Janet Been-Dahmen

Self-Management Support:

A broader perspective on what patients need and nurses could provide

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Self-Management Support:
A broader perspective on what patients need and nurses could provide

Zelfmanagementondersteuning:
Een breder perspectief op wat patiënten nodig hebben en verpleegkundigen kunnen bieden

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TABLE OF CONTENTS

CHAPTER 1

Introduction

Introduction

Mark, a 32-year-old man diagnosed with type 1 diabetes at the age of 10, was recently also diagnosed with rheumatoid arthritis (RA). His complaints started with painful and swollen hands, in combination with fatigue. His general practitioner decided to send him to a rheumatologist when he also developed a red and painful left knee. To decrease the swelling and pain, the rheumatologist prescribed nonsteroidal anti-inflammatory drugs. Yet, improvement failed to happen.

Five years ago, Mark started to use an insulin pump for his diabetes. Since then, he is better able to control his blood sugar level. His HbA1c has decreased and is now on target. Last year he assessed his quality of life as good. However, the last few months have been a roller coaster for him. After receiving the diagnosis RA, his emotions were running high. Frustration, fear and sadness alternated. For example, frustration because he could not pursue the hobbies that normally help him to relax and cope with setbacks. Drawing paintings with small details is too difficult and painful at the moment. Even carrying out his normal work as a consultant is quite a challenge. The long working days at the office behind a computer take a lot of energy. Mark struggles with many questions concerning his current situation: e.g. "Will I ever be able to paint again?"; "What can I do to improve my physical health?"; "How to deal with the misunderstanding of others?".

How can nurses support patients like Mark in the self-management challenges of dealing with a chronic condition in daily life?

INDICENCE AND PREVALENCE OF CHRONIC CONDITIONS

The growing population of people with one or more chronic conditions is worldwide seen as one of the biggest challenges of the 21st century (World Health Organization, 2002). Chronic conditions are responsible for 68 percent of the world's deaths and therefore the leading cause of death globally (World Health Organization, 2014). Chronic conditions can be defined as irreversible disorders with no prospect of complete recovery and with a long disease duration (Hoeymans, Schellevis, Oostrom, & Gijsen, 2008). Depending on the nature and course, four types can be distinguished: 1) Life-threatening diseases such as cancer and stroke); 2) conditions that lead to periodically recurring symptoms as asthma and diabetes mellitus; 3) disorders with a progressive course and/or are disabling in nature such as rheumatoid arthritis and chronic heart failure; and 4) chronic mental disorders such as depression and psychotic disorder (Bos, Danner, Haan, & Schadé, 2000).

In the Netherlands, an estimated 8.5 million adults are living with one or more chronic conditions (Rijksinstituut voor Volksgezondheid en Milieu (RIVM), 2018). More than 90% of people aged 75 and older have at least one chronic condition. The prevalence among people younger than 40 years is around 30%. More women than men suffer from chronic conditions (Nielen & Gommer, 2014). It is expected that in 2040 the number of adults with a chronic condition will rise to 54% of the Dutch population (RIVM, 2018). Especially the percentage of patients[1] with multimorbidity will increase exponentially (RIVM, 2018). Worldwide, negative lifestyle trends (e.g. overweight), population ageing, and greater longevity of persons with many chronic conditions cause a rapid increase in the prevalence of chronic conditions (Rijksinstituut voor Volksgezondheid en Milieu (RIVM), 2014; Wagner et al., 2001). Nevertheless, early detection of chronic conditions and better treatment options ensure that the conditions are less severe and that people with a chronic condition have a longer life expectancy (RIVM, 2014, 2018).

THE CHANGING HEALTHCARE PARADIGM

Historically, hospital care was designed to address someone's acute health problems in accordance to the biomedical model of illness (Wagner et al., 2001). Professionals were seen as experts and patients had a largely passive role (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Wagner et al., 2001). Today, this model does not fit the needs of the growing population of patients struggling with the physical, psychological and social demands of living with one or more chronic conditions (Wade & Halligan, 2017; Wagner et al., 2001). Since treatment of chronic conditions is not focused on cure, a complex and continuous management is required to deal with (irreversible) changes in daily life (Holman & Lorig, 2000). The need for a shift to the biopsychosocial model of illness was already noted forty years ago (Engel, 1977; Wade & Halligan, 2017). In the biopsychosocial model, illness and health are described as an interaction between biological, psychological and social aspects. This model is seen as a potential to contribute to a more successful and sustainable health system (Wade & Halligan, 2017). It is the basis for the development of patient-centred care, which has become a main policy driver in today's healthcare and focuses more explicitly on support tailored to the patient's individual needs (Kitson, Marshall, Bassett, & Zeitz, 2013).

A NEW PATIENT ROLE

The current generation of patients no longer accepts being told what to do. Individual freedom of choice and self-determination are important values nowadays (Wilde &

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[1] In this thesis, I used the term 'patient' rather than 'person with a chronic condition' for reasons of brevity and also, because I refer her to the clinical encounter between a health care professional/ nurse and the patient in the context of the outpatient hospital care.

Garvin, 2007). Patients decide for themselves how to adjust daily life to a chronic condition (Grijpdonck, 2010). Equality and shared decision making are increasingly considered as the norm (Olthuis, Leget, & Grypdonck, 2014; Rademakers, 2016; Stiggelbout et al., 2012). Responsibilities are more shared between the patient and the nurse or other healthcare professionals (Rademakers, 2016), which is expected to improve the effectiveness and efficiency of healthcare provision (Holman & Lorig, 2000). Patients wish that not only the disease is considered very important, but also the person behind the disease (Rademakers, 2016). Nurses can support their patients in making health-related decisions (Holman & Lorig, 2000), although not all decisions of patients will be the most appropriate from a professional point of view (Grijpdonck, 2010). Such decisions could be regarded as the patient's right to not always put his chronic condition as top priority (Grijpdonck, 2013).

Nurses and other healthcare professionals expect patients to be flexible and to take an active role in the disease process in the form of self-management (Rademakers, 2016). Informed and activated patients may lead to satisfying consultation sessions and improved outcomes (Bodenheimer et al., 2002; Wagner, 1998). This active role for patients is also emphasised in the new conception of health: "*health as the ability to adapt and to self-manage*" (Huber et al., 2011 p. 237). The emphasis is placed less on state of health, but more on abilities to learn to live with health problems (Huber et al., 2011). Not only nurses and other healthcare professionals, but also researchers and governments consider self-management important to ensure the quality of the changing healthcare for patients with a chronic condition (Ursum, Rijken, Heijmans, Cardol, & Schellevis, 2011).

SELF-MANAGEMENT

Self-management is commonly used in the literature as an essential method to improve care for patients with a chronic condition. To date, no generally accepted definition exists (Jones et al. 2011; Udlis 2011). Context and perspectives greatly influence one's conceptualisation of the definition (Udlis, 2011). The concept of self-management is often reduced to compliance with a medical regimen. Professionals are seen as experts and the success of self-management interventions is measured by improvement of clinical outcomes and reduced healthcare expenditures (Udlis, 2011). However, also broader perspectives that focus on more than just the medical aspects of living with a chronic condition are in circulation (Lorig & Holman 2003, Coleman & Newton 2005, Singh 2005, Udlis 2011). From such perspective, living with a chronic condition requires ongoing adjustment to the medical, emotional and social challenges in daily life (Lorig & Holman, 2003). Outcome measures should match with these intervention contents (Sattoe et al., 2015). For example, a self-management intervention developed to improve patients' empowerment should be evaluated with measurements that focus on empowerment.

Although there are good reasons for focusing on the patient's role in dealing with the medical aspects of a chronic condition, this is only one part of the concept. In daily life, patients are challenged to find the best possible compromise between the medical requirements and the demands of daily life. From the patient perspective, self-management is adequate or successful if it improves the quality of life (Grijpdonck, 2013).

In this thesis, the holistic definition of Barlow et al (2002) is used: *'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 2001, P. 547, Barlow et al. 2002, p.178). This definition was inspired by the theory of Corbin and Strauss (1988), which proposes there are three patient-related types of work: illness-related work (dealing with medical aspects), everyday life work (dealing with a condition in daily life) and biographical work (accepting changes and giving a new meaning to life). Work in this context is defined as: *'as set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of patients and their partners'* (Corbin & Strauss, 1988). Planning and coordination is required to smoothly perform all these tasks, which is described as 'articulation work' (Corbin & Strauss, 1985). Similar to this theory of Corbin and Strauss, Schulman-Green and colleagues argue for a more holistic picture of self-management. They identified three categories of self-management processes: focusing on illness needs; activating resources such as family members and professionals, and living with a chronic illness (Schulman-Green et al., 2012).

ROLES OF THE NURSING PROFESSION IN CARING FOR PATIENTS WITH CHRONIC CONDITIONS

Self-management assumes patients' responsibility and engagement in their own care (Lawn, McMillan, & Pulvirenti, 2011). This requires certain skills to solve problems, make decisions, find and utilise resources, form partnership with healthcare professionals, and take action. Patients are also expected to be capable of 'self-tailoring': internalise information and skills to their own situation. To achieve, most patients likely will need support from healthcare professionals (Lorig & Holman, 2003). It is not clear, however, what kind of self-management support patients wish to receive.

Self-management support is now seen as an important task that is part of the basic competencies of every healthcare professional (Grijpdonck, 2010). A multidisciplinary approach is required in self-management support (Wagner et al., 2001). In practice, however, self-management support is often provided by nurses (Elissen et al., 2013). Nurses are in an excellent position to play a significant role in self-management support. They are highly trusted by their patients and trained to provide patient-centred care (Alleyne, Hancock, & Hughes, 2011; Jonsdottir, 2013). Nurses are pivotal in the division of care and are able to reconcile patients' wishes with hospital guidelines (Allen, 2004). They are therefore of added value for patients with a chronic condition (Grijpdonck, 2010).

Originally, 'caring' was seen as the core of nursing, which perception does not fit with the complex activity of nursing nowadays (Barker, Reynolds, & Ward, 1995). To date, nurses are expected to form a partnership with the patient and have insight in the impact of a chronic condition (Bodenheimer et al., 2002; Holman & Lorig, 2000). They need to be competent to lobby, advocate, educate, inform and support patients (Alleyne et al., 2011). Patients' self-management can be facilitated if nurses adopt a more supportive role instead of the traditionally caring role (RIVM, 2014). Obviously, they need to be properly equipped for this new role (Wilde & Garvin, 2007). In the Netherlands, the new professional profile of nurses stresses the importance of providing self-management support. It encourages Dutch nurses to discuss with their patients (and informal caregivers) their abilities to deal with their chronic condition in daily life (Schuurmans, Lambregts, Grotendorst, & Van Merwijk, 2012). Providing self-management support should become a basic skill of all nurses.

INTERVENTIONS TO SUPPORT PATIENTS IN SELF-MANAGEMENT

To be able to meet patients' support needs and to provide effective support, nurses need new competencies, adequate training and sufficient interventions (Alleyne et al., 2011; Elissen et al., 2013; Macdonald, Rogers, Blakeman, & Bower, 2008; Nolte & Mckee, 2008). Without sufficient training and interventions, it will be difficult to operationalise self-management support in working routines (Elissen et al., 2013). Interventions for supporting self-management should be aimed at equipping patients with competencies and skills to enable them to actively participate and take responsibility in the management of their chronic condition, with the aim to optimally function in daily life (Jonkman et al.; Trappenburg et al., 2014). This can be achieved by supporting patients in acquiring knowledge and skills about (dealing with) the symptoms and treatment, in combination with one or more of the following components: stimulating self-monitoring; promoting therapy-adherence; acquiring problem-solving or coping skills; stimulating shared decision making; encouraging lifestyle changes; acquiring skills for increasing social and mental well-being; and supporting the family (Been-Dahmen, Ista, & Van Staa, 2018; Jonkman et al.)

Many practical self-management interventions have been developed to guide nurses, such as action plans (Turnock, Walters, Walters, & Wood-Baker, 2005), educational programs (Coster & Norman, 2009; Otsu & Moriyama, 2011), tele-monitoring (Trappenburg et al., 2008), and coping interventions (Akyil & Ergüney, 2013). Several systematic reviews aimed to provide insight in the effectiveness of self-management tools and interventions with regard to patients' clinical outcomes, quality of life, self-efficacy, knowledge and compliance. Although many reviews conclude that these interventions are effective in practice, they often fail to provide solid evidence to draw conclusions and guide intervention development in daily practice (Coster & Norman, 2009). Only small effects were found, for example on health-related quality of life (Taylor et al., 2005) or clinical outcomes such as haemoglobin levels or systolic blood pressure (Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Variances in effect sizes are large due to heterogeneity in characteristics such as the target group, intensity and delivery of self-management programs (Trappenburg et al., 2013). Often it is not clear what particular components of self-management support interventions contribute to their success (Jones, Lekhak, & Kaewluang, 2014; Radhakrishnan, 2012; Wenjing, Guihua, & Shizheng, 2015).

Due to the absence of solid evidence about the efficacy of nurse-led self-management programs, it is not clear how nurses can effectively support patients to optimise their self-management.

The **main research question** in this thesis is:
"How can nurses effectively support the self-management of patients with a chronic condition in dealing with their disorder in daily life?"

In this thesis, the research question is explored in three parts: experiences and needs for self-management support; development of a self-management intervention; evaluation of self-management support interventions. Below, these parts are introduced.

Nursing Research into Self-management and Empowerment

All studies in this thesis were part of the Nursing Research into Self-management and Empowerment (NURSE-CC) research program of Rotterdam University of Applied Sciences (Research Centre Innovations in Care), the Department of Health Policy and Management of Erasmus University Rotterdam, and Erasmus Medical Centre. NURSE-CC was a five-year research program that started in 2012 and aimed to (1) enhance the effectiveness of self-management support provided by nurses to people with chronic conditions (this thesis); and (2) improves nurses' competencies and nursing education in this regard (van Hooft, 2017). The ultimate aim is excellent care provision. The projects included in this thesis were carried out within the context of the Erasmus MC departments of Rheumatology and Internal Medicine.

THIS THESIS

Thesis outline and methodological approach

PART I: Experiences with and needs for self-management support

PART I consists of three chapters exploring experiences and needs for self-management support. It is not clear how self-management support is currently provided by nurses and what kind of support patients with a chronic condition wish to receive. Therefore, the aim of the studies of PART 1 is to explore patients' and nurses' experiences with and needs for self-management support.

The qualitative study in Chapter 2 unravels nurses' views on the role of people with chronic conditions in self-management, nurses' own support role, and establishes how these views related to nurse-led self-management interventions. In Chapter 3, support needs to self-manage a rheumatic disorder are identified using a qualitative design. The interview study in Chapter 4 provides insight into the self-management challenges and support needs among kidney transplant recipients.

PART II: Development of a self-management intervention

PART II provides an overview of the working mechanisms and the development of a nurse-led self-management intervention. Until now, working mechanisms of self-management interventions have not been identified. Insights into nurses' and patients' needs (PART I) as well as into such working mechanisms are necessary to develop a nurse-led self-management intervention in a structured way, which is the aim of the studies of PART II.

The realist review in Chapter 5 provides understanding of how nurse-led interventions that support self-management of outpatient with chronic conditions work, and in what context they work successfully. Working mechanisms were unravelled. Chapter 6 describes the development process of a nurse-led self-management intervention using the Intervention Mapping Approach (Bartholomew, Parcel, & Kok, 1998). This generic intervention was tailored to the specific needs of kidney transplant recipients and called ZENN intervention, an acronym derived from the Dutch name (*ZElfmanagement Na Niertransplantatie*), which translates as Self-Management After Kidney Transplantation.

PART III: Evaluation of self-management support interventions

PART III contains two chapters that address the evaluation of two nurse-led self-management support interventions. The reported studies provide insight into the usefulness and feasibility of nurse-led self-management interventions for outpatients with different chronic conditions.

In Chapter 7, the effects of a smartphone-application in patients with a rheumatic disease were evaluated. Chapter 8 discusses the feasibility and first effects of a nurse-led intervention (ZENN) in outpatients after a kidney transplantation in a mixed-methods evaluation project.

The thesis ends with a discussion of the results in Chapter 9. This chapter also includes practice implications and recommendations for further research.

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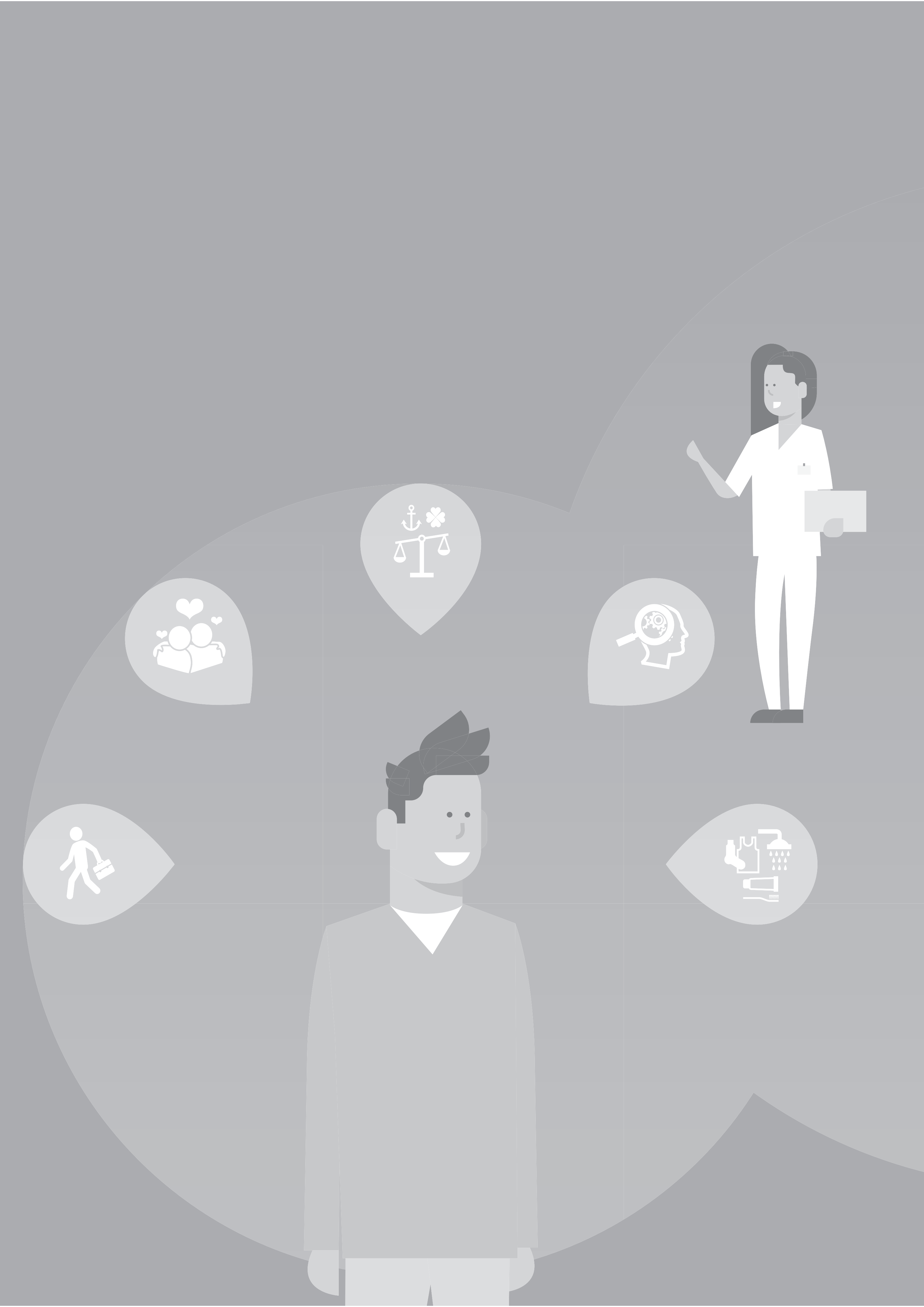

PART I

Experiences with and needs for self-management support

CHAPTER 2

Nurses' views on patient self-management: a qualitative study

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ABSTRACT

Aims

To unravel outpatient nurses' views on the role of people with chronic conditions in self-management, nurses' own support role, and to establish how these views relate to nurse-led self-management interventions.

Background

Providing self-management support is a core task of nurses in outpatient chronic care. However, the concept of self-management is interpreted in different ways and little is known about nurses' views on patients' role in self-management and nurses' own support role.

Design

Qualitative design.

Methods

Individual semi-structured interviews were held in 2012-2013 with outpatient nurses at a university medical hospital in the Netherlands. After transcription, data-driven codes were assigned and key elements of views and experiences were discussed within the research team. Finally, insights were merged to construct and characterise types.

