1.48 (0.81 – 2.16)	Cholesterol 0.25 (-0.35 – 0.85)
	High-density lipoprotein (HDL) 0.20 (-0.40 – 0.80)
	Low-density lipoprotein (LDL) 3.47 (2.53 – 4.42)

Knowledge 1.26 (0.71 – 1.81) Behavioural change (self-care) 0.07 (-0.43 – 0.57) Blood Urea Nitrogen (BUN) 0.38 (-0.12 – 0.89) Creatinine (C) 0.45 (-0.06 – 0.95) Sodium (Na) 0.33 (-0.17 – 0.84) Potassium (K) 0.24 (-0.26 – 0.75) Calcium (Ca) 0.11 (-0.39 – 0.62) Phosphate (P) 0.20 (-0.31 – 0.71) Haemoglobin (Hb) 0.18 (-0.33 – 0.68) Glomerular Filtration Rate (GFR) -0.48 (-0.92 – 0.09)

Author(s); year of publication	Design	Theory mentioned in study	Patient group characteristics (n; diagnosis)
Howden et al. (2015)	RCT	Not mentioned	n=83 CKD
Huang et al. (2008)	RCT	Not mentioned	n=148 Asthma
Jiang & He (2012)	RCT	Transitional model of stress and coping	n=96 COPD
Kara & Asti (2003)	RCT	Social Cognitive Theory	n=60 COPD
Kaşıkçı (2010)	Case-study	Social cognitive theory	n=1 COPD
Lee et al. (2014)	RCT	No specific theoretical framework	n=151 COPD
Lindskov et al. (2007)	Naturalistic non- randomized waiting list controlled trial	No specific theoretical framework	n=48 Parkinson's Disease
van der Meer et al. (2009)	RCT	Not mentioned	n=200 Asthma
Monninkhof et al. (2003)	RCT	Not mentioned	n=248 COPD
Moriyama et al. (2009)	RCT	Theory of cognitive behaviour	n=65 DM type 2

## Supplement 3. (continued)

Outcomes Hedges (G)* - Knowledge - Behavioural change - Skills - Coping - Self-efficacy Only reported / calculated if measured in the original study	Outcomes Hedges (G)* - Clinical outcomes - Quality of Life Only reported / calculated if measured in the original study
	Exercise capacity 0.73 (0.24 - 1.23) Heart rate -0.53 (- 1.02 -0.04) Systolic blood pressure - 0.04 (-0.52 - 0.44) Diastolic blood pressure -0.09 (-0.57 - 0.39)
$1^{st} value = Education / 2^{nd} value = Education + PFM$ Knowledge 1.45 (1.00 - 1.89) / 1.53 (1.08 - 1.97) Behavioural change (self-care behaviours 1.68 (1.22 - 2.14) / 2.42 (1.90 - 2.94) Skills 0.23 (-0.17 - 0.62) / 0.33 (-0.07 - 0.73) Coping (asthma control indicator) -0.08 (-0.48 - 0.31) / 0.10 (-0.30 - 0.49) Self-efficacy 1.14 (0.72 - 1.57) / 1.94 (1.47 - 2.42)	Peak expiratory flow rate 0.17 (-0.23 - 0.56) 0.52 (0.12 -0.92) FVC 0.44 (0.04 - 0.83) 0.38 (-0.02 - 0.78) Pre-bronchodilation FEV1 0.24 (-0.15 - 0.64) 0.08 (-0.32 - 0.47) * FEV1/ FVC 0.01 (-0.38 - 0.41) 0.09 (-0.30 - 0.48) Post- bronchodilation FEV1 0.15 (-0.25 - 0.54) 0.10 (-0.29 - 0.49) FEV1/FVC 0.06 (-0.34 - 0.45) 0.03 (-0.36 - 0.43)
Coping self-statement 0.33 (-0.08 - 0.73) Praying/hoping -0.05 (-0.46 - 0.35) Ignoring 0.25 (-0.15 - 0.65) Increasing behavioural activities 0.25 (-0.15 - 0.65) Catastrophizing -0.20 (-0.60 - 0.20) Diversion of attention 0.40 (-0.01 - 0.80)	Health related quality of life Physical 0.08 (-0.31 - 0.48) Mental health 0.38 (-0.02 - 0.79)
Self-efficacy 1.93 (1.32 – 2.54)	
 Problem-oriented coping 0.08 (-0.24 - 0.40)	Depressive symptoms 0.16 (-0.16 - 0.48)
	Quality of life Physical component = 0.08 (-0.32 - 0.48) Mental component = 0.31 (-0.09 - 0.71) Difference in daily dopaminergic drug therapy: -0.29 (-0.69 - 0.11)
	Health Related Quality of Life (total) = -0.10 (-0.43 - 0.08)

Supplement 3. (continued)					
Author(s); year of publication	Design	Theory mentioned in study	Patient group characteristics ( <i>n; diagnosis</i> )		
van Os-Medendorp	Mixed-methods	Coping strategies	n=65		
et al. (2007a)					
van Os-Medendorp et al. (2007b)	RCT	Coping strategies	n=65 Chronic pruritic skin disease		
Otsu & Moriyama (2011)	RCT	Theory of cognitive behaviour	n=102 CHF Retired elderly persons		

Otsu & Moriyama	RCT	Theory of cognitive behaviour	n=94
(2012), Japan			CHF
			Retired elderly persons

Ronning et.al. (2013)	Single group before- after design	Theory of constructivism	n=55 Congenitally malformed hearts
Rootmensen et al. (2008)	RCT	Not mentioned	n=191 COPD
Sarian et al. (2012)	Single group before after test	Chronic Care Model	n=10 Peritoneal dialysis patients
Scheurs et al. (2003)	Single group before- after design	Self-regulation model & proactive coping theory	n=83 Asthma, DM, and CHF

Outcomes Hedges (G)* - Knowledge - Behavioural change - Skills - Coping - Self-efficacy Only reported / calculated if measured in the original study	Outcomes Hedges (G)* - Clinical outcomes - Quality of Life Only reported / calculated if measured in the original study
Itch-related coping Catastrophizing and helpless coping 0.28 ( -0.27 - 0.84) Problem-focused coping 0,17 (-0.39 - 0.72) Skin Related psychosocial morbidity 0.02 (-0.53 - 0.57) General Psychosocial morbidity 0.47 (-0.08 - 1.02)	
Frequency of itching/scratching 0.34(-0.16 - 0.83). Intensity of itching/ scratching 0.41 (-0.09 - 0.90) Catastrophizing and helpless coping 0.32 (-0.13 - 0.78) Problem-focused coping 0.09 (-0.37 - 0.54) Skin related psychosocial morbidity 0.25 (-0.21 - 0.70)	Quality of life 0.08 (-0.37 - 0.54)
Quit smoking 0.18 (-0.22 – 0.59) Quit drinking 0.02 (-0.39 – 0.42) Symptom deterioration 0.24 (-0.17 – 0.64)	Systolic blood pressure 0.31 (-0.10 – 0.72) Diastolic blood pressure 0.23 (-0.17 – 0.64) Pulse pressure 0.27 (-0.13 – 0.68) Heart function level, Grade II 0.08 (-0.32 – 0.48) Heart function level, Grade III 0.44 (0.03 – 0.85) Ankle oedema 0.29 (-0.11 – 0.70) Shortness of breath 0.46 (0.05 – 0.87) Health-Related Quality of Life 0.74 (0.32 – 1.16) Compliance: Sodium restriction 0.88 (0.45 – 1.30) Medicine 0.29 (-0.11 – 0.70) Activities/ exercises 2.10 (1.59 – 2.60) Weight- monitoring 0.00 (040 – 0.40)
	Systolic blood pressure 0.17 (-0.26 - 0.60) Diastolic blood pressure 0.04 (-0.40 - 0.47) Pulse pressure 0.19 (-0.25 - 0.62) Brain Peptide 0.32 (-0.12 - 0.76)

Knowledge 0.00 (-0.31 - 0.31) Coping 0.04 (-0.27 - 0.35) Skills Inhalation technique 0.45 (0.12 - 0.78)

Supplement 3. (co	ntinued)		
Author(s); year of publication	Design	Theory mentioned in study	Patient group characteristics ( <i>n; diagnosis</i> )
Smeulders et al. (2010a/b)	RCT	Social Cognitive Theory	n=317 Congestive heart failure
Trappenburg et al. (2008)	Non randomized controlled multicenter study	Not mentioned	n=115 COPD
Tsay et al. (2005)	RCT	Transitional model of stress and coping	n=57 End-stage renal disease
Williams et al. (2012)	RCT	Health Belief Model	n=78 CKD, DM, and cardiovascular disease
Wilson et al. (2008)	RCT	Theory of Planned Behaviour & stage of change	n=91 COPD
Yildiz & Kurcer (2012)	Single-group before- after design	Not mentioned	n=84 CKD
Yu et al. (2014)	Non-randomized controlled trial	Social Cognitive Theory	n=84 COPD
Zoffman & Kirkevold (2012)	Qualitative evaluation study	Life skills & Empowerment	n=50 DM type 1
Zoffman & Lauritzen (2006)	RCT	Empowerment & trans- theoretical stage of change theory	n=30 DM type 1

\* Effect sizes of 0.2 were interpreted as small, 0.5 as medium, and 0.8 as large (Fritz et al., 2012)

Outcomes Hedges (G)* - Knowledge - Behavioural change - Skills	Outcomes Hedges (G)* - Clinical outcomes - Quality of Life
- Coping - Self-efficacy Only reported / calculated if measured in the original study	Only reported / calculated if measured in the original study
General self-efficacy -0.04 (-0.26 - 0.18) Cardiac self-efficacy 0.06 (-0.16 - 0.29) Perceived control -0.09 (-0.31 - 0.13) Cognitive symptom management (CSM) 0.11 (-0.11 - 0.33) Self-care behaviour: 0.00 (-0.22 - 0.22)	Cardiac-specific QOL Total -0.12 (-0.35 - 0.10) Physical -0.07 (-0.29 - 0.16) Mental -0.09 (-0.31 - 0.14) Perceived control -0.15 (-0.37 - 0.07) Symptoms of anxiety 0.16 (-0.07 - 0.38) Symptoms of depression -0.24 (-0.460.01)
	Quality of life -0.26 (-0.63 - 0.11) No. Exacerbations 0.26 (-0.11 - 0.62)
Coping Stressor severity 0.14 (-0.38 - 0.66) Physical stressors associated with haemodialysis 0.18 (-0.34 - 0.70) Psychological stressors associated with haemodialysis 0.12 (-0.40 - 0.64).	Mental Quality of Life 0.32 (-0.08 - 0.97) Physical Quality of life 0.44 (-0.08 - 0.97)

Behavioural change:	Quality of life (total) 0.92 (0.60 - 1.23)
Cigarette (number in a day): 0.25 (-0.05 - 0.55)	Serum Albumin (g/dl) 0.69 (0.38 - 1.01)
Alcohol (glass in a week): 0.02 (-0.28 - 0.32)	Serum Urea 0.43 (0.13 - 0.74)
Exercise duration (minute a day): 5,75 (5.06 - 6.43)	Serum creatinine 0.33 (0.02 - 0.63)
	Tension:
	Systolic 0.92 (0.60 - 1.23)
	Diastolic 0.69 (0.38 - 1.01)

Health related quality of life 0.77 (0.32 – 1.21)

Behavioural change: Perceived autonomy support 4.18 (3.18 – 5.17) Treatment self-regulation: Autonomous 1.66 (1.01 – 2.32) Diabetes related problems 3.10 (2.27 – 3.93)

String	Context	Mechanism	Outcome
A) Knowledge leads to Behavioural change	Motivation of patients Recalcitrant smokers with little confidence	Knowledge Providing education about the	Behavioural change These interventions did not lead to behavioural change
(Balk et al., 2008; Choi & Lee, 2012; Gonzalez, 2014;	in a new attempt to quit smoking, who lack symptoms of dyspnoea at the time of the	chronic condition, the risk of smoking or unhealthy food, and	(Grilo et al., 2015; Wilson et al., 2008).
Goossens et al., 2014; Grilo et al., 2015; Howden et al., 2014; Huang et al., 2009;	intervention and live with another smoker, and health illiterate food-insecure patients whose food choices are culturally influenced	how to use medication.	
van der Meer et al., 2009; Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012; Rönning	<b>Difficult patients</b> Patients with less education and visual impairment included in study, 'difficult' patients	Knowledge Re-enforcement education, in which the nurse repeated the information during multiple consultation	<b>Behavioural change</b> This intervention enabled patients to adjust the information to their own situation – which in turn led to a change in behaviour (Huang et al., 2009).
et al., 2011; hootmensen et al., 2008; Trappenburg et al., 2008; Wilson et al., 2008; Vildiz & Kurrer 2013- Yu et		sessions or follow-up telephone calls, and answered individual questions.	
al, 2014)	Recently diagnosed patients Recently diagnosed patients with chronic heart failure	<b>Knowledge</b> Providing feedback about patients' knowledge by self-monitoring.	<b>Behavioural change</b> These interventions stimulated learning and led to knowledge gain. Patients learned to recognize warning signs by which they would change their behaviour (Balk et al., 2008; Huang et al., 2009).
	Motivation of patients Patients who feel relatively well and who are capable of self-care	Knowledge Providing feedback about patients' knowledge through self-monitoring and measurement devices	<b>Behavioural change</b> This intervention did not have a surplus value for this group (Balk et al., 2008).

Supplement 4. (continued	(		
String	Context	Mechanism	Outcome
B) Knowledge leads to Coping (Akyil & Ergüney, 2013; Bakan & Akyol, 2008; Hagberth et al., 2008, Jiang & He, 2012; Lindskov et al.,	Patients in a homogeneous group	Knowledge Sharing experiences and knowledge with peers	<b>Coping</b> This made patients feel acknowledged. They were able to adjust the information to their own situation when they shared information about lifestyle or exercise. It was successful for some topics (Bakan & Akyol, 2008; Hagberth et al., 2008; Sarian et al., 2011).
2007; Monninkhof et al., 2003; van Os-Medendorp et al., 2007a; van Os- Medendorp et al., 2007b; Sarian et al., 2011; Schreurs et al., 2003; Tsay et al., 2005)	<b>Undefined context</b> Patients with various chronic conditions, both group and individual interventions	Knowledge Patients were provided with information about the disease, its symptoms and strategies to deal with symptoms.	<b>Coping</b> Patients learned to reinterpret the situation and thus were better able to cope with the disease (Akyil & Ergüney, 2013; Bakan & Akyol, 2008; Jiang & He, 2012; Lindskov et al., 2007; Monninkhof et al., 2003; Schreurs et al., 2003; Tsay et al., 2005).
	Involvement of relatives	<b>Knowledge</b> Relatives were involved in the intervention.	<b>Coping</b> Patients were better supported in their daily lives (Bakan & Akyol, 2008; Monninkhof et al., 2003; Sarian et al., 2011).
	Patients in a homogeneous group Patients with peritoneal dialysis in a group with fellow patients	<b>Knowledge</b> Discussing scenarios with peers	<b>Coping</b> Patients learned what to do in certain circumstances (Sarian et al., 2011).
	Patients with various chronic conditions in groups	Knowledge Patients who kept a diary to monitor progress became aware of their responses in certain situations, but	<b>Coping</b> Participants were disappointed if goals could not be reached quickly enough (Schreurs et al., 2003; Tsay et al. 2005).

Supplement 4. (continuec			
String	Context	Mechanism	Outcome
<b>C) Knowledge leads to</b> <b>Self-efficacy</b> (Carrieri-Kohlman et al., 2005; Donesky et al., 2014;	Undefined context Patients with COPD in individual counselling sessions	<b>Knowledge</b> Patients were encouraged to discuss everyday disease related problems.	<b>Coping</b> Patients learned to reinterpret the situation, confidence to deal with the disease increased (Donesky et al., 2014; Kaşıkçı, 2011).
Kara & Aşti, 2004; Kaşıkçı, 2011; Smeulders et al., 2010a; Smeulders et al., 2010b)	Patients in a homogeneous group Patients in a group with fellow patients or relatives	Knowledge Patients shared experiences and knowledge about living with the chronic condition.	Behavioural change Patients felt acknowledged and were provided with practical ready-to-use information. This led to reinterpretation of the situation, and to greater confidence to deal with the disease (Kara & Aşti, 2004; Smeulders et al., 2010a; Smeulders et al., 2010b).
D) Skills enhancement leads to Behavioural change (Huang et al., 2009;	<b>Motivation of patients</b> Patients who are poorly motivated to stop smoking	Skills Patients discussed with nurses how to quit smoking and to set goals, the nurse encouraged the patient.	<b>Behavioural change</b> This discussion served as a cue to action for patients (Moriyama et al., 2009; Wilson et al., 2008).
Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012;	Undefined context Patients with asthma	<b>Skills</b> Patients learned to monitor their condition.	<b>Behavioural change</b> The monitoring led to self-care behaviour (Huang et al., 2009).
wountensen et al., 2008) Wilson et al., 2008)	Involvement of relatives Patients with chronic conditions, with involvement of family	<b>Skills</b> Family received instructions about skills which the patient should master, then they could support the patient in this process	<b>Behavioural change</b> This did not in all studies help the patients to change their behaviour (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012).

Supplement 4. (continued	1)		
String	Context	Mechanism	Outcome
E) Skills enhancement leads to Coping (Jiang & He 2012; Lee et al., 2014; Monninkhof et al.,	<b>Undefined context</b> Patients with chronic conditions.	Skills Learning practicing breathing techniques, pleasant imagery and distraction.	<b>Coping</b> The learned skills helped patients to cope with disease related problems (Jiang & He, 2012; van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b).
2003; van Os-Medendorp et al., 2007a; van Os- Medendorp et al., 2003, Tsay et Schreurs et al., 2003, Tsay et	Patients in a homogeneous group Patients with chronic conditions in homogenous groups of fellow patients	<b>Skills</b> Discussing personal goals with fellow patients	<b>Coping</b> Discussing personal goals led to advice, support, and pointing out unrealistic goals by these fellow patients (Schreurs et al., 2003, Tsay et al., 2005).
( CODZ "IB	Patients in a homogeneous group	<b>Skills</b> Practicing skills in a group with fellow patients	<b>Coping</b> This encouraged patients to try these skills, which gave increased confidence (Schreurs et al., 2003; Tsay et al., 2005)
F) Skills enhancement leads to Self-efficacy (Carrieri-Kohlman et al., 2005; Donesky et al., 2014;	<b>Undefined context</b> Patients with COPD	<b>Skills</b> Training and gradual exposure to a fearful stimulus	<b>Self-efficacy</b> This gave patients not always an increase of confidence of being in control of their breathing (Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kaşıkçı, 2011).
Kara & Aşti, 2004; Kaşıkçı, 2011; Smeulders et al., 2010a; Smeulders et al., 2010b)	<b>Patients in a homogeneous group</b> Patients with COPD in homogenous groups	Skills Patients practicing in groups and seeing other patients perform exercises	<b>Self-efficacy</b> Patients gained greater confidence of being able to perform these exercises (Kara & Aşti, 2004).
	<b>Undefined context</b> Patients with COPD	<b>Skills</b> Patients who received feedback from nurses on their improvements, who did daily exercises and mastered gradual steps,	<b>Self-efficacy</b> Patients persevered in their behaviour (Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kaşıkçı, 2011).

#### What do nurse-led self-management interventions achieve?

Supplement 4. (continued)			
String	Context	Mechanism	Outcome
<b>G) Motivation leads to</b> <b>Behavioural change</b> (Williams et al., 2012; Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012)	<b>'Difficult patients'</b> Patients with poorly controlled diabetes	<b>Motivation</b> Reflection of patients on their problems in controlling the diabetes.	<b>Behavioural change</b> Patients became aware of their own role in controlling the diabetes, and they showed more involvement during the consultations (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012).
	<b>'Difficult patients'</b> Patients with poorly controlled diabetes	Motivation Reflection by patients and nurses on the difficulties of living with diabetes.	<b>Behavioural change</b> This intervention led to patients' internal motivation to achieve their goals, and to an actual change of behaviour (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012).
	Culturally and linguistically diverse groups and Involvement of relatives	<b>Motivation</b> Using interpreters and family	Behavioural change The use of interpreters and family made that patients regarded the session as helpful and enjoyed learning about their conditions in their preferred language, but it did not automatically lead to a change of behaviour (Williams et al., 2012).
	Culturally and linguistically diverse groups with multiple chronic conditions	<b>Motivation</b> Using interpreters	<b>Behavioural change</b> Patients learning in their own language stimulated patients to learn about their condition, but did not lead to a behavioural change (Williams et al., 2012).

Supplement 5	. Table Components of self-management support	interventions	
	Components		
A) Knowledge	Brief medical advice (Wilson et al., 2008)	Knowledge questionnaire (Rönning et al., 2011)	Phone calls (Grilo et al., 2015; Huang et al., 2009;
leads to	Computer-based education / CD (Rönning et al.,	Letter to the family describing ways to assist	Moriyama et al., 2009; Yu et al., 2014)
behavioural	2011)	patients (Otsu & Moriyama, 2011; Otsu & Moriyama,	Presentation (Choi & Lee, 2012; Gonzalez, 2014)
change	Computerized intake form/checklist (Goossens et	2012)	Relatives attend sessions/involvement (Moriyama
	al, 2014)	Medication and appointment reminders (Grilo et	et al., 2009; Yu et al., 2014)
	Diary records (Yu et al., 2014)	al., 2015)	Self-monitoring (Huang et al., 2009; van der Meer et
	Daily biomedical self-measurements (Balk et al.,	Monitoring by healthcare professional (Yıldız &	al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama,
	2008; Huang et al., 2009)	Kurcer, 2012)	2012)
	Educational group sessions (with fellow patients	Motivational interviewing (Grilo et al., 2015)	Telemonitoring (Grilo et al., 2015; Trappenburg et
	and/or relatives) (Choi & Lee, 2012; van der Meer et	Patient education brochure (Gonzalez, 2014; Huang	al., 2008)
	al., 2009; Wilson et al., 2008)	et al., 2009; Wilson et al., 2008)	Textbook (Otsu & Moriyama, 2011; Otsu &
	Feedback from monitoring device (Trappenburg et	Personal targets (Grilo et al., 2015)	Moriyama, 2012; Yu et al., 2014)
	al., 2008)	Personalized daily questions (Trappenburg et al.,	Text messaging (Yu et al., 2014)
	Individualized education plan (Balk et al., 2008;	2008)	TV-channel (Balk et al., 2008)
	Wilson et al., 2008; Yu et al, 2014)	Personalized feedback (van der Meer et al., 2009;	Web-based education (van der Meer et al., 2009)
	Individualized face-to-face education sessions	Otsu & Moriyama, 2011; Otsu & Moriyama, 2012)	
	(Choi & Lee, 2012; Gonzalez, 2014; Goossens et		
	al., 2014; Howden et al., 2015; Huang et al., 2009;		
	Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu		
	& Moriyama, 2012; Rootmensen et al., 2008; Wilson		
	et al., 2008; Yıldız & Kurcer, 2012; Yu et al., 2014)		

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Supplement 5.	. Table Components of self-management support i	interventions (continued)	
	Components		
B) Knowledge leads to coping	Audio CD (Jiang & He, 2012) Awareness training by use of diary (van Os- Medendorp et al., 2007a; van Os-Medendorp et al., 2007b) Bank of topics patients want to discuss, which could be used during the meetings (Hagberth et al., 2008) Booklet with information about (adaptation of) the illness (Akyil & Ergüney, 2013; Monninkhof et al., 2007) Medendorp et al., 2007a) Case studies (Sarian et al., 2011) Crossword puzzle (Bakan & Akyol, 2008)	Educational group sessions (with fellow patients and/or relatives) (Bakan & Akyol, 2008; Hagberth et al., 2008; Lindskov et al., 2007; Monninkhof et al., 2003; Sarian et al., 2011; Schreurs et al., 2003; Tsay et al., 2005) Experienced layman from patient association (Hagberth et al., 2008) Home work (Schreurs et al., 2003) Individualized face-to-face education (Akyil & Ergüney, 2013; Bakan & Akyol, 2008; Lindskov et al., 2007; van Os-Medendorp et al., 2007; van Os- Medendorp et al., 2007b; Sarian et al., 2011)	Patient workbook (Schreurs et al., 2003) Peer support (fellow patients) (Bakan & Akyol, 2008; Sarian et al., 2011; Tsay et al., 2005) Phone calls (Akyil & Ergüney, 2013; Bakan & Akyol, 2008; Jiang & He, 2012) Self-help manual (Jiang & He, 2012) Peer support group for family members (Lindskov et al., 2007) Patient education brochure (Bakan & Akyol, 2008) Weekly biomedical self-measurements (Monninkhof et al., 2003)
C) Knowledge leads to self- efficacy	Educational group sessions (with fellow patients and/or relatives) (Smeulders et al, 2010)	Individualized face-to-face education sessions (Carrieri-Kohlman et al., 2005; Donesky et al., 2014) Patient education brochure (Kara & Aşti, 2004; Kaşıkçı, 2011)	Repeated structured education according to needs (Kaşıkçı, 2011) Telephone calls (Kaşıkçı, 2011)
D) Skills enhancement leads to behavioural change	Booklet with exercise instructions (Howden et al., 2015) Calendar to monitor body measurements (Otsu & Moriyama, 2011; Otsu & Moriyama, 2012) Check and correct skills (Rootmensen et al., 2008) Daily exercises (home work) (Moriyama et al., 2009) Face-to-face instruction (Huang et al., 2009; Rootmensen et al., 2008; Wilson et al., 2008)	Group support (Wilson et al., 2008) Home-based training (Howden et al., 2015) Personal targets (Moriyama et al., 2009; Otsu & Moriyama, 2011; Otsu & Moriyama, 2012) Personalized feedback (Moriyama et al., 2009) Monitoring health status (Howden et al., 2015)	Motivational interviewing (Moriyama et al., 2009; Williams et al., 2012) Phone calls (Grilo et al., 2015; Howden et al., 2015) Record keeping of daily practice (Moriyama et al., 2009) Self-monitoring by using a scale (Huang et al., 2009) Supervised exercise training (Howden et al., 2015)

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Supplement 5	. Table Components of self-management support	interventions (continued)	
	Components		
E) Skills enhancement leads to coping	Diary records (van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b; Tsay et al., 2005) Group counselling and support (Monninkhof et al., 2003) Individual counselling and support (van Os- Medendorp et al., 2007a; van Os-Medendorp et al., 2007b) Individualized action plan (Lee et al., 2013; Schreurs et al., 2003) Instruction booklet (Jiang & He, 2012; Lee et al., 2014; Monninkhof et al., 2003)	Motivational interviewing (van Os-Medendorp et al., 2007a; van Os-Medendorp et al., 2007b) Patient workbook (Schreurs et al., 2003) Peer support (fellow patients) (Schreurs et al., 2003, Tsay et al., 2005) Phone calls (Jiang & He, 2012; Lee et al., 2014) Practicing techniques (Tsay et al., 2005) Self-help manual (Jiang & He, 2012)	Self-treatment action plan (Monninkhof et al., 2003) Supervised training and workout sessions (Monninkhof et al., 2003) Tools (eg. laminated cards describing the steps to relax and use calming self-talk) (Jiang & He, 2012) Verbal reinforcement and encouragement (Lee et al., 2014)
F) Skills enhancement leads to self- efficacy	Coaching during exercise (Carrieri-Kohlman et al., 2005; Donesky et al., 2014; Kara & Aşti, 2004) Goal setting (Smeulders et al., 2010) Group support (Kara & Aşti, 2004; Smeulders et al., 2010) Home exercise (Donesky et al., 2014)	Individualized action plan (Smeulders et al., 2010) One-to-one classes with telephone interviews (Kaşıkçı, 2011) Phone calls (Carrieri-Kohlman et al., 2005) Personalized feedback (Donesky et al., 2014; Smeulders et al., 2010)	Personal targets (Kara & Aşti, 2004) Record keeping of daily practice (Carrieri-Kohlman et al., 2005; Donesky et al., 2014) Supervised training and workout sessions (Carrieri- Kohlman et al., 2005; Donesky et al., 2014; Kara & Aşti, 2004; Kaşıkçı, 2011)
G) Motivation leads to behavioural change	Group support (Zoffmann & Lauritzen, 2006) Individualized medication review (Williams et al., 2012) Interpreters (Williams et al., 2012)	Motivational interviewing (Williams et al., 2012) Personal targets (Williams et al., 2012; Zoffmann & Lauritzen, 2006) Phone calls (Williams et al., 2012)	Presentation (in patients' own language) (Williams et al., 2012) Reflection sheets (Zoffmann & Lauritzen, 2006; Zoffmann & Kirkevold, 2012)

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Competencies for self-management support





# Chapter 4

The development and psychometric validation of the self-efficacy and performance in selfmanagement support (SEPSS) instrument

Veerle Duprez\*, Susanne M. van Hooft\*, Jolanda Dwarswaard, AnneLoes van Staa, Ann van Hecke, Mathilde M.H. Strating \*Both authors contributed equally to this work

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# ABSTRACT

## Aim

To develop and psychometrically test the self-efficacy and performance in self-management support (SEPSS) instrument.

# Background

Facilitating persons with a chronic condition to take an active role in the management of their condition, implicates that nurses acquire new competencies. An instrument that can validly and reliably measure nurses' performance and their perceived capacity to perform self-management support is needed to evaluate current practice and training in self-management support.

## Design

Instrument development and psychometric testing of the content and construct validity, factor structure and reliability.

## Methods

A literature review and expert consultation (n=17) identified the content. The items were structured according to the Five-A's model and an overarching category of 'overall' competencies. The initial instrument was tested in a sample of 472 nurses and 51 nursing students from Belgium and the Netherlands, between June 2014 and January 2015.

## Results

Confirmatory factor analyses revealed satisfactory fit indices for the six-factor structure. Discriminating power was demonstrated for subgroups. The overall internal consistency (Cronbach's alpha) was high both for the self-efficacy and the performance items. The test-retest intra-class correlation coefficients were good.

## Conclusion

The SEPSS instrument is a 36-item, Likert-scaled self-reporting instrument with good content and construct validity, as well as good internal consistency reliability, and good test-retest reliability. Therefore it is a promising instrument to measure self-efficacy and performance with regard to self-management support.

## Why is this instrument needed?

To support their patients' self-management, nurses must assume a new role and acquire new competencies.

A valid and reliable instrument is needed to measure the current practice, the educational needs and the effectiveness of training in self-management support.

So far no attention has been given to the assessment of nurses' self-efficacy, which is a strong predictor of behaviour, in the context of self-management support.

## What are the key findings?

Competencies acquired for self-management support can be categorized according to the phases of the Five A's model, but also a sixth overarching category of competencies was identified, including, for example, partnership.

The Self-Efficacy and Performance in Self-management Support instrument has good content and construct validity, as well as good internal consistency reliability.

# How should the findings be used to influence practice and education?

The Self-Efficacy and Performance in Self-management Support instrument is suitable to measure nurses' self-efficacy and performance with regard to self-management support.

The self-reported results should serve as an outcome measure of self-management support practices in clinical and research settings, to identify educational needs, and to evaluate personal growth.

## Impact statement

None of the instruments that measure healthcare professionals' performance in selfmanagement support takes a holistic perspective of performance, including self-efficacy. We developed a 36-item self-report instrument – aptly named the Self-Efficacy and Performance in Self-management Support (SEPSS) instrument – suited to assess nurses' self-efficacy and performance in self-management support for people with chronic conditions. The SEPSS instrument demonstrated good psychometric properties on content and construct validity, as well as on internal consistency reliability. The instrument could be useful to measure current practice, to identify needs for education, and to evaluate nurses' personal growth with regard to self-management support.

#### INTRODUCTION

Chronic conditions account for more than half of the global disease burden (WHO 2014). The steadily increasing prevalence of people with chronic conditions poses new challenges for patients, healthcare providers, and healthcare systems all over the world (Alwan et al. 2010; WHO 2014). The provision of self-management support (SMS) is internationally recognized as a core component of chronic care (Nolte & McKee, 2008; Wagner et al., 2001; WHO, 2014). Self-management can be defined as: "the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established" (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002, p. 178). This definition would imply that patients are expected to take an active role in their treatment, for which they will need specific competencies. To support their patients' self-management, healthcare providers as well must assume a new role and acquire new competencies. In many countries, nurses are the ones who provide SMS (Alleyne, Hancock & Hughes, 2011). This new role, however, is not easily integrated in practice (Elissen et al., 2013; Hibbard, Collings, Mahony & Baker, 2010; Wilson, Kendall & Brooks, 2006). SMS is based on a partnership between patients and nurses, which requires nurses to drop the nurse-expert role (Hook, 2006; McDonald, Rogers & Macdonald, 2008; Thorne, Ternulf Nyhlin, & Paterson, 2000) and expressions of control in patient interactions (Lawn, Delany, Sweet, Battersby & Skinner, 2014). SMS demands a set of competencies on educational, supportive and communicational level in all phases of the support process (Alleyne et al., 2011; Elissen et al., 2013; Nolte & McKee, 2008). One of the leading models in organizing the process of SMS is the Five A's model describing five key activities (Assess, Advise, Agree, Assist, and Arrange) (Glasgow, Davis, Funnell & Beck, 2003). This model provides a framework for professional behaviour in SMS, and thereby facilitates the necessary steps in the provision of SMS. In the Assess phase, nurses must be capable of not only exploring patients' beliefs and motivation about living with the chronic condition but also of personalizing the support offered (Glasgow, Emont & Miller, 2006, Lawn et al., 2009). In the Advise phase, providing information about the disease and its symptoms is an important feature. Education is a precondition for informed decision making – and consequently for self-management as well (Udlis, 2011). The Agree phase requires skills for collaborative goal setting, during which process the nurse and patient together must agree on the goals to aim for, guided by previous positive experiences (Schulman-Green et al., 2012; Stacey, Taljaard, Drake & O'Connor, 2008). In the Assist phase, nurses need competencies to enable patients adapt their daily activities, which may include stimulating patients to seek professional help (Dwarswaard, Bakker, van Staa & Boeije, 2015; Schulman-Green et al., 2012). The Arrange phase refers to organizing follow-up care. SMS is a multidisciplinary approach which relies on effective information sharing and effective coordination of care (Pols, 2009). Importantly, arrangements must be made to evaluate the progress in goal achievement (Glasgow et al., 2003). In addition, nurses need to possess overall competencies for a partnership attitude in each phase of the support process. This includes respecting patients' autonomy in shared decision-making, building a sustainable partnership, and being able to reflect upon one's own actions and recognize ethical dilemmas (Hostick & McClelland, 2002; Kayser, Cossette & Alderson, 2014; Pols, 2009; Sandman, Granger, Ekman & Munthe, 2012).

Studies reveal a discrepancy between the expected proficiency of nurses and their actual performance on SMS (Elissen et al., 2013; Yank, Laurent, Plant & Lorig, 2013). One of the ways to improve the provision of SMS in chronic care is the training of healthcare providers (Kosmala-Anderson, Wallace & Turner, 2010; Zwar et al., 2006). Training is also likely to improve self-efficacy, and thus performance of SMS since self-efficacy is a strong predictor of behaviour (Bandura, 1991), and thereby an important precursor of SMS performance. To the best of our knowledge, there is no instrument to evaluate the confidence nurses have in their own SMS abilities.

A valid and reliable instrument assessing both performance and self-efficacy is useful to guide and measure the current practice, to identify educational needs, and to assess the effectiveness of training programs.

#### Background

Several instruments are available to measure healthcare professionals' performance in SMS. These only address specific aspects, however. The Clinician Support-Patient Activation Measure (CS-PAM) measures beliefs about the importance of activating patients and of SMS (Hibbard et al., 2010). Decision support can be addressed with instruments such as the Observing Patient Involvement (OPTION) scale (Elwyn, Tsulukidze, Edwards, Légaré & Newcombe, 2013), the Shared Decision Making Questionnaire physician version (SDM-Q-Doc) (Scholl, Kriston, Dirmaier, Buchholz & Härter, 2012), and the Decision Support Analysis Tool (DSAT-10) (Stacey et al., 2008). Therapeutic alliance can be measured with the Kim Alliance Scale (KAS) (Kim, Boren & Solem, 2001); and skills in motivational interviewing with for example the Motivational Interviewing Treatment Integrity (MITI) (Moyers, Martin, Manuel, Hendrickson & Miller, 2005) or the Behavior Change Counselling Scale (BCCS) (Vallis, 2013). To our knowledge, only the Practices in SMS (PSMS) covers the broad aspect of SMS (Kosmala-Anderson, Wallace, Turner & Barwell, 2011). This 25-item instrument has three subscales: clinician SMS, organization of services to support self-management, and patient centeredness, which all showed good internal consistency. However, nursing competencies to stimulate patients to take the lead in their self-management are not addressed in detail.

These existing instruments typically focus on performance in SMS. It may be the case, however, that healthcare professionals have the required skills, but lack self-efficacy to effectively apply these skills (Bandura, 1991; Kosmala-Anderson et al., 2010). Self-efficacy refers to a person's confidence in the ability to perform a specific behaviour in a specific situation (Bandura, 1991). Self-efficacy is known to affect behaviour in several ways: it influences the choices individuals make and the course of actions they pursue; it determines their level of effort, persistence, and resilience (Bandura, 2006).

The current evidence demonstrates that other factors than self-efficacy might affect a nurse's performance in SMS (Elissen et al., 2013; Harris, Williams, Dennis, Zwar & Davies, 2008), creating the potential risk of a discrepancy between self-efficacy and performance. Therefore, it is appropriate to develop an instrument that measures not only nurses' actual performance but also self-efficacy to perform SMS for people with chronic conditions.

## THE STUDY

## Aim

To develop and psychometrically test the Self-efficacy and Performance in Self-Management Support (SEPSS) instrument.

#### Methodology

A psychometric instrument validation study was conducted in two phases. Phase one included instrument development and the process of content validation by a panel of experts. Phase two entailed the psychometric evaluation in a sample of nurses and nursing students (see Figure 1).

#### Phase 1 Instrument development & content validation

First, a literature and concept search in scientific and grey literature was performed from March until November 2013 to identify relevant competencies for SMS. We searched in the PubMed, CINAHL, and Cochrane databases for scientific articles about the concept of self-management and the required competencies for SMS, using the keywords 'self-care', 'chronic disease', nurs\*, and competenc\*. We also retrieved information from (inter) national policy documents on self-management. The processes of self-management in patients with chronic conditions, consisting of patient tasks and skills as described by Schulman-Green et al. (2012), formed the basis for a draft list. These processes were converted into competencies for SMS that healthcare professionals should possess. Additionally, competencies such as partnership (Hostick & McClelland, 2000; Keatinge et al., 2002; Leisen & Hyman, 2001; Lorig & Holman, 2003; Visse, Teunissen, Peters, Wid-

dershoven & Abma, 2010), shared decision making, collaborative goal setting (Kriston et al., 2010; Lorig & Holman, 2003; Stacey et al., 2008), and self-efficacy of the patient (Krichbaum, Aarestad & Buethe, 2003; Lorig & Holman, 2003; Yank et al., 2013) were obtained from literature and added. The items in the list were structured according to the Five A's model described above (Glasgow et al., 2003). An overarching sixth category was added to cover 'overall' competencies for SMS that could not be related to one single step of the Five A's model (Glasgow et al., 2003; Hostick & McClelland, 2002; Kriston et al., 2010; Leisen & Hyman, 2001; Pols, 2009; Visse et al., 2010). In the end, the draft list contained 37 competencies, grouped into six subscales: (1) *Assess* -assess the needs and beliefs of the patient, (2) *Advise* – give the patient information he needs, (3) *Agree* – set goals together with the patient, (4) *Assist* – assist the patient to overcome barriers, (5) *Arrange* – arrange follow-up care, and (6) *Overall competencies* - a supportive attitude (Table 2).

This draft list was discussed by a convenience sample of experts in SMS (n=10) during a 3-hour meeting. Given that the instrument should be appropriate for all healthcare settings as well as for educational purposes, the experts represented nurse education, hospital care, elderly care, and psychiatric care. During the meeting the relevance, appropriateness and exhaustiveness of the item pool were discussed. Following on from the qualitative comments of the experts, three competencies were excluded, three competencies were reformulated, and six competencies were added. This resulted in a 40-item draft instrument. The grouping into the six subscales was approved by the experts. In the next step, the researchers split broad competencies into sub-competencies to allow detailed assessment, which increased the number of items to 53.

The relevance and clarity of the 53 item-instrument were pilot-tested in a new group of experts in SMS (n=4), nurses (n=8) and researchers (n=5). This resulted in some minor adjustments that entailed mainly wording ambiguities and in a reduction by seven items due to overlap in content or meaning. To cover the content of each subscale and to allow for items to be deleted during the psychometric testing and refinement of the instrument, at least six items were included for each subscale. Phase one resulted in an initial 46 item-instrument with established content validity, grouped into 6 subscales (Figure 1).

#### **Instrument**

The items were formulated to be measured on a five-point Likert rating scale. As the aim of the instrument was to assess both self-efficacy and performance in SMS, each item was assessed by two questions (additional file 1). Self-efficacy was measured by requesting subjects to consider '*I think I can to do this*', with ratings from '*Not at all*' (0), '*Not sufficient*' (1), '*More or less*' (2), '*Sufficient*' (3), '*Good*' (4). Actual performance was measured by requesting subjects to consider '*I do this*', with ratings from '*Never*' (0), '*Rarely*' (1), '*Occasionally*' (2), '*Frequently*' (3) to '*Always*' (4).



Figure 1. Developmental and validation process of the SEPSS – Instrument

## Phase 2 Psychometric evaluation

The psychometric evaluation (Figure 1) included the testing of the construct validity (confirmatory factor analysis, discriminating power) and reliability (internal consistency and stability) of the SEPSS instrument.

#### Sample\_

The 46-item instrument was tested in a sample of nurses and nursing students in Belgium and the Netherlands. The sample size aimed for was based on the recommended 10 respondents per item as a minimum to support the factor analysis for stable covariates (Polit & Beck, 2008). A total sample approach was used. In Belgium, 122 final-year nursing students were invited (response 51/122; 42%) as well as 58 nurses combining their employment with attending an additional Master of Science in Nursing program (response 37/58; 64%) participated. In the Netherlands, we invited 2,054 nurses from an academic hospital and 107 nurses from a psychiatric institution. Respectively 345 (17%) and 32 (30%) participated in the validation study. Furthermore, 800 nurses employed in different healthcare settings and participating in a Dutch national panel of nurse professionals were invited (response 58/800; 7%). This resulted in a total of 523 participants.

#### Procedure

Data were collected between June 2014 and January 2015. The nursing students completed a paper form of the self-reporting instrument. The nurses completed the ques-



Figure 1. Developmental and validation process of the SEPSS – Instrument (continued)

tionnaire in an online format. Next to the items of the SEPSS, participants were asked for demographic variables and their perception of the importance of SMS, on a scale ranging from 1 (*'not important at all'*) to 10 (*'very important'*). To increase the response rate, for the online procedure, two reminders were sent and small rewards (e.g. movie tickets) were raffled among the participants. As the instrument can be used to measure current practice in SMS, its stability was evaluated using the test-retest procedure. For this purpose, a group of nursing students (n=26) completed the instrument twice, with a 2-hours interval. This short interval was chosen to minimize the possible effect of confounding factors, such as learning by lectures or experiences on clinical placement, and by spontaneous growth (Polit & Beck, 2008). The participants were not informed in advance about the test-retest procedure, making the procedure less sensitive to memory bias. The conditions were the same for both parts of the procedure.

#### Statistical analyses

Statistical analyses were performed using SPSS21 (SPSS Inc., Chicago, II, USA) and LISREL (version 8.8). A significance level of 0.05 was applied. Questionnaires with response patterns indicating a haphazard completion of the questionnaire, i.e. with a repetitive response pattern of at least 42 out of the 46 items, were excluded (n=4). Mean scores were calculated at subscale level (range 0 to 4). The total score was calculated by summing the mean scores of the subscales for self-efficacy (range 0 to 24) and for performance (range 0 to 24) in SMS. Subscale scores were considered as missing when more than 10% of the items of that subscale were left open. These questionnaires were excluded from further calculations. The variables assessing self-efficacy and performance in SMS were normally distributed.

As the reliability (internal consistency) testing of the total scale and subscales of the initial 46-item instrument yielded Cronbach's alphas between 0.79 and 0.97, further validation was justified. Construct validity of the instrument was assessed by a confirmatory factor analysis and discriminating power (known-group technique). To verify the factor structure of the questionnaire and to test whether the relationship between observed variables and their underlying latent constructs exists, confirmatory factor analysis was executed using the LISREL program. No correlation errors either within or across sets of items were allowed in the model. Based on the Five A's model, each subset of items was allowed to load only on its corresponding latent construct. The 'overall' competence items only were allowed to load on a separate second order overarching latent construct. To improve the model fit and reduce the number of items within the instrument, items were removed from the original pool following three criteria: (1) items were excluded one by one following modification indices provided by LISREL and the strength of the loadings; (2) eliminating items was stopped when reliability of each subscale dropped below 0.80; and (3) there should be as few items as possible with a minimum of six, without loss of content and psychometric quality. Four indices of model fit were used. The cut-off criteria for these four indices were those proposed by Hu and Bentler (1999). First, the overall test of goodness-of-fit assesses the discrepancy between the model implied and the sample covariance matrix by means of a normal-theory weighted least squares test. A plausible model has low, preferably non-significant  $\chi^2$  values. However, Chi-square is overly sensitive when the sample size is large (anything over 200), leading to difficulty in obtaining desired non-significant levels (Hayduk, 1988). Second, the Root Means Square Error of Approximation (RMSEA) reflects the estimation error divided by the degrees of freedom as a penalty function. Values on RMSEA below 0.06 indicate small differences between the estimated and observed model. Third, we used
the Standardized Root Means square Residual (SRMR), which is a scale invariant index for global fit that ranges between 0 and 1. Values on SRMR lower than 0.08 indicate a good fit. As a fourth index of model fit the Incremental Fit Index (IFI) was calculated. This index compares the independence model (i.e. observed variables are unrelated) to the estimated model. Preferably, values on IFI should be larger than 0.95. Exclusion of items was not solely based on modification indices. Since the instrument heavily relies on literature and theoretical conceptualization, these considerations were taken into account when interpreting the statistical measures and were essential for decisions on exclusion of items.

Sample adequacy was tested by performing the Kaiser-Meyer-Olkin (KMO) measure over 0.50, and the Bartlett's test of sphericity. Further analyses were determined on the modified instrument (36 items). To study the discriminating power of the instrument, four subgroups with a theoretically expected difference in self-efficacy and performance in SMS were predefined: (1) nurses providing consultations in outpatients clinics versus nurses working in inpatients units; (2) nurses versus nursing students; (3) nurses with a master degree versus those without a master degree; and (4) nurses perceiving SMS as highly important ( $\geq$  9) versus nurses perceiving SMS of little or no importance ( $\leq$ 6). Independent sample t-tests were used to calculate differences between the mean scores of these predefined groups guided by a Levene's test for equality of variances.

The reliability of the instrument was assessed by internal consistency analysis and by test-rest reliability (intraclass correlation). Inter-item correlations were calculated at subscale and at scale level, to determine the internal consistency of the instrument. A Cronbach's alpha higher than 0.80 was considered as satisfactory (Polit & Beck, 2008). The intraclass correlation (ICC) of the test-retest was calculated for each subscale and for the total score on self-efficacy and total score on performance by using a two-way random effects model with absolute agreement. Reliability coefficients of  $\geq$ 0.70 were considered as satisfactory (Polit & Beck, 2008).

Floor and ceiling effects refer to the proportions of individuals scoring near the bottom or the top, respectively. A high floor or a ceiling effect could make it difficult to distinguish individuals from each other and also to measure changes after intervention (Terwee et al., 2007). There is no consensus on the mathematical definition of floor and ceiling effects (Terwee et al., 2007). We determined *a priori* that floor or ceiling effects were present if >15% of the nurses achieved values in the 12.5% lower and upper bound, respectively, of (sub)scale values.

#### **Translation**

For international publication and presentation purposes the initial 46 item instrument was translated from Dutch into English by an independent native speaker. Another independent professional translator re-translated the items in Dutch. The re-translated version was compared with the original wordings, to confirm the accuracy of the English translation. Discrepancies between the translations were resolved by consensus between researchers.