Results

Twenty-seven nurses were interviewed. The analysis identified three divergent views on self-management support: adhering to a medical regimen; monitoring symptoms; and integrating illness into daily life. These views differ with respect to the patient's role in self-management, the support role of the nurse and the focus of activities, ranging from biomedical to biopsychosocial. The first two were mainly medically oriented. Nurses applied interventions consistent with their individual views on self-management.

Conclusion

Nurses had distinct perceptions about self-management and their own role in self-management support. Social and emotional tasks of living with a chronic condition were, however, overlooked. Nurses seem to lack sufficient training and practical interventions to provide self-management support that meets the integral needs of patients with a chronic condition.

Why is this research needed?

- Self-management support is a core element of outpatient nursing care for patients with a chronic condition.
- Although dissimilar concepts of self-management are provided in literature, views of outpatient nurses on patients' core tasks in self-management have not been extensively studied yet.

What are the key findings?

- Nurses' focus in providing self-management support is usually medically oriented and tends to overlook psychosocial challenges patients face in chronic illness.
- Nurses apply interventions that are consistent with their ideas about patients' self-management tasks and the patient and nurse's role in self-management and self-management support.
- Nurses tend to apply interventions that do not activate patients.

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

- Outpatient nurses' should be encouraged to employ a holistic view on patients' needs in providing self-management support.
- Research should focus on testing nurse-led self-management interventions to determine which approaches are feasible and effective.
- Training and co-creation could give nurses insight into their personal views on self-management. Clinical nursing leaders and expert patients could play an important role in challenging nurses' attitudes.

INTRODUCTION

Hospital care was historically designed to address acute health problems according to the biomedical model. This model does not correspond, however, with the needs of the growing population of patients struggling with the physical, psychological and social demands of living with a chronic condition (Wagner et al. 2001). A shift from an acute care model to a chronic care model is needed to close the gap between supply and demand of these health services (Alt & Schatell 2008, Holman & Lorig 2000, WHO 2002). Through its biopsychosocial focus, the chronic care model recognises the importance of the social context and the complementary system devised by society (Engel 1977). Self-management is seen as a critical component to achieve the shift to a chronic care model (Barlow et al. 2002). However, little is known about nurses' views on providing self-management support (SMS) to people with chronic conditions.

Background

Although the term self-management is commonly used in the literature, no generally accepted definition exists (Jones et al. 2011, Udlis 2011). It is often reduced to compliance with a medical regimen (Udlis 2011). However, broader perspectives that focus on more than just the medical aspects of living with a chronic condition are in circulation (Coleman & Newton 2005, Lorig & Holman 2003, Singh 2005, Udlis 2011). In this study, the broad definition of Barlow et al. was adopted: *'the ability to manage one or more chronic conditions (e.g. symptoms, treatment, physical and psychosocial consequences, and lifestyle changes) and to integrate them in day-to-day life with the aim of achieving optimal quality of life'* (Barlow 2001, p. 547, Barlow et al. 2002, p. 178). This definition was inspired by the theory of Corbin and Strauss (1988), which proposes there are three patient-related types of 'work' involved in living with a chronic condition: illness-related work, everyday life work and biographical work. Work in this context is defined as *'a set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of patients and their partners'*(Corbin & Strauss 1988, p. 9).

Given the demands self-management places on people with chronic conditions, they will need support from healthcare professionals (Lorig & Holman, 2003). A qualitative study among healthcare professionals in 13 European countries and a review report including 172 studies showed that this is often provided by nurses (Elissen et al. 2013, Singh 2005). Many practical self-management interventions have been developed to guide nurses in the shift to chronic care, such as motivational interviewing techniques (Efraimsson et al. 2012), action plans (Turnock et al. 2005), educational programs (Otsu & Moriyama 2011, Coster & Norman, 2009), telemonitoring (Trappenburg et al. 2008), and coping interventions (Akyil & Ergüney 2013). Several systematic reviews aimed to gain insight in the effectiveness of self-management tools and interventions (Monninkhof et al. 2003, Warsi et al. 2004, Taylor et al. 2005). However, these systematic reviews often fail to provide solid evidence to draw conclusions and guide intervention development in daily practice (Coster & Norman 2009). Despite the availability of self-management tools, nurses and other healthcare professionals have difficulty in operationalizing SMS in daily work routines (Elissen et al. 2013). The chronic care model expects nurses to form a partnership with their patients (Bodenheimer et al. 2002, Holman & Lorig 2000). However, it is not unusual for nurses to be troubled by expert patients, as nurses themselves are accustomed to play the expert role (Thorne et al. 2000, Wilson et al. 2006). Attitudes such as these could affect successful implementation of interventions and other changes in daily healthcare practices (Grol & Grimshaw 2003). The views of outpatient nurses on roles in self-management have not been extensively studied. Understanding of these views can provide input for improvement of the current nurse-led self-management support in outpatient clinics of hospitals.

THE STUDY

Aim

This study aims to unravel outpatient nurses' views on the role of people with chronic conditions in self-management, nurses' own support role, and to establish how their views relate to self-management interventions applied by nurses.

Design

To gather in-depth information, we applied a qualitative design using semi-structured interviews with nurses working with outpatients. This study was designed as the first step of an intervention mapping process (Bartholomew et al. 1998) that should lead to a tailored SMS program for outpatients with various chronic conditions.

Sample and participants

Because staff composition and working methods of the different study settings – outpatient clinics of the Erasmus MC University Medical Center Rotterdam in the Netherlands – varied considerably, purposeful sampling was used to achieve maximum variation. The main criteria for sampling were gender, age, work experience, type of chronic condition, occupational level and educational level. Nurses were invited if they (1) held consultations with outpatients with a chronic condition and (2) were a registered nurse (RN) (Bachelor of nursing) or a nurse practitioner (NP) (Master degree). Nurses with less than one year experience in the outpatient setting were excluded. Thirty-three nurses were invited to participate.

Data collection

Individual semi-structured interviews were conducted between October 2012 and January 2013. All data was collected by trained healthcare researchers (JB, JD, or other members of the research group) who did not work at an outpatient clinic and held expertise in self-management. An interview between a nurse and a researcher lasted about one hour and was held in a private location at nurse's work site. Sometimes also a student was present. The interview questions had been formulated on the basis of the findings from an extensive literature review (Table 1). All interviews started with the same question: "Could you tell us something about your experience in working with outpatients with a chronic condition?". The order in which the questions were introduced depended on the nurse's responses. They were encouraged to give examples, details and circumstances about their work. Demographic data were collected as well during the interview. The interviews were audio-recorded and transcribed ad verbatim.

Table 1. Interview Questions.

Start question
Could you tell us something about your experience in working with outpatients with a chronic condition?

Open questions
In your opinion, what is self-management?
How do you help outpatients to manage their chronic condition in everyday life?
What type of activities (interventions) do you use for self-management support?
What kind of activities (interventions) work well? And which do not?
Which tasks do your outpatients have in managing their chronic condition?
When does supporting outpatients in managing their chronic condition in everyday life wok well?
What are difficulties in supporting outpatients in managing their chronic condition in everyday life (what type of patient)?
What competencies, attitudes, and skills does a nurse need to support the self-management of outpatients with a chronic condition?

Ethical considerations

A standardised invitation was sent by email to thirty-three nurses. If they did not respond within two weeks, they were contacted by telephone by the first author (JB). All respondents were informed about the study both orally and in writing, and were assured of complete confidentiality. The respondents gave oral consent. Under Dutch law, no ethical approval is needed for research among professionals. The study protocol was reviewed and approved by a committee of the University's Doctoral Research Board, in compliance with the Dutch ethical research regulations.

Data analysis

Data collection and analysis was an iterative and reflexive process (Polit & Beck 2008). Transcripts were read in order to capture an overall impression. Codes were data-driven and assigned to meaningful lines or fragments (inductive analysis) (Creswell 2007). Subsequently, overlapping codes were merged. Themes considered included: 'definition of self-management', 'self-management support interventions', 'conditions for self-management (support)'. Some subthemes were: 'self-management equals adherence' and 'self-management equals monitoring physical changes'. Subthemes under 'self-management support interventions' listed: 'providing motivational interviewing' and 'initializing group consultations'. Afterwards, a typology construction was carried out. A typology is the result of a grouping process in which each type can be defined as a combination of attributes (Kluge 2000). First, key points of each interview were summarised to an A4 sheet and discussed by the members of the research group. During this process relevant attributes were elaborated for the analysis: the definition of self-management; the perception about the patient's role in self-management; the perception about the support role of the nurse; and applied interventions. Cases were subsequently grouped by means of these attributes and types were constructed. Lastly, all of the analysis' insights were merged to characterise the constructed views. Quotes presented in the results section serve to clarify these views. In coding quotes, education level of the nurse in question (RN or NP) was combined with a random number. The qualitative analysis package Atlas.ti 6.2 was used for analysis.

Strategies to establish rigor

Credibility was established by researcher triangulation and member checks. Participants received a summary of the main themes discussed during the interview to enable them to affirm the interpretation of the researchers (Lincoln & Guba 1985). After ten interviews the member check stopped, because no additional information was obtained. Researcher triangulation was achieved because the data were collected and analyzed in a team-based fashion. The first author (JB) analyzed all data in detail. The second author (JD) analyzed the first fourteen interviews also. JB and JD discussed the results of their coding to reach agreement. The first author coded the remaining interviews in the same way. To increase the dependability, the design, methods, summaries, analyses and results were all discussed within the research team. Details of the participants and settings are described below, allowing readers to conclude on the degree of transferability. The description of the methods also contributes to the conformability of the study.

FINDINGS

Twenty-seven out of 33 invited outpatient nurses participated (response rate 81.8%). Two nurses did not respond to repeated email or telephone messages and four others declined participation because of an excessive workload or provided no explanation.

Twenty-four out of these 27 nurses (88.9%) were female, which proportion reflects the gender distribution in Dutch hospital care. Their median age was 42 years (ranging from 29 to 56); eight participants (29.6%) were over 50 years old. Seventeen participants (63.0%) held a Master's degree in advanced nursing. The frequency and duration of their consultations differed. NPs had more responsibilities than RNs: NPs also diagnosed health problems, ordered treatments and prescribed medications by protocol and under supervision of a physician.

Sample demographic and clinical characteristics are shown in Table 2. The desired maximum variation was achieved with this sample.

Divergent nursing views on self-management

The analysis showed that nurses had divergent perceptions about self-management. Even if they initially used the same keywords, they could attach different meanings. For example, although they all considered 'patient choice' as an important element of self-management, they aimed for different choices. Some nurses referred to:

Making choices about the treatment process. (NP7)

The options they provided were limited to biomedical decisions, such as a choice between oral and liquid medication. Others argued from a broader perspective. For them it was important that patients:

Determine what fits with their personal life. (RN4)

They need to:

Make a choice about the life they want. (NP13)

This could also imply that a patient's choice did not contribute to health status improvement. For example, a patient might decide to quit treatment because of perceived side effects that hinder daily life and outweigh treatment benefits. The nurses evaluated such choices in different ways.

Nurse perceptions of self-management ranged from a biomedical focus to a wider biopsychosocial perspective. Differences in perceptions also concerned the contributions of the patient and the nurse's role. Some nurses mentioned a major support role for themselves, while others stressed the importance of an active role for patients. Based on these two issues, three views on the patient's role in self-management, and subsequently nurses' own goals in supporting patients, were identified: 1) Adhering to a medical regimen; 2) Monitoring symptoms; and 3) Integrating illness into daily life. Each view represents a dominant definition of self-management and attributes other roles to patient and nurse. Consequently, nurses also applied different interventions. Table 3 provides an overview of the specific characteristics of these views, and Figure 1 provides

Table 2. Demographic and clinical characteristics

	Total N (%)
Gender	
Male	3 (11.1)
Female	24 (88.9)
Education level	
Registered Nurse	10 (37.0)
Nurse Practitioner	17 (63.0)
Age	
20 – 29 years	1 (3.7)
30 – 39 years	11 (40.8)
40 – 49 years	7 (25.9)
> 50 years	8 (29.6)
Years working in current job	
< 5 years	12 (44.4)
5-10 years	10 (37.1)
> 10 years	5 (18.5)
Chronic conditions	
Internal medicine	
- Cardiac diseases (e.g. heart failure, familial hypercholesterolemia)	3
- Endocrine diseases (e.g. diabetes, pituitary disease)	2
- Hematologic diseases (e.g. sickle cell disease and haemophilia)	3
- Infectious diseases (e.g. human immunodeficiency virus (HIV))	1
- Pulmonology (cystic fibrosis)	1
- Rheumatic diseases (e.g. rheumatoid arthritis and ankylosing spondylitis)	2
- Transplantation medicine (Kidney and liver transplantation)	2
Neurology	
- Amyotrophic lateral sclerosis and progressive muscular atrophy	1
- Cerebrovascular accident	1
Oncology	
- Head and neck cancer	1
- Colorectal carcinoma	1
- Radiotherapy	1
- Experimental cancer treatments	1
- Testicular cancer	1
Paediatrics	
- Birth defects (cleft and lip palate)	1
- Infectious diseases (e.g. human immunodeficiency virus (HIV))	1
- Neurological disorders (e.g. behavioural problems and epilepsy)	2
- Pulmonology (e.g. asthma and home ventilation)	2

Table 3. Specific characteristics of the views of what self-management entails

	1) Adhering to a medical regimen (n=12)	2) Monitoring symptoms (n=10)	3) Integrating illness into daily life (n=5)
Definition self-management support	• The ability of the patient to live as healthy as possible • Biomedical model	• Monitoring medical symptoms and being able to take action if things are not going well • Biomedical model	• Coping with a chronic condition in daily life • Biopsychosocial model
Nurses perception of the patient's and nurse's role	• Patients should adhere to prescribed health regimens • Nurses should provide information about the health regimen which is expected to cause behaviour change	• Patients should have an active role so as to be better able to manage their condition • Nurses should provide education to equip patients to be able to monitor their symptoms	• Patients are the prime agent in determining how life can be adjusted to a chronic condition • Nurses should provide holistic support and help patients' to adapt to their chronic condition
Interventions applied by nurses to support self-management	• Objectifying current health status through screening instruments • Providing protocolled information and instruction about the medical regimens • Convincing patients to adhere by using motivational interviewing • Training medical and technical skills • Distributing tools for medication adherence • Supervising the medication administration • Organizing educational meetings for family members	• Objectifying current health status by asking questions • Providing protocolled information about identifying health problems and performing correct actions • Teaching early signal and act skills • Distributing (digital or paper-based) diaries to help patients get insight in their health status	• Observation through listening and informing about any kind of problems in daily life • Supporting by discussing problems individually • Discussing problems in group consultations • Providing tailored information about experienced problems/ gaps of knowledge

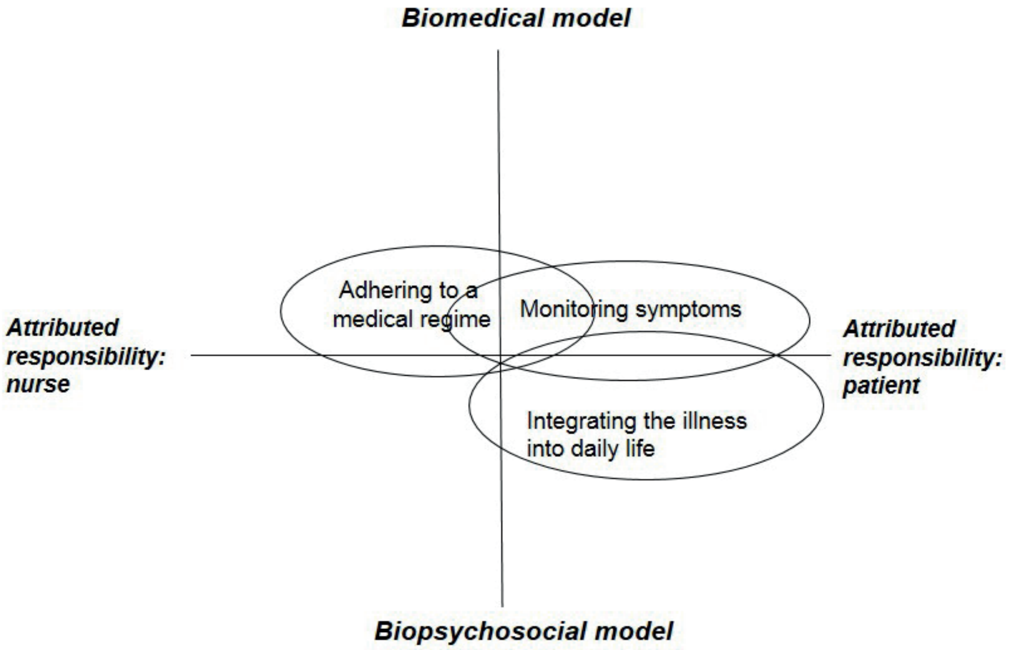

Figure 1. Focusses of the three dominant views

a graphical representation. The vertical axis ranges from a focus on the disease to a focus on daily life. The horizontal axis ranges from a leading role of the nurse to a leading role of the patient.

1. Adhering to a medical regimen

Definition of self-management

Nurses holding this view interpreted self-management as the ability of the patient to live as healthily as possible. These nurses mainly argued from a biomedical perspective. Patients were seen as good self-managers if they adhered to the treatment and lifestyle rules. Self-management was defined as:

> *Self-management means for example that patients are well able to nebulise the prescribed liquid medication and to accurately clean the equipment. (RN1)*

As a patient, you should be able:

> *To cope well and integrate prescribed health regimens into daily life. (NP10)*

Noteworthily, many oncology nurses held this view.

Perceptions about the patient's and the nurse's role

Nurses holding this view had different opinions about the division of tasks. A common opinion was that nurses needed to provide information about health regimens, in the expectation of triggering behavioural change, and that patients should adhere to these prescribed regimens:

> *I have made treatment schedules that show what patients have to do every day[…]. These schedules, in combination with my explanation, create self-management. (NP7)*

However, some nurses considered being adherent as the prime responsibility of the patient. Their task was to only facilitate information and skills needed for good adherence:

> *We explain the regimen to our patients, but finally they must decide if they want to follow it. (RN3)*

It was mentioned that patients:

> *Only succeed if they are intrinsically motivated. (RN2)*

Other nurses emphasised a bigger responsibility for nurses with regard to patient adherence:

> *As a nurse, I have a guiding role. The easier I make it, the more willing they are to adhere. (RN1)*

For most nurses, it was difficult and sometimes frustrating when patients did not perform these tasks well and made unhealthy choices:

> *Every now and then I think: 'Why am I doing this?' Sometimes it is just not possible to activate patients. (RN2)*

Nursing interventions to support patients

Nurses who held this view considered it very important to start their consultation with an objectification of the patient's current health situation:

> *I always start with taking a history, so it will be clear what's going on and if there are any problems. (NP12)*

To detect these disease-related problems, they often used screening methods such as measuring pain with a Visual Analogue Scale. These results objectified the patient's medical situation, indicated whether changes in the medical regimen would be necessary, and ultimately guided the choice of subsequent interventions. If they detected emotional problems with standard screening instruments (such as the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983), the patient was referred to a specialist, for example a psychologist.

Nurses often focused on providing information and instruction about the medical regimen in order to:

> *Encourage and motivate [patients] to take their medication. (RN5)*

Motivational interviewing techniques were used to convince patients to adhere to and to continue treatment. Nonetheless, education was considered the most important prerequisite of adequate self-management. Hence, the main role of the nurse is:

> *To provide education to patients. (NP4)*

Information provision was usually protocolled, e.g. by using a PowerPoint presentation outlining all information considered to be important:

> *We have a number of fixed items that are addressed in the PowerPoint presentation. (RN3)*

Besides, nurses taught medical and technical skills:

> *When patients have a stoma, I teach them how to deal with this in specific situations. (NP12)*

Mostly this was taught in an incremental way:

> *The first time I will explain the subcutaneous puncture step by step. […] The second time, we will do it together. The third time, I try to let them do some steps by themselves. And the fourth time they take a sort of exam. (NP2)*

To support medication adherence, nurses used tools, such as pre-packaged medicaments or text messages as reminders, which make medical and health-related tasks easier for the patient:

> *I think that's one of the prerequisites of SMS. When tasks are difficult, patients' self-management will be poorer. Patients will do their tasks when they're easy to perform. (RN1)*

Some nurses supervised the medication administration more directly:

> *I let them come more often. [..] If we do it [medication administration] together I can see where problems arise. (NP2)*

Some nurses also directed their support towards family members by organizing family meetings. These meetings were solely focused on providing information about the medical regimen. These nurses reasoned that self-management is more difficult when a patients' network is not well informed about the chronic condition and its consequences:

The people around the patient create so many challenges for them, [by saying things like] *'some cake every now and then doesn't do any harm. (RN2)*

Knowledge is an important prerequisite to family members: *'To be able to support their partner or child in managing the chronic disease'. (NP4)*

2. Monitoring symptoms

Definition of self-management

In this view, nurses specified self-management as monitoring medical symptoms. Self-management is:

> *Patients' ability to monitor that things aren't going well today, or to notice weight gain or shortage of breath. (NP1)*

As a patient you must be able to take action in these kinds of situations, e.g. by calling the hospital for assistance:

> *[..] that patients are aware of the symptoms. [..] If they think it is not okay, they call me. That is self-management. (NP6)*

These nurses placed their symptom monitoring in a biomedical perspective. This view was held by nurses from a diverse range of hospital departments and patient populations.