#### Ethical considerations

In Belgium, the study protocol was approved by the Ethical Review Committee of Ghent University Hospital (B670201422154 and B670201422381). While in the Netherlands no ethical approval was required, permission was obtained from the executive boards of all participating institutions. All participants received detailed information about the aim and procedures, and were informed of confidentiality. The nursing students gave their written informed consent before completing the instrument. For the other participants, completing the online survey was considered as consent.

## RESULTS

## Sample characteristics

The sample included 472 nurses and 51 nursing students. The nurses worked in different settings, more than half of them (56%) on in-patient units in a general or academic hospital. About one sixth of the nurses (16.6%) worked on an outpatient clinic providing consultations with chronically ill on a daily basis. For further details see Table 1.

## **Construct validity**

#### Factor analysis

The confirmatory factor analysis on the self-efficacy items yielded the following results:  $\chi^2$  was 12086; RMSEA 0.13; SRMR 0.11 and IFI 0.90 all indicating that the model was not yet sufficient. Factor loadings of this initial 46 items model ranged from 0.44 to 0.87 (Table 2). Following the factor loadings, modification indices, and an internal consistency check of each subscale, the stepwise procedure, as described in the method section, resulted in the elimination of 10 items (bold in Table 2). The final model consisted of 36 items with six items for each subscale. This final model resulted in a better fit of the model, although the fit indices still showed room for improvement;  $\chi^2$  decreased to 7238; RMSEA decreased to 0.12; SRMR decreased to 0.10 and IFI increased to 0.93. A similar procedure was done for the performance items, which resulted in a similar fit of the model for both the initial and the final model. Also, the exact same items were removed following the procedure for improving the model. Sample adequacy was confirmed by the KMO test (0.95) and Bartlett's test of sphericity ( $\chi^2$ =7654.23, df = 630, p < .001) indicating that correlations between items did not occur by chance.

Characteristics (n=523)	N	(%)
Gender		
Female	409	(78.2)
Male	110	(21.0)
Missing	4	(0.8)
Age (years)		
<23	43	(8.2)
23-29	144	(27.5)
30-39	104	(19.9)
40-49	96	(18.4)
>49	132	(25.2)
Missing	4	(0.8)
Setting		
Student nurses	51	(9.7)
Academic hospital		
Inpatient units	269	(51.4)
Outpatients clinics	87	(16.6)
General hospital		
Inpatient units	24	(4.6)
Psychiatric institution	33	(6.4)
Primary & elderly care nursing	9	(1.7)
Other (not specified)	50	(9.6)
Work experience (years)		
0-5	124	(23.7)
6-10	97	(18.5)
11-15	58	(11.1)
>15	171	(32.7)
Missing	73	(14.0)
Educational degree		
Student nurses, vocational educational level	51	(9.7)
Vocational education level <sup>*</sup>	100	(19.1)
Bachelor degree	268	(51.3)
Master degree**	59	(11.3)
Missing	45	(8.6)

**Table 1.** Demographic characteristics of the sample

\* Vocational educational level is a three years nurse training education at qualification level 5 of the European Higher Education Area

\*\* Both academic and professional Master degrees

## Table 2. Factor loadings of the initial 46 items model

		Self-efficacy** Performance**		:e**				
léann		l Valid	lean	Q	I Valid	lean	Q	,
Subs	cale Assess	2	~	<u> </u>	~	~	<u>м</u>	Λ
<u>5005</u> 1.	Asking the patient what he expects from living with a (chronic) condition in the near future	520	2.89	0.86	520	1.81	1.03	.73
2.	Asking the patient about his own experiences with his (chronic) condition	520	3.15	0.77	519	2.31	0.99	.63
3.	Asking the patient what he knows about his (chronic) condition	520	3.16	0.75	520	2.31	1.06	.75
4.	Asking the patient about how he can share his emotions about the (chronic) condition with important others	521	3.00	0.83	519	2.14	1.07	.70
5.	Asking the patient about the available motivation and discipline to integrate the chronic condition in his life	521	2.70	0.92	518	1.72	1.06	.72
6.	Asking the patient how much confidence he has in his own abilities	520	2.82	0.88	517	1.83	1.01	.66
7.	Asking the patient what he can and will do in his daily health care	520	3.20	0.78	517	2.52	1.08	.72
8.	Asking the patient which fundamental values (e.g. religious, cultural, independence) are of influence of his perception of the condition	519	2.51	1.00	520	1.44	1.03	.62
<u>Subs</u>	cale Advise							
9.	During each contact, asking the patient what information he needs	484	3.03	0.79	483	2.27	1.03	.79
10.	Asking the patient for permission before giving information or advice	483	2.76	0.92	480	1.68	1.14	.69
11.	Letting the patient restate the information that I gave	482	2.84	0.84	480	1.82	1.01	.81
12.	Giving the patient information and instruction about the (chronic) condition	481	3.16	0.80	479	2.50	1.03	.67
13.	Helping the patient to formulate questions to discuss with other healthcare professionals	483	2.70	0.93	480	1.61	1.01	.66
14.	Informing the patient of the choices he has (which he can discuss with other healthcare professionals)	482	2.75	0.90	479	1.78	1.05	.55
15.	Involving the family when providing information and instruction	479	3.20	0.76	479	2.40	1.11	.66
<u>Subs</u>	<u>cale Agree</u>							
16.	Helping the patient to identify earlier positive experiences with achieving goals	452	2.64	0.89	447	1.56	1.02	.48
17.	Allowing the patient to determine his own priorities when developing goals	451	2.68	0.86	448	1.56	1.06	.74
18.	Jointly with the patient, developing a plan of action to achieve the goals	452	2.52	0.98	446	1.34	1.09	.55
19.	Documenting the goals and agreements in the patient's record	452	2.82	1.00	448	2.00	1.31	.79

## Table 2. Factor loadings of the initial 46 items model (continued)

		Self-efficacy** Performa		rmanc	nance <sup>**</sup>			
Item	·	N Valid	Mean	SD	N Valid	Mean	SD	λ
20.	Helping the patient to make decisions concerning his treatment jointly with me and/or the other healthcare professionals	451	2.57	0.94	448	1.53	1.04	.56
21.	Recognizing the patient's anxiety about making a treatment decision	452	2.92	0.84	446	1.94	1.03	.68
<u>Subs</u>	cale Assist							
22.	Inviting the patient to talk about deteriorating health and changes in his life	423	2.77	0.91	424	1.88	1.08	.52
23.	Discussing with the patient who he will inform about his chronic condition	423	2.58	0.97	420	1.34	1.12	.67
24.	Stimulating the patient's self-confidence so that he can integrate the chronic condition in his life	426	2.83	0.85	422	1.95	1.08	.61
25.	Encouraging the patient to perform as many daily living activities as possible	425	3.16	0.74	423	2.59	0.99	.73
26.	Helping the patient to choose the activities that he can realistically perform	423	2.98	0.74	421	2.23	1.01	.62
27.	Discussing with the patient who (i.e. family, friends, network) can provide daily support	421	3.00	0.78	420	2.16	1.08	.81
28.	Discussing with the patient how he can make use of self-management assistive devices (i.e. diary) in his daily activities	421	2.48	1.05	420	1.38	1.15	.73
29.	Assisting the patient to monitor his own health and physical reactions	420	2.68	0.89	419	1.71	1.12	.63
30.	Supporting the important others in dealing with the chronic condition	422	2.92	0.86	421	2.11	1.14	.44
<u>Subs</u>	cale Arrange							
31.	Asking the patient about a suitable moment and a suitable approach for follow-up care	409	2.71	0.95	406	1.65	1.17	.78
32.	Referring the patient to the appropriate healthcare professional, health care facility or source of information that conforms to the patient's values	409	2.82	0.84	407	1.86	1.04	.62
33.	Consulting and making mutual plans with other healthcare professionals	409	3.05	0.83	405	2.21	1.14	.86
34.	Using assistive devices and technology (i.e. e-health) to provide remote guidance to the patient	409	1.53	1.27	404	0.50	0.89	.70
35.	Facilitating the patient to easily stay in contact between appointments	409	2.86	1.02	404	2.08	1.39	.87
36.	Initiating contact between appointments with the patient, to discuss his health and to solve possible difficulties	407	2.44	1.21	405	1.16	1.23	.72
37.	Together with the patient, examining progress of the care plan actions	408	2.51	1.04	405	1.34	1.16	.72

#### Table 2. Factor loadings of the initial 46 items model (continued)

	Self-efficacy**		Performance**					
Item	·	N Valid	Mean	SD	N Valid	Mean	SD	λ
<u>Subs</u>	cale Overall Competencies							
38.	Valuing and respecting the patient as a partner in his care	402	3.30	0.75	399	2.97	1.00	.54
39.	Acknowledging the patient's experiential knowledge as valuable information concerning my own care delivery	402	3.28	0.68	399	2.83	0.92	.79
40.	Considering the (cultural) background of the patient	401	3.17	0.70	400	2.87	0.95	.66
41.	Together with the patient, determining how much of the care coordination I take over for him	399	2.97	0.81	399	2.40	1.11	.74
42.	Using the patient's choice as the basis for care, even if it is not ideal from a medical perspective	399	2.74	0.86	399	1.96	1.08	.64
43.	Showing understanding when the patient does not succeed in achieving the established goals	400	3.05	0.80	398	2.36	1.09	.74
44.	Deviating from protocols when necessary	401	3.01	0.85	398	1.76	1.04	.61
45.	Reflecting upon my own management (of care)	400	3.26	0.70	398	2.73	0.92	.77
46.	Applying principles of negotiation and conflict- management	400	2.77	0.87	398	1.93	0.98	.58

\*Items in bold were excluded in 36-item SEPSS instrument; \*\* Item scores range from 0 to 4

#### Discriminating power

The results on discriminating power demonstrated significant differences between most of the predefined groups, as shown in Table 3. Nurses providing out-patient consultations had higher scores than nurses in inpatients units at all subscales and at the total scale level for self-efficacy (respectively 18.71 vs. 16.75, t = 3.70, df = 78.90, p < .001) and for performance (respectively 13.99 vs. 11.47, t = 4.17, df 78.58, p < .001). Nurses had higher scores than nursing students at all subscales and at the total scale level for self-efficacy (total scores respectively 17.22 vs. 16.06, t = 2.21, df = 394, p < .05) and for performance (respectively 12.02 vs. 9.39, t = 4.23, df = 391, p < .001). Nurses who perceived SMS as highly important had higher scores for self-efficacy than nurses believing SMS of little or no importance for chronic care, (total scores respectively 12.60 vs. 11.33, t = 1.73, df = 108, p < .05) and for performance (total scores respectively 12.60 vs. 11.33, t = 1.73, df = 108, p < .05). Nurses with a master degree had higher levels of performance than those without such a degree (total scores respectively 13.00 vs. 11.54, t = 2.38, df = 74.16, p < .05), but self-efficacy did not significantly differ between these groups (17.48 vs. 17.07, t = 0.94, df = 366, p = .35).

		Mean (ma	x. 24) (SD)			
Group	Ν	Group with theoretically expected higher score (A)	Group with theoretically expected lower score (B)	- t°	df°°	p°°°
Self-efficacy items		. ,	. ,			
Nurses providing consultations (A) vs. Nurses on hospital units(B)	60 219	18.71 ( <i>3.81</i> )	16.75 (2.92)	3.70	78.90	<.001
Nurses (A) vs. Nursing students (B)	352 44	17.22 (3.22)	16.06 (3.83)	2.21	394	.03
Nurses with a master degree (A) vs. nurses without master degree (B)	59 309	17.48 ( <i>3.68</i> )	17.07 (3.26)	0.94	366	.35
Nurses perceiving SMS highly important† (A) vs. nurses perceiving SMS of little to no importance <sup>‡</sup> (B)	87 23	17.75 ( <i>3.05</i> )	16.24 ( <i>3.09</i> )	2.10	108	.04
Performance items						
Nurses providing consultations (A) vs. Nurses on hospital units (B)	60 219	13.99 (4.36)	11.47 (3.31)	4.17	78.58	<.001
Nurses (A) vs. Nursing students (B)	352 41	12.02 (3.74)	9.39 (3.97)	4.23	391	<.001
Nurses with a master degree (A) vs. nurses without master degree (B)	59 306	13.00 (4.43)	11.54 (3.70)	2.38	74.16	.02
Nurses perceiving SMS highly important† (A) vs. nurses perceiving SMS of little to no importance <sup>‡</sup> (B)	87 23	12.60 (3.26)	11.33 (2.67)	1.73	108	.02

Table 3.	Discriminating	power of the	SEPSS instrument	(known groups)
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° value independent sample t-test; °° degrees of freedom; °°° p-value

<sup>+</sup> score  $\geq$  9; <sup>+</sup> score  $\leq$  6;

## Reliability

#### Internal consistency

Cronbach's alpha was 0.96 for the total self-efficacy scale. For the subscales of selfefficacy, Cronbach's alpha was 0.85 for 'Assess', 0.82 for 'Advise', 0.89 for 'Agree', 0.87 for 'Assist', 0.84 for 'Arrange', and 0.83 for 'Overall competencies'. For the performance scale, Cronbach's alpha was 0.95 for the total instrument. The Cronbach's alpha was 0.84 for the subscale 'Assess', 0.75 for 'Advise', 0.88 for 'Agree', 0.85 for 'Assist', 0.82 for 'Arrange' and 0.81 for 'Specific competencies'.

## Test-retest stability

A group of 26 final-year nursing students completed the questionnaire twice. On the first occasion the mean total score for self-efficacy was 16.84 (*SD 3.65*) and for performance in SMS 10.45 (*SD 4.28*). At retest, the corresponding figures were 15.51 (*SD 5.51*) and 9.78 (*SD 4.97*). The overall intra-class correlation coefficient was 0.95 (95% CI = 0.88-0.98) for the self-efficacy items and 0.94 (95% CI = 0.85-0.98) for the performance items. The

intra-class correlation coefficient for the subscales ranged between 0.84 (95% CI = 0.62-0.94) and 0.95 (95% CI = 0.87-0.98) for self-efficacy in SMS, and between 0.83 (95% CI = 0.60-0.93) and 0.96 (95% CI = 0.90-0.98) for performance in SMS.

## Floor and ceiling effects

Table 4 presents the proportions of nurses scoring in the 12.5% lower and upper bound, respectively, of (sub)scale values. Floor or ceiling effects were not found, apart from a ceiling effect for the Overall Competence scale concerning self-efficacy.

	Self-efficacy							
	Mean	SD	% Min	% Max	Mean	SD	% Min	% Max
Subscale Assess <sup>*</sup>	2.96	.63	.40	11.90	2.05	.78	1.60	2.50
Subscale Advise	2.94	.61	.20	12.70	2.05	.71	1.00	1.50
Subscale Agree	2.69	.74	1.10	6.20	1.66	.86	7.20	1.30
Subscale Assist	2.81	.67	.00	11.20	1.90	.82	2.60	2.10
Subscale Arrange	2.51	.79	.20	7.60	1.49	.85	10.90	1.00
Subscale Overall Competencies	3.08	.56	.00	16.00	2.53	.73	.00	4.50
Total scale <sup>**</sup>	17.09	3.31	.00	11.10	11.75	3.84	.00	1.00

Table 4. Subscale and scale scores, including floor and ceiling effects (%)

\* Subscale scores range from 0 to 4; \*\*Scale scores range from 0 to 24.

## DISCUSSION

As self-management has become the leading paradigm for chronic care in many countries, it would seem essential to develop SMS training programs for nurses and to measure the effectiveness of these programs. In this regard, the SEPSS instrument provides for accurate assessment of a nurse's performance and self-efficacy in applying SMS. Other than the PSMS instrument (Kosmala-Anderson et al., 2011), the SEPSS places an emphasis on competencies needed to stimulate patients to take the lead in self-managing their chronic condition.

The SEPSS instrument assesses the performance and the perceived self-efficacy of essential competencies for SMS derived from literature and expert advice, complemented with competencies reflecting key attitudes, such as partnership and patient centredcare. It relies on a broad holistic perspective on SMS, based on what patients need to take the lead in self-managing their chronic condition (Schulman-Green et al., 2012). Although the instrument uses the framework of the Five A's model, familiarity with this model is not a prerequisite for using the SEPSS. The underlying competencies are feasible for all professionals supporting self-management.

Regarding construct validity of the SEPSS, the confirmatory factor analysis yielded satisfactory fit with the 36-item SEPSS-instrument, wherein the 'overall' competencies can be considered as overarching for the other five subscales according to the Five A's model. By removing 10 items, we aimed to develop a brief instrument that still has enough sensitivity to measure what it is supposed to measure. For that reason we did not allow  $\alpha$  <0.80 and maintained at least six items in each subscale. Although the fit indices showed room for improvement, factor loadings were high and sample adequacy to perform the factor analysis was confirmed by the KMO test and Bartlett's test of sphericity. The results of the known-group technique analysis supported the discriminating properties of the instrument, with expected higher levels of self-efficacy and performance in SMS. Discriminating properties at self-efficacy level were not provided for masters educated nurses; yet they demonstrated a markedly higher performance than non-master educated nurses. Master-educated nurses are supposed to possess the reflective and critical thinking abilities needed in more complex care settings (ter Maten-Speksnijder, Grypdonck, Pool & Streumer, 2012). A more reflective attitude on professional performance is desirable, but can make persons more stringent in judging their self-efficacy (Desmedt, 2004; Koole et al., 2012). This might explain why masters educated nurses performed better, while being more prudent in the confidence of their own capacities. The small proportion of master-educated nurses, whereby equal variance between groups could not be assumed at performance level, may also explain these unexpected results. Nevertheless, some between-group differences could be the result of insufficient variation in professional status (nurses vs. students) between the country samples, and thereby reflect differences in conceptualization and implementation regarding SMS between both countries, rather than predefined group differences.

The evidence to support the internal consistency of the instrument and its sub-scales was strong. The high Cronbach's alpha values, ranging from 0.75 to 0.96, indicate a good to very good internal consistency or homogeneity for the instrument and for the subscales. The results of the test-retest procedure indicate that the stability of the instrument was good, as the intra-class correlations reached the recommended values ≥0.70. Hardly any floor or ceiling effects were found, indicating the possibility to distinguish between individuals and to measure changes after intervention. Attention is needed on the estimation of self-efficacy for the Overall Competencies, reflecting the self-efficacy towards having a partnership attitude, as an effect might be missed due to a possible ceiling effect.

The SEPSS is an instrument that captures nurses' performance and self-efficacy in performing SMS. Given the importance of self-efficacy as a precursor for behaviour (Bandura, 1991), we strongly recommend to assess the performance and self-efficacy items in an integrated way, so as to make it feasible to work simultaneously on both areas where needed. The division in the six subscales enables to measure outcomes on

subscale level and to focus on a particular aspect of the SMS-process, while the total score presents a more overall view of how SMS is provided. Scores range from 0 to 4 for the subscales and from 0 to 24 at total scale level. Higher scores on the SEPSS instrument reflect a higher level of self-efficacy or performance in SMS.

As the format of the SEPSS instrument requires nurses' to rate both self-efficacy and performance on the same set of items, a high correlation between both was not unimaginable in view of the possibility of maintaining some coherence and consistency in responses. However, the response patterns for self-efficacy and performance differed markedly, as evidenced by the moderate correlation (r=.63, p<.001) found.

The instrument has several potential applications for healthcare settings shifting towards SMS. First, the assessment of current SMS practice from a self-reported perspective, which may bring to light areas to improve on at an individual or department level. Second, this assessment can help trainers in tailoring the content and teaching strategies of training courses. Third, but this is a more reflective application, making nurses aware of possible discrepancies between their confidence and their performance, and the causes of these discrepancies. Fourth, training effectiveness and personal growth through training can be evaluated, as well as the effectiveness of other interventions aimed at improving SMS competencies. However, the instrument's sensitivity to change has not yet been established.

Considering that SMS is the responsibility of a multidisciplinary team whose members are expected to possess the same competencies (Wagner et al., 2001), it is recommended to investigate the psychometric characteristics in groups of other healthcare professionals than the nurses and nursing students in the present study. To ensure international validity we encourage initiatives to translate the SEPSS instrument into other languages, and to validate it for use in the respective countries.

## Limitations

The study had some limitations. First, the low response rate in some subsamples and the lack of knowledge on the reasons for drop-out during the online completion of the questionnaire, might limit the generalizability of the findings. Nevertheless, we were able to recruit a heterogeneous sample from different settings, representing nurses with and without experience in SMS, and from two different countries, each having a different history regarding self-management. This heterogeneity may have enhanced the representativeness of the sample. Second, the test-retest procedure was performed in a small group, and the intensive procedure may have adversely affected attention during completion of the re-test. Besides, the short time interval could have inflated the ICC values by the recall of the statements, although this seems not so obvious for a comprehensive tool. Therefore, the results of the stability tests should be considered an initial trend. Further stability testing in a larger sample is recommended. Third, by mea-

suring at one point in time, we were not yet able to establish the instruments' sensitivity to change in competence development, which is one of the proposed applications. In the future, we intend to use the SEPSS to measure the effect of SMS training.

## CONCLUSION

In view of its good psychometric properties, the new SEPSS instrument is a promising instrument to measure nurses' self-efficacy and performance with regard to SMS. The self-reported results could serve as an outcome measure of SMS practices in clinical and research settings, to identify educational needs, and to evaluate personal growth and to assess the effectiveness of training or other interventions to improve SMS.