Perceptions about the patient's and the nurse's role

Opinions on this issue differ from that expressed by nurses holding the 'adhering to a medical regimen' view in the acknowledgement of an active patient role:

> *I expect them to think for themselves and to not be reckless. (NP5)*

The nurses believed that taking the lead will help patients manage their condition well:

> *It's easier for patients to live with their disease when they are less dependent on us. (RN6)*

Despite the importance of the patient's personal responsibility, nurses emphasised there is a limit to this agency. Nurses needed:

> *To be aware of the danger that patients do not receive enough care. (RN6)*

They described that patients can be good self-managers, but nurses need to:

> *Help them if necessary. (NP5)*

Nursing interventions to support patients

Being well informed was seen as a conditional component of self-monitoring the medical aspects of a chronic condition:

> *I got back to information. Be careful with infections. If people know the ins and outs of their condition it is easier for them to self-manage. (RN6)*

Nurses taught patients how to identify health problems and to act if necessary, e.g. by contacting the nurse, taking additional medication or taking rest. Nurses usually transferred knowledge in a protocolled way:

> *We trained him by means of this information book. (NP6)*

Serious problems and consequences needed to be prevented with training in early signaling:

> *Gradually, I just see patients deteriorate. Their ankles are increasingly swollen or they are getting short of breath. When this happens, I wonder why they did not call me earlier. [..] If they had reported this earlier, all I had to do was adjusting medication for three days. (NP1)*

In order to create awareness of predictive signs several nurses asked the patient to keep a diary (digital or paper-based). To check how a patient managed the disease, nurses often asked about this:

> *I will always tell them what they can do [when the disease is deteriorating]. Later on, I ask how things are going. (NP7)*

If it turned out that patients were not properly monitoring symptoms, nurses tended to use motivational interviewing techniques to convince patients of its necessity. These nurses rarely asked about emotional problems. If patients wished to discuss emotional issues, they were usually referred to a specialised professional.

In addition to protocolled knowledge transfer, nurses held group meetings or information sessions to educate relatives as well, so they would be able to help the patient monitor the disease:

> *One also would like to explain the disease to [patients'] relatives. (NP1)*

3. Integrating the illness into daily life

<u>Definition of self-management</u>

Nurses holding this view defined self-management as:

> *Coping with a chronic condition in daily life. (NP17)*

These nurses did not argue from a biomedical perspective but rather endorsed to the biopsychosocial model. Adapting life to a chronic condition was seen as a crucial part of self-management. For example:

> *People saying they are going to work less. They adapt their daily activities to the disease. (RN3)*

Acceptance was seen as the most important prerequisite to adaptation. Similar to the nurses holding the previous view, this group of nurses also worked in a diverse range of hospital departments and supported patients with different chronic conditions.

Perceptions about the patient's and the nurse's role

Nurses holding this view highly valued patients' agency in daily life. Only patients themselves know how to adjust to the chronic condition:

> *Ultimately they [patients] need to adapt their daily activities to the disease. (NP3)*

These nurses were of the opinion that a supportive role was needed to encourage adaptation:

> *Through coaching a nurse can help. (RN4)*

However, patients still need to take the lead.

Nursing interventions to support patients

Support was, in addition to managing medical aspects, more focussed on aspects of daily living with a chronic condition. According to these nurses, support could be provided by observing and exploring in an open way:

> *Whether there are other kinds of problems. (RN3)*

These problems might be related to social life, relations or work. In the other views, nurses paid very little attention to these kinds of problems. These nurses listened to and talked with their patients about such problems. For example, how to achieve that treatment is as bearable as possible in daily life taking into account work, school and other activities. One of the nurses used the theory of presence (Baart, 2012):

> *[My task is] mainly to be present. By remaining dedicated to your patients and taking walks with them. (RN4)*

Some talked individually with their patients and others used group consultations in which:

> *Patients can become aware that they are not the only ones with this disease. Many of the patients feel alone'. (NP8)*

If serious emotional problems (e.g. depression or anxiety) were apparent, the patient was referred to a psychologist or other specialist. Besides, these nurses also educated their patients about the chronic condition; not strictly protocolled but more tailored to patients' needs. For example, one nurse tried to anticipate patients' needs by administering a questionnaire aimed to identify knowledge gaps:

> *This questionnaire has simple questions, such as 'how much do you know about your disease, and the treatment', and 'do you use the prescribed treatment'? When a patient scores poorly I customise my education to the knowledge gaps. (NP17)*

DISCUSSION

This study pointed out three divergent views of outpatient nurses on what self-management for a chronic patient entails: 'adhering to a medical regimen'; 'monitoring symptoms'; and 'integrating illness into daily life'. Nurses' perceptions about the definition of self-management ranged from a biomedical focus to a biopsychosocial focus. The views 'adhering to a medical regimen' and 'monitoring symptoms' were mainly focused on the biomedical aspects of self-management. Patients' agency was limited according to the nurses adhering to the biomedical model, while these nurses themselves assumed a higher level of responsibility. Those stressing that 'integrating illness into daily life' is a core adaptive task for patients also take into account the social and emotional elements of self-management. Nurses who held this view attached more importance to the agency of patients, in the line with the definition of self-management adopted in this study (Barlow 2001, Barlow et al. 2002). Nurses with a distinct view on self-management applied different self-management interventions.

The finding that nurses' views on SMS are divergent is consistent with the current debate in literature (Jones et al. 2011, Udlis 2011, van Hooft et al. 2015). It is encouraging to see that we did not find a view fitting the lower left quadrant of Figure 1. While some nurses gave support to patients who difficulty managing daily life, they did not fully take over a patient's own responsibility for this.

Supporting psychosocial health problems is an indispensable part of nurses' competency framework (ter Maten-Speksnijder et al. 2015). Still, many nurses in the present study considered medical management as the core element of SMS. Their interventions aimed to support patients' medical tasks, such as teaching them how to inject medication subcutaneously. These nurses offered little support to patients' challenges in daily life, or to emotional problems. This lack of psychosocial support was also shown by Kennedy et al. (2014). From a patient perspective, it would be desirable that nurses expand their (conceptions of) SMS. People with chronic conditions have not only to deal with illness-related adaptive tasks, but also with so-called everyday life work and biographical work (Corbin & Strauss 1988) for which they must achieve a new equilibrium (Moos & Holahan 2007). This argues for a more holistic view on supporting patients' core tasks in self-management.

Partnership between nurses and patients is an important prerequisite to successful SMS (Bodenheimer et al. 2002, Holman & Lorig 2000). Nurses in our study held different opinions about the role division between the partners. Some nurses acknowledged patients as the experts in their own lives and aimed to support patients by using their professional expertise. However, most nurses played the traditional role of the expert who will tell the patient what to do. Patients are passive in this situation (Bodenheimer et al. 2002, Holman & Lorig, 2000). It seems difficult to achieve a collaborative partnership (Thorne et al. 2000, Wilson et al. 2006, ter Maten-Speksnijder et al., 2015).

The lack of a holistic view on self-management and the difficulties in achieving partnership also became apparent in the limited repertoire of nursing interventions. Nurses mostly used some way of traditional (standardised) patient education. It is known that educational programmes have benefits for patients. However, merely conveying information will not lead to behavioural change and is insufficient to improve patients' self-management skills (Coster & Norman 2009). SMS should include interventions that improve patients' problem-solving skills, increase self-efficacy, and support application of knowledge in real-life situations (Coleman & Newton 2005). Nurses' repertoire now mainly consists of interventions with a passive role for patients (Novak et al. 2013). It would seem better to apply interventions such as action plans and programs designed to activate patients by improving problem-solving skills (Zoffmann & Kirkevold 2012, Zoffmann & Lauritzen, 2006, Handley et al. 2006).

A possible explanation for the nurses' limited repertoire is the idea that there is nothing new to self-management and that there is no reason to change current healthcare provision (Kennedy et al. 2014, de Veer & Francke 2013). Adequate training of nurses in principles of behavioural change and in developing interventions, in co-creation with patients, could give nurses the resources to effectively support patients' self-management (Macdonald et al. 2008, The Health Foundation 2011). Without sufficient tools and training it will be difficult to operationalise SMS in working routines (Elissen et al. 2013). On the other hand, nurses should keep in mind that not everyone with a chronic illness desires or is able to be engaged in self-management (Novak et al. 2013). Preferences, personal context, and self-management abilities can vary according to patients' illness and life course (Dwarswaard et al. 2015, Paterson et al. 2001). SMS should therefore be tailored to the appropriate context, patients' needs and preferences (Trappenburg et al. 2013).

We had expected to find a relationship between nurses' views on self-management and their educational level. NPs are expected to operate at higher levels, both in the nursing domain and in the physician domain (ter Maten-Speksnijder et al. 2014). Their tasks and responsibilities go beyond direct patient care, as these include nurse management, nursing research, and nursing education (Bryant-Lukosius et al. 2004). However, we could not detect such a relationship. We also expected to find a relationship between nurses' views and the specific characteristics of a chronic condition. For if daily medical management is needed, such as in diabetes or end stage renal disease, the main focus is likely to be on the medical aspects, whereas for patients with rheumatic disorders coping with pain and disabilities in daily life can be expected to be more important. However, we could only detect a link between oncological diseases and the 'adhering to a medical regimen' view. All oncology nurses argued from this view. This might be explained by the fact that cancer is often still considered an acute healthcare problem. However, survivorship and new technologies increase the importance of long-term cancer care (IKNL 2014, VIKC 2010). This new recovery perspective is likely to influence oncology nurses' view on self-management in the future. The fact that we were not able to detect further connections between views and disease characteristics could suggest that nurses' personal characteristics have more impact on the view on self-management. Attributing responsibility to the patient and establishing partnership might be more difficult for nurses who are inclined to keep everything under control. However, a qualitative design is not suited to detect such correlations. Further quantitative research is needed to determine what kind of factors affect nurses' views on self-management.

Limitations of the study

A limitation of the study is that all data was collected in one country and a university hospital setting only. Therefore, data may not be representative of nurses working in non-academic hospitals, the community, or in other settings. Also, similar studies need to be conducted in other cultures in order to unravel nurses' views on patients' core tasks in self-management. In addition, due to the qualitative nature of the study, we cannot say anything about the influence of nurses' views on patient outcomes. For this purpose, further quantitative research is needed.

The results of this study are based on nurses' self-reported ideas and activities. The relationship between nurses' views and the SMS interventions they apply has not been studied before. Observations of nurse-led consultations could increase the validity of the results (Creswell 2007), as this could reveal interventions and activities that nurses unconsciously apply.

CONCLUSION

Nurses had distinct perceptions about self-management and their role in self-management support. Three different views were identified: 'adhering to a medical regimen'; 'monitoring symptoms'; and 'integrating illness into daily life'. Each view differs with respect to the definition of self-management and the role division between the patient and the nurse. The first two views attach great importance to the management of the medical aspects. This is a characteristic of the traditional acute care model with its focus on compliance with the medical regimen. This model does not fit with the psychological and social support needs of patients with a chronic condition. Nurses are recommended to provide self-management support in conformity with the biopsychosocial model. Furthermore, the nurses in this study seemed to mostly use traditional interventions, and were not inclined to use interventions that activate patients. Sufficient tools and additional training can help nurses operationalise self-management support in their daily working routines.

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CHAPTER 3

What support is needed to self-manage a rheumatic disorder: a qualitative study

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ABSTRACT

Background

Today, patients are expected to take an active role in the form of self-management. Given the burden of a rheumatic disorder, the patients cannot be expected to self-manage on their own. In order to develop self-management interventions that fit patients' needs and preferences, it is essential to examine patients' perspective on how support can be optimised. This study aimed to identify support needs of outpatients with rheumatic disorders and preferences for who should provide self-management support.

Methods

A qualitative study was conducted using focus groups and individual interviews with outpatients with rheumatic disorders treated in a Dutch university hospital. Interview data was analysed with Directed Content Analysis and coded with predetermined codes derived from our model about support needs of chronically ill patients. This model distinguished three types of support: instrumental, psychosocial and relational support.

Results

Fourteen patients participated in two focus group interviews and six were interviewed individually. Most patients preferred an active role in self-management. Nonetheless, they notably needed support in developing skills for self-managing their rheumatic disorder in daily life. The extent of support needs was influenced by disease stage, presence of symptoms and changes in one's situation. A trusted relationship and partnership were conditional for receiving any kind of professional support. Patients wanted to be seen as experienced experts of living with a rheumatic disorder. Acquiring specific disease-related knowledge, learning how to deal with symptoms and fluctuations, talking about emotional aspects, and discussing daily life issues and disease-related information were identified as important elements of self-management support. It was considered crucial that support be tailored to individual needs and expertise. Professionals and relatives were preferred as support givers. Few patients desired support from fellow patients.

Conclusion

Self-management was primarily seen as patient's own task. Above all, patients wanted to be seen as the experienced experts. Professionals' self-management support should be focused on coaching patients in developing problem-solving skills, for which practical tools and training are needed.

Background

Having a rheumatic disorder requires ongoing psychosocial adjustment and behavioral change to deal with fluctuations, pain, restricted mobility and fatigue in daily life (Dures et al., 2014; Homer, 2005). It may also affect one's mood, self-esteem, role, relationships, and control perceptions (S. Ryan, 1996). Today, patients are expected to take an active role (Anderson & Funnell, 2005; Wagner et al., 2001) in the form of self-management, defined as "managing one or more chronic conditions (e.g. symptoms, treatment, physical and psychosocial consequences, and lifestyle changes) and integrate them in day-to-day life with the aim of achieving optimal quality of life" (Barlow, 2001: p.547; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002: p.178). Given the burden of a rheumatic disorder, however, the patients cannot be expected to self-manage on their own; they will need support not only from health care professionals (Lorig & Holman, 2003) but also from relatives and fellow-patients (Kroon et al., 2014).

Many self-management support (SMS) interventions aimed at patients with a rheumatic disorder are available, including educational programs (Kroon et al., 2014), cognitive behavioral therapy (Dures & Hewlett, 2012; Hewlett et al., 2011) and goal setting interventions (Arends, Bode, Taal, & Van de Laar, 2013). At outpatient clinics, SMS is mostly provided by nurses (Elissen et al., 2013). There is limited empirical evidence, based on lived experiences (Laquinta & Larrabee, 2004; Kristiansen, Primdahl, Antoft, & Horslev-Petersen, 2012), on what kind of support outpatients with rheumatic disorders desire. A recent scoping review showed that people with rheumatoid arthritis desire informational, emotional, social and practical support (Zuidema, Repping-Wuts, Evers, Van Gaal, & Van Achterberg, 2015). Another recent qualitative review presented a model of various chronic patients' support needs distinguishing three types of support: instrumental, psychosocial and relational support (Dwarswaard, Bakker, van Staa, & Boeije, 2016). Moreover, professional SMS is often medically oriented, with a tendency to overlook social and psychosocial problems (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015; Elissen et al., 2013). It must be noted, that patients' support needs are unique and may change over time (Dwarswaard et al., 2016). While their needs can be disease-specific, recent research had indicated that challenges in self-management are partly generic. Most types of Chronic Conditions had a small effect on patients' self-management challenges (van Houtum, Rijken, Heijmans, & Groenewegen, 2015). Both disease-related and individual factors, e.g. flare up of symptoms, cultural backgrounds, gender, and changes in patient's personal situation, seem to influence one's self-management support needs (Dwarswaard et al., 2016).

Professionals could facilitate patients' self-management by seeing healthcare as a shared responsibility. Patients want to be seen as the daily life experts (Dures, Hewlett, et al., 2016). Good understanding of patients' needs could help professionals in designing effective interventions.

We used the model of 'SMS needs' (Dwarswaard et al., 2016) to identify what kind of support outpatients with rheumatic disorders need and who they would like to receive support from. This study is part of an intervention mapping process (Bartholomew, Parcel, & Kok, 1998) that is expected to lead to the development of a nurse-led self-management intervention that fits patients' needs and preferences for support.

METHODS

Design

A cross-sectional qualitative study was applied involving a variety of outpatients with rheumatic disorders and using the directed content analysis.

Sample and participants

A full sampling strategy was used, inviting Dutch-speaking patients treated at the outpatient clinic of the Rheumatology department of the Erasmus MC, University Medical Center Rotterdam. During seven weeks, three rheumatologists and one nurse practitioner (MW) distributed a flyer with information about the focus groups to eligible patients.

Eligible patients were those diagnosed with rheumatoid arthritis (RA), psoriatic arthritis or ankylosing spondylitis and a minimum age of eighteen years. These patients were recruited because they represent the most common disease of our outpatient clinic. Patients who have been diagnosed recently were excluded. Sixty-three patients were actually invited. Using principles of purposeful sampling (Polit & Beck, 2008) in order to create a sample with maximum variation in terms of age, employment, disease type and years of diagnosis, 63 patients were finally invited for group or individual interviews.

Data collection

Between March 2014 and February 2015, in-depth information was gathered through focus group interviews and face-to-face interviews. Both methods were used because not all patients could attend the focus group sessions. Focus group interviews were considered an appropriate data collection method because participants can be encouraged to discuss and react to others' remarks. This type of intensive interaction enables a broad exploration of experiences and attitudes, which can enrich data (Kitzinger, 1994; Kitzinger, 1995; Polit & Beck, 2008; Wibeck, Dahlgren, & Öberg, 2007). Additionally, individual interviews were held to allow for maximum variation sampling. Individual interviews helped us to gain a deeper understanding of the topics discussed during focus group interviews because participants could explain their view more elaborately.

In the analysis, results of both interview types were pooled to develop a comprehensive understanding of patients' needs and to validate conclusions (Polit & Beck, 2008).

The primary researcher, a nurse with basic training in qualitative research methods (JB), conducted the focus group interviews assisted by an independent moderator, a psychologist and psychotherapist who was very experienced with group interaction. This moderator stimulated patients to share their ideas and opinions, but was not involved in data analysis.

These interviews lasted about two hours and were held in a private location outside the hospital. Face-to-face interviews were conducted by JD, an experienced qualitative researcher. These lasted about one hour and were conducted in a private space in the hospital. Leading interview questions are shown in Table 1. Prior to the interview, patients did not receive any information about what kind of support could be provided by whom. This was done in order to encourage them to freely describe their needs for support and preferences for any team member who should provide this support. All interviews were audio-recorded and transcribed verbatim.

Table 1. Leading interview questions

- What can you tell me about your life with a rheumatic disorder?
- What kind of support do you receive in dealing with your rheumatic disorder?
- What kind of support would you need and/or prefer in dealing with your rheumatic disorder?
- Who would you preferably like to provide this self-management support?

Ethical considerations

All invited patients received a flyer and all included participants provided informed consent. Participants were assured of confidentiality and data were processed anonymously by the first researcher. The researchers (JB, JD, AvS, and EI) had no access to patient records, while MW and JH –who were involved in the medical care of some patients- were neither involved in data collection nor had access to non-anonymous data. The study protocol was approved by the Medical Ethical Committee of the Erasmus MC (MEC-2013-350).

Data analysis

Patients' support needs were explored through the Directed Content Analysis (DCA) approach, which is appropriate when prior research exists about a phenomenon (Hsieh & Shannon, 2005). Of the two DCA coding strategies, we opted for the one that starts with applying predetermined codes from an existing theoretical framework, in this case the model of 'SMS needs' further detailed below (Dwarswaard et al., 2016). First, the first and second author (JB and MW) read the interview transcripts to gain an overall impression of the contents. Subsequently, they applied predetermined codes based on the different components of the model of SMS needs: (need for support) knowledge – information and instruction, internalizing knowledge, instrumental, adjusting daily life, recognition of emotional aspects, building self-confidence and empowerment, partnership and sympathy. Subthemes of these codes were (support from) professionals, relatives and fellow patients. Factors contributing to the uniqueness of this support were also coded. JB and MW discussed and refined these codes during the coding process. Data considered interesting but which could not be coded with this initial coding scheme were analyzed later *'to determine if they represent a new category or a subcategory of an existing code'*(Hsieh & Shannon, 2005: p. 1282).

Data saturation was achieved after having analyzed two focus group interviews and four individual interviews when the data became repetitive (Polit & Beck, 2008).

Theoretical framework: model of SMS needs

To analyze the data, we used the model of SMS needs (figure 1), constructed by Dwarswaard and colleagues (2016). This generic model, developed in a qualitative review of 37 articles, distinguishes three types of support to be provided by professionals, relatives (family and friends) and fellow patients to chronically ill patients: relational,

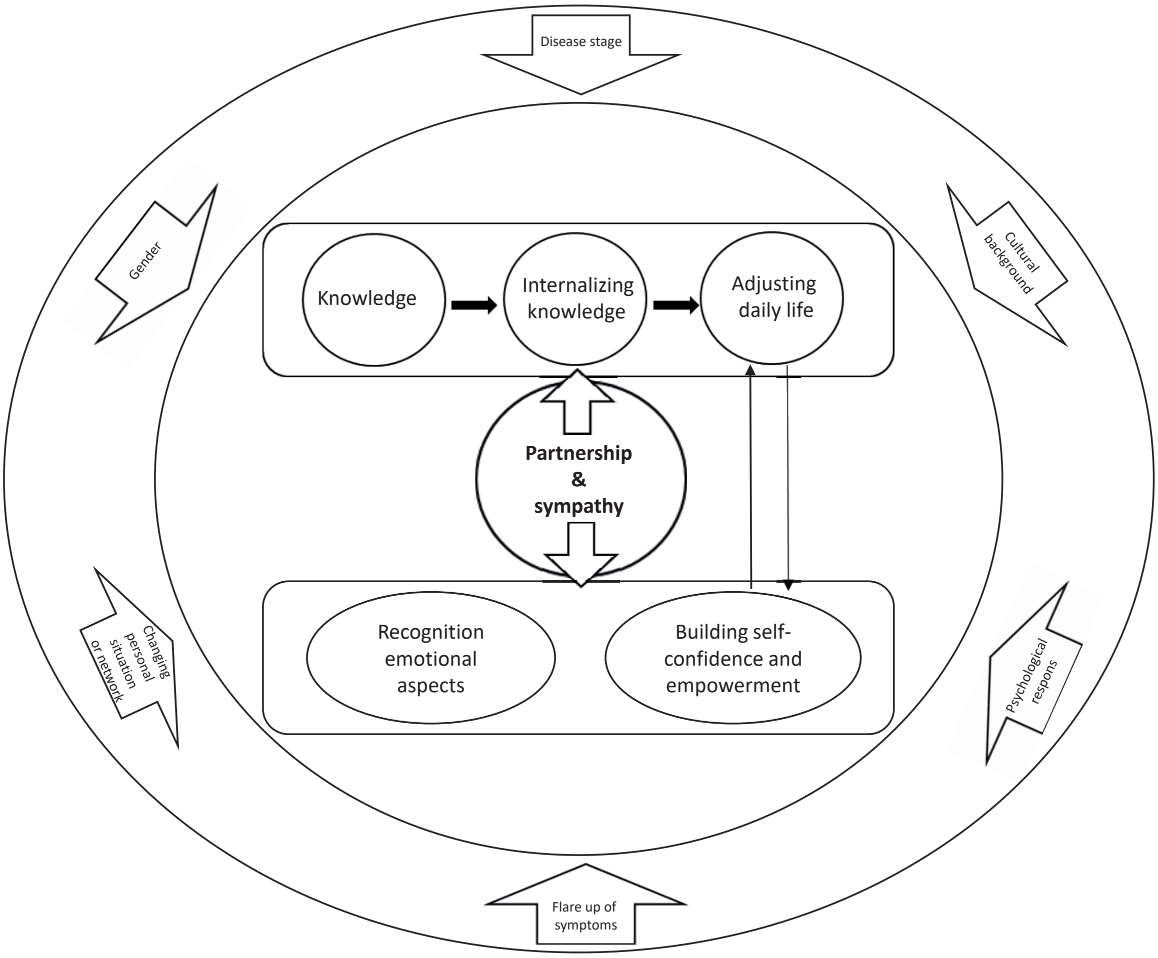

Figure 1. Model of SMS Needs (Dwarswaard et al., 2016)

instrumental, and psychosocial (Dwarswaard et al., 2016). This model of SMS needs will be explained more clearly in the Results section and in Table 3.

Strategies to establish rigor

Both researcher and method triangulation (Polit & Beck, 2008) were used to enhance the validity of the data. All data was collected and analyzed in a team-based fashion. Agreement in coding was reached by consensus between the two coders. To increase the dependability of the research, the design, methods, (preliminary and final) analyses and results were all discussed within the research team. Readers can conclude on the degree of transferability from the provided details of the participants and settings. The description of the methods also contributes to the conformability of this study.

RESULTS

Forty-three (68%) patients declined to participate, mostly due to logistical difficulties with planning. Eventually, fourteen patients participated in two focus groups interviews (FGI) and six were interviewed individually (II). Sample characteristics are shown in Table 2.

Views on self-management

Self-management was primarily seen as one's own task: *"I want to do it [managing a rheumatic disorder] myself" (II-R1).* Most patients preferred an active role, thinking that others could not manage the rheumatic disorder for them: *"Finally, I'm in charge. I want to experience things myself. Other persons cannot explain everything" (II-R5).* Ultimately, they themselves have to deal with the disorder: *"in the end no one can really help" (FG1-R1).* Patients wished to "*determine [themselves] what works or does not work […]" (II-R4).* Problems are solved by trial and error*: "Initially, you ask too much of your own body…. But at some point you'll recognize your limits. To get there, you must be familiar with your own body" (FG2-R2).* Still, actively adapting to the rheumatic disorder can be difficult: e.g. *"Sometimes, I go beyond my physical limits. But eventually, you'll hit a brick wall" (FG1-R7).*

Support needs

Even though self-management was primarily seen as the patient's responsibility, support from professionals (doctors and nurses), relatives and fellow patients could be accepted. Support might strengthen their empowerment: *"I often have inflammations in my wrist. The pain is terrible. Apart from taking pills, I did not know other solutions. A nurse helped me by sharing the experiences of other patients... At some point I learned to live with it. However, I would like to be guided in managing these challenges in daily life*" (*II-R2*).

Table 2. Sample characteristics

	Face-to-face interviews (n; %)	Focus group interviews (n; %)	Total (n; %)
Gender			
Female	3 (50.0)	11 (78.6)	14 (70.0)
Male	3 (50.0)	3 (50.0)	6 (30.0)
Age			
34 – 44 years	2 (33.3)	0 (0.0)	2 (10.0)
45 – 54 years	0 (0.0)	3 (21.4)	3 (15.0)
55 – 64 years	3 (50.0)	7 (50.0)	10 (50.0)
> 65 years	1 (16.7)	4 (28.5)	5 (25.0)
Marital state			
Cohabiting / married	4 (67.3)	8 (57.2)	12 (60.0)
Widow	0 (0.0)	1 (7.1)	1 (5.0)
Single	2 (33.3)	5 (35.7)	7 (35.0)
Diagnosis			
Rheumatoid arthritis	6 (100)	10 (71.4)	16 (80.0)
Psoriatic arthritis	0 (0.0)	2 (14.3)	2 (10.0)
Ankylosing spondylitis	0 (0.0)	2 (14.3)	2 (10.0)
Years of diagnosis			
< 5 years	0 (0.0)	1 (7.1)	1 (5.0)
5-10 years	2 (33.3)	7 (50.0)	9 (45.0)
> 10 years	4 (66.7)	6 (42.9)	10 (50.0)
Employment			
Yes	4 (66.7)	2 (14.2)	5 (25.0)
No	2 (33.3)	12 (85.8)	15 (75.0)

Preferences are described below following the 'SMS needs' model (Dwarswaard et al., 2016). Table 3 provides an explanation.

1. Relational support

Partnership and sympathy

Having a trusting relationship with professionals, relatives and fellow patients was seen as conditional for receiving SMS. Only then, one may comfortably talk about problems at home or work, express one's own opinion and feel one can rely on the capabilities of the other person. If such relationship is lacking, one may be less open to support: *"I did not want any kind of support from her [a specific professional]… She was not unfriendly, but I did not trust her" (II-R1).* This applies also to relatives and fellow patients: *"First, they [relatives] need to show some genuine interest in me" (FG1-R1)*. Sympathy can affect this level of trust. A sympathetic person was defined as a good listener, someone who is empathic, shows interest and understands.

Continuity of care was important for those who preferred support from professionals. Continuous rotation was seen as counterproductive for building a relationship of trust as becomes clear from a discussion in one of the focus groups: *"At first, I had different doctors. This was very annoying" (FG2-R7). "Yes, that is really annoying" (FG2-R2). "Every*

Table 3. Model of SMS needs (Dwarswaard et al., 2016)

Themes	Subthemes	Quotations to explain the model[a]
Relational support refers to supporting aspects of interactions with other persons. This involves two subthemes: partnership, and sympathy.	Partnership	*"It is not possible to hold professionals responsible for everything. It ought to be co-operation. Every patient should consider what is good for him of her" (II-R5)*
	Sympathy	Patients highly appreciate when their symptoms and side effects are taken seriously: "*Action was taken immediately. In a few days I felt better. I was really accepted" (FG2-R3)*
Instrumental support is related to the medical management of a chronic condition, This involves three subthemes: Knowledge – information and instruction, internalizing knowledge, and adjusting daily life.	Knowledge – information and instruction	*"For example, I want information about what can happen if I do not wish to be operated on my hand" (FG2-R4)*
	Internalizing knowledge	Having the opportunity to discuss disease-related information: *"I calm down when a nurse tells me how to interpret side effects I've noticed" (II-R4)*
	Adjusting daily life	*"I liked to get advice on how to deal with a rheumatic disorder in daily life. To hear that on the one day you're capable of house cleaning and the next day you're not" (FG1-R2)*
Psychosocial support pertains to the resources needed to manage the emotional and psychosocial aspects in living with a chronic condition. This involves two subthemes: recognition of emotional aspects of the chronic condition, and building self-confidence and empowerment.	Recognition of emotional aspects of the chronic condition	*"Just ventilating [my emotions or feelings] is enough" (II-R3)*
	Building self-confidence and empowerment	*"For me, it was a psychological transition to inject myself. First, the nurse showed me how to administer this medication. Then she instructed me stepwise. Afterwards I felt confident enough do it myself" (II-R3)*

[a] Quotations were derived from the focus group (FGI) and individual interviews (II)

time I had to repeat my story. There was a story in the computer, e.g. about blood levels. However, this was not my personal story" (FG2-R7). Confidence in professionals *"needs to emerge over time" (II-R1)*.

Apart from trust, also partnership with professionals was seen as an important component of SMS: *"It is not possible to hold professionals responsible for everything. It should be a matter of co-operation. Every patient should consider what is good for him of her" (II-R5).* Patients wished to be involved in decision-making and preferred to *"think together about treatment options" (II-R4).* Even though professionals were seen as the medical experts, patients wanted professionals to "*respect the choices" (FG1-R8)* they make. Above all, they wanted to be seen as experienced experts of living with a rheumatic disorder.

2. Instrumental support

Knowledge – information and instruction

Patients said they needed specific disease-related knowledge (e.g. about diagnosis, symptoms, treatment options, assistive devices, and the necessity of physical exercise).

Not everyone needed the same amount and type of information at the same time. Once they had received the diagnosis, patients just wanted information about their rheumatic disorder or how to recognize early symptoms. They did not wish to hear about all possible complications: because, *"I am not ready for it" (FG2-R6)*. They were not open to this kind of information until after a certain degree of acceptance has been reached. Sometimes after diagnosis, patients wanted to receive information related to their personal situation (e.g. about new devices, medication, or symptoms related to complications. Patients' information needs are also influenced by the disease activity and the symptoms experienced.

In this study, patients preferred a stepwise knowledge provision tailored to personal needs. Failure to provide tailored education carries the risk of patients being *"overwhelmed by all information" (FG2-R6)*. Most patients prefer advice about reliable literature: *"Nowadays, you can find information anywhere. Professionals could help by offering information about reliable sources" (II-R5)*.

In terms of knowledge provision, not much was expected from relatives. However, patients found it important that professionals provide tailored information about the rheumatic disorder to relatives, as lack of knowledge could lead to less optimal support.

Internalizing knowledge

Having the opportunity to discuss disease-related information with professionals, relatives, and fellow patients was seen as a way to internalize knowledge. *"I calm down when a nurse tells me how to interpret side effects I've noticed" (II-R4)* and *"It helps me to talk with […], someone [a fellow patient] who knows what it means to have a rheumatic disorder" (II-R2)*. However, not everyone liked this kind of support from fellow patients: *"I don't need this [support from fellow patients], because they will constantly talk about their ailment. It gets worse and worse" (FG1-R6)*.

Adjusting to daily life

Since *"nothing is as difficult as changing your lifestyle" (II-R2),* almost all patients needed support in integrating their rheumatic disorder in daily life. The extent of support need was influenced by the disease stage, the presence of symptoms and changes in one's situation. Right after diagnosis, more and specific support is needed: *"In the beginning I needed a lot of support. I felt I had my back to the wall. You do not know where it will go" (FG1-R7)*.

Patients highly appreciated professionals who just *"listen and ask how you are doing at home and work" (II-R4)*. Besides, professionals could give practical advice about dealing with the disorder: "*peeling potatoes is very hard for me, professionals can advise me on appropriate assistive devices" (II-R4)*. Disease fluctuations can be hard to handle. Patients wanted to know how to deal with these.

Some patients needed relatives to monitor their limits: *"Sometimes it is helpful when someone else tells you it is enough" (II-R2).* However, others said: *"I just want to do this all by myself" (II-R1)*. Patients were less ready to accept this kind of monitoring from their children than from their partners. While relatives may provide practical support such as cleaning and cooking, for some patients *"it is difficult to accept help" (II-R5)*.

Most patients said they did not need support from fellow patients. Some acknowledged that *"it is good to know that they [fellow patients] understand how you feel" (FG1-R4)*. Several patients also felt supported by experiential stories in the patient association's magazine. One patient was active in a social media group because, *"you can ask fellow patients how they are dealing with certain symptoms…. these people face similar problems. A professional does not have this experience" (II-R4).*

3. Psychosocial support

<u>*Recognition of emotional aspects of a rheumatic disorder*</u>

Accepting that a rheumatic disorder is a lifelong disease was a deep emotional process for many: *"for me, it felt like an execution" (FG2-R7);* and *"I was really panicking after diagnosis" (FG1-R4).* Mostly it was already helpful when professionals proactively asked and listened: *"just ventilating [my emotions or feelings] is enough" (II-R3).* For some of the patients this was insufficient, however, because they had long-term problems: *"the pain and sadness remain" (FG1-R2).* These patients needed to *"receive guidance" (FG2-R7)* from a specialist e.g. psychologist or social worker, to accept a life with a rheumatic disorder.

Generally, it was easier for patients to discuss emotional aspects when professionals proactively asked about these. Not all patients had the courage to discuss these kinds of problems, sometimes because they *"do not want to be perceived as a bore" (FG1-R1).* Patients preferred to discuss emotional issues with a nurse, because nurses tended to be *"able to create a moment to listen" (FG1-R6).*

Most patients just wanted a listening ear from relatives, but some pointed out that relatives did not always recognize their emotional issues. Not all relatives were able to *"imagine what it is to be a chronic patient with daily pain" (II-R4).* As a result, not all patients received the support they needed. Compared to children and friends, partners seemed more capable in recognizing such emotional issues.

Fellow patients could be of help when they have the same experiences: *"I want to talk with someone who is experiencing the same" (II-R4).* However, patients were not interested in meeting fellow patients in a group session organized by the hospital. Some patients preferred to meet them informally.

<u>*Building self-confidence and empowerment*</u>

Although described implicitly, encouragement and reassurance supported the building self-confidence and empowerment: *"For me, it was a psychological transition to inject* *myself. First, the nurse showed me how to administer this medication. Then she instructed me stepwise. Afterwards I felt confident enough do it myself" (II-R3).* Positive reinforcement seems to help patients to solve problems or change behavior. For example, when a physician told a patient "*that she would be able to exercise" (FG1-R7)* and that it should help her, she felt confident to exercise more often so that her body became more flexible. It could also be helpful to see other patients exercising. On the other hand, some thought it would be confrontational to see the consequences of rheumatism in others.

DISCUSSION

In this qualitative study we explored the support needs of people living with rheumatic disorders. The analysis learned that they saw self-management primarily as a task for themselves but nevertheless appreciated support to help them achieve this. Most of the interviewed outpatients preferred support from professionals and relatives; only few appreciated psychosocial support from fellow patients.

Although the concept of self-management assumes an active role for patients in managing and integrating a chronic condition(s) in daily life (Barlow, 2001; Barlow et al., 2002), it was striking to find that this concept seems to fit so well to outpatients with a rheumatic disorder. However, even when patients appear to be autonomous self-managers their need for support should not be underestimated. It is not reasonable to expect patients to manage a rheumatic disorder on their own (Campbell et al., 2003; Vassilev et al., 2013). All patients need encouragement (Coates & Boore, 1995) to develop enough self-confidence to manage a disorder. Bandura found self-efficacy to be an accurate predictor of patients' fulfillment in managing a disorder (Bandura, 1977, 2004). The core element of professionals' support should therefore be coaching patients to develop problem-solving skills. It should be remembered, however, that not everyone believes in their capacity of self-managing. Patient with less confidence need more encouragement and recommendations from others e.g. professionals and relatives (Audulv, Norbergh, Asplund, & Hörnsten, 2009).

We found that learning how to deal with symptoms and fluctuations, talking about emotional aspects, and discussing daily life issues e.g. work and household were important aspects. All important aspects of the broad definition about self-management that we used in this study (Barlow, 2001; Barlow et al., 2002). Chronically ill patients are challenged to deal with the medical, emotional and social issues of their disorder in daily life (Lorig & Holman, 2003). These aspects also came to the fore in two reviews (Dwarswaard et al., 2016; Zuidema et al., 2015). One of these reviews shows that patient-related factors influence support needs (Dwarswaard et al., 2016). In this qualitative study we did not found any difference for gender, age and work status. Moreover, the time since diagnosis and course of the rheumatic disorder affected support needs. Patients who experienced more problems or disease activity had more need for support, in line with previous research (van Houtum, Rijken, Heijmans, & Groenewegen, 2013). It would be worthwhile to study how SMS could be tailored to individual needs and expertise (Rijken, Jones, Heijmans, & Dixon, 2008).

The interviewees in this study saw partnership and a trusted relationship as conditional for receiving SMS. Continuity of care and professionals taking the problems seriously could help build a trusted relationship. A good professional-patient relationship is therefore the cornerstone of care, especially in view of achieving behavioral change (Goold & Lipkin, 1999; Richard M Ryan, Patrick, Deci, & Williams, 2008). Partnership is generally recognized as an important part of SMS (E. Dures, Almeida, et al., 2016; Holman & Lorig, 2000; Lorig & Holman, 2003). However, it can be difficult for professionals to achieve collaborative partnership (Ter Maten-Speksnijder, Grypdonck, Pool, Meurs, & Van Staa, 2015; Thorne, Ternulf Nyhlin, & Paterson, 2000; Wilson, Kendall, & Brooks, 2006) as they may be inclined to play the expert role (Been-Dahmen et al., 2015). Patients in this study appreciated support from nurses and doctors alike. Usually, nurses took more time to discuss emotional and social aspects.

Partnership and a relation of trust were not only conditional for support from professionals, but also from relatives and fellow patients. Relatives were especially prized for their emotional and practical support. Fellow patients can help by sharing their lived experiences. However, not all patients appreciate this kind of support, unless this can help in managing a chronic condition well (Wagner et al., 2001). Modeling, observing others in performing new behavior patterns successfully, can serve as a guide for translating behavioral conceptions to appreciate actions (Campbell et al., 2003).

Operationalizing SMS may not be easy for professionals (Elissen et al., 2013). They tend to resort to traditional (standardized) patient education (Been-Dahmen et al., 2015), instead of providing the recommended tailored patient education (Zangi et al., 2015). Moreover, interventions that solely provide education have been found least successful (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Coster & Norman, 2009). Interventions focusing on patients' intrinsic processes seem to be most successful (van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2017). Focusing on more internal perceived locus of control is important for persistence and performance of new behavior (Ryan, Plant, & O'Malley, 1995). Still, professionals lack skills to facilitate psychosocial challenges in self-management (Dures, Almeida, et al., 2016). Additional training could help professionals to incorporate coaching into their repertoire of SMS interventions.