## Additional file SEPSS – 36 Self-Efficacy and Performance in Self-management Support

# Subscale Assess

		l thi	nk I can do this	·	
	Not at all	Not sufficient	More or less	Sufficient	Good
Asking the patient what he					
condition in the near future			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good				
Asking the patient what he knows about his (chronic) condition									
			l do this						
	Never	Rarely	Occasionally	Frequently	Always				

		l thi	nk I can do this	;	
Asking the patient about how he	Not at all	Not sufficient	More or less	Sufficient	Good
can share his emotions about the					
(chronic) condition with important others			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		l thi	nk I can do this	;	
Asking the patient about the	Not at all	Not sufficient	More or less	Sufficient	Good
available motivation and discipline					
to integrate the chronic condition			l do this		
in his life	Never	Rarely	Occasionally	Frequently	Always

		I think I can do this						
	Not at all	Not sufficient	More or less	Sufficient	Good			
Asking the patient how much								
confidence he has in his own abilities			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
Asking the patient what he can and							
will do in his daily health care			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

## Subscale Advise

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
During each contact, asking the							
patient what information he needs			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
Asking the patient for permission							
before giving information or advice			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
Letting the patient restate the							
information that I gave			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

	I think I can do this				
Giving the patient information and instruction about the (chronic)	Not at all	Not sufficient	More or less	Sufficient	Good
condition (for example about the					
treatment, the associated symptoms			l do this		
and a healthy lifestyle that fits with the (chronic) condition)	Never	Rarely	Occasionally	Frequently	Always

		l thi	nk I can do this		
	Not at all	Not sufficient	More or less	Sufficient	Good
Helping the patient to formulate					
healthcare professionals			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
Involving the family when providing							
information and instruction			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

# Subscale Agree

		l thi	nk I can do this	5	
Helping the patient to identify earlier positive experiences with achieving goals	Not at all	Not sufficient	More or less	Sufficient	Good
			l do this	, in the second s	
	Never	Rarely	Occasionally	Frequently	Always

		l thi	nk I can do this		
	Not at all	Not sufficient	More or less	Sufficient	Good
Allowing the patient to determine					
his own priorities when developing goals			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good		
Jointly with the patient, developing							
a plan of action to achieve the goals			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

	I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good	
Documenting the goals and						
agreements in the patient's record			l do this			
	Never	Rarely	Occasionally	Frequently	Always	

	I think I can do this					
Helping the patient to make	Not at all	Not sufficient	More or less	Sufficient	Good	
decisions concerning his treatment						
jointly with me and/or the other			l do this			
healthcare professionals	Never	Rarely	Occasionally	Frequently	Always	

		l thi	nk I can do this		
	Not at all	Not sufficient	More or less	Sufficient	Good
Recognizing the patient's anxiety					
about making a treatment decision			l do this		
	Never	Rarely	Occasionally	Frequently	Always

## Subscale Assist

		I think I can do this				
	Not at all	Not sufficient	More or less	Sufficient	Good	
Discussing with the patient who						
he will inform about his chronic condition			l do this			
	Never	Rarely	Occasionally	Frequently	Always	

		l thi	nk I can do this		
	Not at all	Not sufficient	More or less	Sufficient	Good
Encouraging the patient to perform					
as many daily living activities as			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		l thi	nk I can do this		
	Not at all	Not sufficient	More or less	Sufficient	Good
Helping the patient to choose the					
activities that he can realistically perform			l do this		
	Never	Rarely	Occasionally	Frequently	Always

	I think I can do this						
	Not at all	Not sufficient	More or less	Sufficient	Good		
Discussing with the patient who (i.e.							
daily support			l do this	, i i i i i i i i i i i i i i i i i i i			
	Never	Rarely	Occasionally	Frequently	Always		

	I think I can do this				
Discussing with the patient how he	Not at all	Not sufficient	More or less	Sufficient	Good
can make use of self-management					
assistive devices (i.e. diary) in his			l do this		
daily activities	Never	Rarely	Occasionally	Frequently	Always

		l thi	nk I can do this	;	
	Not at all	Not sufficient	More or less	Sufficient	Good
Assisting the patient to monitor his own health and physical reactions					
			l do this		
	Never	Rarely	Occasionally	Frequently	Always

# Subscale Arrange

	I think I can do this						
	Not at all	Not sufficient	More or less	Sufficient	Good		
Asking the patient about a suitable							
follow-up care			l do this				
	Never	Rarely	Occasionally	Frequently	Always		

	nk I can do this	;			
	Not at all	Not sufficient	More or less	Sufficient	Good
Consulting and making mutual plans with other healthcare professionals					
			l do this		
	Never	Rarely	Occasionally	Frequently	Always

		I think I can do this					
Using assistive devices and	Not at all	Not sufficient	More or less	Sufficient	Good		
technology							
(i.e. e-health) to provide remote			l do this				
guidance to the patient	Never	Rarely	Occasionally	Frequently	Always		

	I think I can do this					
	Not at all	Not sufficient	More or less	Sufficient	Good	
Facilitating the patient to easily stay in contact between appointments						
			l do this			
	Never	Rarely	Occasionally	Frequently	Always	

		I think I can do this					
Initiating contact between appointments with the patient, to discuss his health and to solve	Not at all	Not sufficient	More or less	Sufficient	Good		
			l do this				
possible difficulties	Never	Rarely	Occasionally	Frequently	Always		

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Together with the patient, examining progress of the care plan actions								
			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

# Subscale Overall Competencies

	I think I can do this							
Acknowledging the patient's	Not at all	Not sufficient	More or less	Sufficient	Good			
experiential knowledge as valuable								
information concerning my own care			l do this					
delivery	Never	Rarely	Occasionally	Frequently	Always			

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Considering the (cultural)								
background of the patient			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Together with the patient,								
coordination I take over for him			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Using the patient's choice as the								
from a medical perspective			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Showing understanding when								
achieving the established goals			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

	I think I can do this							
	Not at all	Not sufficient	More or less	Sufficient	Good			
Reflecting upon my own								
management (of care)			l do this					
	Never	Rarely	Occasionally	Frequently	Always			

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# Chapter 5

What factors influence nurses' behaviour in supporting patient self-management? An explorative questionnaire study

Susanne M. van Hooft, Jolanda Dwarswaard, Roland Bal, Mathilde M. Strating & AnneLoes van Staa

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# ABSTRACT

## Background

A major challenge for nurses in hospital care is supporting chronically ill patients in selfmanaging their chronic condition. Self-management support requires a broad range of competencies and is often regarded as difficult to implement in daily practice. So far, we have no insight in nurses' behaviour in daily practice with regard to self-management support and what factors may influence their behaviour.

# Objectives

The aim of this survey was to explore (i) the self-reported behaviour on self-management support of nurses in a university hospital; and (ii) the factors influencing this behaviour.

## Design

Total sample approach with cross-sectional design.

## Participants and setting

Nurses employed by a university hospital received an invitation for the research through e-mail containing a link to the survey. Of the 2,054 nurses who had been invited to participate, 598 responded (29.11%). The entire questionnaire was completed by 379 nurses, 32 of whom indicated they did not work with patients on a daily basis. After excluding those 32, the final sample included 347 valid responses (16.9%). 90.5% of the respondents was female, mean age was 38.8 years.

## Methods

In a web-based questionnaire, the Self-Efficacy and Performance in Self-management Support instrument (SEPSS-36) was used, with additional questions about attitude, subjective norms, and perceived barriers for self-management support.

## Results

This study shows that nurses are self-confident of their capabilities to support selfmanagement. They also feel that most of the time they acted accordingly. Still, a significant gap between self-efficacy and behaviour of self-management support was found (p < .001). Nurses themselves perceive lack of time and patients' lack of knowledge as barriers for self-management support, but this did not influence their behaviour (p >.5). Regression analysis showed that perceived lack of own knowledge, the presumed absence of a patients' need for self-management support, and nurses' self-efficacy in self-management support are factors that influence the behaviour of self-management support. 41.1% of the variance of behaviour is explained by these three factors.

## Conclusion

This study shows a significant gap between self-reported self-efficacy and behaviour in self-management support in nurses working in a university hospital. To enhance self-management support, managers and educators should take these influential factors into account. A third of the nurses did not report a need for additional training on self-management support. This implies that programs should also aim to improve reflective skills and raising awareness.

## INTRODUCTION

One of the major tasks of nurses is supporting patients in self-managing their chronic condition (Alleyne, Hancock, & Hughes, 2011; Kralik, Koch, Price, & Howard, 2004). Due to the increase in prevalence of chronic conditions, healthcare is shifting from an acute care model towards a chronic care model (WHO, 2005). Consequently, nurses are meeting chronically ill patients in more acute settings such as hospitals. Although patients with chronic conditions may encounter many different professionals, self-management support is often provided by nurses because they are highly trusted by patients (Alleyne et al., 2011; Elissen et al., 2013).

Self-management skills enable patients to incorporate the chronic condition into their lives and to remain as self-dependent as possible (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). Self-management encompasses elements of autonomy and shared decision-making (Udlis, 2011). Therefore, the support of patients' self-management requires a broad range of competencies (Elissen et al., 2013; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007). In the literature, many different interpretations of the concepts of self-management and self-management support are given (Jonsdottir, 2013), and consequently nurses often do not know exactly what is expected from them with regard to self-management support (Sadler, Wolfe, & McKevitt, 2014). Studies of our research group showed that nurses have diverse views on self-management support. These views differ with respect to the relation between the patient and the goal of self-management. Where some nurses focus on the everyday life of patients and on coaching, other nurses stress the importance of optimal biomedical outcomes and promote adherence (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015a).

The literature on competencies needed for self-management support is sparse. Often they are broadly formulated (WHO, 2005), applicable to specific contexts only (Lawn et al., 2009), or not aimed at nurse professionals (Pols, 2009). A detailed overview of required competencies for nurses was published only recently by our research group (van Hooft, Dwarswaard, & van Staa, 2015b). Six categories of competencies are described: five of these are named after the phases of the Five A's Model: Assess, Advise, Agree, Assist, and Arrange (Glasgow, Davis, Funnel & Beck, 2003). This cyclic model is a framework for the process of self-management support and is therefore a useful explication of required competencies. The first phase (*Assess*) involves assessment of motivation and the beliefs of patients so the nurse is able to adjust her support to the specific needs of the patient (Glasgow, Emont & Miller, 2006; Lawn et al., 2009). In the second phase (*Advise*), the nurse gives information and instruction, as information is a prerequisite for the patient to make informed decisions (Udlis, 2011). The third phase (*Agree*) involves shared decision-making and relates to mutual goal setting (Schulman-Green et al., 2012;

Stacey, Taljaard, Drake & O'Connor, 2008). In the next phase, the nurse *Assists* the patient with overcoming barriers in daily living with a chronic condition (Schulman-Green et al., 2012). The fifth phase (*Arrange*) involves follow-up care (Pols, 2009). The sixth category of the overview of competencies encompasses overall competencies for self-management support, like a partnership approach or deviating from protocols where necessary (Hostick & McClelland, 2002; Kayser, Cossette & Alderson, 2014; Pols, 2009; Sandman, Granger, Ekman & Munthe, 2012). The essential competencies for self-management support are basis of the SEPSS-36 (Self-efficacy and Performance into self-management support), an instrument to assess how nurses use these competencies in daily practice (Duprez et al., 2016).

Nurses' behavior in self-management support can be influenced by various factors such as attitude, subjective norms, and self-efficacy as proposed in the ASE model (Fig. 1) (de Vries, Dijkstra, & Kuhlman, 1988).



Figure 1. The Attitude, Subjective norms, and Self-Efficacy (ASE) model (de Vries et al., 1988).

Based on the Theory of Planned Behaviour (Ajzen, 1985) and the Theory of Reasoned Action (Fishbein & Ajzen, 2010), the ASE-model model assumes that the intention to perform a certain behaviour is the best predictor for such behaviour. One of the factors influencing the intention to perform a certain behaviour is 'attitude'. In a previous study we distinguished four dissimilar attitudes towards self-management support (van Hooft

et al., 2015a). A nurse with a coach attitude regards self-management support as a natural part of her job; a nurse with a gatekeeper attitude believes that self-management support is a means to lower health care costs; a nurse with a clinician attitude regards self-management support as a way to increase patients' adherence; and, a nurse with an educator attitude believes that education about lifestyle changes is the most important component of self-management support.

The 'subjective norms' in the ASE-model refer to perceived support or pressure from others, such as patients or the team of professionals. Subjective norms related to self-management support as described in literature are for example 1) a team culture of having a focus on more urgent medical issues (Whitlock, Orleans, Pender, & Allan, 2002); 2) patient-related factors, such as (presumed) mental or physical inability to self-manage and making decisions (Barnes, Hancock, & Dainton, 2013; Norris & Kilbride, 2014; Thorne, Ternulf Nyhlin, & Paterson, 2000), and 3) low patient demand for self-management support (Whitlock et al., 2002).

Self-efficacy, then, i.e. the belief one has about one's capabilities and the control to perform, is an important predictor of behaviour. It bears upon the choices a person makes and on the person's reactions to obstacles encountered (Bandura, 1991). Low self-confidence of nurses regarding self-management support is described as a cause for hampering self-management support behaviour (Whitlock et al., 2002).

While in the ASE-model, attitude, subjective norms, and self-efficacy determine the intention to perform a certain behaviour, the actual behaviour is also influenced by other factors; i.e. barriers and skills (de Vries et al., 1988). Lack of time is frequently described as a barrier to self-management support (Hook, 2006; Lawn & Schoo, 2010; Norris & Kilbride, 2014; Whitlock et al., 2002). Nurses having limited skills regarding self-management support is a previously described factor negatively influencing their behaviour in self-management support (Lawn & Schoo, 2010; Whitlock et al., 2002). The work setting could also be of influence. Whereas nurses working in outpatient clinics often have scheduled appointments with patients for self-management support, ward nurses have to support patients during non-scheduled contacts.

So far, however, we have no insight in nurses' behaviour with regard to self-management support competencies and what factors may influence their actual practice.

## Aim

We performed a survey among nurses of a university hospital to assess (i) their self-reported behaviour with regard to self-management support; and (ii) factors influencing their behaviour.

The hypotheses we developed are described in BOX 1.

#### BOX 1. Hypotheses about factors that influence nurses' self-management support behaviour

**Hypothesis 1:** A positive attitude towards self-management support has a positive influence on the self-management support behaviour of nurses.

**Hypothesis 2:** The preferred attitude (coach, educator, clinician, or gatekeeper) is significantly associated with the self-management support behaviour of nurses.

**Hypothesis 3:** The perception that the team does not support self-management support has a negative influence on the self-management support behaviour of nurses.

**Hypothesis 4:** The perception that patients are not capable to make choices has a negative influence on the self-management support behaviour of nurses.

**Hypothesis 5:** The perception that patients are not motivated for self-management support has a negative influence on the self-management support behaviour of nurses.

**Hypothesis 6:** The perception that patients do not have a need for self-management support has a negative influence on the self-management support behaviour of nurses.

Hypothesis 7: The perception that patients have insufficient knowledge for self-management negatively influences self-management support behaviour of nurses.

**Hypothesis 8:** Self-efficacy is positively correlated with the self-management support behaviour of nurses. **Hypothesis 9:** Lack of time negatively influences self-management support behaviour of nurses.

**Hypothesis 10:** Insufficient knowledge about self-management support negatively influences the self-management support behaviour of nurses.

**Hypothesis 11:** Nurses working at outpatient clinics have a higher score on self-management support behaviour than nurses working at inpatient wards.

#### **METHODS**

The study employed a cross-sectional design, using a web-based questionnaire. Under Dutch law, no ethical approval is needed for research among professionals. Nonetheless, in order to protect the welfare of the research subjects, the study protocol was reviewed and approved by the University's Institutional Review Board. Confidentiality and anonymity of the nurses was ensured in an invitational e-mail.

#### **Participants**

The initial sample consisted of all nurses employed by a university hospital in Rotterdam, the Netherlands. Exclusion criteria were: working with anesthetized and highly sedated patients (e.g. in the operation room and the recovery room), or working at an emergency room.

#### Measurements

The questionnaire was divided into five sections: demographic variables, the nurse's attitude to patient self-management support, self-efficacy and behaviour, subjective norms, and educational needs. The following background variables were collected: age, gender, educational level, work experience, and work setting.

## Attitude towards self-management support (hypotheses 1 and 2)

Respondents were asked how they valued the importance of self-management support for nursing care, on a scale from 1 to 10. In addition, the respondents' attitude towards self-management support was measured with short descriptions of the four diverse attitudes on self-management support previously mentioned in the introduction section (van Hooft et al., 2015a). Nurses were asked to indicate which description fitted best and which fitted least.

## Self-efficacy and behaviour (hypothesis 8)

Self-perceived *self-efficacy* and *behaviour* with regard to self-management support was assessed with the SEPSS-36. This newly developed and validated instrument consists of 36 items addressing competencies required for self-management support (Duprez et al., 2016). It assesses both self-efficacy and behaviour for each item. The SEPSS-36 consists of six subscales containing six items each. As previously described in the introduction section, five subscales are based on the cyclic Five A's Model of Self-Management Support that distinguishes five sub-sequential phases: *Assess, Advise, Agree, Assist, and Arrange* (Glasgow et al., 2003). The sixth subscale involves overall competencies needed in each phase of the self-management process. Self-efficacy was assessed from the statement 'I think I can do this', to be rated on a five-point Likert scale ranging from 0 ('Not at all'), 1 ('Not sufficient'), 2 ('More or less'), 3 ('Sufficient'), to 4 ('Good'). Behaviour was assessed from the statement 'I do this', with response categories ranging from 0 ('Never'), 1 ('Rarely'), 2 ('Occasionally'), 3 ('Frequently'), to 4 ('Always'). In the validation study, the Cronbach's alpha (*a*) for the measurement of self-efficacy was 0.96; for the measurement of behaviour *a* was 0.95.

## Subjective norms, barriers and knowledge (hypotheses 2-7, and 9-10)

*Subjective norms* related to patients (their motivation, knowledge, needs, and capabilities) and related to the team (support) were listed as potential barriers to self-management support (5 items).

Also, barriers such as lack of time and insufficient knowledge were added to this list (2 items).

The subjective norms, barriers, and knowledge were combined in one list of items. Respondents were asked to mark the three items they found most relevant to their situation.

Respondents were also asked to state their *educational needs* regarding self-management support. We formulated an educational need for each subscale of the SEPSS-36 (e.g. 'I need education about assessing the preferences and experiences with regard to the patient's illness'). Respondents were asked to indicate which educational needs were applicable to them.

## **Data collection**

Data collection took place from December 2014 - January 2015. Eligible candidates received an invitation to participate via an e-mail that contained a link to the survey. The instructions on the questionnaire included information about whom to contact if the nurse experienced any problems connecting with the online questionnaire. Nurses were able to complete the questionnaire at quiet moments during their work time, or in their own time. Reminders were sent to all potential respondents after two weeks and after four weeks. In addition, flyers drawing attention to the survey and paper versions of the questionnaire were distributed to all the departments to achieve a higher response rate (de Leeuw, Hox, & Dillman, 2008). As an incentive to complete the questionnaire, the team with the highest response rate was to receive a gift box with wellness products, e.g. body lotion and shower gel.

## Analysis

Descriptive data were generated for all variables. Statistical analyses were performed using SPSS21 (SPSS Inc., Chicago, II, USA). Level of significance was set at p-value p < 0.05. Prior to analysis the data was screened for repetitive response patterns (>10% of the answers the same on the SEPPS-36; n=5), and missing subscale scores (>10% of the items of the subscale). The data of the dependent variables were checked for normal distribution.

To determine self-efficacy and behaviour, sum scores were calculated for each of the six subscales (range 0 to 4), as well as total sum scores for self-efficacy and behaviour (total range of 0 to 24). Also, differences between the sum scores of self-efficacy and behaviour were calculated.

We used different tests for the different hypotheses. These tests are described below. All t-tests were two-tailed.

## Hypothesis 1: A positive attitude towards self-management support

Pearson's correlation tests served to determine the correlation between the scores on perceived importance of self-management support and sum scores of behaviour.

## Hypothesis 2: The preferred attitude

One-way ANOVA variance analysis with a Bonferoni post hoc test was performed to measure associations between the descriptions of the attitude towards self-management support and the sum scores on behaviour.

## Hypothesis 3, 4, 5, 6, and 7: Subjective norms

Frequencies were calculated for all subjective norms variables. To test for differences in sum scores of behaviour between the different groups we used independent samples t-test for all subjective norms.

## Hypothesis 8: Self-efficacy

Pearson's correlation test was performed to determine the correlation between the scores on self-efficacy and behaviour. A paired sample T-test was conducted to analyse differences in means between sum scores on self-efficacy and behaviour.

# *Hypothesis 9: Lack of time and hypothesis 10: Insufficient knowledge about selfmanagement support*

Correlations between sum scores and educational level were assessed with Spearman's correlation tests. One-way ANOVA variance analysis with a Bonferoni post hoc test was performed to measure associations between behaviour and educational level.

Independent samples T-tests were performed to compare differences in sum scores of behaviour between nurses who perceived lack of skills or lack of time as a barrier and nurses who did not.

## Hypothesis 11: Work setting (outpatient versus inpatient wards)

Independent samples T-tests were performed to compare differences in sum scores of behaviour between nurses working at an inpatient ward and at an outpatient department.

## Predictors of self-management support behaviour

To determine which factors influence the behaviour of self-management support a stepwise regression analysis was executed with the significant variables of the ASE-model.

## Results

## Response

Of the 2,054 nurses who had been invited to participate, 598 responded (29.11%). The entire questionnaire was completed by 379 nurses, 32 of whom indicated they did not work with patients on a daily basis (e.g. team managers). After excluding those 32 from data-analysis, the final sample included 347 valid responses (16.9%). Characteristics of the respondents are shown in Table 1.

In the current study the  $\alpha$  for self-efficacy was 0.95, and the  $\alpha$  for behaviour 0.94.

Characteristics (n=347)	n	(%)
Gender		
Female	314	(90.5)
Male	33	(9.5)
Age (years)		
20-29	111	(32.0)
30-39	81	(23.3)
40-49	63	(18.2)
>49	92	(26.5)
Setting		
Inpatient department	288	(83.0)
Outpatient department	59	(17.0)
Work experience (years)		
0-5	70	(20.2)
6-10	72	(20.7)
11-15	45	(13.0)
>15	160	(46.1)
Educational degree		
Student nurse	2	(0.6)
Basic degree in nursing	90	(25.9)
Bachelor degree in nursing	142	(40.9)
Master degree in nursing	20	(5.8)
Scientific degree	5	(1.4)
Other additional education	51	(14.7)
Missing	37	(10.7)

**Table 1.** Demographic characteristics respondents

## Behaviour

The mean scores of the subscales for behaviour varied from 1.47 to 2.47. The total mean (SD) sum score of behaviour was 11.69 (3.40), which implies that, on average, nurses tend to carry out self-management support activities more than rarely, but less than frequently (Table 2).

## Attitude

The importance of self-management support for nursing care was rated with a mean (SD) value of 7.92 (1.13). Higher importance was significantly related to a higher score on behaviour (r = 0.215; p = 0.001), indicating that a positive attitude towards self-management is related to a positive perception of nurses' own self-management support behaviour (hypothesis 1).

	9	icore b	ehavio	r	Score self-efficacy			су		
Subscales ( <i>n</i> )	Mean sumscore	Std. dev	Min∧	Max	Mean sumscore	Std. dev	Min	Max	Mean difference	Educational needs % of all cases (n)
Assess (347)	2.07	0.71	.00	4.00	2.93	0.61	0.50	4.00	0.85*	6.9% (24)
Advise (322)	2.11	0.65	.00	4.00	2.97	0.56	1.33	4.00	0.85*	7.8% (27)
Agree (298)	1.60	0.77	.00	3,83	2.65	0.69	0.00	4.00	1.04*	20.2% (70)
Assist (273)	1.86	0.75	.00	4.00	2.78	0.63	0.83	4.00	0.92*	14.7% (51)
Arrange (263)	1.48	0.76	.00	3.83	2.49	0.72	0.67	4.00	1.01*	13.0% (45)
Overall (255)	2.47	0.68	.83	4.00	3.04	0.51	1.50	4.00	0.57*	7.5% (26)
Total sum score	11.69	3.40	3.83	21.00	16.96	3.03	5.67	24.00	5.27*	
No educational ne	eds									34.0% (118)

Table 2. Scores on behaviour and self-efficacy

\* significance p<.05

^observed range

The most preferred attitude towards self-management support was the coach attitude (38.0%; n=132). Next came the educator (32.6%; n=113), the clinician (15.6%; n=54), and the gatekeeper (13.8%; n=48) attitudes. Analysis of variance showed no significant difference in the sum scores of behaviour between the different attitudes, implying that the preferred attitude (coach, educator, clinician, or gatekeeper) was not significantly associated with nurses' self-management support behaviour (hypothesis 2).

## Subjective norms

With regard to subjective norms, respondents mentioned a patient's lack of knowledge (37.5%, n=130), patients' lack of ability to make choices (21.0%, n=73), and unmotivated patients (16.1%, n=56) as the most important factors influencing their behaviour of self-management support (Table 3). But the respondents who found these subjective norms relevant for their situation did not have a significantly lower sum score on behaviour, so the perception that patients are not capable of making choices (hypothesis 4), that patients are not motivated for self-management support (hypothesis 5), and that patients have insufficient knowledge for self-management (hypothesis 7) did not negatively influence self-management support behaviour of nurses. Respondents who held the opinion that patients do not have a need for self-management support (11.0%, n=38) had a significantly lower sum score on behaviour than respondents who did not hold that opinion (t = -3.055; df = 253; p = 0.002). This means that the perception that patients do not have a need for self-management support had a negative influence on the self-management support behaviour of nurses (hypothesis 6). Only 9 respondents perceived that the team did not support them in self-management support (hypothesis 3). We could not draw any conclusions based on this low number.
	% of all cases (n)
Subjective norms	
I believe my patients have insufficient knowledge for self-management of their chronic condition	37.5 % (130)
I believe my patients are not capable to make choices by themselves	21.0% (73)
I believe my patients are not motivated for self-management of their chronic condition	16.1% (56)
I believe my patients don't have the need for self-management of their chronic condition	11.0% (38)
l don't feel supported by my team	2.6% (9)
Barriers and knowledge	
l do not have enough time	46.4% (161)
I notice that my own knowledge is insufficient to support the self-management of my patients	17.9% (62)

#### Table 3. Subjective norms, barriers and skills for self-management support (n=347)

#### Self-efficacy

The total mean (SD) sum score of self-efficacy was 16.96 (3.03), which implies that most nurses are self-confident about their self-management support competencies. Self-efficacy was significant related with behaviour, r = .60, p < 0.001 (hypothesis 8).

The difference between the total sum scores of behaviour and self-efficacy was significant (t = 29.03; df = 254; p < 0.001) (Table 2), indicating a lower behaviour than expected based on the scores on self-efficacy.

#### Barriers and knowledge

Lack of time (46.4%) was seen as the most important barrier to self-management support (Table 3). However, the respondents in question did not have a lower score on self-management behaviour than other respondents (t = 0.21; df = 160.28; p = 0.83). So lack of time did not negatively influence self-management support behaviour of nurses (hypothesis 9).