The model of 'SMS needs' (figure 1) (Dwarswaard et al., 2016) we employed was helpful in that we benefitted from previous descriptions and could create a deeper understanding of the support needs of people with a rheumatic disorder. On the other hand, the DCA approach carries the risk of fitting data to the predetermined coding scheme. Relevant data can be missed when applying this highly structured method. To minimize this risk, we also applied inductive coding if data could not be categorized. This enabled us to unravel the importance of the 'self' in self-management for patients with rheumatic disorders. Lastly, collecting data from not only focus group interviews but also face-to-face interviews was very useful. Individually interviewed participants in elaborated more on their experiences, which helped to create a comprehensive understanding of patients' needs. However, findings from the two interview types did not differ essentially.

A possible limitation of this study is that mostly elderly, retired patients with RA participated in the focus groups. It was difficult to recruit younger persons for the focus groups. Still, given that the prevalence of RA is much higher than the prevalence of psoriatic arthritis and ankylosing spondylitis, that RA occurs at older age, and that most of the RA patients were women, the composition of our sample seems to correspond to the normal distribution in the general population (Helmick et al., 2008). However, to minimize the risk of selection bias, we purposefully searched for younger or employed patients for the individual interviews.

In this study, we decided to exclude patients who have been diagnosed recently and to ask patients in retrospect what their supports needs were at the time. Thus we did not provide insight in support needs of recently diagnosed patients. Furthermore, all data was collected in one hospital in the Netherlands and the findings may therefore not be representative for patients in others countries. Hence, we recommend to study whether of outpatients in other countries may perhaps have other SMS needs.

CONCLUSION

Self-management was primarily seen as one's own task, but patients still appreciated support to help achieve this. Above all, they wanted to be seen as experienced experts of living with a rheumatic disorder. Preferred support givers were professionals and relatives. Professionals' self-management support should be focused on coaching patients in developing problem-solving skills for managing the medical, emotional and social challenges experienced in dealing with a rheumatic disorder in daily life. Practical tools and training are needed to operationalize coaching as a part of professional self-management support in working routines.

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CHAPTER 4

Self-management challenges and support needs among kidney transplant recipients: A qualitative study

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ABSTRACT

Aims

This study investigated self-management challenges and support needs experienced by kidney transplant recipients.

Background

After kidney transplantation, recipients are expected to take an active role in self-management. However, evidence suggests that nurses experience difficulties operationalizing self-management support. Greater insight into the recipients' perspective could help to improve the adequacy and efficacy of nurse-led self-management support.

Design

A cross-sectional qualitative study

Methods

Focus groups and individual interviews were carried out with kidney transplant recipients treated in a Dutch university hospital. Directed content analysis (DCA) was used.

Results

Forty-one kidney transplant recipients participated. Challenges after transplantation included becoming an expert patient, adjusting daily life activities, dealing with medical regimen, forming relationships with nurses, dealing with social consequences, dealing with emotions related to transplantation and the donor, and improving self-image. In order to be able to deal with these challenges, participants wished to receive disease specific knowledge and instruction, share personal experiences with fellow patients, share and discuss not only medical but also emotional and social issues with nurses, and wanted to be encouraged through positive feedback. 'One-size fits all' education was seen as insufficient in meeting their needs.

Conclusions

After kidney transplantation, recipients experienced various challenges in dealing with the medical, emotional and social tasks. Current support from nurses overlooked recipients' emotional and social support needs. Nurses need adequate tools and training to be able to meet recipients' self-management support needs.

Why is this research needed?

- After kidney transplantation, recipients needs to learn how to integrate medication and lifestyle advice into daily life routines, adapt changes in social roles and cope with the emotional impact.
- Evidence suggests that nurses experience difficulties operationalizing self-management support.
- Greater insight into recipient's perspective could help to improve the adequacy of nurses' self-management support.

What are the key findings?

- Current self-management support was mostly focused on the medical challenges and overlooked recipients' needs for support in dealing with the emotional and social challenges after kidney transplantation.
- Potential targets for self-management support interventions include a holistic approach, tailoring to individual needs, promoting intrinsic motivation and confidence, and building a relationship of trust.
- Cultural sensitivity is required when assessing needs and tailoring of support offered.

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

- Tools and training are needed to help nurses to meet the emotional and social support needs of recipients.

INTRODUCTION

Kidney transplantation has become the preferred treatment for patients with end stage renal failure because of better quality of life (Wyld, Morton, Hayen, Howard, & Webster, 2012) and survival (Wolfe et al., 1999) compared to dialysis. After transplantation, recipients need to learn how to integrate medication and lifestyle advice into their daily routines, adapt changes in social roles and cope with the emotional impact (Gordon, Prohaska, Gallant, & Siminoff, 2009). Recipients are expected to take an active role in their post-transplant care in the form of self-management (Anderson & Funnell, 2005; Wagner et al., 2001), which indirectly improves their quality of life (Weng, Dai, Huang, & Chiang, 2010). However, they cannot be expected to self-manage the consequences on their own (Lorig & Holman, 2003). At outpatient clinics in European countries, self-management support is often provided by nurses (Elissen et al., 2013).

In clinical practice, evidence suggests that nurses experience difficulties operationalizing self-management support (Elissen et al., 2013). Distinct perceptions exist about the definition and operationalization of self-management support (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015; Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011; Udlis, 2011; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). Self-management support can be defined as the provision of interventions to increase patients' skills and confidence in managing their chronic condition (Institute of Medicine Committee on Identifying Priority Areas for Quality, 2003). Due to the clinical importance of a strict regimen of immunosuppressive medication for maintaining graft functioning and the difficulties experienced with adherence (De Geest et al., 2014; Dew et al., 2007), self-management support in the post-transplant period has tended to focus on promoting medication adherence and self-monitoring (De Bleser, Matteson, Dobbels, Russell, & De Geest, 2009; De Geest et al., 2014; van Lint et al., 2017). However, chronically ill patients indicate that they also struggle with the psychological and social demands of living with their condition (Wagner et al., 2001).

Greater insight into the recipients' perspective could help to improve the adequacy of nurses' support (Fowler, 2017; Schipper & Abma, 2011; Trappenburg et al., 2013). A review of the qualitative literature (Jamieson et al., 2016) highlighted five main themes of motivations, challenges and attitudes to self-management after kidney transplantation: empowerment through autonomy, prevailing fear of consequences, burdensome treatment and responsibilities, medicalizing life, and social accountability and motivation. Self-efficacy and having sense of accountability were conditional for recipients' self-management. Support should consist of multicomponent interventions that included personalised care planning, education, psychosocial support, decision aids, and other self-monitoring tools (Jamieson et al., 2016). Little is known about kidney transplants' needs and preferences for self-management support to help them deal with these self-management challenges.

Background

Self-management is defined as managing one or more chronic conditions (e.g. symptoms, treatment, physical and psychosocial consequences, and lifestyle changes) and integrating them into daily life with the aim of achieving optimal quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Self-management challenges are often experienced in one or more of these domains: 1) Medical management: managing symptoms, managing treatment; 2) Role management: forming relationships with health-care providers, relating to family members and friends; 3) Emotion management: preparing for an uncertain future, managing emotions, and managing a positive self-image (Lorig & Holman, 2003; Moos & Holahan, 2007). Self-management support can improve patients' lifestyle or adherence; increase quality of life, or empower them (Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011; Wilkinson & Whitehead, 2009). In addition to support for self-management from professionals, they may also receive support from relatives and fellow-patients (Dwarswaard, Bakker, van Staa, & Boeije, 2016). In a model developed by Dwarswaard and colleagues, generic types of self-management support for chronically ill patients were categorised into relational, instrumental and psychosocial (Dwarswaard et al., 2016). Relational support refers to support that helps patients to interact with others, including: forming partnership and getting sympathy. Instrumental support refers to medical management and involves three themes: knowledge/information and instruction, internalizing knowledge, and adjusting daily life to the chronic condition. Lastly, psychosocial support refers to the resources needed to manage the emotional and psychological aspects of living with a chronic condition. Psychosocial support includes recognition of the emotional burden of the chronic condition, and building self-confidence and empowerment (Dwarswaard et al., 2016). Besides generic challenges, chronically ill patients also experience disease specific self-management challenges and support needs (van Houtum, Rijken, Heijmans, & Groenewegen, 2015). To date, little is known about disease specific self-management support needs after kidney transplantation.

THE STUDY

Aims

In this study, as part of a needs assessment in the development of a nurse-led intervention we aimed to gain insight into (a) recipients' perspectives on self-management challenges after kidney transplantation and (b) what kind of support is needed.

Design

We conducted a cross-sectional qualitative study using focus groups and individual interviews.

Sample and participants

This study was held at the outpatient post-transplantation clinic of the Department of Internal Medicine of the Erasmus Medical Center in Rotterdam (the Netherlands). Recipients are discharged from the hospital 2-3 weeks post-transplant, they receive explanation about self-management from a nurse practitioner prior to discharge and visit the out-patient clinic weekly in the first few weeks thereafter. The frequency is gradually decreased once the patient and their medication stabilise. All recipients (N=195) who visited the outpatient post-transplantation clinic between December 18, 2013 and January 15, 2014, were invited to participate. The nephrologist determined who could be invited, those with acute issues such as rejection or infection requiring re-hospitalization were not approached. No limitations were set as to the number of transplants, the type of donor, time since transplantation, or previous renal replacement therapy. Recipients with difficulties attending the focus groups, were invited for an individual interview. Additionally, recipients with insufficient proficiency of the Dutch language were purposefully selected and invited to participate in an individual interview with an official interpreter.

Data collection

Focus groups (FG) and individual interviews (II) were conducted between January 2014 and March 2015. Each FG lasted a maximum of two hours and was led by a psychologist (JWG), and a trained nursing researcher (JB) who took field notes, recorded participant characteristics, and who acted as a seconder. The FGs were held in the private room in the hospital. The intensive interaction in FGs enabled a broad exploration of experiences and attitudes (J. Kitzinger, 1994; J. Kitzinger, 1995; Polit & Beck, 2008; Wibeck, Dahlgren, & Öberg, 2007). The individual interviews allowed us to include recipients who otherwise have been excluded. Two researchers (JWG and JD) conducted the interviews; these lasted about one hour and were conducted at in a private space in the hospital or at participant's home. Sometimes a partner was present during the interview. To gain insight into the recipients' demographic characteristics, a questionnaire was completed by participants before the start of the individual interviews or focus groups. All interviews were audio recorded and transcribed verbatim. Both focus groups and individual interviews focused on post-transplant life, received self-management support, and preferred support. Table 1 provides an overview of the main questions addressed during the focus group and individual interviews. An item pool was developed and discussed within the research team and patient panel to come to a final set of questions. Participants were encouraged to give examples, details and circumstances.

Table 1. Interview questions about recipients' self-management challenges and support needs

- Could you please tell me about the challenges you face in dealing with the consequences of your kidney transplantation?
- What kind of support do you receive in dealing with the consequences of your kidney transplantation? And how do you experience this support?
- What kind of support do you need and/or prefer in dealing with the consequences of your kidney transplantation?
- Do you have suggestions for nurses with regard to providing self-management support?

Ethical considerations

All invited recipients received written information via post or during their outpatient clinic visit from their nephrologist or nurse practitioner. Those who returned the signed informed consent form were invited for the focus groups and individual interviews. Participants received financial compensation for travel costs and a gift voucher (€10). All participants were assured of confidentiality, the anonymous processing of the data, and that medical staff did not have access to the data. The researchers (JB, JWG, EI, AvS, EM) had no access to patient records, while LM and WW – who were involved in the medical care – were neither involved in data collection nor had access to non-anonymous data. The study protocol was approved by the Institutional Review Board of the University Medical Center Rotterdam (MEC-2013-350).

Data-analysis

A directed content analysis (DCA) approach was used to analyze the focus groups and individual interviews. This form of content analysis uses a more structured analytic strategy than the conventional open approach. Using this analytic method helps to focus the analysis and is appropriate when there is prior research or an existing theoretical framework about a phenomenon (Hsieh & Shannon, 2005). First, JB and JWG read the interview transcripts to gain an overall impression of the content. Subsequently, these researchers independently assigned data-driven codes to the text. The results were compared and discussed to reach agreement. Thereafter, all codes were sorted into predetermined categories based on existing theoretical models described in the introduction. To analyze data about recipients' perspectives on self-management challenges we used the models of Lorig and Holman (2003) and Moos and Holahan (2007). To analyze the data about support needs we used the model reported by Dwarswaard et al. (2016). Table 2 provides overview of how these three models were integrated. The qualitative analysis package Atlas.ti 6.2 was used for analysis. Data saturation was achieved when the data became repetitive after analyzing four focus groups and nine individual interviews (Polit & Beck, 2008).

Table 2. Integration of the models of Lorig and Holman(Lorig & Holman, 2003), Moos & Holahan(Moos & Holahan, 2007), and Dwarswaard et al (Dwarswaard et al., 2016) about self-management tasks and support needs of chronically ill patients

	RESEARCH QUESTION 1	RESEARCH QUESTION 2
Three domains of self-management tasks (Lorig & Holman, 2003)	*Adaptive tasks of living with a chronic condition (Moos & Holahan, 2007)*	*Self-management support needs of chronically ill patients (Dwarswaard* et al.*, 2016)*
Medical management	- Managing symptoms - Managing treatment	Instrumental support: - Knowledge: information and instruction - Internalizing knowledge - Adjusting daily life to the chronic condition
Role management	- Forming relationships with health-Care Providers - Relating to family members and friends	Relational support: - Partnership - Sympathy
Emotion management	- Preparing for an uncertain future - Managing emotions - Managing a positive self-image	Psychosocial support: - Recognition of emotional aspects of the chronic condition - Building self-confidence and empowerment

Study rigour

Both researcher and method triangulation (Lincoln & Guba, 1985; Polit & Beck, 2008) were used to enhance the validity of the data. All data was collected and analyzed in a team-based fashion. Agreement in coding was reached by consensus between the two researchers. To increase the dependability of the research, the design, methods, (preliminary and final) analyses and results were all discussed within the research team. Details of the participants and settings are described below, allowing readers to conclude on the degree of transferability. The description of the methods also contributes to the conformability of this study. The COREQ guidelines were followed in reporting the methods.

FINDINGS

One hundred and ninety-five recipients were handed out the information packet, of which 53 agreed to participation in a focus group. Due to logistical difficulties with planning and acute illness, 32 recipients eventually participated in one of 4 FG (7-9 participants per FG). Six non-Dutch and three Dutch-speaking recipients participated in an individual interview. Sample characteristics are shown in Table 3. One non-Dutch speaking participant did not fill out the sample characteristics form.

Table 3. Patients' characteristics

Characteristics	Participants focus groups (n=32)	Participants individual interviews (n=9[a])
Age: in years (mean; SD)	56 (8.7) Median = 56.5; Range = 31-69	56 (11.3) Median 52; Range = 42-71
Gender: Male (n; %)	20 (62.5)	3[a] (37.5)
Marital status: Married/living together (n; %)	26 (81.3)	6[b] (75)
In paid employment (n; %)	8 (25)	0[a] (0)
Highest educational attainment (n; %)		
None		3[a] (37.5)
Primary school	3 (9.4)	2 (25)
Secondary school	15 (46.9)	2 (25)
Further education	14 (43.7)	1 (12.5)
Nationality		
Dutch	26 (81.3)	2[a] (25)
Indonesian	1 (3.1)	-
German	1 (3.1)	-
English-Ghanaian	1 (3.1)	-
Iraqi	1 (3.1)	-
Dutch-Surinamese	1 (3.1)	-
Dutch-Antillean	1 (3.1)	-
Filipino	-	1 (33)
Turkish	-	3 (37.5)
Moroccan	-	2 (25)
Number of transplants (mean; SD)	1.3 (0.5); Median = 1; Range = 1-3	1.38 (0.7); Median = 1; Range = 1-3
Comorbidity[c]: yes (n; %)	14 (43.8)	6 (75)

[a] one respondent did not fill out the sample characteristics form

[b] two missing values

[c] The most commonly reported comorbidity were cardiovascular problems (n=7) and diabetes (n=6). Others included cancer, rheumatoid arthritis, and amputations.

Self-management challenges after kidney transplantation

Participants described a variety of challenges they experienced after their kidney transplantation, varying from medical to psychological and social challenges (Table 4). Depending on participants' unique personal situation, these challenges posed specific problems. For example, difficulties dealing with medical regimens in daily life: some

Table 4. Recipients' self-management challenges after kidney transplantation

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
MEDICAL MANAGEMENT			
	Managing symptoms	*Becoming an expert patient in transplantation* - Understand all aspects of the condition, lifestyle and medication regimen - Receive accurate and correct information about the condition - Understand the information and instructions provided by professionals correctly - Develop self-awareness to recognize bodily signals and understand when there is a real problem - Struggling to find solutions for experienced medical problems - Dealing with relatives who have an insufficient level of knowledge	- *"You almost become a doctor." (FG1-R5)* - *"You've got to be careful of course. There are always stories, I mean, I'm not the kind of person who goes looking for information on the Internet…What happens if… you read the most horrendous stories." (FG1-R6)* - *"At a certain point you get the hang of it [self-management]." (FG3-R4)* - *"One of my cousins used sea salt in the cooking because she thought it wasn't real salt. So I have to explain again and again that no, I can't have any sodium. Not even sea-salt." (FG2-R5)*
		Adjusting daily life activities - Adapt their daily life program to their current physical condition - Manage the impact of medical problems and side-effects of medication in daily activities - Find a balance between activity and rest - Find a new and meaningful daily routine	- *"I realized I have a rickety car and I should drive not too fast in it. Now I drive according to the recommended speed limit. I know it and I need to deal with it. I'd be crazy if I didn't." (FG1-R6)* - *I pretend nothing is wrong. Then you make it difficult for yourself. I make it "difficult for myself I know. I don't let on to my husband and kids, who don't live at home anymore, that there's anything wrong. So I make it difficult for myself. I am aware of that." (FG4-R3)* - *"I've been unemployed since last year. So yeah, I don't do anything anymore, just sit behind the computer." (FG2-R3)*

Table 4. Recipients' self-management challenges after kidney transplantation (*continued*)

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
	Managing treatment	*Dealing with medical regimen in daily life* - Adhere to the prescribed lifestyle rules and the medication regimen - Internalize and find work routines for dealing with the various regimens in daily life - Find balance in adhering to the regimen	- *"You can't even tell a healthy person not to eat at a café occasionally, I get that. That's why I understand that it's difficult to get people [patients] to stick to a healthy eating programme. I think that will always be hard."(FG3-R1)* - *"I had to get used to it [taking medication]. We weren't used to it in the beginning. I was thinking 'did or didn't I use my medication'. Now it is a habit." (II-R2)* - *"I actually don't have my meds with me now, I forgot them. Normally, I take them at eleven…So I need to be at home at eleven o' clock at the latest. So I'm sat here thinking what if my car breaks down? Than they [family] will have to come and bring my medication, so I can take them at eleven. It's never happened, this is the first time." (FG2-R4)*
ROLE MANAGEMENT			
	Forming relationships with health-care providers	*Forming a relationship with nurses* - Work on a relationship of trust - Deal with staff changes - Deal with nurses and health care professionals who do not have any attention for personal issues - Deal with non-empathic professionals - Learn to defend own interests - In case of a language barrier, communication with nurses and other health care professionals is more difficult	- *"Now if I don't like the ways things are going I will tell them [professionals]. I wouldn't have done that twenty years ago, because I was very shy. I did not tell [the nurse and doctor] when I was in pain. I was scared he [doctor] was thinking: "What an old nag". Then a lady doctor told me: "How can I know if you're in pain if you don't tell me? I can't see from the outside if you're in pain or not". Since then, I sometimes say something."(II-R2)* - *"I try to create some kind of relationship. Something more personal. I don't want to get too personal, but to show some personality. It's also important for him to know about not only the medical side but also the emotional one, you have to take that into consideration." (II-R9)* - *"I missing some personal attention [from my doctor]. Someone who looks further than just at my blood and urine levels." (FG1-R3)* - *"We have been to a couple of [patient education] sessions. But we don't speak the language, that's our own fault. I wanted to understand. I would like to have an interpreter so I could have understood it. It was a waste of time each time." (II-R3)*
	Relating to family members and friends	*Dealing with social consequences* - Indicate limits to others - Deal with evolving relationships	- *"[After transplantation] I was so selfish that I ruined my marriage." (FG3-R1)*

Table 4. Recipients' self-management challenges after kidney transplantation (*continued*)

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
EMOTION MANAGEMENT			
	Preparing for an uncertain future	*Dealing with emotions related to kidney transplantation* - Deal with the emotional and serious impact of transplantation - Deal with positive emotions: e.g. thankfulness and happiness - Deal with negative emotions: e.g. impatience, disappointment, anger, sadness, worry, and stress - Accept being chronically ill - Accept to receive this kidney as a gift from their God - Reconsider life goals	- *"Here I am, very happy [with the received kidney]. [Because of the transplantation] Because I'm a grandfather now. And those are the things I get to experience." (FG3-R1)* - *"I'm always scared when I'm shopping. With kids. They're of course always running around and what if the shopping trolley hits my side. I always try to be aware of that. … You've got to be careful with physical contact." (FG2-R1)* - *"It is always on your mind. It starts with taking all that medication of course. You're confronted with it three or four times a day. If I want to go on holiday, I've got to get a letter about which medication I take, permission to go, take it with you blablabla." (II-R2)* - *"After my first transplantation, I really panicked when I didn't pee enough. Looking back I think nobody pee's the same amount every day. But you first need to experience it before you know what to look for." (II-R2)* - *"You can do loads of really fun things. Just a month after transplantation I was already going to the gym. But you know, you just divide you energy better over the day. You're more conscious of it. You think about it first. And I didn't do that before. I used to think I'll see how it goes, just do it and enjoy." (FG3-R4)*
	Managing emotions	*Emotions related to the donor (relative)* - Deal with high expectations of expressing (a lot of) gratitude for receiving a kidney - Feel pressure to live healthy, feel well, and be adherent - Feel responsible for the health of their donor	- *"I don't dare to say anything to my sister if it's not going so well. Once I did say something but go told off by my mother for saying something, she said I shouldn't burden my sister with it and just be happy I got her kidney. Then I think, do I have to be grateful all my life?" (FG1-R3)* - *"[After donation] my brother developed diabetes. I find that hard. When I think about it. Cos yeah, his life is, he often has to go to the hospital, that kind of thing, you have to call and ask how it's going you know." (FG2-R7)* *"Do you feel guilty?" (FG3-R4). "Yes, of course I do." (FG3-R7)*
	Managing a positive self-image	*Improving self-image* - Building up (new) confidence in own body and capability to self-manage	- *"You need to learn to deal with it [having a chronic disorder] and need to learn to listen to your body. Then it's do-able" (FG4-R1)*

participants experienced difficulties with medication regimen during irregular working hours; others struggled to find ways to exercise when they have a busy family life. The extent to which participants experienced challenges after their kidney transplantation varied. The disease-specific self-management challenges experienced by kidney transplant recipients fit into the generic domains and adaptive tasks of chronic illness self-management (Lorig & Holman, 2003; Moos & Holahan, 2007). Several self-management challenges were identified: becoming an expert patient in transplantation, dealing with medical regimen in daily life, dealing with emotions related to kidney transplantation, dealing with emotions related to the donor (relative), daily life activities (leisure and work), and social consequences.

Support needs

Participants' needs for receiving support seemed to vary according to the number of transplantations, duration of illness, time since transplantation, presence or absence of a social network, dialysis prior to transplantation, and their current medical condition. For example, patients had a greater need for support when they experienced a lot of challenges and less need for support the longer ago they received the transplant. We found some differences between Dutch-speaking and non-Dutch speaking participants. In contrast to Dutch-speaking participants who would have liked more emotional support, Non-Dutch speaking participants stressed that they did not wish to share their emotions with others.

Participants support needs are described below according to the 'self-management support needs' model (Dwarswaard et al., 2016). Support could be provided by nurses (or other health care professionals), relatives and fellow patients. Table 5 provides an overview of the reported support needs linked to the three self-management domains.

Instrumental support

Providing knowledge and instruction

Becoming an expert patient in transplantation was mentioned as one of the biggest challenges after kidney transplantation. In order to reach this goal, participants wished to receive adequate information and instruction from nurses. 'One-size fits all' education was seen as insufficient in meeting their needs. More tailored education was desirable because personal circumstances, disease history and current medical situation of participants vary greatly. Participants wished to be involved in deciding what kind of information and instruction was needed for their specific situation. In the period directly after transplantation, a lot of participants struggled to find solutions for medical issues. Then participants expressed a greater need for tailored information about their specific medical situation.

Table 5. Preferences for self-management support after kidney transplantation

Self-management Task (Lorig & Holman, 2003)	Self-management challenges	Types of support needs (Dwarswaard et al., 2016)	Indicated self-management support needs by recipients in this study		
			Nurses	*Relatives*	*Fellow patients*
MEDICAL MANAGEMENT	*Becoming an expert patient*	Instrumental support	*Providing knowledge and instruction* - Providing tailored information and instruction (very important for non-Dutch speaking recipients) - Arranging an interpreter during consultation if knowledge and instruction will be provided to non-Dutch speaking recipients	*Providing knowledge and instruction* - Reading disease specific information - Listening to nurses' education and instructions about kidney transplantation - Trying to understand the medical consequences where recipients are dealing with. - Fulfilling the role of interpreter (in case of non-Dutch speaking recipients)	*Providing knowledge and instruction* NOT MENTIONED
	Adjusting daily life activities		*Internalizing knowledge* - Giving space to ask questions - Discuss personal circumstances	*Internalizing knowledge* NOT MENTIONED	*Internalizing knowledge* - Sharing their experiences of a kidney transplantation
	Dealing with medical regimen in daily life		*Adjusting to daily life* - Paying attention to recipients' daily life changes - Discussing how to reorganize daily life structures and find new routines	*Adjusting to daily life* - Stimulating recipients to modify their lifestyle or be adherence - Offering practical support in daily life	*Adjusting to daily life* - Discussing experiences with kidney transplantation
ROLE MANAGEMENT	*Forming a relationship with nurses* *Dealing with social consequences*	Relational Support	- Investing in a relationship of trust with recipients - Supporting shared decision making (less important for non-Dutch speaking recipients) - Paying attention to recipients social changes in daily life	NOT MENTIONED	NOT MENTIONED

Table 5. Preferences for self-management support after kidney transplantation (*continued*)

Self-management Task (Lorig & Holman, 2003)	Self-management challenges	Types of support needs (Dwarswaard et al., 2016)	Indicated self-management support needs by recipients in this study		
EMOTION MANAGEMENT	*Dealing with emotions related to kidney transplantation* *Emotions related to the donor (relative)*	Psychosocial support	*Recognition of emotional aspects after kidney transplantation* - Recognizing the emotional impact of kidney transplantation - Providing opportunities to discuss emotional issues - Proactively asking about recipients' emotions - Listening to recipients' personal stories - Providing education about emotions that frequently occurs - Paying attention to potentially emotionally taxing relationship with the living donor	*Recognition of emotional aspects after kidney transplantation* - Listening to recipient's stories - Providing the opportunity for recipients to talk about their emotions and feelings	*Recognition of emotional aspects after kidney transplantation* - Share and discuss experienced emotions with other recipients
	Improving self-image		*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient	*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient	*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient

> *"[Then] I wanted to get information because it [the side-effects and complications] makes me restless." (FG2-R1)*

The complex medical aspects of kidney transplantation can be difficult for participants to understand and they complained about 'conflicting and vague advice'. This confused them. Some participants felt that they had to translate general information provided by nurses to their own situation, indicating that education was not always tailored to participants' specific situation. Participants described that it would help them if nurses explore gaps in knowledge and provide information accordingly. In contrast, the majority of non-Dutch speaking participants did not wish to receive information about their chronic disorder from nurses. They did not search for information in Dutch or in their native language even though they often had difficulties understanding their disease.

> *"For me it is not important to know [what kind of medication] I use (…). The doctor prescribed them, so it'll be good for something. And they seem to work." (II-R5)*

Next to education, participants wanted to be trained in developing self-awareness to recognise bodily signals and understand when there is a real problem. Receiving instruction by nurses about recognising these issues was seen as an important prerequisite for effective self-management. It helps participants to build confidence in their capability to self-manage.

Many participants indicated an insufficient level of knowledge among their relatives. As a result, relatives did not always recognise or acknowledge the challenges participants were dealing with in daily life. Relatives could support participants by reading information about participant's chronic disorder and listen to nurses' instructions. Trying to understand their situation was also considered helpful.

Participation of family members during outpatient consultations was important for non-Dutch speaking participants. They often fulfilled the role of interpreter. However, most of the non-Dutch speaking participants preferred a professional interpreter given that family members are not always able to explain medical content sufficiently.

Internalizing knowledge

To be able to integrate knowledge and instruction provided, participants need the opportunity to ask questions and discuss personal circumstances with nurses during outpatient consultations. It is important for nurses to create an environment where this is enabled:

> *"Sometimes you plan to ask some questions beforehand. But, during the appointment he [doctor] is so preoccupied that it's over before you realise [it]." (FG1-R3)*

When nurses did discuss participant's personal issues and questions, this appeared to their understanding of how to self-manage in daily life. Fellow patients could support them by sharing their experiences, thus helping them to understand their own situation:

"It is helpful to hear from fellow patients that it's normal to be tired." (FG2-R4)

However, sometimes fellow patients' experiences added confusion for example when it contradicts nurses' advice.

Adjusting daily life

After kidney transplantation, participants needed to adapt daily life to their current medical situation. Given that the new regimen can be stressful, discussing changes participants are dealing with was seen to be important. Nurses could help to find new routines to bring structure to daily life, which assists in adhering to lifestyle and medication regimens. Tailoring was a requirement, because life circumstances were unique. For example:

"[seeking for a] routine. In the beginning it was very difficult. Now I have found one." (II-R3)

Positive stimulation by relatives could also help participants to modify their lifestyle or be adherent: Practical support from relatives, for example with housekeeping or buying groceries was also very much appreciated. Particularly, non-Dutch speaking participants seemed to receive a lot of practical support from relatives, mentioned to be customary within their own culture.

Several participants wished for contact with fellow patients for the purpose of sharing and discussing experiences about coping with the regimen and consequences of kidney transplantation. Participants also wanted to support others by sharing their experiences on how they dealt with medical problems, the lifestyle regimen and therapy adherence. But there was variation in the extent to which participants appreciated support from peers.

Relational support

One condition for receiving self-management support from anyone was a relationship of trust. When there is no relationship of trust, participants did not want interference. Being empathetic, reliable and a good listener were mentioned as important competences for nurses when building a relationship of trust with participants. It was also appreciated when nurses proactively asked about medical and personal issues.

Continuity of care was also important for building up this relationship. Given that participants often seek a balance between quality of life and limitations, nurses are expected to create an environment in which adjustments can be discussed and tried out.

"You [the recipient] search for a balance between quality of life and the limitations… They [nurses] should give you tools [for making choices], which is missing now." (FG1-R7)

Also, shared decision-making is favored: participants wanted to work together with nurses on the basis of collaborative partnership. This was less important for non-Dutch speaking participants who tended to rely on nurses' expertise.

> *"I told them several times to do what is right. I am not a professional. They should decide what is good for me. I hope it makes me better." (II-R12)*

Psychosocial support

<u>*Recognition of emotional aspects after kidney transplantation*</u>

Kidney transplantation was reported to be an emotional and serious life-event. Apart from medical support that was given high priority by all, most Dutch-speaking participants wanted support fitting their emotional needs. Participants needed to deal with various emotions, such as thankfulness, happiness, regret and fear. Given the fact that most participants were very emotional, it was appreciated when nurses were empathetic and recognised the psychological impact. Instead, according to participants, nurses mostly overlooked the social and emotional challenges they faced:

> *"The technical support is good...But, the human support [for emotional issues] is lacking. I expected to receive this kind of support." (FG1-R6)*

Participants appreciated the opportunity during consultations to share and discuss emotional issues. It was helpful when nurses proactively asked about their emotions and just listening to their personal story was already sufficient in most cases. Participants would appreciate receiving information about frequently occurring emotions after kidney transplantations. The fact that they are not alone in these emotions would reassure them. Nurses were considered the most appropriate persons to provide this kind of support, because doctors were reported to have 'a business-like attitude'.

Nurses should also pay attention to potentially emotionally taxing relationships with the living donor:

> *"The second time, I received a kidney from my sister. Although I am very happy with it, it also feels somewhat like a burden…Just a conversation about this would have helped me." (FG3-R9)*

One participants needed more intense professional support, because of psychological problems. In these situations, a referral to mental health services was appreciated.

Relatives can offer emotional support by listening to participants' stories. They should provide participants the opportunity to talk about their emotions and try to understand them. Discussing these emotions with fellow patients would also be helpful. In contrast, non-Dutch speaking recipients did not wish to discuss emotions.

Building self-confidence and empowerment

Participants indicated the need for feedback from nurses, relatives and fellow patients on how they are fulfilling their role as expert patient:

> *"You can motivate each other [fellow patients]." (II-R9)*

Moreover, encouragement from positive feedback about how others performed the different adaptive tasks would help to build self-confidence and regain confidence in one's own body.

DISCUSSION

This qualitative study aimed to gain insight into recipients' perspectives on self-management challenges after kidney transplantation and what kind of support they need for optimal self-management. Self-management challenges after transplantation have been investigated before (Jamieson et al., 2016), however the exploration of the fit between patients' needs and support offered is particularly unique to this study.

To become an expert patient in transplantation, participants felt the necessity to understand all relevant aspects of their condition, lifestyle and medication regimen. They wished to develop self-awareness to recognise bodily signals and understand when there is a real problem. They indicated a need to receive tailored, disease-specific information from nurses. Supporting recipients in increasing their disease-specific knowledge could have medical and psychological benefits (Coster & Norman, 2009). Tailored education has been shown to lead to larger effects than standardised patient education (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Instead, nurses tended to provide standardized patient education rather than tailoring, as has previously been reported (Been-Dahmen et al., 2015). Given that participants vary in their attitude, needs and preferences toward self-management support, personalised support after kidney transplantation is necessary (Grijpma et al., 2016). To enable nurses to respond to recipient's unique educational needs, they must assess recipient's knowledge, information needs and desired methods of education (Bos-Touwen et al., 2015). Providing standard education alone will not lead to behavioral change and is not sufficient for improving recipients' self-management skills (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Coster & Norman, 2009). Also nurses should consider involving relatives in this personalised educational strategy to ensure sufficient knowledge among the recipients' social network.

Having a relationship of trust was reported as conditional to receiving any kind of support. This is in line with previous studies, which have found that partnership between nurses and recipients is an important prerequisite to successful self-management support (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003). However, realizing collaborative partnership is often difficult for nurses (Ter Maten-Speksnijder, Grypdonck, Pool, Meurs, & Van Staa, 2015; Thorne, Ternulf Nyhlin, & Paterson, 2000; Wilson, Kendall, & Brooks, 2006). Traditionally in healthcare, professionals were the authority on medical issues and patients to passively followed their instructions. This has changed over the past decades into a more collaborative, less hierarchical model. Chronically ill patients have greater access to medical information, play a more active role in decision-making and expect partnership with professionals (Alt & Schatell, 2008; Holman & Lorig, 2000; World Health Organization, 2002). Participants in this study reported that being empathetic, reliable and a good listener were important competencies for nurses to build a trustful relationship. It was also appreciated when they proactively ask about medical and personal issues. This corresponds with literature, which describes communication as the cornerstone of a good patient-professional relationship that determines the quality of patient-centered care. Underlying principles of a therapeutic relationship are respect, genuineness, empathy, and active listening (Kennedy Sheldon & Foust, 2013).

In this study, kidney transplantation was reported to be a major life-event with emotional impact. Participants had to deal with several positive and negative emotions such as thankfulness, fear and sadness. Emotions can affect patients' self-efficacy to cope well with challenging situations (Bandura, 2004). For example, depressive symptoms can affect patients' therapy adherence after kidney transplantation (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Self-efficacy is a predictor of patients' successfulness in managing a chronic disorder (Bandura, 1977, 2004). The core element of nurses' self-management support should therefore be coaching recipients to develop problem-solving skills and increase their self-efficacy. Support focusing on internal processes and perceived locus of control is effective for the persistence and performance of new behavior (van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2016) and generalization of acquired skills to new challenges in the future. Nurses mostly overlook these emotional challenges and importance of promoting these skills (Been-Dahmen et al., 2015; Ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). We note that not all participants wished to discuss emotional challenges, in particular the non-Dutch speaking participants (Mesquita & Frijda, 1992). This again highlights the importance of the assessment phase, adequate tailoring and cultural sensitivity.

Limitations

For qualitative research a large sample is not necessary, but it is important to have varied respondents that represent differing views on the topic. Therefore, an important strength of this study was the sample variation with regard to sociodemographic and medical characteristics. In contrast to other studies that often exclude potential participants who do not speak the dominant language, we involved them in individual interviews. Moreover, in the Dutch-speaking group various nationalities were also represented. Including a broad sample and using both group and individual interviews helped to develop a more comprehensive understanding of recipients' needs and to validate conclusions (Polit & Beck, 2008). Despite our efforts to create a representative sample, half of those approached did not participate, often due to illness. There may be specific self-management support needs among those who did not participate that we did not capture here. Furthermore, the study was conducted in a single-centre in the Netherlands. Therefore, results may be not generalizable to all kidney transplant recipients in other settings. Finally, although using pre-existing theoretical frameworks to guide the categorization of data could be seen as restrictive, we highlight that we were alert for new themes that fell outside these models in order to capture novel information that could inform the development of such models. This study goes beyond a description of challenges through giving recipients a voice to improve support.

Practice Implications

Findings should inform the development of self-management interventions, education and training, particularly of nurses who are often the first port of call for self-management support. Tools and training are needed to help nurses and other health care professionals to meet the emotional and social support needs. For example, self-management support skills should be a core competency in nursing training. To connect to recipients' individual daily life challenges, we encourage nurses to assess post-transplant self-management needs and tailor education and support accordingly. For example, for some patients using trained fellow patients could be a welcome addition. Cultural sensitivity is also required, for example, following the patient in which topics they wish to focus on according to their cultural values and norms.

CONCLUSION

Participants in this study expressed various challenges in dealing with the medical, emotional and social tasks after kidney transplantation: becoming an expert patient in transplantation, managing treatment, forming relationship with professionals, adjusting daily life activities, dealing with social consequences, improving self-image, and dealing with emotions related to transplantation and the donor. Current support from nurses was mostly focused on the medical challenges and overlooked recipients' needs for support in dealing with the emotional and social challenges after kidney transplantation. There was a need for more holistic support. Recipients agreed that nurses, relatives, or fellow patients can only provide self-management support effectively when there is a relationship of trust. In this study, some differences were found between Dutch and non-Dutch speaking participants therefore cultural sensitivity is required when assessing needs and tailoring of support offered.

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PART II

Development of a self-management support intervention

CHAPTER 5

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

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ABSTRACT

Aim

The aim of this study was to examine how nurse-led interventions that support self-management 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 self-management 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 self-efficacy). 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 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?

- 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 (Wilkinson & Whitehead 2009, Kendall et al. 2011, Jonsdottir 2013). 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 (Schenk & Hartley 2002, Alleyne et al. 2011, Elissen et al. 2013).

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 (Coster & Norman 2009, Bonell et al. 2012).

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 (Radhakrishnan 2012, Jones et al. 2014, 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, Radhakrishnan 2012, Bonner et al. 2014). 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 synthesise 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).

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

Step	Summary 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 (Supplement 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.

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 (Van Houtum et al. 2013, Dwarswaard et al. 2016).

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.

Quality appraisal

Methodological quality of the qualitative studies was assessed with the Qualitative research review guidelines - RATS (Clark 2003). Methodological quality of RCTs was

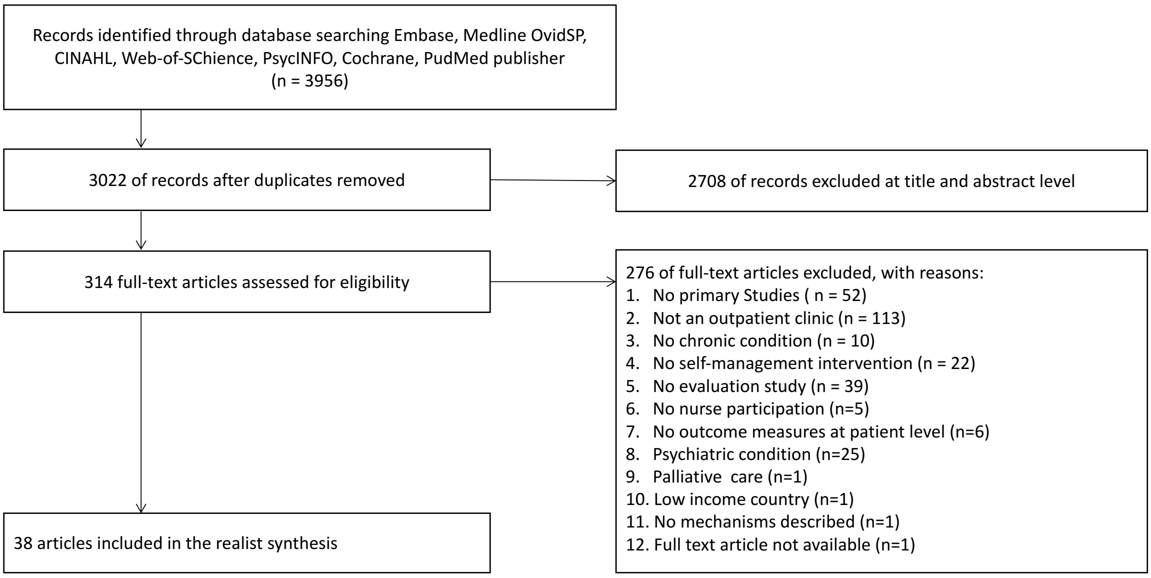

Figure 1. Flowchart of studies from identification to inclusion

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 (Leeman et al. 2010, Hoare et al. 2012). 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 studies 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.