No relationship was found between educational level and behaviour. With regard to knowledge and skills on self-management support, 17.9% (n=62) of the nurses perceived their own knowledge about self-management support as insufficient. These respondents had a significantly lower score on behaviour of self-management support (mean (SD) value of 10.00 (3.12)), than respondents who did not hold that opinion about their knowledge (mean (SD) value of 12.24 (3.32)) (t = -4.68; df = 253; p < 0.001). This means that insufficient knowledge about self-management support negatively influenced the self-management support behaviour of nurses (hypothesis 10).

Almost one third of the nurses felt that they did not require additional education about self-management (n=118). Nurses who did report a need for education (66%) indicated that this is most needed on mutual goal-setting (20.2%, n=70), assisting patients in helping overcome problems related to the disease (14.7%, n=51), and in arranging follow-up care (13.0%, n=45).

#### **Background variables**

Respondents working in an inpatient ward had a significantly lower sum score on behaviour (mean (SD) value of 11.45 (3.31)) than nurses working in outpatient departments (mean (SD) value of 13.11 (3.66)); (t = -2.82; df = 253; p = 0.005) (hypothesis 11). They also had a significantly lower score on self-efficacy (mean (SD) value of 16.72 (2.88)) than nurses working in an outpatient clinic (mean (SD) value of 18.29 (3.50); (t = -2.98; df = 253; p = 0.003).

## Predictors of self-management support behaviour

Stepwise regression analysis showed that three factors were significant predictors for self-management support behaviour. We first controlled for setting (inpatient or outpatient ward). This accounted for 3.1% of the variance (adjusted  $R^2$  2.7%). In the subsequent steps the *importance of self-management support*, the presumed *absence of a patients' need for self-management support*, the perceived knowledge gap, and self-efficacy respectively, were entered. In the final model, importance of self-management support (attitude) and setting were mediated by self-efficacy. The final model explained 41.1% of the variance of behaviour of self-management support (adjusted  $R^2$  39.9%) (Table 4).

	Step 1		Step 2		Step 3		Step 4	
Behaviour	β	PValue	β	PValue	β	PValue	β	PValue
Background								
Working in an inpatient ward or outpatient department	.18	.005	.14	.020	.13	.025	.06	.274
Attitude								
Importance			.19	.002	.15	.010	.06	.228
Subjective norms & knowledge								
Patients do not have a need					19	.001	16	.002
Own insufficient knowledge					26	<.001	14	.005
Self-efficacy							.53	<.001
Explained variance	$R^2 = .03$	<.05	$R^2 = .07$	<.001	$R^2 = .17$	<.001	$R^2 = .41$	<.001
F-value (df)	7.97 (253)		8.96 (252)		12.37 (250)		34.68 (249)	

Table 4. Determinants of self-management support behaviour

## DISCUSSION

In this study we used the SEPSS-36 to determine the self-management support behaviour of nurses. This instrument is able to operationalize self-management support competencies, which is an important feature in this regard because nurses' interpretations of the concept of self-management support tend to differ (Been-Dahmen et al., 2015). Several factors were found to influence whether nurses actually support patients' self-management in practice. One of these factors is knowledge about how to provide self-management support, which is in line with a previous study on determinants of self-management support (Kosmala-Anderson et al., 2010). Interestingly, one third of the nurses indicated they did not need extra education, and only 17.9% reported to find their own knowledge of self-management support lacking. Another influential factor is the assumption that patients have no need for self-management support. These two factors were both significantly associated with a lower score on behaviour. A tendency not to involve patients in the self-management or decision process was described earlier (Aasen, Kvangarsnes, & Heggen, 2012). Although it has been acknowledged that every patient with a chronic condition has certain adaptive tasks to fulfil (Corbin & Strauss, 1985; Kralik et al., 2004; Schulman-Green et al., 2012), nurses may be reluctant to give patients more autonomy and have a paternalistic attitude because they foresee health threats if patients make 'the wrong choices' (Dwarswaard & van de Bovenkamp, 2015).

Lack of time was acknowledged as an important barrier to self-management support, which is in line with other studies (Whitlock et al., 2002). Previous studies showed that education of patients, making nursing care plans or talking with patients are activities nurses tend to drop first when they run out of time (Ausserhofer et al., 2014; West, Barron, & Reeves, 2005). Many tasks described in the SEPSS-36 involve such activities. However, in this study lack of time was not significantly related to the self-reported self-management support behaviour.

Several patient-related factors were also considered influential on the behaviour of self-management support. For example, patients having no need for self-management support, being incapable of making choices, or lacking the knowledge to adequately self-manage their condition. This is a remarkable finding, since motivating and informing patients are crucial aspects of self-management support itself (Glasgow et al., 2003; Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011).

Many barriers for self-management support described in literature are external factors (Barnes et al., 2013; Lawn & Schoo, 2010; Norris & Kilbride, 2014; Thorne et al., 2000; Whitlock et al., 2002). Also in this study, most of the barriers nurses found applicable to their situation were considered to be beyond nurses' own sphere of influence, e.g. lack of time and patient-related factors. This could be labelled as external attribution, in which failures (not performing as one could can be regarded as a failure) often are ascribed to determinants external to the person (Weiner, 2001). Identifying this external attribution is important for educational practice because learning difficulties may arise when (student) nurses believe that failures are caused by external, stable, and uncontrollable factors (Weiner, 2001). Education and additional courses teaching self-management

support should aim at teaching (student) nurses strategies to cope with these external factors (Dunn, Osborne, & Rakes, 2013).

We hypothesized that the attitudes towards self-management support, derived from a previous Q-methodological study (van Hooft et al., 2015a), would determine nurses' behaviour, but we could not establish this correlation. Although the results showed diversity in attitudes, it is possible that responses to the questions about the described attitude or about the behaviour were biased by social desirability. Of course, Q-methodology reveals existing differences in attitudes of groups, rather than differences in behaviour (Cross, 2005).

Compared to a large survey among European nurses working in a general hospital on non-specialized nursing units, the response rate in the present study was low (Aiken et al., 2012; Sermeus et al., 2011). This could have influenced the results, but it is unknown in what direction. Some nurses reported that they found the questionnaire difficult as they could not relate to the subject very well. In the Netherlands, self-management is not yet well-established amongst nurses, and nurses may be under the impression that they do not treat chronic patients in hospitals. Nurses who already have an interest in self-management may have been more tempted to complete the questionnaire. This could explain the fact that the respondents overall regarded themselves as rather self-sufficient in self-management support.

This study shows that nurses were self-confident of their capabilities to support selfmanagement. They also felt that most of the time they acted accordingly. Still, a significant gap between self-efficacy and behaviour of self-management support was found. This suggests that believing to have the capability to support the self-management of patients may not always relate to actual practice. The largest gap was found in the subscale *Agree*, which was also the subscale whose subject was related with the highest need for education. Since the *Agree* phase requires shared decision-making skills, training aimed at integrating these skills in daily practice could help reduce this gap. Nurses valued the importance of self-management support as high (almost 8 out of 10). Still, they sometimes felt hampered to put the concept into action. We recommend that nurses receive support in reflecting further on the association between their positive views of how self-management support is part of their everyday practice and the reality of care work they face. This could also enhance their self-efficacy, as this is an important factor contributing to self-management support behaviour.

Self-reported behaviour may be different from directly observed patient-nurse interactions. We recommend additional observations for a more practice-based assessment of how self-management support is executed in practice. These observations may also raise awareness about the way nurses actually support self-management.

## CONCLUSION

This study showed a significant gap between self-reported self-efficacy and behaviour in self-management support in nurses working in a university hospital. The behaviour of self-management support was influenced by perceived lack of own knowledge, by the presumed absence of a patients' need for self-management support, and by nurses' self-efficacy in self-management support. To enhance self-management support, managers and educators should take these factors into account. A third of the nurses did not report a need for additional training on self-management support. This implies that programs should also aim to improve reflective skills and raising awareness.

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Teaching self-management support



## Chapter 6

Teaching self-management support in Dutch Bachelor of Nursing education: a mixed methods study of the curriculum

Susanne M. van Hooft, Yvonne N. Becqué, Jolanda Dwarswaard, AnneLoes van Staa & Roland Bal

Revisions submitted

## ABSTRACT

## Background

Since nurses are expected to support patients' self-management, during their training they need to master such competencies as assessing patients' needs and preferences, shared decision-making, and respecting and enhancing patients' autonomy. Adapting nursing education programmes to meet this goal requires insight into the when and how of teaching self-management support. In curriculum research, we can distinguish between the intended, the taught, and the received curriculum.

## Objectives

This study aims to explore how Dutch Bachelor of Nursing students are trained to support patient self-management in clinical practice.

## Design

Mixed methods, including curriculum review, focus groups, interviews, and a student questionnaire.

## **Methods and participants**

Focus group meetings with 30 teachers, and qualitative semi-structured interviews with four managers and four (associate) professors of four Dutch schools for Bachelor of Nursing education. Syllabuses were screened for learning objectives related to self-management. A questionnaire measuring self-efficacy and behaviour with regard to self-management support was distributed among 444 final-year students of these schools, resulting in 238 valid responses (response rate 53.6%).

## Results

The curriculum pays much attention to assessment of patient preferences and patient education but gives less attention to arranging follow-up care. The study further reveals that students have problems transferring theory into practice because of conflicting values between their training at school and internships.

## Conclusions

Currently, students are prepared to provide patients with self-management support (SMS) by learning about theoretical models, developing communication skills, and reflecting on their internships. This approach seems inadequate to prepare students for this task in daily practice. A shared view on SMS based on authentic situations, having role models at school and on internships, and empowering students may enable them to practice patient SMS in their internships.

#### INTRODUCTION

With the rising prevalence of chronic medical conditions, self-management by patients is considered a way of curbing growing health care expenditure without negatively affecting quality of care (Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011; WHO, 2005). Self-management is regarded as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one's condition and affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established." (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002 p. 178) Self-management requires active patient participation, informed decision-making, and the use of knowledge and skills regarding living with the chronic condition (Udlis, 2011). If patients need support with self-management, the focus of this support lies on enabling them to take care of themselves (Stuckey et al., 2015). Paying attention to the preferences of the individual patient is a key component of self-management support (SMS), as part of person-centred care (Udlis, 2011).

Consequently, more than ever before, nurses need to develop competencies such as assessing patients' needs, shared decision-making, and respecting patients' autonomy (Duprez et al., 2016). The 5-A model captures the cyclic process of SMS (Glasgow, Davis, Funnell, & Beck, 2003). As its name suggests, the model divides SMS into five phases. In the first phase (Assess) the nurse enquires into the patient's previous experiences and motivation. In the next phase (Advise), the nurse provides information the patient needs. This is followed by the Agree phase, when patient and nurse mutually agree on the goals. In the Assist phase, the nurse helps the patient to overcome barriers to attaining the goals. The last phase (Arrange) includes follow-up care and informing other health care professionals. Essential competencies for SMS are based on this model (Duprez et al., 2016) (Box 1).

## Assess

- Asking the patient what he expects from living with a (chronic) condition in the near future
- · Asking the patient what he knows about his (chronic) condition
- Asking the patient about how he can share his emotions about the (chronic) condition with important others
- Asking the patient about the available motivation and discipline to integrate the chronic condition in his life
- · Asking the patient how much confidence he has in his own abilities
- · Asking the patient what he can and will do in his daily health care

## Advise

- · During each contact, asking the patient what information he needs
- · Asking the patient for permission before giving information or advice
- · Letting the patient restate the information that I gave
- Giving the patient information and instruction about the (chronic) condition
- · Helping the patient to formulate questions to discuss with other healthcare professionals
- · Involving the family when providing information and instruction

## Agree

- · Helping the patient to identify earlier positive experiences with achieving goals
- · Allowing the patient to determine his own priorities when developing goals
- · Jointly with the patient, developing a plan of action to achieve the goals
- · Documenting the goals and agreements in the patient's record
- Helping the patient to make decisions concerning his treatment jointly with me and/or the other healthcare professionals
- · Recognizing the patient's anxiety about making a treatment decision

## Assist

- · Discussing with the patient who he will inform about his chronic condition
- Encouraging the patient to perform as many daily living activities as possible
- · Helping the patient to choose the activities that he can realistically perform
- Discussing with the patient who (i.e. family, friends, network) can provide daily support
- Discussing with the patient how he can make use of self-management assistive devices (i.e. diary) in his daily activities
- · Assisting the patient to monitor his own health and physical reactions

#### Arrange

- Asking the patient about a suitable moment and a suitable approach for followup care
- · Consulting and making mutual plans with other healthcare professionals
- Using assistive devices and technology (i.e. e-health) to provide remote guidance to the patient
- · Facilitating the patient to easily stay in contact between appointments
- Initiating contact between appointments with the patient, to discuss his health and to solve possible difficulties
- · Together with the patient, examining progress of the care plan actions

#### **Overall Competencies**

- Acknowledging the patient's experiential knowledge as valuable information concerning my own care delivery
- · Considering the (cultural) background of the patient
- Together with the patient, determining how much of the care coordination I take
   over for him
- Using the patient's choice as the basis for care, even if it is not ideal from a medical perspective
- Showing understanding when the patient does not succeed in achieving the established goals
- · Reflecting upon my own management (of care)

As self-management has been in the limelight for several years now (Kendall et al., 2011), one could assume that it had already been incorporated in nursing education curricula. Providing SMS is indeed considered a key nursing competency in the new Dutch general competency framework for Bachelor of Nursing education (LOOV, 2015). However, the extent to which Dutch nursing schools have embraced this topic is unknown.

Based on social constructive learning theory focussed on learning experiences that take place in a certain social context (Thomas, Menon, Boruff, Rodriguez & Ahmed, 2014), we define the curriculum as "a social construction which focuses on students' experiences and values teacher judgements" (Leibbrandt, Brown, & White, 2005, p. 420). This implies that the 'written curriculum' is not the only reality, and that studying curricula also requires addressing experiences.

We can distinguish several levels in the curriculum. Wachtler and Troein (2003) distinguish between the learning objectives (intended curriculum), teacher intention (taught curriculum), and student's experiences (received curriculum). Each school transforms the general competencies for nursing into learning objectives in correspondence with its view on education and self-management. Formulated broadly or narrowly, these objectives are converted into study programmes and internships. The students' learning experiences determine the outcome of the curriculum (Figure 1).

In the Netherlands, the four-year Bachelor of Nursing programme prepares students for a variety of nursing positions. Internships are an important feature and by Dutch law these should involve at least 2,300 hours. This study aims to explore how Dutch Bachelor of Nursing students are trained to support patient self-management in clinical practice.



Figure 1. Layers of the curriculum and the methods used in this study

## **METHODS**

We employed a mixed methods approach combining qualitative data on the *intended* and the *taught* curriculum with quantitative data on the *received* curriculum, i.e. the students' competencies for SMS. We invited six nursing schools, spread out over the Netherlands to participate and four agreed. We collected data between April 2015 and January 2016.

## Intended and taught curriculum

Our contact person in each school facilitated the practical aspects of the study, such as providing access to the course guides and emailing the invitations to participate to the people who met our selection criteria. We wanted to interview 8-12 people at each school –, including a manager, an (associate) professor, and teachers – to gain a wide range of views on the curriculum. We expected the managers and the professors to have to have a broad scope and a certain influence on the content of the curriculum. In the selection of teachers, we sought diversity in the grade levels they taught, and in their courses (e.g., nursing, communication skills, medical-technical skills). In total, we interviewed 39 participants (Table 1).

	S1	S2	S3	S4	Total
Number of respondents	9	8	10	12	39 (100.0%)
Nursing background	7	3	7	8	25 (64%)
Role	Teacher (6) Manager (1) Associate professor (1)	Teacher (5) Manager (1) (Associate) professor (2)	Teacher (9) Manager (1)	Teacher (10) Manager (1) Professor (1)	Teacher (30; 77%) Manager (4; 10%) (Associate) professor (4; 10%))

Table 1. Interview participant	S
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Managers and (associate) professors were interviewed individually. Teachers were interviewed in groups (2–5 participants). All interviews were held at the school in question, recorded and transcribed verbatim. All participants were informed about the study and gave their consent prior to the interviews. Participation was voluntary; there was no reward in return. Under Dutch law, no ethical approval was needed for research among professionals.

The semi-structured interviews included such topics as one's view on SMS, view on learning, how to teach SMS in education, and barriers and facilitators in teaching SMS.

Prior to the interviews, the research team inventoried the learning objectives of core courses, such as 'nursing' and 'communication skills' and compared these to the list of essential competencies for SMS (Duprez et al., 2016) (Box 1). This document analysis created researcher familiarity with organisational language, and gave us insight into which competencies were dealt with at various stages of the four-year curriculum. We addressed the questions derived from this scan during the interviews.

Data collection and analysis was an iterative, reflexive process (Creswell, 2013). First, we read and summarised the transcripts, then inductively coded the transcripts, using Atlas.ti 7. Then we constructed a thematic framework from the codes. Elements of this framework were: views on self-management, the nursing profession, and nurse education; the theoretical curriculum; learning in clinical practice; and the transfer from theoretical learning to internship. Coding was conducted separately by two authors

(SH & YB) and later on compared until consensus was reached, to improve reliability. Interpretations of the data were discussed within the research team.

## The received curriculum

We used the SEPSS-36 questionnaire to measure the received curriculum. We expected it to provide insight into how much the students believed they had mastered the SMS competencies (Duprez et al., 2016). This validated instrument measures the student's self-reported self-efficacy and behaviour related to the essential SMS competencies (Box 1) on a 5-point Likert scale. In addition, participants selected the barriers they had experienced in supporting patient self-management from a list of potential barriers derived from the relevant literature (Hook, 2006; Lawn & Schoo, 2010; Whitlock, Orleans, Pender, & Allan, 2002).

We used a total sample approach. All final-year Bachelor of Nursing students from the participating schools were informed about the study and invited by e-mail to complete the questionnaire online. Confidentially was ensured and completing the questionnaire was regarded as informed consent. In three schools (S1, S2, S4), the students had the option to complete the questionnaire in class. To further motivate students to complete the questionnaire, they could win a gift token worth ten euros. A reminder was sent after two weeks.

We used SPSS 21 for statistical analysis with the level of significance set to p < 0.05. Before analysis the data were screened for repetitive response patterns (>10% of same answers on the SEPPS-36) and for missing subscale scores (>10% of subscale items). Self-efficacy and behaviour were calculated with the sum scores for each subscale (0–4), and total sum scores for all scales combined (range 0–24). Differences between self-efficacy and behaviour were tested using paired t-tests. We tested associations between separate schools and scores on behaviour and self-efficacy with one-way ANOVA with a Bonferroni post-hoc test.

For each perceived barrier, we performed independent t-tests to compare differences in sum scores between respondents who felt that this barrier affected their SMS behaviour and respondents who did not.

#### RESULTS

#### The intended and taught curriculum

#### Scan of learning objectives

The learning objectives scan revealed that in some schools the concept of self-management was an explicit part of the curriculum. One school (S3) barely used the term selfmanagement. Most schools combined different courses (e.g. communication skills and medical-technical skills) to facilitate a holistic approach. Comparing learning objectives with essential competencies for SMS (Box 1) showed that attention was paid most to the *assess* and *advise* phases, and least to the *Arrange* phase. Aspects of self-management are taught mainly in the first two years. The learning objectives are seldom translated into behavioural goals but often in cognitive goals like 'being able to mention', or 'being able to describe'. The importance of focusing on the patient perspective is stressed in the first year. Still, the vague formulations used – e.g. 'the patient is central in the care giving process' – leave it up to the students to decide how they should operationalise this. One school (S3) explicitly mentions 'agreeing with the patient' is in the objectives for internships. All schools included communication skills such as motivational interviewing in their curricula. Two schools (S2 and S4) seem to place more emphasis than the others on models, theoretical frameworks, and lifestyle adaptations as key features of SMS. Two schools (S2 and S3) mentioned health technology and e-Health as important aspects, while these were virtually absent in the other curricula.

#### Interviews

The analysis of the interviews revealed three major themes, each representing a different variable in the process of teaching SMS: 'Practice what you preach' (the teachers), 'Patience, please' (the students), and 'This is not how it is supposed to be' (nursing practice) (Table 2). These are discussed separately below.

#### Practice what you preach

#### View on self-management

The concept of self-management can be interpreted in various ways. Participants acknowledged that a shared view on self-management is essential to preventing individuals from teaching SMS differently. In one school only (S2) had participants recently discussed with the assistant professor how they should interpret SMS, which led to a shared view on self-management.

At another school (S3), whose written curriculum barely mentioned self-management, participants reported that although they had not discussed the meaning of self-management, they shared a common, person-centred view on nursing. This school will give 'self-management' a more explicit position in the new curriculum because at present students do not realise that they are learning about all kinds of aspects of self-management (see Table 2, for quotes).

The interviews revealed little difference in the views of teams that had not discussed the meaning of SMS. Still, this could result in individual differences in teaching SMS.

Theme Practice what you prea	cn
View on self-management	I still believe that the entire curriculum reflects self-management. That's because it has to do with your view on clients, on people. Our teaching framework uses the word 'person', not 'patient' or 'client' or whatever. It's one of the starting points we set as a team. That's what it's all about. (School (S)3, Participant (P)10)
Parallel processes	The relationship between student and teacher, how you interact with students? Yes, I believe that reveals something about how you interact with your patient. (S4, P12)
The <b>me Patience, please</b>	
View on profession	At first, self-management and helping people feels like a contradiction to them. The very nature of our students makes self-management not the most popular subject. (S2, P8)
	l believe it is difficult, partly because of their [young] age, and that we overestimate students. (S4, P10)
Facilitation personal growth	Constantly asking questions, but I never give answers. Together with them [students] I try to assess how they could have behaved. We provide them with a beautiful theoretical framework, but the reality is different. They should be able to reason why things happen the way they do. They shouldn't judge what happens. I believe that's very important because people sometimes just do things (S3, P6)
This is not how it is supposed	to be
Contradictory values	I stand fully behind the student, of course. I say: as a school we want you [the student] to perform these actions because we want [you] to act in favour of the patient's self-management, to assess what they can do for themselves. (S3, P10)
	I advised her to do what was asked for a while and then restart the conversation. [] It feels a bit like us against them. I'm watching from a distance and don't have direct contact with the hospital ward. (S4, P5)
Assessment of students' performance during internships	Sometimes it feels like a you're fighting a futile battle, like tilting windmills in 'Don Quixote' .! notice it when I visit a student on the internship ward. I feel the ward nurses' mood and then I think: this student has to follow the ward culture, or else they will mark her down as not proficient. So that's hard. For the student as well. (S1, P6)
	We try to give the students the knowledge they need for the job but then they need to make the transition to nursing practice. It would be so nice if they [the ward nurses] demanded the same things we do and asked the student why they behave the way they do. What kind of things did they ask [the patient]?. You hope that this would happen, but you can't tell for sure that it does (54, P8)

Table 2. Results: Themes and quotations from the interviews about teaching self-management support

Many teachers reported that students often see self-management as an abstract concept and they found it important to draw connections between different aspects of SMS in the curriculum. Some connections are in the written curriculum, e.g. communication and medical-technical skills are assessed in a combined test and aspects of self-management are taught in various ways at different times. Students should not only be alerted to these connections, but also shown how they link up with their own experiences. Students rarely understand this relationship spontaneously. Because it is not explicitly mentioned in course manuals, it depends on individual teachers to address this.

#### Parallel processes

Participants pointed out that the nurse-patient relationship resembles the teacherstudent relationship. Teaching nurses to encourage a patient's self-management and autonomy conflicts, however, with a directive approach towards students and mandatory work groups (Table 2).

Participants also thought that students would be unable to support a patient living with a chronic condition until they themselves had learned to manage their own lives. They saw it as their task to help students achieve this, because students need role models.

## Patience, please

#### View on profession

According to the teachers, at the start their education students' have an incorrect perception of the nursing profession and what they should do after graduation. Students expect to help and cure patients and value medical-technical competencies over socalled soft communication skills. The teachers felt that developing communication skills was difficult for mostly young and inexperienced new students, who are not yet ready to address the emotional needs of patients.

Participants felt that teachers should encourage students to practice their communication skills a great deal, although most students would rather not do this. Students need time to grow and build on their own experiences, so teaching about self-management requires patience (Table 2).

According to the teachers, an important feature of SMS is person-centred care. A patient's preferences, motivation and abilities are assessed and nurses should tailor their care to the findings of the assessment. Providing tailored care is difficult for students, however, as they tend to rely on guidelines and protocols. Some participants held the view that students first should learn how to follow protocols in order to be able to deviate from them later on. Others felt students should learn from the start that personcentred care involves tailoring care to the individual patient.

#### Facilitating personal growth

Participants mentioned that using authentic situations could facilitate the students' growth because it would help students to apply theoretical knowledge to the practical situations they may encounter in clinical practice. Examples include descriptions of patient situations (cases), patient experiences, and discussion of experiences during internships. These help students to envisage clinical practice even without rich internship experience. Some participants of S2 objected to this on the grounds that written descriptions do not encourage students to report on a patient's preferences. Instead, they learn to project their own assumptions onto the patients.

Bringing the patient into the classroom could give students insight into what it really means to live with a chronic condition and be dependent on other people. Participants had noticed that students were moved by patients' stories and hoped this would have a positive influence on their nursing.

All schools discussed the students' internship experiences in class. The discussions included the difficult situations encountered, e.g. dealing with 'unmotivated' patients. Teachers and co-students reflected on how students had or could have coped in these situations. Asking critical questions facilitates learning and teachers saw these debriefing sessions as essential to guiding students during their internships (Table 2).

#### This is not how it is supposed to be

#### Contradictory values

Participants noticed that students often encountered contradictory values: on the one hand they are expected to work efficiently and be 'productive' in practice; they are praised by their colleagues for working quickly. At school, though, they learn to apply a person-centred view, and it takes time to discover a patient's preferences.

Participants reacted differently towards students with respect to these contradictions. At one school (S3) the teachers stood by their students, even if it meant potential conflict with ward nurses (Table 2). At another school (S4) students were advised to be cooperative and put their own values aside for the time being.

#### Assessment of students' performance during internships

At S4, participants considered a safe learning environment vital for successful learning. Such a safe environment is difficult to establish in clinical practice because the ward nurses are the ones who assess the student's performance. Participants in other schools also saw that students are vulnerable and dependent in internships, awaiting the final evaluation. Students tend to adjust their actions and attitudes to the ward culture. At two schools (S1 and S3), teachers visit the wards where the students are based and thus have more insight into the difficulties the students meet (Table 2).

According to several participants, an assessment tool would be more relevant as it does away with the question whether or not a student fits into the ward's culture. For example, participants at S1 mentioned that students write a 'reflection' in preparation of the final evaluation of their internship. Both teacher and ward nurse ask the student critical questions based on their reflection. In this case the opinion of the ward nurse is less important and the assessment encourages more critical thinking.

Safety in the learning environment could also be enhanced if the school and clinical practice share common values. Every school invites the nurses from healthcare organisations to discuss their curriculum and attend conferences about learning objectives or innovations in nursing. Although deemed importance, this collaboration does not automatically lead to congruence in support and evaluation of the students' internship (Table 2).

#### **Received curriculum**

Of the 444 students invited to complete the questionnaire, 260 responded (initial response rate 63.5%). Respondents were excluded from analysis if they had a repetitive response pattern (n=1) or missed too many items (>10%) on the SEPSS-36 (n=21). This led to a total of n=238 (53.6%) valid responses. See Table 3 for the background characteristics.

Table 3.	students	responses	to qu	estionna	arres – :	DEP35	-30	
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	Total	School 1	School 2	School 3	School 4
Number of valid cases, n (%)	238 (53.6%)	54 (41.2%)	77 (75.5%)	33 (64.7%)	74 (46,0%)
Mean age (in years)	26.1	24.4	28.7	23.2	25.8
Female, n (%)	207 (87.0%)	45 (83.3%)	67 (87.0%)	30 (91.0%)	65 (87.8%)

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In S2, the students were older on average than students in the other schools. This could be explained by the larger number of students with previous vocational nursing education. Response rates differed between schools, but we have no explanation for this.

The total mean ( $\pm$ SD) sum score of self-efficacy was 18.14 ( $\pm$ 2.61), indicating that students felt they were sufficiently capable of supporting patient self-management. The total mean ( $\pm$ SD) sum score of behaviour was 13.47 ( $\pm$ 3.34), implying that on average students performed SMS activities occasionally, but not frequently. The difference between the total sum scores of behaviour and self-efficacy was significant (t = 25.25; df = 214; p < 0.001), indicating a lower behaviour score than expected based on the self-efficacy score. Analysis of variance showed a significant difference in the sum scores of behaviour on the overall competencies (F(3,218) =2,83, p = .039), and in the sum scores of self-efficacy on the overall competencies (F(3,219)=3,23, p= .023). Bonferroni post-hoc testing revealed statistically significant differences between S3 and S2 for self-efficacy with regard to overall competencies (p= .024), implying that S3 was significantly associated with higher scores in self-efficacy for the overall competencies. Significant differences. Significant differences were also shown between S3 and S2 (p= .022) and between S3 and S4 (p= .037) for behaviour with regard to overall competencies, compared to students in S3 had higher scores on behaviour for the overall competencies, compared to students from S2 and S4.

Almost one third of the respondents (27.3%) claimed not to have received enough education with regard to SMS. Most educational needs were focussed on the *Arrange* phase (34.5%), and the *Assist* phase (28.6%) (Table 4).

Of perceived barriers, lack of time came first (54.2%, n= 129), followed by the assumption that patients have insufficient knowledge for self-management (50.8%, n= 121). Paired t-tests showed that students who did not feel supported by their team (t = 2.85; df = 86; p < 0.01), and students who thought that patients have insufficient knowledge (t = 2.09; df = 176; p < 0.05) had a significantly lower score on self-management behaviour than students who did not experience these barriers (p<0.05).

Barriers	N (% of all students)
l do not have enough time	129 (54.2%)
I believe my patients do not know enough to manage their own chronic conditions	121 (50.8%)*
I believe my patients are not motivated to manage their chronic condition themselves	78 (32.8%)
I notice that I do not know enough to support my patients' self-management	74 (31.1%)
l do not feel supported by my team	50 (21.0%)*
I believe my patients are not capable of making choices/decisions by themselves	47 (19.7%)
I believe patients do not need to manage their own chronic conditions	43 (18.1%)

Table 4. Perceived barriers t	o providing patient se	lf-management support (	n=238)
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\* Significantly related to lower self-management support behaviour P<0.05

#### DISCUSSION

This study used a mixed methods approach based on social constructive learning theory. We studied not only the written curriculum, but also the experiences of teachers (the taught curriculum) and the students' experiences (the received curriculum). In studying several layers of the curriculum, we obtained a broad and deep insight into how the Dutch education system trains Bachelor of Nursing students for SMS in clinical practice.

This study shows that teaching student nurses to support patient self-management is challenging for several reasons. The interviews revealed that not all teams of teachers held a shared view [consensus] on self-management. In the absence of a shared view, it may not be clear what students should be taught in this regard. The learning objectives scan revealed that most attention is given to assessing patient preferences and delivering patient education. Less attention is given to the *Arrange* phase, which is reflected by the students' experiences in the questionnaire. One third of the students felt there was insufficient attention for this during their education.

Our questionnaire showed that during their internship students' self-reported SMS behaviour was negatively influenced by a perceived lack of support from the qualified nurses on the ward team. If student nurses in clinical practice are assessed on other criteria than in the school environment, it is less likely that they will show the desired behaviour. Trying to 'fit in', 'get the work done', and 'learn the rules' are strategies that student nurses use to feel accepted by the ward team and cope with the challenges of

clinical internships (Levett-Jones & Lathlean, 2008). Teachers should guide students in the dilemma of conflicting values, i.e. applying the person-centred care they learn at school and the sense of belonging (being a part of the team) as crucial conditions for learning in clinical practice (Levett-Jones & Lathlean, 2008).

In the interviews, teachers recognised that the teacher-student relationship parallels the nurse-patient relationship. The way teachers interact with students constitutes what Tanner calls the 'hidden curriculum' (Tanner, 1990). Teachers acknowledged that role models are important for students, not only in clinical practice, but also in the school environment. Indeed, 'practice what you preach' enables students to show the required supportive attitude in clinical practice (Hawks, 1992).

Another challenge in teaching SMS lies in the fact that most students are young and are somewhat lacking in life experience. While the guestionnaire showed that students felt they could communicate well with patients, teachers demonstrated less confidence in their students' abilities. Teaching communication skills has some challenges: students do not always recognise the importance of these skills, and even gualified nurses do not always value the importance of communication with patients (Boschma et al., 2009, Deane & Fain, 2016). Another difficulty arises if the communication skills taught differ considerably from other skills required in practice (Deane & Fain, 2016). Nursing education is responsible for transfer of learning, i.e. students should be able to demonstrate their learned behaviour or skills in various contexts. Perkins and Salomon (1992) describe several conditions for transfer, including thorough practice, active self-monitoring, and mindfulness, i.e. alertness to the situation. Teachers can prepare students for transfer by creating learning situations that resemble the situation during internship, by analysing the situations encountered in internships and by discussing coping strategies for these situations (Perkins & Salomon, 1988). Using authentic situations as examples may also be useful to prepare students for the reality of clinical practice (Hawks, 1992; Norbye, 2016). Inviting patients to share their experiences could be beneficial. A student's sensitivity to patient needs and their attitude towards patients with chronic conditions both tend to improve when students are exposed to patient stories (Towle, 2010).

This study analysed different approaches to teaching SMS: either as an aspect of nursing, or by incorporating the underlying values of SMS in the curriculum. Teaching separate components poses the risk that students will have problems integrating SMS aspects in practice (Deane & Fain, 2016). Because not all nurses in practice adequately support patients' self-management, nursing students could lack role models and have to bridge the gap between theory and practice on their own. Nursing education should invest in empowering students to achieve a balance between person-centred care and 'getting the work done' (Adam & Taylor, 2013).

## **Study limitations**

Participants were not selected at random but by the contact person at the school, so this could have resulted in selection bias. It cannot be excluded that the participants had a more positive attitude towards SMS than their colleagues and may [not] have overestimated the amount of attention given to SMS in the curriculum.

The scan of learning objectives did not provide enough detailed information on what is actually taught in the curriculum. Some schools formulated broad learning objectives, while others used more specific goals.

Schools differed with regard to whether or not schools should improve nursing practice, the extent to which teachers stood by their students during internship difficulties and whether or not they visited internship sites. Since we spoke only to a limited number of teachers per school, it is not clear whether these differences represent real differences between the school policies or just between the participating teachers.

## CONCLUSION

Nursing students are prepared for SMS by learning theoretical models and communication skills, and also by reflecting on their internships. This mixed methods study established three main reasons why teaching SMS is difficult: i) the teachers seldom hold a shared view [consensus] on what exactly students need to know and do in SMS; ii) students lack role models both at school and in clinical practice; iii) it requires patience and many hours of training and practice to give students self-confidence and strengthen their communication and organisational skills.

The current approach to teaching SMS seems not up to the job of training student nurses to perform SMS for patients in clinical practice. Developing a shared view on SMS among teachers, applying authentic situations as examples, ensuring that role models are available at school and on internships, and empowering students are all improvements that may better enable students to practice patient SMS properly during their training.

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# Chapter 7

Conclusion, main findings, general discussion, and future directions

The central aim of this thesis was to explore the role of nurses in self-management support, the competencies needed to fulfil this role, and how the Dutch Bachelor of Nursing education prepares nurses for these competencies. This was elaborated in three parts: the nurses' role in self-management support, the competencies needed for self-management support, and teaching about self-management support. The main findings of these three parts will be further discussed in the first part of this chapter. Then, I will turn to a critical reflection on the methodology used. The chapter concludes with a general discussion, presenting implications for nursing practice, education, and research.

#### **MAIN FINDINGS**

#### Nurses' role in self-management support

The Q-methodological study revealed four perspectives of nurses on self-management support; the *Coach* perspective, the *Gatekeeper* perspective, the *Clinician* perspective, and the *Educator* perspective (Chapter 2). These perspectives differ in the perceived goal of self-management support. According to nurses who prefer the *Coach* perspective, this goal is to integrate the chronic condition in a patient's life. Nurses holding a *Gatekeeper* perspective believe that the aim of self-management support is reducing health care expenditures. The self-management support goal of nurses holding a *Clinician* perspective is to attain adherence resulting in good clinical outcomes. Similar, nurses preferring an *Educator* perspective believe that self-management support should lead to good clinical outcomes as well. But they want to attain this by teaching patients how to interpret symptoms and what to do when symptoms deteriorate.

It does not come as a surprise that nurses hold different views on self-management support. In health care debates, perspectives similar to the nurses' perceptions are described (Bodenheimer, Lorig, Holman & Grumbach, 2002; Jonsdottir, Litchfield, & Pharris, 2004; Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011). The *Coach* perspective resembles the broad definition of self-management we use the most in our NURSE-CC program: "*Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inher-ent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established." (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002 p. 178) The role of nurses working according to the <i>Coach* perspective expands to the patient's psychosocial domain. It is no longer sufficient to address the needs related to medical issues alone (Coleman & Newton, 2005). Nurses will have to have an eye for what motivates their patients in life. Nurses who act according a coach perspective have

to shift between the kinds of support they give, because patients have diverse needs. These needs can differ between individuals but also change over time (van Houtum, Rijken, Heijmans, & Groenewegen, 2013; 2015). The main goal of a nurse with a Coach perspective is to collaborate with patients so they can incorporate the chronic condition into their lives. But, this does not imply that providing information, or paying attention to adherence is irrelevant in this perspective. These aspects are all involved in self-management support from that perspective (Chapter 4). The most important difference with other perspectives is that the *Coach* has a partnership relation with patients based on equality. The patients' experiences are as important as the nurses' professional knowledge.

A diversity of goals was also visible in the results of the realist review into self-management interventions (Chapter 3). In this study we determined the theories-in-use in the literature and described the pathways the interventions followed. The interventions of the selected studies showed a diversity of (assumed) outcomes of self-management support. The outcomes we determined were behavioural change, self-efficacy, or coping. The starting points of the pathways of the interventions, i.e. the main element of the intervention, were providing knowledge, skills enhancement, or encouraging motivation. This review further revealed that aiming at intrinsic processes such as motivation and self-efficacy was most successful. In contrast, interventions focusing solely on education were least successful, as was concluded in other reviews (Barlow, Cooke, Mulligan, Beck, & Newmann, 2010; Coster & Norman, 2009). This is an important recognition, especially for nurses holding an *Educator* perspective as these nurses emphasize the importance of patient education.

Although it is recommended to have a theoretical basis for an intervention (Michie & Prestwich, 2010), not all studies included in the realist review described an underlying theory (Chapter 3). A theory provides guidance as to what outcome and the mechanisms to achieve this goal the intervention should be aimed at. Most effective interventions aimed at intrinsic patient processes. These helped patients to take an active, participating role, which corresponds with the *Coach* perspective. In practice, we will encounter nurses with the different kinds of perspectives. Nurse education however, should preferably promote a *Coach* perspective because it seems to contribute the most to enhancing patients' self-management abilities.

It seemed that the influence of the nurse's role as a component of the interventions was underestimated in the research papers. Another finding was that little attention was paid to the role and training of the nurses involved, while the importance of the health care professional as a factor of influence of the intervention has been acknowledged earlier (Clark, 2013; Disler, Gallagher & Davidson, 2012). This underlines the importance of more elaboration in research papers about received training and competencies needed for these interventions, which could enhance nursing practice and education.
## **Competencies for self-management support**

The study into competencies for self-management support (Chapter 4) revealed essential competencies structured according to the five phases of the self-management support process (Glasgow, Davis, Funnell & Beck, 2003; Whitlock, Orleans, Pender & Allan, 2002). We chose to use these phases (Assess, Advise, Agree, Assist, and Arrange) because they describe the self-management support process in a structured way. The phases describe what activities nurses should undertake in the self-management support process. In each step, patients and nurses collaboratively work on mutual goals. Our list of essential competencies for self-management support was derived from literature research and expert consultations. The processes of self-management, consisting of patient tasks and skills as described by Schullman-Green et al. (2012) formed a starting point for the list of competencies regarding the partnership attitude which is needed in self-management support. In the end, thirty-six competencies were determined: six for each phase of the self-management support process, and six overarching competencies.

The SEPSS (Self-Efficacy and Performance into Self-management Support) questionnaire was developed and validated to measure nurses' self-efficacy regarding these 36 competencies, and to assess how often nurses use these competencies in practice according to their own estimation (Chapter 4). The results of this self-reported questionnaire showed a significant gap between nurses' self-efficacy and their behaviour in practice (Chapter 5). Factors that influence the behaviour of nurses with regard to supporting self-management are self-efficacy in self-management support, the perceived lack of own knowledge, and the presumed absence of patients' need for self-management support.

Nurses themselves mentioned a lack of time as an important barrier for supporting self-management. Lack of time is often mentioned as a barrier for preferred behaviour (Dierckx de Casterlé, 2015; Whitlock et al., 2002). But we did not find a relation between the reported barrier lack of time and the reported behaviour of nurses. The second and third most important hampering factors that nurses marked were the belief that patients have insufficient knowledge for self-management, and that patients are not motivated for self-management. This is remarkable because paying attention to insufficient knowledge and to motivation is essential to self-management support itself. These patients could have supportive needs which nurses should acknowledge. Some of these nurses worked with patients in a specific context, such as the intensive care unit. Whether one would consider self-management attainable or not with such difficult target groups might depend on the view on self-management. If one regards self-management support merely as providing health education, some patients groups will be very challenging to support. However, if one considers self-management support as

a broad concept as we have operationalized with the self-management competencies, then self-management support is suitable for (almost) all patient groups.

Nurses reported the highest scores on behaviour in the phases of Assess, Advise, and the Overall competencies. It is possible that nurses feel that assessing the patients' needs and providing information is what they already do in practice. Providing information about the chronic condition is congruent with other studies in the NURSE-CC program (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015; Been-Dahmen et al., 2017; ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). Some studies also showed that nurses not always have an eye for what really goes on in a patient's daily life of patients and also partnering with patients was not self-evident (Been-Dahmen et al., 2015; ter Maten-Speksnijder, Grypdonck, Pool, & Streumer, 2012; ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). In those studies, the focus of the nurses lied mainly on supporting the illness work, instead of integrating the condition in everyday life.

Also, our review showed that many self-management interventions involve patient education, which is part of the Advise phase (Chapter 3). And then, the scan of the curricula of four schools for Bachelor of Nursing education showed that patient education often was regarded as main feature of self-management support (Chapter 6).

The largest gap between nurses' self-efficacy and their behaviour in practice was in the Arrange phase. The Arrange phase could be regarded as organizing work around the patient. This is a part of nurses' work that is often not acknowledged by nurses, and it therefore could be considered as *the invisible work of nurses* (Allen, 2015). The curriculum scan also showed that the Arrange phase got the least attention in the curricula, while this was also the phase on which most students reported educational needs (Chapter 6).

The questionnaire revealed how nurses themselves assess their own behaviour. It creates awareness of what self-management support encompasses and provides insight in what nurses believe they do in this regard. It also provides an indication of which phases of self-management support could be improved.

## **Teaching self-management support**

Our study in Chapter 6 showed that, for various reasons, teaching self-management support can be considered as a complex matter. One of the reasons was that a shared view on self-management and on nursing was often lacking, resulting in differences between teachers within a school in what is taught about self-management. It seemed that self-management was mainly taught by providing theoretical concepts and paying attention to the importance of educating patients for behavioural change. Furthermore, while communicative skills are deemed crucial for self-management support, students seem to be more attracted to technical skills. Students are often very young at the start

of their nursing education. According to the teachers, the lack of life experience hampers them to address patients' needs and worries.

Another reason why teaching self-management is difficult is the existence of a large gap between what students are taught and what they have to show in practice to be accepted in the clinical team. Students are praised by the nurses on the ward when they 'get the work done' (i.e. washing patients, measuring clinical parameters). When students encounter time constraints they find it difficult to combine the daily-routine tasks with supporting patients' self-management. The SEPSS questionnaire, which was distributed among students, showed that students believed that they were capable of self-management support. But it also confirmed the gap teachers had noticed, that the students had lower scores on self-management support behaviour in practice compared with their scores on self-efficacy.

Many interviewees in the curriculum scan mentioned the parallel between the nursepatient relationship and the teacher-student relationship. In self-management support, nurses are expected to build partnerships with patients, where patients are in the lead. If students are taught to motivate patients and to respect the patients' choices, then teachers should give a similar example with regard to students. Being a role model and using language in line with self-regulation and shared decision-making (other self-management values), is part of the hidden curriculum, an important part of what students learn (Tanner, 1990). Students need role models, both at school and in clinical practice (Hawks, 1992). As long as role models in practice are sparse, education should equip students well enough to enable them to balance between the demands of their internship ward and the demands of education (Adam & Taylor, 2014). Using authentic situations and analysing situations students encounter during their internships would be supportive for this purpose (Hawks, 1992; Norbye, 2016; Perkins & Salomon, 1988). The use of reflective case studies in which nurse students reflect on their own clinical practice behaviour has proved to enhance students' reflective capabilities (ter Maten-Speksnijder et al., 2012).

As mentioned in the previous section on competencies for self-management support, we noticed that the Arrange phase got little attention in the curricula. More attention in nurse education for these organisational competencies is therefore needed to equip nurses to focus on patients in the organisational context. This could be done by interdisciplinary assignments so nurses learn to collaborate with other health care professionals, or by paying more attention to follow up care.

#### METHODOLOGICAL CONSIDERATIONS

We used a variety of methods to obtain insight in nurses' self-management support: a realist review, a Q-methodological study, a survey, and a curriculum scan which included qualitative interviews and a scan of documents (learning objectives). Three of these are not frequently used methodologies. The use of these 'non-traditional' methodologies provides knowledge which probably could not have been obtained with 'traditional' methodology. The variety of methods gave insight in the motivation and reasoning of nurses and nurse teachers with regard to self-management. It showed how they themselves view this role and how they experience self-management support in practice.

The Q-methodology, the survey, and the curriculum scan had in common that the method in itself influenced the participants' views on (their own) self-management support or student education about the subject. The participants who completed the questionnaire had to reflect on whether they thought to what extent they mastered certain competencies and how often they performed these competencies in practice. We asked for certain activities which nurses who are not well informed about selfmanagement support might not relate to self-management support, i.e. 'Consulting and making mutual plans with other healthcare professionals, or 'Documenting the goals and agreements in the patient's record'. As a consequence, completing the guestionnaire could have expanded their view on self-management support compared to what they in advance believed self-management support comprehends. The same could have had happened with participants in the Q-methodological study. By sorting the statements of the Q-methodology, participants were invited to shape their (often tacit) views on self-management. After sorting the statements they had to motivate their Qsort. Thus they had to give words to their view on self-management which presumably shaped their view even further. With the questionnaire and the Q-methodological study we provided the participants a framework on self-management support. The questionnaire contained items which represented our view on self-management support, while the statements in the Q-study represented several possible views on self-management support.

These approaches differed from the approach to the interviews of the curriculum scan. In these, participants were not given any information on self-management support when we asked for their view on self-management. Consequently, the view on self-management was (further) shaped by participants themselves by expressing their thoughts aloud, and by sharing these with their colleagues. Respondents mentioned afterwards that these interviews helped them to formulate their views more explicitly, and that they had realised it was important to share their views with team members.

In the study into the self-efficacy and behaviour of nurses regarding self-management support, we used self-reported questionnaires (Chapters 4 and 5). While self-efficacy

could only be reported by the nurses themselves, the extent to which nurses perform these competencies in practice might be underrated or overrated. However, an observational study into self-management support behaviour of nurse practitioners also showed that these nurses held another -more positive- image of their supporting behaviour compared to what was observed (ter Maten-Speksnijder et al., 2016). Another study using audio recordings of consultation sessions showed similar results: in spite of the professionals' intentions to collaborate with patients on an equal partnership base, in practice this appeared to be difficult for them (Paterson, 2001). Observations of nurses in a diversity of health care settings would provide useful additional knowledge about how and to what extent nurses really use the competencies for self-management support in practice and about how patients experience this support.

Patients' self-management is supported by the whole range of nurse professionals: Nurse practitioners, Bachelor of nurses, vocational nurses and nurse assistants. The questionnaire study and the Q-study were aimed at nurse practitioners, bachelor of nurses, vocational nurses, and their students. For the curriculum scan we only studied the curricula of four bachelor of nursing education schools. This was mainly for practical reasons, because the study was extensive and time consuming. It would be interesting, however, to study how self-management support is taught in the other levels of nursing.