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*)
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

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*)
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
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
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
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

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*)
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
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
Van der Meer et al. (2009), The Netherlands	Education Groups Telemonitoring	RCT	*n=200* Asthma
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
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

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

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 et al. (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)

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 realised. The CMO-strings we identified by comparing all studies are described below and presented in Supplement 4.

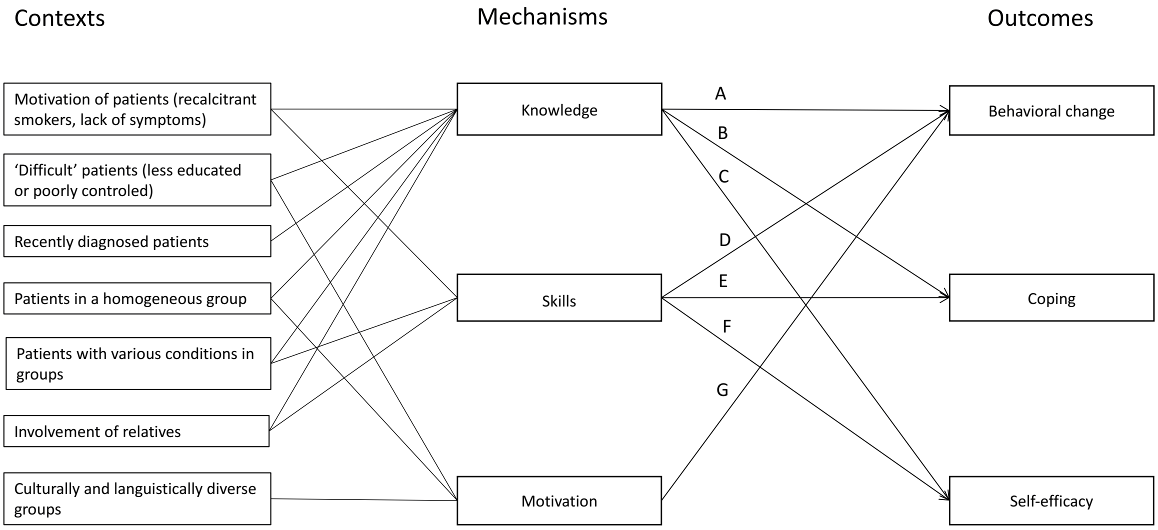

Figure 2. A to G: strings between Mechanisms and Outcomes

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, Rootmensen et al. 2008, Trappenburg et al. 2008, Huang et al. 2009, Van der Meer et al. 2009, Rönning et al. 2011, Yıldız & Kurcer 2012, Gonzalez 2014, Goossens et al. 2014, Howden et al. 2014, Yu et al. 2014, Grilo et al. 2015), on the one aiming at behavioural change (Wilson et al. 2008, Moriyama et al. 2009, Otsu & Moriyama 2011, Choi & Lee 2012, Otsu & Moriyama 2012), 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-)monitoring was applied to provide patients feedback about their knowledge gain and behavioural change (Balk et al. 2008, Trappenburg et al. 2008, Huang et al. 2009, Moriyama et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012, Grilo et al. 2015). 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 (Huang et al. 2009, Choi & Lee 2012). 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 recognise warning signs that required behaviour change (Balk et al. 2008, Huang et al. 2009). However, self-monitoring 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 (Trappenburg et al. 2008, Wilson et al. 2008, Moriyama et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012, Yıldız & Kurcer 2012, Gonzalez 2014, Howden et al. 2014, Lee et al. 2014, Yu et al. 2014, Grilo et al. 2015). 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, Rootmensen et al. 2008, Huang et al. 2009, Choi & Lee 2012, Goossens et al. 2014). But change of behaviour was only achieved if re-enforcement and repeated education sessions were provided (Huang et al. 2009, Choi & Lee 2012). 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 (Monninkhof et al. 2003, Schreurs et al. 2003, Tsay et al. 2005, Van Os-Medendorp et al. 2007a, Van Os-Medendorp et al. 2007b, Bakan & Akyol 2008, Hagberth et al. 2008, Jiang & He 2012, Akyil & Ergüney 2013). 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 (Monninkhof et al. 2003, Van Os-Medendorp et al. 2007a, Van Os-Medendorp et al. 2007, Bakan & Akyol 2008, Hagberth et al. 2008, Jiang & He 2012, Akyil & Ergüney 2013). Through this reinterpretation, patients were more successful in dealing with these symptoms (Van Os-Medendorp et al. 2007a, Van Os-Medendorp et al. 2007b, Jiang & He 2012, Akyil & Ergüney 2013). 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 (Monninkhof et al. 2003, Bakan & Akyol 2008), activating the family (Monninkhof et al. 2003, Bakan & Akyol 2008, Sarian et al. 2011), or keeping a diary so as to raise awareness of how they dealt with symptoms (Schreurs et al. 2003, Tsay et al. 2005, Van Os-Medendorp et al. 2007b). 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 personalised. 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 4).

String C Knowledge leads to self-efficacy

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

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 self-efficacy (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 (Rootmensen et al. 2008, Huang et al. 2009) and on the one emphasizing behavioural change (Wilson et al. 2008, Moriyama et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012). All interventions aimed at learning 'how-to'- skills, such as inhalation (Rootmensen et al. 2008) and relaxation techniques (Wilson et al. 2008), abandoning smoking (Rootmensen et al. 2008, Wilson et al. 2008, Moriyama et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012), 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 (Rootmensen et al. 2008, Wilson et al. 2008, Otsu & Moriyama 2011, Otsu & Moriyama 2012). For instance, this combination of *string*s was less successful in the context of poorly motivated patients and reluctant smokers (Wilson et al. 2008, Moriyama et al. 2009). 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 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 (Monninkhof et al. 2003, Schreurs et al. 2003, Tsay et al. 2005, Van Os-Medendorp et al. 2007a, Van Os-Medendorp et al. 2007b, Jiang & He 2012, Lee et al. 2014). 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 (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Smeulders et al. 2010a, Smeulders et al. 2010, Kaşıkçı 2011, Donesky et al. 2014). 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' (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Smeulders et al. 2010a, Smeulders et al. 2010b, Kaşıkçı 2011, Donesky et al. 2014), 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 self-management 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 (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Zoffmann & Lauritzen 2006, Kaşıkçı 2011, 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 (Coster & Norman 2009, Barlow et al. 2010). 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. 2016). 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 (Lagger et al. 2010, Faradji et al. 2012); 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 (Kane et al. 2010, Wong et al. 2010, Higgins et al. 2012). 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 (Van Os et al. 2004, Michie & Prestwich 2010).

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.

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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))

Supplement 2. Table Quality appraisal

Items of quality appraisal	Risk of Bias (RCT's)^a						Quality other quantitative studies^b						Quality of qualitative studies^c									
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 et al. (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										
Monninkhof et al. (2003), The Netherlands	+	+	0	+	0	+																
Moriyama et al. (2009), Japan	0	0	0	+	0	-																
Otsu & Moriyama (2011) & (2012), Japan	+	0	+	+	0	0																

Supplement 2. Table Quality appraisal (*continued*)

Items of quality appraisal	Risk of Bias (RCT's)[a]						Quality other quantitative studies[b]						Quality of qualitative studies[c]									
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
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																
Van der Meer et al. (2009), The Netherlands	+	+	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
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																

[a] 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

[b] Quality rating according to Huis et al. (2012)

[c] 1= Not at all/ 2= A little/ 3= Reasonable/ 4= Very

Supplement 3. Table Overview of selected studies with effect sizes (in alphabetical order by first author)

Author(s); year of publication	*Design*	*Theory mentioned in study*	*Patient group characteristics (n; diagnosis)*
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)
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
Howden et al. (2015)	RCT	Not mentioned	n=83 CKD

Outcomes Hedges (G)[a] *- Knowledge* *- Behavioural change* *- Skills* *- Coping* *- Self-efficacy* *Only reported / calculated if measured in the original study*	*Outcomes Hedges (G)*[a] *- Clinical outcomes* *- Quality of Life* *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)
	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)

Supplement 3. Table Overview of selected studies with effect sizes (in alphabetical order by first author) (*continued*)

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
Monninkhof et al. (2003)	RCT	Not mentioned	n=248 COPD
Moriyama et al. (2009)	RCT	Theory of cognitive behaviour	n=65 DM type 2
Otsu & Moriyama (2011)	RCT	Theory of cognitive behaviour	n=102 CHF Retired elderly persons
Otsu & Moriyama (2012), Japan	RCT	Theory of cognitive behaviour	n=94 CHF Retired elderly persons

1st value = Education/ 2nd 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) COPD self-efficacy 0.13 (-0.19 – 0.45)	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)
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)

Supplement 3. Table Overview of selected studies with effect sizes (in alphabetical order by first author) (*continued*)

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
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
Van der Meer et al. (2009)	RCT	Not mentioned	n=200 Asthma
Van Os-Medendorp et al. (2007a)	Mixed-methods	Coping strategies	n=65 Chronic pruritic skin disease
Van Os-Medendorp et al. (2007b)	RCT	Coping strategies	n=65 Chronic pruritic skin 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

Knowledge 0.00 (-0.31 - 0.31) Coping 0.04 (-0.27 - 0.35) Skills: Inhalation technique 0.45 (0.12 - 0.78)	
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 (-0.46 - -0.01)
	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)
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)

Supplement 3. Table Overview of selected studies with effect sizes (in alphabetical order by first author) (*continued*)

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

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

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

:Supplement 4. Table Context, mechanism, outcome of self-management interventions

String	Context	Mechanism	Outcome
A) Knowledge leads to Behavioural change (Balk et al. 2008, Rootmensen et al. 2008, Huang et al. 2009, Moriyama et al. 2009, Trappenburg et al. 2008, Wilson et al. 2008, Van der Meer et al. 2009, Otsu & Moriyama 2011, Rönning et al. 2011, Choi & Lee 2012, Otsu & Moriyama 2012, Yıldız & Kurcer 2012, Gonzalez 2014, Goossens et al. 2014, Howden et al. 2014, Yu et al. 2014, Grilo et al. 2015)	*Motivation of patients* Recalcitrant smokers with little confidence in a new attempt to quit smoking, who lack symptoms of dyspnoea at the time of the intervention and live with another smoker, and health illiterate food-insecure patients whose food choices are culturally influenced	*Knowledge* Providing education about the chronic condition, the risk of smoking or unhealthy food, and how to use medication.	*Behavioural change* These interventions did not lead to behavioural change (Wilson et al. 2008, Grilo et al. 2015).
	Difficult patients 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 sessions or follow-up telephone calls, and answered individual questions.	*Behavioural change* 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).
	Recently diagnosed patients Recently diagnosed patients with chronic heart failure	*Knowledge* Providing feedback about patients' knowledge by self-monitoring.	*Behavioural change* 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	*Behavioural change* This intervention did not have a surplus value for this group (Balk et al. 2008).

Supplement 4. Table Context, mechanism, outcome of self-management interventions (*continued*)

String	Context	Mechanism	Outcome
B) Knowledge leads to Coping (Monninkhof et al. 2003, Schreurs et al., 2003, Tsay et al. 2005, Lindskov et al. 2007, Van Os-Medendorp et al. 2007a, Van Os-Medendorp, et al. 2007b, Bakan & Akyol 2008, Hagberth et al. 2008, Sarian et al. 2011, Jiang & He 2012, Akyil & Ergüney 2013)	*Patients in a homogeneous group*	*Knowledge* Sharing experiences and knowledge with peers	*Coping* 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).
	Undefined context 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.	*Coping* Patients learned to reinterpret the situation and thus were better able to cope with the disease (Monninkhof et al. 2003, Schreurs et al. 2003, Tsay et al. 2005, Lindskov et al. 2007, Bakan & Akyol 2008, Jiang & He 2012, Akyil & Ergüney 2013).
	Involvement of relatives	*Knowledge* Relatives were involved in the intervention.	*Coping* Patients were better supported in their daily lives (Monninkhof et al. 2003, Bakan & Akyol 2008, Sarian et al. 2011).
	Patients in a homogeneous group Patients with peritoneal dialysis in a group with fellow patients	*Knowledge* Discussing scenarios with peers	*Coping* 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	*Coping* Participants were disappointed if goals could not be reached quickly enough (Schreurs et al. 2003, Tsay et al. 2005).

Supplement 4. Table Context, mechanism, outcome of self-management interventions (*continued*)

String	Context	Mechanism	Outcome
C) Knowledge leads to Self-efficacy (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Smeulders et al. 2010a, Smeulders et al. 2010b, Kaşıkçı, 2011, Donesky et al. 2014)	*Undefined context* Patients with COPD in individual counselling sessions	*Knowledge* Patients were encouraged to discuss everyday disease related problems.	Coping Patients learned to reinterpret the situation, confidence to deal with the disease increased (Kaşıkçı 2011, Donesky et al. 2014).
	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 (Rootmensen et al. 2008, Wilson et al. 2008, Huang et al. 2009, Moriyama et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012)	*Motivation of patients* 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.	*Behavioural change* This discussion served as a cue to action for patients (Wilson et al. 2008, Moriyama et al. 2009).
	Undefined context Patients with asthma	*Skills* Patients learned to monitor their condition.	*Behavioural change* The monitoring led to self-care behaviour (Huang et al. 2009).
	Involvement of relatives Patients with chronic conditions, with involvement of family	*Skills* Family received instructions about skills which the patient should master, then they could support the patient in this process	*Behavioural change* 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. Table Context, mechanism, outcome of self-management interventions (*continued*)

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

Supplement 4. Table Context, mechanism, outcome of self-management interventions (*continued*)

String	Context	Mechanism	Outcome
G) Motivation leads to Behavioural change (Zoffmann & Lauritzen, 2006, Williams et al. 2012, Zoffmann & Kirkevold 2012)	*'Difficult patients'* Patients with poorly controlled diabetes	*Motivation* Reflection of patients on their problems in controlling the diabetes.	*Behavioural change* 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).
	'Difficult patients' Patients with poorly controlled diabetes	*Motivation* Reflection by patients and nurses on the difficulties of living with diabetes.	*Behavioural change* 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	*Motivation* 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	*Motivation* Using interpreters	*Behavioural change* 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 leads to behavioural change	Brief medical advice (Wilson et al. 2008) Computer-based education / CD (Rönning et al. 2011) Computerized intake form/checklist (Goossens et al. 2014) Diary records (Yu et al. 2014) Daily biomedical self-measurements (Balk et al. 2008, Huang et al. 2009) Educational group sessions (with fellow patients and/or relatives)(Wilson et al. 2008, Van der Meer et aL.2009, Choi & Lee 2012) Feedback from monitoring device (Trappenburg et al. 2008) Individualized education plan (Balk et al. 2008, Wilson et al. 2008, Yu et al, 2014) Individualized face-to-face education sessions (Rootmensen et al. 2008, Wilson et al. 2008, Huang et al. 2009, Moriyama et al. 2009, Otsu & Moriyama 2011, Choi & Lee 2012, Otsu & Moriyama 2012, Yıldız & Kurcer 2012, Gonzalez 2014, Goossens et al. 2014, Yu et al. 2014, Howden et al. 2015)	Knowledge questionnaire (Rönning et al. 2011) Letter to the family describing ways to assist patients (Otsu & Moriyama 2011, Otsu & Moriyama 2012) Medication and appointment reminders (Grilo et al. 2015) Monitoring by healthcare professional (Yıldız & Kurcer 2012) Motivational interviewing (Grilo et al. 2015) Patient education brochure (Wilson et al. 2008, Huang et al. 2009, Gonzalez 2014) Personal targets (Grilo et al. 2015) Personalized daily questions (Trappenburg et al. 2008) Personalized feedback (Van der Meer et al. 2009, Otsu & Moriyama 2011, Otsu & Moriyama 2012)	Phone calls (Huang et al. 2009, Moriyama et al. 2009, Yu et al. 2014, Grilo et al. 2015) Presentation (Choi & Lee, 2012, Gonzalez 2014) Relatives attend sessions/involvement (Moriyama et al. 2009, Yu et al. 2014) Self-monitoring (Huang et al. 2009, Van der Meer et al. 2009, Otsu & Moriyama, 2011; Otsu & Moriyama 2012,) Telemonitoring (Grilo et al. 2015, Trappenburg et al. 2008) Textbook (Otsu & Moriyama 2011, Otsu & Moriyama 2012, Yu et al. 2014) Text messaging (Yu et al. 2014) TV-channel (Balk et al. 2008) Web-based education (Van der Meer et al. 2009)
B) Knowledge leads to coping	Audio CD (Jiang & He 2012) Awareness training by use of diary (Os-Medendorp et al. 2007a, 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 (Monninkhof et al. 2003, Os-Medendorp et al. 2007a, Os-Medendorp et al. 2007b, Akyil & Ergüney 2013) Case studies (Sarian et al. 2011) Crossword puzzle (Bakan & Akyol 2008)	Educational group sessions (with fellow patients and/or relatives) (Monninkhof et al. 2003, Schreurs et al. 2003, Tsay et al. 2005, Lindskov et al. 2007, Bakan & Akyol 2008, Hagberth et al. 2008, Sarian et al. 2011) Experienced layman from patient association (Hagberth et al. 2008) Home work (Schreurs et al. 2003) Individualized face-to-face education (Lindskov et al. 2007, Os-Medendorp et al. 2007a, Os-Medendorp et al. 2007b, Bakan & Akyol 2008, Sarian et al. 2011, Akyil & Ergüney 2013)	Patient workbook (Schreurs et al. 2003) Peer support (fellow patients) (Tsay et al. 2005, Bakan & Akyol 2008, Sarian et al. 2011) Phone calls (Bakan & Akyol 2008, Jiang & He 2012, Akyil & Ergüney 2013) 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)

Supplement 5. Table Components of self-management support interventions (*continued*)

	Components		
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 (Rootmensen et al. 2008, Wilson et al. 2008, Huang et al. 2009)	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)
E) Skills enhancement leads to coping	Diary records (Tsay et al. 2005, Os-Medendorp et al. 2007a, Os-Medendorp et al. 2007b) Group counselling and support (Monninkhof et al. 2003) Individual counselling and support (Os-Medendorp et al. 2007a, Os-Medendorp et al. 2007b) Individualized action plan (Schreurs et al. 2003, Lee et al. 2014) Instruction booklet (Monninkhof et al. 2003, Jiang & He 2012, Lee et al. 2014)	Motivational interviewing (Os-Medendorp et al. 2007a, 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)

Supplement 5. Table Components of self-management support interventions (*continued*)

	Components		
F) Skills enhancement leads to self-efficacy	Coaching during exercise (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Donesky et al. 2014) 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 (Smeulders et al. 2010, Donesky et al. 2014)	Personal targets (Kara & Aşti 2004) Record keeping of daily practice (Carrieri-Kohlman et al. 2005; Donesky et al. 2014) Supervised training and workout sessions (Kara & Aşti 2004, Carrieri-Kohlman et al. 2005, Kaşıkçı 2011, Donesky et al. 2014)
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 (Zoffmann & Lauritzen 2006, Williams et al. 2012) Phone calls (Williams et al. 2012)	Presentation (in patients' own language) (Williams et al. 2012) Reflection sheets (Zoffmann & Lauritzen 2006, Zoffmann & Kirkevold 2012)

CHAPTER 6

The development of a nurse-led self-management support intervention for kidney transplant recipients using intervention mapping: the ZENN-study

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Submitted

ABSTRACT

This study describes the development of a self-management support intervention for kidney transplant recipients using Intervention Mapping. Needs were assessed by reviewing the literature and conducting qualitative research among nurses and patients. Change objectives were formulated based upon these needs and theories of behaviour change. Evidence-based methods to achieve these objectives were translated into implementation strategies. The intervention protocol describes how nurses support patients in assessing challenges using the Self-Management Web, setting goals, making action plans, and developing problem-solving skills. The Intervention Mapping protocol proved useful for systematically developing a nursing intervention that integrates needs, evidence-based methods and theories.