#### **GENERAL DISCUSSION**

Nursing theories (e.g. Brink-Tjebbes & Keij, 1997; King, 1981; Orem, Taylor, & Renpenning, 1995) advocate a holistic, person-centred view in which nurses should address more than only the medical needs of patients. But many nursing theories are normative, and not empirical theories (Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007). Although nurses are expected to support patients' self-management with respect to all the lines of work with patients – that is: biographical, illness, everyday life, and articulation work (Corbin & Strauss, 1985) – this is not necessarily current practice, neither in clinical nursing practice, nor in Dutch Bachelor of Nursing education (Chapters 5 and 6).

Chapter 2 showed four nurse perspectives on self-management and the way nurses can support this. But holding a certain perspective does not predict how nurses support self-management in practice. We developed a list of competencies for self-management support, representing the Coach perspective, creating awareness about what self-management support entails (Chapter 4). The list was transformed into a questionnaire (SEPSS-36). With this list, we were able to measure the self-reported self-management support behaviour of nurses. As self-efficacy is an important factor for success (Bandura, 1991), we also measured nurses' self-efficacy regarding self-management support (Chapter 4 and 5). Our study into nurses' self-efficacy and self-reported behaviour showed

that both nurses and nursing students feel confident they can support patients' selfmanagement (Chapter 5 and Chapter 6). But it also revealed a significant gap between 'being able to' and 'doing so' in practice. The finding that aspects of self-management are not easily integrated in practice confirms the results of other studies (Elissen et al., 2013; Hibbard, Collins, Mahoney & Baker, 2010; Wilson, Kendall, & Brooks, 2006). The questionnaire in Chapter 5, and the curriculum scan in Chapter 6 revealed several aspects of influence on the implementation of self-management support in practice, next to self-efficacy. But there are other factors that influence the role nurses have or take in self-management support. First, I will address the expectations of self-management from health care policy and the nursing profession itself. In the last part of this section I will reflect on the nurses' role in self-management support at an individual level: in relation with the patients and in the context of everyday practice.

## Expectations...

#### How health care policy shapes nurses' role in self-management support

In the Netherlands, a major shift in current health care is the delegation of power to lower entities. Underlying pillars of these regulations are more responsibility to people, reducing residential care, decentralisation, and decrease of expenditure (Maarse & Jeurissen, 2016). Patients are expected to monitor their condition, to solve problems on their own, with help from their social network and, as a result, to consume less health care (Besseling, van Ewijk, & van der Horst, 2013; RVZ, 2010a). Health care organisations hold an increasing focus on production and efficiency (Allen, 2015; Schoot, 2006). The implication of this is that nurses are expected to act as a *Gatekeeper* (Chapter 2). Nurses are to stimulate people to act as independently of health care professionals as possible. For example, the financing of homecare is based on the assessment of patients' needs by community nurses, using professional nursing diagnoses. But at the same time, nurses are also confronted with budget cuts. Thus, community nurses have to negotiate with patients about the need and justification of (the amount of) professional help. Competencies as 'being able to negotiate', and 'being able to handle conflicts' are needed and should be incorporated in nurse education (Kriston et al., 2010).

Another emphasis in policy documents lies on maintaining or gaining a healthy lifestyle. The focus on the influence of (un)healthy behaviour is explicitly stated in policy documents (RVZ, 2010a; 2010b). Patients are encouraged to lifestyle adjustments, to adhere to medical regimes and thus prevent complications (Esmeijer, van der Klauw, Bakker, Kotterink & Mooij, 2014; Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011). According to this new lifestyle politics, patients are regarded as health care consumers and are held responsible for their health and illness (Cumella, 2008; Larsen, 2012). Patients can only take more responsibility, however, if they are properly informed. Nurses are expected to take an *Educator*'s role in this respect: supporting (i.e. educate and motivate) patients in undertaking preventive activities (Chapter 4). Insurance companies stimulate self-management (CVZ, 2010), often based on the rationale that health care expenditure should be reduced (Henkemans, 2010).

Despite the emphasis on self-management, the organisation of health care does not always facilitate effective self-management support. For example, our realist review (Chapter 3) showed that interventions aiming at intrinsic processes are most successful. Problem solving skills are one of the six self-management skills described by Lorig and Holman (2003) and could be regarded as intrinsic processes. Dutch health insurers however regard problem solving skills as general human competencies, and consequently interventions aimed at achieving these skills are not reimbursable (CVZ, 2010). Also, the focus of health care policy on patient education is contradictory with the results of our review, which show that patient education alone is not effective in achieving behavioural change. Furthermore, instructing and educating patients, and taking patients' preferences into account are sometimes off balance with today's increase of administrative burden, focus on technical tasks and emphasis on protocols and guidelines (Allen, 2007; Jonsdottir et al., 2004; Maurits, de Veer & Francke, 2016). This was also acknowledged by nurses, nurse students and teachers participating in the studies addressed in Chapter 5 and Chapter 6 of this thesis. Self-management support is thus recognized as an essential ingredient of current healthcare politics, whereas practical obstacles abound as a result of healthcare policies.

#### The nursing profession changes

The changing health care context not only demands new competencies for health care professionals (Kaljouw & van Vliet, 2015; RVZ, 2010c; RVZ, 2011; WHO, 2005), it also calls for a reflection on the division of professional tasks. The future health care professional is indeed subject of debate in the Netherlands (Kaljouw & van Vliet, 2015; Stavenuiter et al., 2015). New professions that can substitute tasks of other health care professions have been introduced, e.g. the nurse practitioner and physician assistant professions (Wallenburg, Janssen & de Bont, 2015). This has changed the organisation of care. Much caring activities are carried out by nurse assistants, while nurse practitioners have a medical and educational focus. Based on empirical studies, Allen (2007) stated that the core of nursing is the articulation work around individual patients and facilitating the goals of different actors. This resembles the Arrange phase in the self-management support process as described in this thesis. But, although this may be what nurses do in practice, it is a completely different way of describing the nursing profession that is prevalent in both nursing practice and education. Often, the focus lies on the caring activities when nursing activities are described.

In many health care organisations, the Bachelors of nursing form a minority among care professionals. Much of the direct patient care is delivered by nurses with a voca-

tional education or by healthcare assistants. Compared to the vocational nurse, the Bachelor of nursing has a more reflective, coordinating role (Lambregts & Grotendorst, 2012). With all the different kinds of health care professionals involved, it is important to guarantee the continuity of care in self-management support (RVZ, 2009). As our studies showed, nurses and students had the lowest scores on the coordinating tasks (the Arrange phase), and these tasks also received the least attention in nurse education (Chapters 5 and 6). Considering what was stated above, the coordinating role of nurses, which obviously also facilitates self-management support, should be acknowledged as a more important aspect of the profession of Bachelor of Nursing than it is today.

## ...And reality

Self-management is an empirical fact in the lives of people with chronic conditions (Grypdonck, 2013). They have no other choice than to integrate the condition into their lives, and they experience many challenges by doing so (Lorig & Holman, 2003; Schulman-Green et al., 2012). With the acknowledgement that patients' experiences are valuable and that patients should be regarded as equal partners, self-management has an empowering function for patients (Splaine Wiggins, 2008). When we asked nurses to choose from four perspectives on self-management, the most preferred one was the *Coach* perspective (38% of the nurses) representing an equal partnership relation and a focus on living with the chronic condition (Chapter 5). In everyday clinical practice, however, the focus often lies on 'getting the job done' and on medical and/or clinical outcomes (Chapter 6, and Jonsdottir et al., 2004), representing the Gatekeeper and Educator perspectives on self-management (Chapter 2). One explanation for this focus could be that nurses have to cope with time constraints. Almost half of the nurses and more than half the students who completed the SEPSS (Chapter 5 and Chapter 6) reported limited time as an important barrier for self-management support behaviour. And although we did not find an association of this barrier with self-reported selfmanagement support behaviour, these nurses' and students' feelings should be taken seriously. Other studies also found that nurses are hampered by time constraints and pressure to 'get the job done' (washing and dressing patients, taking care of wounds, infusions and medication, and controlling clinical parameters). Under these conditions, it is increasingly difficult to provide person-centred care (Papathanasiou, Sklavou, & Kourkouta, 2013). Offering choices and subsequently waiting for answers takes time, and is something nurses are not always willing or able to do (Anderson & Funnell, 2005; Dierckx de Casterlé, 2015). Based on studies into patients' experiences with care, Dierckx de Casterlé (2015) distinguishes three kinds of care: 'minimal' care, 'professional' care, and 'skilled companionship'. Minimal care is basic, instrumental and functional as nurses act routinely. Professional care addresses individual patients' needs, but the relationship between nurses and patients is asymmetric; the nurse is the expert. Skilled companionship is regarded as the integration of nursing competences and a caring attitude. The patient's lived experience is acknowledged and taken as a starting point for care. The nurse-patient relationship is based on mutual trust and equality. A nurse with a *Coach* perspective on self-management (Chapter 2) seeks for this skilled companionship in patient care.

Another explanation for the absence of equal partnership in everyday practice could be that some nurses experience difficulties with expert patients (Anderson & Funnell, 2005; Thorne, Ternulf Nyhlin & Paterson, 2000; Kendall et al., 2011). They tend to adopt a paternalistic approach, i.e. advising patients and limit the possible choices, because they feel threatened in their identity (McDonald, Rogers & Macdonald, 2008; Wilson et al., 2006; Yen et al., 2011). Nurses believe that patients do not always know what is in their best interest (Dwarswaard & van de Bovenkamp, 2015; McDonald et al., 2008; Paterson, 2001). Patients may well choose to prioritize quality of life over a strict medical regimen. People with chronic conditions have the right to make unhealthy choices just as much as 'healthy' people do (Grypdonck, 2013) – although in health care debates questions arise about whether unhealthy choices made by 'healthy' people should be discouraged (ten Have, 2013). When patients make 'unhealthy' choices, nurses may find it difficult to combine 'partnering with patients', and 'respecting their opinions', with 'protecting and supporting patients health' (Dwarswaard & van de Bovenkamp, 2015; Wilkinson, Whitehead & Crowe, 2016).

Respecting patients' autonomy does imply not turning away from people who make unhealthy choices. Some patients indeed have difficulties with managing the chronic condition. A healthier life style is associated with higher education and higher incomes (Alleyne, Hancock & Hughes, 2011; Besseling et al., 2013). Not every patient wants to, or is able to, take an active role in the health care process (Coventry, Fisher, Kenning, Bee & Bower, 2014; Gazmararian, Williams, Peel & Baker, 2003; Rademakers, 2016). Some people lack the capacity to make a reasonable judgement about the condition, have difficulties in maintaining planned (i.e. healthier) behaviour, or sometimes other priorities prevail (such as financial problems) (Grypdonck, 2005; Rademakers, 2016). This requires more support from nurses for these patients, instead of regarding this as a barrier for self-management support (Chapter 5). Our survey among nurses in a university hospital, revealed - in line with the literature - that nurses regarded certain patients as a disabling factor in self-management support (Chapter 5 and Barnes, Hancock, & Dainton, 2013; Coventry et al., 2014). But, taking self-management support seriously would mean nurses should see these patients as people with extra supportive needs. Nurses should assess what motivates or hampers these patients and not leave them on their own or just tell them what is best for them (Chapter 4).

Nurse education should teach students how to partner with empowered patients, but also with patients who have difficulties with self-management. A starting point could

be the way in which teachers depict 'the patient'. The scan of the curriculums of four Dutch schools for Bachelor of Nursing showed that in only one school special attention was given to the way patients were regarded (Chapter 6). This school had chosen to consequently name patients 'human beings'. This is one example of how this school embodied the equal relationship between nurses and patients. Another point was the use of patients' experiences in education. By listening to patients telling about how they cope in everyday life, and about their contacts with nurses, students can become aware of the impact of their actions. Meeting patients at home, in their own environment, might help students realize that health care professionals play just a (sometimes minor) part in the lives of patients. Future nurse students' perception on nursing is often related to acute, hospital care (Chapter 6), but also nurse education itself had this focus in its curriculum (van lersel, Latour, de Vos, Kirschner & Scholte op Reimer, 2016), hampering an attitude that is needed to embrace a patient centred perspective.

## **Between expectations and reality**

This thesis contributed to the understanding of the nurse's role in self-management support of patients with chronic conditions. The competencies nurses need for self-management support are described and can be used in nurse education. More insight has been gained about the working mechanisms of interventions. We also learned that everyday nursing practice is not necessarily in alignment with the expectations about the nurse's role. In order to prepare nurse students for their future tasks, nurse education should reflect on its current curriculum. Nurse students should be better prepared for reality by empowering them, by teaching them about what nurses actually do in practice, and how they can cope with the often time-pressing circumstanced of nursing practice. A broad view on self-management not only implies that self-management involves a broad holistic scope on living with a chronic condition, it also implies a broad scope on the tasks nurses have in self-management support. In particular, more focus is needed on the Arrange phase.

In the Introduction section, I presented the story of Emily as an example of a woman living with chronic conditions. What Emily mostly needed from nurses was articulation work, that is, the work needed to bridge tasks and manage care (Allen, 2015). She could manage her daily activities, and yet, sometimes she needed information about risks or side-effects of medication. But she mostly needed someone who anticipated what could happen if she went home by herself. Someone who was truly interested in her situation, and who could assess what she really needed. She needed someone to arrange that she always could contact someone in the hospital when she felt awful at home, and that the next health care professional knew what has happened to her in the past few weeks. All those activities are about supporting patients' self-management; it enabled Emily to cope and to live with her conditions. Both nurses and Bachelor of Nursing education should acknowledge that self-management support arises not only in direct patient care, but also by arranging activities of all actors involved.

# **FUTURE DIRECTIONS**

#### Implications for nursing practice

#### **Operationalization of self-management support**

In this thesis, I determined the essential competencies for self-management support by nurses. These competencies are structured by the five A's of the self-management process (Whitlock et al., 2002), which provide a practical framework. Self-management support is now more operationalized, making it more explicit for nurses to know what is expected from them.

#### Validated questionnaire (SEPSS)

The validated questionnaire, based on the essential competencies, is self-reported and gives insight into the participants' self-efficacy and behaviour at both the aggregate and the individual level. This questionnaire could be used not only in research, but also as a reflective tool in education and training for graduated nurses. It both demonstrates what nurses believe they are capable of, and indicates their educational needs or gaps in their competencies.

#### Four distinctive perspectives on self-management support

We determined four distinctive perspectives on self-management support. These perspectives help to clarify the debate about the goal of self-management support. The *Coach* perspective is the perspective which best reflects the broad definition on self-management. Nurses should be aware of the perspective they adhere to and be able to shift between perspectives. Not all patients need or wish to be supported by a nurse coach.

#### More attention is needed for the Arrange phase

The survey and the curriculum scan showed that more attention is needed for the Arrange phase. Nurses should acknowledge that this phase is an important part of the self-management process. Especially in the face of budget cuts nurses have to prioritize their tasks. By making choices nurses still can give person-centred care, from a *Coach* perspective. Being more equipped in competencies of the *Arrange* phase could help them with this.

# Implications for nurse education

## A team of teachers needs a shared view on self-management support

Education has a main role in enabling nurses to support patients' self-management. A shared view on self-management and thereby on nursing in the team of teachers is a precondition. With a shared view, the aim of self-management should be clear for everyone.

## A person-centred approach as the basis of all nursing activities

In the curriculum a person-centred approach should be the basis of all nursing activities. This should also be reflected in the hidden curriculum; it should not only consist of words on paper which can be forgotten during internships or during lessons on clinical reasoning. Internships constitute main part of nursing education. By providing personcentred care in a culture where this is not self-evident, students learn to be an innovator. If students provide patient-centred care in a busy environment, they show other nurses that it can be done. Teachers should empower and coach their students in doing so, by discussing how priorities can be set, by rewarding 'good' care, and by facilitation of students' reflection.

## Teachers as role models

Teachers are role models for students, but they can also coach nurses in clinical practice in how to support patients' self-management. In order to do so, they should visit the wards where students are placed during an internship.

# **Directions for future research**

# Additional observations of nurses supporting patient's self-management

Observations of nurses providing self-management support in a variety of settings would add to the understanding of how nurses master and perform the essential competencies in practice.

## The contribution of nurses in self-management interventions is needed

More attention should be given to the contribution of nurses in studies into selfmanagement interventions. Nurses are important actors in the failure or success of self-management interventions. However, our review showed that descriptions of the training the nurses received and the competencies nurses had to master for the intervention were scarce.

## The role division with regard to supporting patient's self-management

We developed the competencies for self-management support for nurses. In everyday practice nurses collaboratively work with nurse assistants, especially in home care

and elderly care. It would be recommended to study the role division between nurse practitioners, nurses with a bachelor degree, vocational nurses, and nurse assistants, with regard to self-management support. In addition, the SEPSS questionnaire could be tested for nurse assistants as well.

#### Evaluation of the contribution of the new curriculum to self-management support

All Dutch Bachelor of nursing education schools are currently revising their curricula to the new educational framework. In this framework, self-management support is described as one of the core components of nursing. It would be interesting to evaluate whether the new curriculum actually contributes to more self-management support and, if so, how this is achieved.

## Self-management support in the various levels of nursing

Further research is needed on how self-management support is taught in the various levels of nursing and how this varies between the various levels in practice.

In this thesis, I plead for more attention to the Arrange phase of the self-management support cycle. We already have formulated six essential competencies for this phase, but it would be interesting to study this more in-depth in clinical practice and in nurse education. This is recommended not only for the Bachelor of Nursing education, but also for the other levels of nursing because it is not clear what level of nursing should and could address these competencies.

#### Nursing theory on self-management support in everyday practice

Further development of nursing theories with regard to supporting patient's self-management is needed. These could offer guidance in everyday nursing practice, instead of providing a merely normative direction.

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# Chapter 8

Summary Samenvatting

## SUMMARY

Integrating a chronic medical condition into one's life requires performing certain adaptive tasks. Often patients can perform these tasks themselves of with help from their family. But at some points in time, they may require help from professionals – usually nurses specialized in self-management support. Many definitions have been proposed for the term self-management, representing different focuses on the goals of selfmanagement. In this thesis, we use the definition of Barlow et al. (2012):

'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.'

This definition implies that self-management is concerned with how people are able to integrate the condition into their lives, instead of focusing solely on medical regimens.

Self-management support requires that nurses have a partnering approach, where patients and nurses mutually agree upon the goals. The new Dutch professional profiles acknowledge self-management support as a key-feature of nursing. What this entails is not self-evident, however. The competencies described in literature are often broadly formulated, and it is not clear which interventions are effective. Also, various stakeholders hold a variety of aims of self-management, which all demand for different roles of nurses.

Nurse education programs need to be adapted in view of the increasing attention to self-management. Until now it is not clear how nurses are prepared for self-management support during their education.

The studies in this thesis are part of the research program NURSE-CC (NUrsing Research into Self-management and Empowerment in Chronic Care).

This thesis consists of three parts. In the first part, the role of nurses in supporting patient self-management is explored (chapters 2 and 3). The second part describes what competencies for self-management support nurses need to possess (chapters 4 and 5). The third part describes how self-management is taught in nurse education (chapter 6).

**Chapter 2** describes a Q-methodological study with 39 nurses from various settings. Nurses had to sort statements about self-management on a table with a forced-choice frequency distribution. Next, they explained the motivation for the sorting in individual interviews.

The goal was to identify nurses' perspectives on self-management. Four distinctive perspectives were revealed, which we described as the Coach perspective, the Clinician

perspective, the Gatekeeper perspective, and the Educator perspective. The differences between the perspectives lie in the perceived goal of self-management, and in the patients' and nurses' roles in the self-management process. A nurse with a Coach perspective considers integration of the chronic condition in the patients' lives the main goal of self-management support. The patients have a prominent and leading role in the process, whereas the nurse has a more responsive role. A nurse with a Clinician perspective focuses predominantly on adherence in the self-management process. While this nurse has a dominant role, the patient has a compliant one. According to a nurse with a Gatekeeper perspective on self-management, the goal is to reduce health care expenditure by focusing on patients' independency. Here, the nurse is in the lead, while the patient is independent. The goal of self-management according to the Educator perspective is living with a chronic condition, which entails having good clinical patient outcomes. The role of the nurse is that of a teacher, with the patient as active student.

Different patients and situations require different perspectives. Not all patients or all situations benefit from nurses with a Coach perspective. Nurses should incorporate some aspects of each perspective into their repertoire.

The realist review in **Chapter 3** aims to examine how nurse-led interventions that support self-management of outpatients with chronic conditions work and in what contexts they work successfully. A realist review is aimed to examine underlying mechanisms of interventions, rather than to evaluate these for effectiveness. We searched in databases, using various search terms for self-management, evaluation, chronic disease, and nurses. We included 35 different interventions, described in 38 papers. For each study, we determined the espoused theories (the theory mentioned as base for the interventions) and the theories in use (how interventions had actually worked).

Our realist review showed three different mechanisms in the interventions: increase patients' knowledge, enhance patients' skills, and increase patients' motivation. These were the starting points for the interventions. Also, three outcomes of the interventions were identified: behavioural change, increase of coping, and increase of self-efficacy. Based on the theory in use, we described seven different strings that linked the mechanisms and the outcomes. The contexts could determine whether or not the aim of the interventions could be realized. These contexts are the involvement of relatives, the target group, the use of peers and group homogeneity (or heterogeneity). Interventions that focused on patients' intrinsic processes (self-efficacy and motivation) were most successful. Least successful was the string where education was assumed to lead to behavioural change. The implication for practice is that nurses should preferably choose interventions which aim at the intrinsic self-management support processes.

**Chapter 4** describes the development and the psychometric evaluation of the selfefficacy and performance in self-management support (SEPSS) instrument. Based on scientific articles about self-management support and (inter)national policy documents, we identified competencies for self-management support. We structured the initial list of competencies according to the Five A's model, with its sub sequential phases Assess, Advise, Agree, Assist, and Arrange. We added a sixth category which entails overall competencies, such as a partnership approach. The draft list was discussed with a group of experts (n=10). This resulted in a list of 53 competencies. We constructed an instrument which measures self-reported competencies on a five-point Likert rating scale. With this instrument we assessed both self-efficacy (the extent to how confident participants were that they were able to perform the asked competency), and performance (the extent to how often participants performed this competency). We tested the instrument in a sample of Belgian, and Dutch nurses and nurse students (n=523).

The psychometric evaluation consisted of testing for construct validity with confirmatory factor analysis, and testing for discrimination power between sub groups (known-groups technique). With regard to reliability we assessed internal consistency (Cronbach's alpha values ranging from 0.75 to 0.96), test-retest stability, and floor and ceiling effects. The psychometric evaluation showed that the final 36-item instrument has good content and construct validity, as well as good internal consistency reliability.

The instrument can be used to gain insight in nurses' self-reported self-management support competencies as well as the aspects of self-management support that demand for extra training or attention, at both individual and team level. Furthermore, the instrument enables nurses to reflect on their own activities with regard to self-management support.

**Chapter 5** describes a study exploring nurses' self-reported behaviour in self-management support and the factors that influence this behaviour. We used a total sample approach with a cross-sectional design. All nurses from one university hospital were invited to participate (n=2,054). The final response rate was 16.9% (n=347). The nurses completed the Self-Efficacy and Performance in Self-management Support instrument (SEPSS-36), supplemented with additional questions about attitude, subjective norms, and perceived barriers for self-management support. We used the ASE model to explain the factors influencing self-management support behaviour.

Results showed that a positive attitude towards self-management is related to selfmanagement behaviour. Nurses perceived a patient's lack of knowledge, lack of ability to make choices, and lack of motivation as the most important factors potentially influencing their self-management behaviour. But these did not affect the self-management support behaviour of these nurses. However, presuming that a patient does not need self-management support had a negative influence on self-management support behaviour. Self-efficacy was significantly related with self-management behaviour, but the differences in scores between self-efficacy and behaviour were also significant. This implies that nurses had a lower score on behaviour than expected from the scores on self-efficacy. Lack of time was regarded as the most important barrier for self-management support. But the nurses who perceived this as an important barrier did not have a lower score on behaviour than other nurses. Nurses who perceived their own knowledge about selfmanagement support as insufficient scored lower on self-management behaviour than other nurses. Stepwise regression analysis showed that three factors were significant predictors for self-management support behaviour: perceived lack of own knowledge, the presumed absence of a patients' need for self-management support, and nurses' self-efficacy in self-management support. Most educational needs were for the Agree phase, which contains collaborative goalsetting. This phase also had the largest gap between self-efficacy and behaviour. Managers and trainers of self-management support should take these influential factors into account when implementing self-management support.

The study in **Chapter 6** aims to describe how Dutch Bachelor of Nursing students are prepared for self-management support in practice. We employed a mixed methods design, which included a curriculum review, interviews, and a student questionnaire. Four Bachelor of Nursing schools participated. Interviews (in groups and individual) were held with teachers (n=30), managers (n=4) and (associate) professors (n=4). We screened course manuals for learning objectives related to self-management. All final year students of the participating schools were invited to complete the SEPSS questionnaire (n=444). This instrument measures the self-efficacy and behaviour regarding self-management support. The response rate was 53.6% (n=238).

The scan of learning objectives showed that self-management was often taught in relation to communicative skills, models for behaviour change, and lifestyle adaptations. Most attention was given to the Five A's model's phases Assess and Advise. Least attention received the Arrange phase. This was confirmed by the results of the students' questionnaire. The interviews revealed that teachers can be influential. What is taught depends often on an individual teacher's interpretation of the concept of self-management. Students encounter contradicting values when they have to apply what they have learned about self-management into clinical practice. Teachers could be more supportive in this, by facilitating reflection and empowering the students.

#### Conclusion

This thesis contributed to the understanding of the role of nurses in self-management support.

Nurses are expected to support patients with chronic conditions in their self-management, based on nursing theories and the professional profiles, but also based on expectations of policy makers. Supporting patients' self-management, according to the broad view on self-management, is however not necessarily current practice, neither in clinical nursing practice nor in Dutch Bachelor of Nursing education. Most nurses seem to focus on the Advise phase, on medical outcomes and on 'getting the work done'.

Reflection on nurses' tasks is needed, since many studies in this thesis show that the Arrange phase received least attention in education, and was assigned the lowest scores in the questionnaires. Yet, the tasks in this phase represent an important aspect of self-management support and of the nursing profession. Equal partnership, which is an essential aspect of self-management support, seems to be difficult for nurses in everyday practice. Nurse education could facilitate students in empowering them and teaching them the value of patient's expertise.

## SAMENVATTING

Een patiënt die een chronische aandoening in zijn of haar leven moet integreren staat daarbij voor een aantal adaptieve opgaven. Vaak zijn patiënten goed in staat die zelfstandig of met hulp van hun sociale omgeving te volbrengen, maar soms hebben zij bij hun zelfmanagement ondersteuning van zorgprofessionals nodig. Veelal zijn het verpleegkundigen die deze ondersteuning bieden.

Er zijn veel verschillende definities van zelfmanagement. Ze zijn een afspiegeling van hoe er naar zelfmanagement wordt gekeken. Binnen het NURSE-CC onderzoeksprogramma hanteren we de definitie van Barlow et al. (2012, p178): 'Zelfmanagement verwijst naar het vermogen van een individu om te gaan met de symptomen, benadelingen, fysische en psychische consequenties en veranderingen in leefstijl, die inherent zijn aan het leven met een chronische aandoening. Effectief zelfmanagement omvat het vermogen de conditie te monitoren en de cognitieve, gedragsmatige en emotionele reacties te beïnvloeden die nodig zijn om een bevredigende kwaliteit van leven te handhaven. Op die manier ontstaat een dynamisch en continu proces.' Volgens deze definitie is de kern van zelfmanagement dat de chronische aandoening in het hele leven van de patiënt wordt geïntegreerd. Het gaat om meer dan het uitvoeren van behandelings-voorschriften en adviezen voor de aandoening.

Zelfmanagementondersteuning vraagt om een benadering van verpleegkundigen op basis van partnerschap. Samen met de patiënt bepalen de verpleegkundigen wat de doelen van de zorgverlening zijn. In de nieuwe verpleegkundige beroepsprofielen wordt zelfmanagement als kern van het verpleegkundige beroep genoemd. Toch is niet vanzelfsprekend wat het ondersteunen van zelfmanagement inhoudt. Wanneer in literatuur competenties voor zelfmanagement worden beschreven, zijn deze vaak zo breed geformuleerd dat nog steeds niet duidelijk is wat er van verpleegkundigen wordt verwacht. Ook is onduidelijk welke zelfmanagementinterventies effectief zijn, omdat de effectiviteit van zoveel factoren afhangt. Tenslotte bepaalt ook het doel dat met zelfmanagementondersteuning wordt nagestreefd wat van verpleegkundigen wordt verwacht. Maar dit doel is vaak niet eenduidig en vaak impliciet.

De toenemende aandacht voor zelfmanagement vraagt van de verpleegkunde opleidingen dat verpleegkundigen goed worden voorbereid op het ondersteunen van zelfmanagement in de praktijk. Tot nu toe is niet duidelijk hoe (het ondersteunen van) zelfmanagement in de opleidingen wordt aangeleerd.

De studies in dit proefschrift maken deel uit van het onderzoeksprogramma NURSE-CC (NUrsing Research into Self-management and Empowerment in Chronic Care). Het proefschrift bestaat uit drie onderdelen. In het eerste wordt de rol van de verpleegkundige bij het ondersteunen van zelfmanagement verkend (hoofdstuk 2 en 3). Het tweede deel beschrijft de essentiële verpleegkundige competenties voor het ondersteunen van zelfmanagement (hoofdstuk 4 en 5). Het derde deel beschrijft hoe zelfmanagementondersteuning in de opleiding voor hbo-verpleegkundigen wordt aangeleerd (hoofdstuk 6).

**Hoofdstuk 2** beschrijft een Q-methodologische studie waarin 39 verpleegkundigen uit verschillende werkvelden participeerden. De verpleegkundigen hebben stellingen over zelfmanagement gesorteerd in een tabel met een vast patroon, waardoor zij een rangorde aanbrachten in de mate waarin zij het eens of oneens waren met de stellingen. Na het sorteren werden interviews met de verpleegkundigen afgenomen waarin zij hun keuzes konden motiveren.

Het doel van dit onderzoek was om verschillende perspectieven van verpleegkundigen op zelfmanagement te achterhalen. We vonden vier verschillende perspectieven, die we het Coachperspectief, het Poortwachterperspectief, het Behandelaarperspectief, en het Leraarperspectief hebben genoemd. De perspectieven verschillen van elkaar door het doel dat met zelfmanagement wordt nagestreefd en de positie die de patiënt en de verpleegkundige innemen in het proces van zelfmanagementondersteuning. Een verpleegkundige die vanuit een Coachperspectief werkt, vindt dat zelfmanagement ertoe moet leiden dat de patiënt de chronische aandoening kan integreren in zijn of haar leven. De patiënt heeft hierin een leidende rol, terwijl de rol van de verpleegkundige meer een afwachtende is. Een verpleegkundige met een Behandelaarperspectief legt in de ondersteuning van zelfmanagement vooral de nadruk op therapietrouw. De rol van de verpleegkundige is dominant en de patiënt is vooral volgzaam in het opvolgen van adviezen. Volgens de verpleegkundige met het Poortwachterperspectief is het doel van zelfmanagement het beperken van de kosten in de gezondheidszorg, doordat patiënten zo min mogelijk afhankelijk zijn van zorgprofessionals. De verpleegkundige neemt hier het voortouw, maar de patiënt heeft een onafhankelijke rol. Het doel van zelfmanagementondersteuning volgens verpleegkundigen met het Leraarperspectief is dat de aandoening wordt geïntegreerd in het leven van de patiënt, maar hierbij wordt vooral gekeken naar de klinische parameters als uitkomstmaat. De verpleegkundige heeft volgens dit perspectief de rol van leraar, terwijl de patiënten een (actieve) rol als leerling hebben. Van hen wordt verwacht dat zij het geleerde in praktijk brengen.

Elke patiënt en elke situatie vraagt om verplegen volgens specifieke perspectieven. Het Coachperspectief sluit het meest aan bij de definitie van zelfmanagement van Barlow, omdat beide zelfmanagement zien als middel om de chronische aandoening in brede zin in het leven van de patiënt te integreren. Maar niet elke patiënt is gebaat bij zelfmanagementondersteuning vanuit het Coachperspectief. Om de ondersteuning te kunnen aanpassen aan de behoefte van de patiënt en de situatie, zouden verpleegkundigen iets van alle perspectieven in huis moeten hebben.

De realist review in **Hoofdstuk 3** onderzoekt hoe en in welke context verpleegkundige interventies voor zelfmanagementondersteuning van patiënten met een chronische aandoening werken. Bij een realist review gaat het eerder om de onderliggende mechanismen van een interventie dan om de effectiviteit ervan. We hebben naar interventies gezocht in verschillende databases, waarbij we verschillende zoektermen hebben gebruikt voor zelfmanagement, evaluatie, chronische aandoening en verpleegkundigen. Er zijn 35 interventies geïncludeerd, die werden beschreven in 38 papers. Van elke aangetroffen interventie werd de theoretische basis achterhaald. Verder werd bekeken hoe de interventies in werkelijkheid werkten. Onze review liet zien dat in de interventies drie verschillende mechanismen te vinden waren, namelijk het vergroten van de kennis van patiënten, het verbeteren van de vaardigheden van patiënten en het vergroten van de motivatie van patiënten. Dit waren de uitgangspunten van de interventies. Daarnaast vonden we drie verwachte uitkomsten: gedragsverandering, toename van copingvaardigheden en toename van zelfeffectiviteit. In onze analyse van de praktische werking van de interventies hebben we zeven verschillende paden gevonden waarlangs de interventies lopen. Hierbij worden de mechanismen verbonden aan de uitkomsten. Contexten waren vaak van invloed op de haalbaarheid van het verwachte doel. Relevante contexten waren de betrokkenheid van familieleden, de doelgroep, de inzet van lotgenoten en de homogeniteit of heterogeniteit van de groep bij groepsinterventies. De interventies die gericht waren op intrinsieke processen (zelfeffectiviteit en motivatie) waren het meest succesvol. De interventies waarbij werd aangenomen dat het vergroten van kennis automatisch zou leiden tot gedragsverandering waren het minst effectief. Verpleegkundigen wordt aangeraden om bij zelfmanagementondersteuning in de praktijk te kiezen voor interventies die de intrinsieke processen van patiënten versterken.

**Hoofdstuk 4** beschrijft de ontwikkeling en de psychometrische evaluatie van de vragenlijst Self-Efficacy and Performance in Self-management Support (SEPSS). Wetenschappelijke literatuur en (inter)nationale beleidsdocumenten over zelfmanagement vormden de basis voor een lijst met competenties voor zelfmanagementondersteuning. Deze lijst met competenties werd gestructureerd volgens het 5A-model, met daarin de achtereenvolgende fases Achterhalen, Adviseren, Afspreken, Assisteren en Arrangeren. We hebben hier een zesde categorie aan toegevoegd die overkoepelende competenties omvat, zoals samenwerken met de patiënt op basis van partnerschap. De conceptlijst is bediscussieerd met een groep experts (n=10). Dit leidde tot een lijst van 53 competenties. Op basis hiervan is een vragenlijst samengesteld die zelfgerapporteerde competenties van verpleegkundigen meet, op een vijfpunts Likertschaal. Met dit instrument meten we zowel de *zelfeffectiviteit* (de mate van vertrouwen die de verpleegkundige erin heeft dat ze de desbetreffende competentie kan uitvoeren) en *het doen* (de mate waarin de verpleegkundige de desbetreffende competentie uitvoert in de praktijk). We hebben deze vragenlijst getest bij een sample van Belgische en Nederlandse verpleegkundigen en verpleegkundestudenten (n=523). In de psychometrische evaluatie hebben we de constructvaliditeit gemeten met behulp van factoranalyse, discrimination power (onderscheidend vermogen) tussen subgroepen. De betrouwbaarheid is geëvalueerd door de interne consistentie te meten (Cronbach's alpha tussen 0,75 en 0,96), de test-herteststabiliteit te meten en de vloer- en plafondeffecten te meten. Deze evaluatie liet zien dat het uiteindelijke 36-item instrument een goede inhouds- en constructvaliditeit en een goede interne stabiliteit heeft.

Het instrument kan worden gebruikt om inzicht te verkrijgen in de zelfgerapporteerde competenties van verpleegkundigen. Het laat zien welk aspect van zelfmanagement nog extra training of aandacht behoeft, zowel op individueel niveau als op afdelingsniveau. Daarnaast heeft het invullen van de vragenlijst een reflecterende werking op verpleegkundigen omdat ze over hun eigen kunnen en handelen in relatie tot zelfmanagement moeten nadenken.

**Hoofdstuk 5** beschrijft een studie die als doel heeft te onderzoeken wat het zelfgerapporteerde zelfmanagementgedrag van verpleegkundigen is en welke factoren hierop van invloed zijn. In deze studie hanteerden we een total sample approach met een crosssectioneel design. Alle verpleegkundigen van een universiteitsziekenhuis zijn benaderd met de vraag of zij wilden participeren in het onderzoek (n=2054). De uiteindelijke respons was 16,9% (n=347). De verpleegkundigen hebben de vragenlijst Self-Efficacy and Performance in Self-management Support (SEPSS-36) ingevuld, aangevuld met vragen over houding, subjectieve normen en ervaren barrières voor zelfmanagementondersteuning. We hebben het ASE-model gebruikt om de factoren die van invloed zijn op zelfmanagementondersteuning te verklaren.

De resultaten van het onderzoek lieten zien dat een positieve houding ten aanzien van zelfmanagementondersteuning positief gerelateerd is aan het uitvoeren van ervan. De factoren die volgens de verpleegkundigen van invloed waren op hun zelfmanagementondersteuning waren het gebrek aan kennis bij de patiënt, het onvermogen van patiënten om keuzes te maken en ongemotiveerde patiënten. Deze factoren waren echter niet significant gerelateerd aan het gerapporteerde gedrag van verpleegkundigen. De aanname dat patiënten geen behoefte hebben aan zelfmanagementondersteuning was daarentegen wel gerelateerd aan het ondersteunen van zelfmanagement. Zelfeffectiviteit was significant gerelateerd aan het uitvoeren van zelfmanagementondersteuning. De verschillen tussen de scores voor zelfeffectiviteit en gedrag waren ook significant. Dit betekent dat verpleegkundigen minder zelfmanagementondersteuning geven dan verwacht op basis van de scores op zelfeffectiviteit. Gebrek aan tijd werd door verpleegkundigen gezien als de grootste barrière voor het ondersteunen van zelfmanagement. Maar de verpleegkundigen die dit als een barrière ervoeren scoorden niet lager op het in praktijk brengen van zelfmanagementondersteuning dan verpleegkundigen die deze barrière niet ervoeren. Verpleegkundigen die hun eigen kennis op het gebied van zelfmanagementondersteuning als onvoldoende ervoeren, deden volgens hun eigen rapportage minder aan zelfmanagementondersteuning. Een stapsgewijze regressieanalyse liet zien dat drie factoren van invloed zijn op het uitvoeren van zelfmanagementondersteuning door verpleegkundigen: ervaren gebrek aan eigen kennis, de veronderstelde afwezigheid van behoefte bij patiënten aan zelfmanagementondersteuning en de zelfeffectiviteit van verpleegkundigen. Er was het meest behoefte aan scholing over het Afspreken (gedeelde besluitvorming). Bij deze fase was het verschil tussen de zelfeffectiviteit en het gedrag ook het grootst. Opleiders van verpleegkundigen zouden zich bewust moeten zijn van deze factoren, die meespelen bij het uitvoeren van zelfmanagementondersteuning.

De studie in **Hoofdstuk 6** heeft als doel te beschrijven hoe het Bacheloronderwijs voor verpleegkundigen voorbereidt op zelfmanagementondersteuning in de praktijk. Dit mixed-methodsonderzoek bestond uit een screening van het curriculum, interviews en een vragenlijst voor studenten. Vier hbo-v-opleidingen hebben geparticipeerd in deze studie. De interviews (in groepen en individueel) zijn gehouden met docenten (n=30), onderwijsmanagers (n=4) en hoofddocenten en lectoren (n=4). We hebben de studiehandleidingen doorgenomen en hierbij gezocht naar leerdoelen die gerelateerd waren aan zelfmanagement. Alle studenten uit het laatste jaar van de opleidingen werden uitgenodigd om deel te nemen aan het onderzoek door de SEPSS in te vullen (n=444). Deze vragenlijst meet de zelfeffectiviteit en het gedrag ten aanzien van het ondersteunen van zelfmanagement. De uiteindelijke respons was 53.6% (n=238).

De scan van leerdoelen liet zien dat zelfmanagement vaak gerelateerd werd aan communicatieve vaardigheden, modellen van gedragsveranderingen en leefstijlaanpassingen. De meeste aandacht gaat naar de fases Achterhalen en Adviseren van het 5A-model. De minste aandacht lijkt de fase Arrangeren te krijgen. De resultaten van de vragenlijst die de studenten hadden ingevuld bevestigde dit. Uit de interviews bleek dat docenten een belangrijke rol spelen bij het aanleren van zelfmanagementvaardigheden. Waar docenten nadruk op leggen hangt vaak af van individuele voorkeuren en van hun eigen interpretatie van het begrip zelfmanagement. Studenten lopen aan tegen conflicterende waarden wanneer zij stage gaan lopen en zelfmanagementondersteuning in de praktijk willen uitvoeren. Docenten kunnen hun studenten hierin meer ondersteunen, door hen meer te laten reflecteren en door de studenten meer weerbaar te maken.

## Conclusie

Dit proefschrift levert een bijdrage aan ons inzicht in de rol van verpleegkundigen bij het ondersteunen van zelfmanagement van mensen met een chronische aandoening. Van verpleegkundigen wordt op basis van verpleegkundige theorieën, de beroepsprofielen en het gezondheidszorgbeleid verwacht dat zij patiënten ondersteunen bij hun zelfmanagement. Het ondersteunen van zelfmanagement volgens de brede visie is niet vanzelfsprekend in de huidige verpleegkundige praktijk, maar ook niet in de verpleegkundige Bacheloropleidingen. De meeste verpleegkundigen lijken te focussen op de fase van het Adviseren, op medische uitkomsten en op het 'afhebben van het werk dat gedaan moet worden'. Reflectie op de taken van de verpleegkundige is nodig, omdat veel studies in dit proefschrift laten zien dat er in de opleiding weinig aandacht is voor de fase van het Arrangeren en dat deze de laagste scores krijgt in de vragenlijst, terwijl die toch een belangrijk onderdeel van zelfmanagementondersteuning en van het verpleegkundige beroep is. Samenwerking met de patiënten, gebaseerd op partnerschap – een essentieel aspect van zelfmanagementondersteuning – lijkt in de dagelijkse praktijk moeilijk voor verpleegkundigen. De verpleegkundige opleidingen kunnen hun studenten faciliteren in het leren van deze gelijkwaardige samenwerking met patiënten door ze weerbaarder te maken en hen de waarde van ervaringskennis van patiënten in te laten zien.



# Appendices

Dankwoord PHD portfolio List of publications Curriculum vitae

# DANKWOORD

Het afronden van een promotietraject is een moment om stil te staan bij de steun die ik van veel mensen heb ontvangen. Ik heb enorm veel geleerd in de afgelopen vijf jaar en ben dankbaar voor de mogelijkheid die ik hiervoor heb gekregen.

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## PHD PORTFOLIO

Name PhD student:	Susanne van Hooft
Department:	Erasmus University Rotterdam, Institute of Health Policy and Management
PhD period:	2012-2017

PhD training		Year	Workload
	Dr. Jolanda Dwarswaard		
Supervisors:	Dr. AnneLoes van Staa		
Promotor:	Prof. dr. Roland Bal		
PhD period:	2012-2017		

		Hours
Research Skills		
Atlast.ti for qualitative data analysis, Evers Research and Training	2012	16
Foundations of Survey Research, Universiteit Utrecht (Summer Course)	2013	40
Pre-conference workshop Q-methodology, ISSS Amsterdam	2013	8
Applied multivaried analysis	2014	80
Herhalingscursus Atlas Ti, Evers Research and Training	2014	4
Intensive Course on Nursing Ethics, KU Leuven, Leuven	2016	32
Research groups		
<ul> <li>Research meetings Nursing Research into Self-Management and Empowerment in Chronic Care</li> <li>Meetings 'Promovendiclub Zelfmanagement'</li> </ul>	2012-2016	
Presentations at international conferences		
Nurse's profiles into self-management support in people with chronic conditions. Oral presentation; 29th Annual Conference of the International Society for the Scientific Study of Subjectivity (Q conference), Amsterdam	2013	
Four perspectives on self-management support by nurses for people with chronic conditions: a Q-methodological study; Sigma Teta Tau International 2nd Biannual European Conference Gothenburg, Zweden	2014	
A demand for new nurse competences: are nurses prepared for self-management support?; COHEHRE conference, Budapest Hongarije	2015	
Nurses' self-efficacy and performance, and what they see as barriers to self- management support.; EDCNS, Graz, Oostenrijk	2015	
l would and could support patient self-management, if only; STTI 3rd Biannual European Conference, Utrecht	2016	
Nurses' competencies in self-management support in chronic care: where are we now? Where do we need to go?; Care4conference, Antwerpen, België	2017	
Other		
Intervisie and coaching promovendi, Rotterdam University	2013-2014	10
Peer reviewer for international academic journals (Health Expectations, Journal of Advanced Nursing, International Journal of Nursing and Midwifery, PLOS One, Nurse Education Today)	2014-now	60

#### Teaching qualifications and activities

Training		
Didactisch coachen	2015-now	24
Lecturing		
Bachelor of Nursing (Rotterdam University)	2007 - now	800
Minor Chronische aandoeningen (Rotterdam University)	2009 - 2012	80
Minor Wijkzorg (Rotterdam University)	2016	2
Master Advanced Nursing Practice (Rotterdam University)	2015-2016	4
Supervising and appraising theses		
Bachelor of Nursing (Rotterdam University)	2008-now	800
Other		
Supervising interns and trainees	2014-now	30

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Duprez V., van Hecke A., van Hooft S.M. & van Staa A.L. (2017). Nurses' competencies in self-management support in chronic care: where are we nog? Where do we need to go?; Care4conference. Antwerpen, België. *Symposium*.

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### **CURRICULUM VITAE**

Susanne van Hooft is geboren op 15 juni 1971. Na de HAVO (1983-1988) heeft ze de hbo-v aan de Leidse Hogeschool afgerond (1988-1992). Omdat Susanne op de hbo-v al docent wilde worden heeft zij, zodra ze de verplichte twee jaar werkervaring had opgedaan, de Eerstegraads Lerarenopleiding Gezondheidzorg aan de Universiteit van Maastricht gevolgd en afgerond (1994-1995). Werkervaring als verpleegkundige heeft zij opgedaan in het Bronovo Ziekenhuis in Den Haag, op de afdeling neurologie (1992-1995) en daarna in de wijkzorg bij Zorggroep Horst- en Vlietstreek, later Florence (1995-1999). In deze laatste organisatie heeft zij verschillende functies gehad, zoals gespecialiseerd verpleegkundige en later beleidsadviseur zorg (1999-2007). Die functie omvatte het schrijven van beleidsadviezen en het leiden van zorginhoudelijke verbeterprojecten. In deze periode volgde zij de opleiding VO Zorginnovatie (HAN, 2005-2006) en schreef zij op freelance basis mee aan enkele leerboeken voor verpleegkundigen en verzorgenden voor uitgeverij ThiemeMeulenhoff.

Het duurde tot 2007 voor zij inderdaad als docent ging werken, bij Hogeschool Rotterdam. In 2009 is ze gestart aan de Erasmus Universiteit met het Schakelprogramma Beleid en Management in de Gezondheidszorg, gevolgd door de Master Health Economic, Policy, and Law (Erasmus Universiteit Rotterdam, 2009-2011). In 2012 is zij als docentonderzoeker gestart bij Kenniscentrum Zorginnovatie, bij het onderzoeksprogramma SPIL. Dit heeft zij een half jaar gedaan, tot zij in 2012 startte met het promotieonderzoek binnen het onderzoeksprogramma NURSE-CC.