INTRODUCTION

Kidney transplantation is the best option for end stage renal decease (ESRD). However, kidney transplant recipients need to adhere to a lifelong medication regimen and optimal self-management is essential for patient and graft survival, reducing comorbidity and healthcare costs while improving quality of life (Agarwal et al., 2011; Butler, Roderick, Mullee, Mason, & Peveler, 2004; Denhaerynck et al., 2005; Hoogeveen et al., 2011; Hurst et al., 2011; Weng, Dai, Huang, & Chiang, 2010). This has led to an increasing interest in optimizing patients' self-management skills (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Self-management can be defined as the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, psychosocial, cultural, and spiritual consequences of health conditions to maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Despite the importance of optimal self-management after transplantation, non-adherence to immunosuppressive medication, diet and exercise has been reported to be relatively high, (20 - 35%) (Dew et al., 2007; Massey et al., 2013; Nevins, Robiner, & Thomas, 2014). Recipients themselves also report self-management tasks to be challenging, such as adhering to immunosuppressive medication, monitoring symptoms and managing side-effects, lifestyle changes and coping with psychological consequences (Schmid-Mohler, Schafer-Keller, Frei, Fehr, & Spirig, 2014) and report the need for improved self-management support (SMS) from healthcare professionals (Elissen et al., 2013; Udlis, 2011; van Houtum, Rijken, Heijmans, & Groenewegen, 2013; Wagner et al., 2001). Studies have revealed that SMS can lead to higher patient wellbeing and quality of life, improved health and a decrease in care consumption (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Jamieson et al., 2015; Weng et al., 2010).

Interventions aimed at optimizing kidney transplant recipients' self-management are, however, scarce. Furthermore, the existing interventions have a number of limitations (De Bleser, Matteson, Dobbels, Russell, & De Geest, 2009; Low, Williams, Manias, & Crawford, 2015): 1) a focus on medication adherence without sufficiently integrating psychosocial and behavioural challenges, (2) insufficient tailoring to individual patient needs and (3) lack of theoretical framework and use of evidence-based behavioural change techniques. There is therefore a need for the development and testing of better-quality interventions which improve upon these short-comings.

An important consideration when developing an intervention is the choice of healthcare professional providing SMS. Traditionally, professionals had a paternalistic approach typified by a directive style rather than shared decision making, and a main focus on medical issues (Teutsch, 2003). This approach may be less effective in establishing a relationship of trust and behaviour change (Gallagher & Updegraff, 2012; Teutsch, 2003). Nurse practitioners (NPs) are often key actors in psychosocial support and are in an excellent position to create an environment in which patients feel confident to talk about their concerns (Alleyne et al., 2011; Allen, 2004). A self-management support intervention delivered by NPs may therefore help increase effectiveness. However, little is known about current SMS practices, attitudes towards SMS among nurses and their needs to help improve the support offered.

The aim of this study was to develop a nurse-led SMS intervention in which the needs of kidney transplant recipients and NPs as well as theory and evidence-based methods are taken into account. To ensure that these components were incorporated, the Intervention Mapping (IM) protocol was used (Bartholomew, Parcel, & Kok, 2011).

Method

Intervention Mapping

The IM protocol (Kok, Schaalsma, & Ruiter et al., 2004) distinguishes six steps with corresponding tasks. Here, we present the first five steps of the IM protocol (Figure 1). In total, the development and implementation of the intervention took two years (2015-2017).

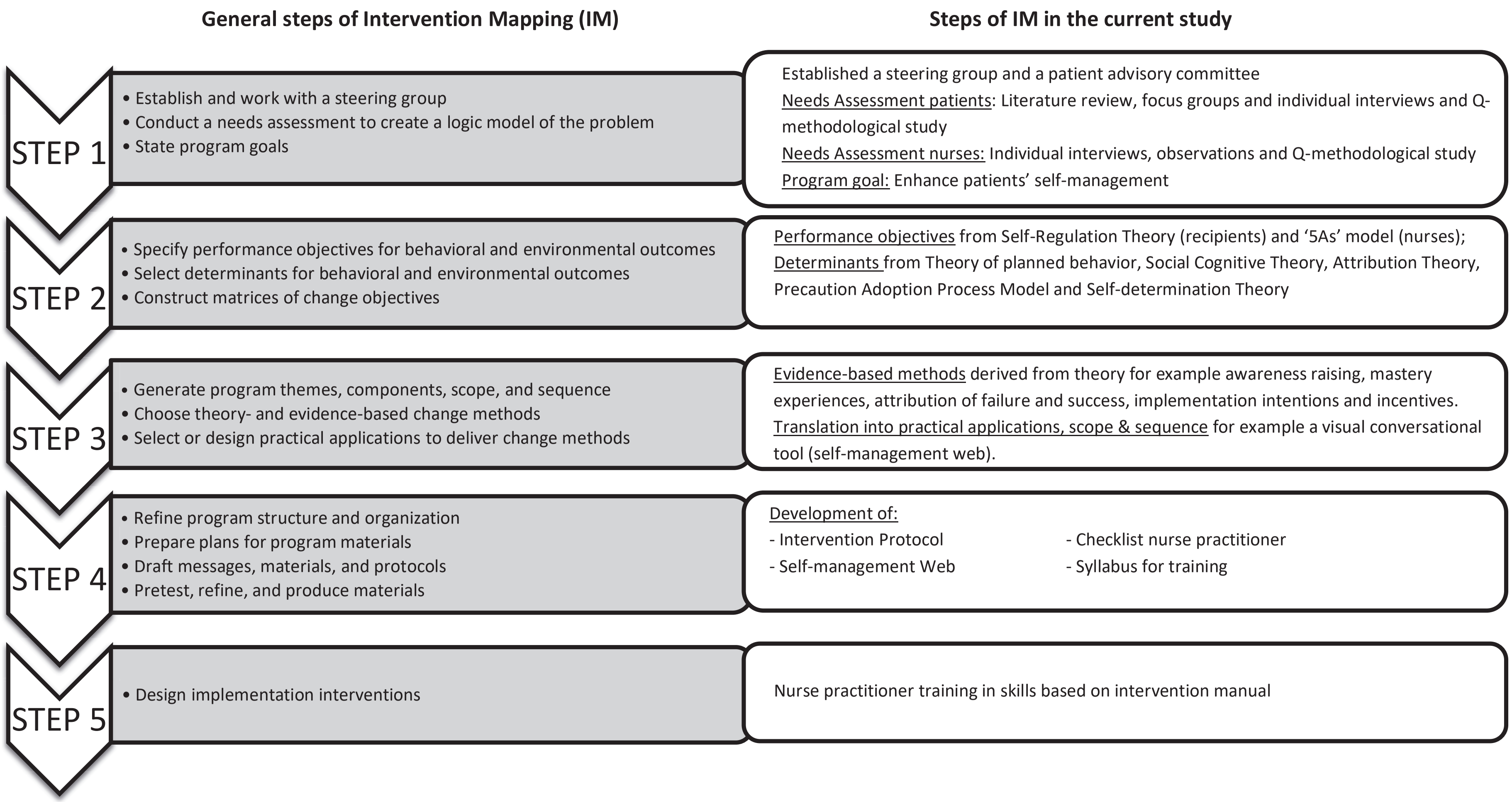
Step 1 Needs assessment

The first step is the needs assessment; a comprehensive exploration of the health problem and the needs of the targeted population. To ensure that important issues for both the patients and NPs were addressed throughout the process, a steering group consisting of NPs, nephrologists, nurse scientists (experts in self-management) and psychologists and a patient advisory committee were established.

The needs of kidney transplant patients and NPs regarding self-management (support) were explored in several studies including a literature review of qualitative studies, interviews and observations.

Assessment of patients' needs

Firstly, we reviewed the qualitative literature on patient needs and preferences for SMS (Dwarswaard, Bakker, van Staa, & Boeije, 2016. This review revealed that it is important to patients that SMS is tailored to their individual needs. Furthermore, they need not only 'information', but also instrumental, psychosocial and relational support. Patients often reported that these needs were unmet as professionals focus on informational and instrumental support alone (Dwarswaard et al., 2016). Developing a collaborative partnership with shared decision-making is key to improving SMS (Dwarswaard et al., 2016).



	General steps of Intervention Mapping (IM)	Steps of IM in the current study
STEP 1	• Establish and work with a steering group • Conduct a needs assessment to create a logic model of the problem • State program goals	Established a steering group and a patient advisory committee Needs Assessment patients: Literature review, focus groups and individual interviews and Q-methodological study Needs Assessment nurses: Individual interviews, observations and Q-methodological study Program goal: Enhance patients' self-management
STEP 2	• Specify performance objectives for behavioral and environmental outcomes • Select determinants for behavioral and environmental outcomes • Construct matrices of change objectives	Performance objectives from Self-Regulation Theory (recipients) and '5As' model (nurses); Determinants from Theory of planned behavior, Social Cognitive Theory, Attribution Theory, Precaution Adoption Process Model and Self-determination Theory
STEP 3	• Generate program themes, components, scope, and sequence • Choose theory- and evidence-based change methods • Select or design practical applications to deliver change methods	Evidence-based methods derived from theory for example awareness raising, mastery experiences, attribution of failure and success, implementation intentions and incentives. Translation into practical applications, scope & sequence for example a visual conversational tool (self-management web).
STEP 4	• Refine program structure and organization • Prepare plans for program materials • Draft messages, materials, and protocols • Pretest, refine, and produce materials	Development of: - Intervention Protocol - Self-management Web - Checklist nurse practitioner - Syllabus for training
STEP 5	• Design implementation interventions	Nurse practitioner training in skills based on intervention manual

Figure 1 The Five steps of the IM protocol

This encouraged us to further assess the specific needs, preferences and challenges with regard to SMS of kidney transplant recipients through focus groups and individual interviews (n=32) (Been-Dahmen et al., *2018*). Results indicated a need for a holistic approach after kidney transplantation. While patients were satisfied with the medical care received, psychosocial support focusing on emotional challenges of living with a transplant was often lacking. Patients wanted to participate in shared decision-making and be collaborators in the process. To achieve this a relationship of trusts was an essential basis. This type of support was particularly important in the first year after transplantation. However, one size does not fit all and SMS should be adapted to individual needs and circumstances. This was confirmed in a Q-methodological study which found differing attitudes towards self-management support (Grijpma et al., 2015).

Assessment of nurses' needs

To explore nurses' perceptions, attitudes and potential needs, interviews and observations were used. Individual semi-structured interviews with nurses and NPs were held (n=27) to investigate nurses' views on the concept of self-management in general and how these views relate to the self-management interventions they use in clinical practice (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015). Results showed three distinct views on SMS: adhering to a medical regimen, monitoring symptoms and integrating illness into daily life. Only the last viewpoint reflected a holistic approach with the nurse focusing on coaching. Medical management was the focus of SMS for many nurses. The lack of attention for psychosocial aspects may be due to a lack of confidence, skills needed to address psychosocial issues or available tools/interventions which limits them in offering psychosocial support. Providing training or practical interventions protocols or tools for holistic SMS could partially resolve this problem by giving nurses resources to effectively support to self-management.

In order to more objectively assess NPs' roles in outpatient consultations and how this compares to their perception of their responsibilities for patients with chronic conditions, NPs (n=5) were observed during daily practice (Ter Maten-Speksnijder, Dwarswaard, Meurs, & Van Staa, 2016). While NPs reported they considered building a relationship with their patients of utmost importance, their consultations were mostly based on a conventional medical model of medical history taking. Little attention was paid to the social, psychological and behavioural dimensions of illness. Finally, a realist review of the literature was conducted to assess the mechanisms by which nursing interventions successfully promote self-management. Interventions focusing on intrinsic processes were found to be the most effective, as opposed to focusing solely on psycho-education (van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2016). Box 1 outlined the main findings from the needs assessment.

Box 1. Summary of findings from the needs assessment

Patients' Needs Assessment	*Nurses' Needs Assessment*
- Medical and psychosocial issues should both be addressed; attention to psychosocial needs often lacking	- Nurses place an emphasis on medical management to the detriment of psychosocial management
- Tailoring of support to specific needs and preferences is important to patients	- Nurses focus on education rather than on patient empowerment and coaching
- SMS most needed first year post-transplant	- Nursing interventions focusing on intrinsic process are more successful in promoting self-management
- Shared-decision making is preferred	

<u>*Program goals*</u>

Based on the needs assessment described above, we developed a nurse-led SMS intervention that included the following key elements: (1) a general, open structure that leaves room for individual preferences and tailoring of support, (2) a holistic approach encompassing medical, emotional and social self-management challenges, (3) promoting shared-decision making between nurse and patient, and (4) patient empowerment through supporting self-efficacy and intrinsic motivation. The overall goal of the intervention is for patients to enhance their self-management skills in order to integrate their treatment- and life goals and subsequently optimize their quality of life and health-related outcomes. In addition, we aimed to improve NPs' skills to optimize self-management support.

Step 2 Matrices of change objectives: Patients

The second step of IM links the overall goals of the intervention to concrete actions by stating change objectives (COs); the most detailed and proximal goals that will be addressed in the intervention. The COs specify who and what will change because of the intervention. In order to generate COs, performance objectives (POs) are generated and determinants of these behaviours are sought. POs and the relevant determinants are combined into a matrix in order to generate COs. Over 50 change objectives were formulated and integrated in the intervention.

<u>*Performance objectives*</u>

The overall program goal was translated into performance objectives (POs) that specify the behavioural actions the target groups need to perform in order to successfully change behaviour. The target groups were kidney transplant recipients and NPs. Optimizing self-management after kidney transplantation requires intrinsic processes (e.g. motivation and self-efficacy) (Lorig & Holman, 2003) and long-term skills to establish and maintain behaviour change, but also abilities to adapt behaviour when circumstances change. Well-developed self-regulation skills are supportive in performing these tasks. Therefore, the specific behavioural actions that contribute to the overall goal of the intervention were specified in POs based on the principles of self-regulation theories (Maes & Karoly, 2005). Studies in other chronic illnesses showed that interventions based on self-regulation theories were able to improve behavioural outcomes (Clark et al., 2007; Janssen, De Gucht, van Exel, & Maes, 2013; Knittle, Maes, & de Gucht, 2010). Eight POs were defined, which include goal setting, planning, self-monitoring, feedback and relapse prevention, see Box 2.

Box 2. Performance objectives for patients and nurses

Patients

1) Patients decide to improve their self-management on medical or emotional tasks they perceive as challenging
2) Patients set at least one SMART-goal
3) Patients make an action plan to actively pursue and attain their chosen goal, taking into account possible facilitators, barriers and resources
4) Patients carry out their goal-attainment action plan at home
5) Patients monitor their goal-pursuit behaviour in daily life
6) Patients evaluate their progress with NPs
   6a) If successful, patients maintain their new behaviour or set a new goal
   6b) If unsuccessful, patients adjust their goal, action plan, or outcome expectations
7) Patients are able to cope with relapse and re-initiate goal pursuit
8) Patients are able to generalize learned self-management skills to new goals

Nurses

1) The NPs carry out the intervention during their consultations with patients included in the study
   1a) The NPs assess whether patients perceive medical, social or emotional tasks as challenging
   1b) When patients indicate that there is a problem in a specific life area, the NPs stimulate and guide the patients to set a SMART goal to solve the problem and agrees with the patient on the goal
   1c) The NPs stimulate and assist patients to make and implement action plans for attaining their goals
   1d) The NPs encourage patients to monitor and evaluate their progress towards goal attainment
   1e) The NPs stimulate patients to maintain goal pursuit or adapt goals or action plans
   1f) The NPs help patients to anticipate relapse and discuss relapse prevention
   1g) The NPs help patients to generalize learned techniques to new problems and goals
2) The NPs focus on the positive desired outcomes rather than on the negative aspects of living with the kidney transplant

Determinants

After the definition of POs, we explored which determinants were associated with the performance of the desired behaviour as stated in the POs. The determinants were selected from the following health behaviour change theories: Self-Regulation Theory (Maes & Karoly, 2005), Theory of Planned Behaviour (Ajzen, 1991), Social Cognitive Theory (Bandura, 1991), Attribution Theory (Weiner, 1982), Relapse Prevention Theory (Marlatt & Gordon, 1985), Precaution Adoption Process Model (Weinstein & Sandman, 1992) and Self-Determination Theory (Deci & Ryan, 1985). The most important determinants for the first four performance objectives are specified in Table 1.

Table 1: Examples of Change Objectives for Patients derived from combining the Performance Objectives and determinants

Performance objective	*Behavioural determinants*						
	Awareness	Attitude	Self-efficacy	Autonomous motivation	Social support	Commitment	Skills
1. Patients decide to improve an aspect of their life	Acknowledge improvement is possible in one or more areas in their life Are aware of discrepancy between desired and current situation	Have stronger positive feelings towards improving self-management than negative	Feel able to improve aspect of their life	Are intrinsically motivated to improve aspect of life			
2. Patients set at least one SMART-goal	Are aware of the desired outcome	Have positive feelings towards goal	Formulate a change/goal that they feel self-efficacious about				Are capable of setting a SMART-goal
3. Patients make an action plan to attain and actively pursue their chosen goal.	Are aware of possible habits, facilitators, barriers and resources	Have positive feelings towards the action plan	Draw up an action plan they feel able to carry out		Consider possible social support when making action plan		Are capable of making an action plan in which facilitators, barriers, habits and resources are considered
4. Patients carry out their goal-attainment action plan at home		Have stronger positive feelings towards carrying out the plan than negative	Feel able/self-efficacious about performing the action plan	Are intrinsically motivated to carry out action plan	Use their social resources according to plan	Show commitment to pursuing the behavior in daily life	

Table 2: Examples of Change Objectives for Nurses derived from combining the Performance Objectives and determinants

Performance objective	*Behavioral determinants*					
	Awareness	Knowledge	Skills	Self-efficacy	Attitude	Professional role and identity
1. NPs carry out the intervention during their consultations with patients who have been included in the study	Are aware of benefits using the intervention protocol	Know how to use intervention protocol and when to use which techniques	Have skills (i.e. conversational and motivational techniques) to carry out the intervention	Feel self-efficacious to carry-out intervention	Have stronger positive feeling towards carrying out the intervention than negative	Deem SMS and carrying out the intervention as part of their professional role
1a. NPs assess if patients experience challenges or problems in several areas of life	Become aware of problems in patients' life on other than medical domains and the benefits of assessing psychosocial areas		Have skills to assess and discuss psychosocial and medical aspects	Feel self-efficacious about assessing and discussing psychosocial and medical aspects	Have stronger positive feelings about assessing psychosocial and medical aspects than solely assessing medical aspects	
1b. When the patient indicates that there is a problem in a specific life area, NPs stimulate the patients to set a SMART goal and agree with the patient on the goal		Know how to set a SMART-goal together with the patient		Feel self-efficacious about assisting patient in setting a SMART-goal		
1c. NPs assist and stimulate patients to make and implement action plans for attaining their goals		Know how to make an action plan which is achievable for the patients		Feel self-efficacious about assisting patient in making an action plan		

Step 2 Matrices of change objectives: Nurse practitioners

Performance objectives

The POs for the NPs were also guided by Self-Regulation Theory. Additionally, three components of the Five A's model of behaviour counseling (Glasgow, Davis, Funnell, & Beck, 2003; Whitlock, Orleans, Pender, & Allan, 2002) were incorporated namely *assessing* behaviour, beliefs and motivation, *agreeing* with the patient on realistic goals and *assisting* to anticipate barriers and develop a specific action plan. Two components of the 5A's model (*advising* and *arranging*) were not integrated in the intervention, because they are less in line with the focus on patient empowerment. In order to achieve the overall program goal and taking the needs assessment into consideration, two POs for the NPs were formulated, see Box 2.

Determinants

The determinants deemed most pertinent in predicting these performance objectives for the NPs were: knowledge, skills, social/professional role and identity, self-efficacy, attitude, and outcome expectations. Table 2 shows examples of the COs derived from combining the POs and determinants. The full change objectives matrices are available on request (DB or EKM).

Step 3 Theory-Based Methods and Practical strategies

The aim of Step 3 is to identify and select theory-based methods and translate these into practical strategies to influence each determinant in order to achieve the change objective. For example, modeling (method) can be used to influence self-efficacy (determinant) by showing videotaped demonstrations of other patients performing self-management tasks (practical application). Methods and practical applications were reviewed and discussed with the steering group and patient advisory committee. From the methods identified, we selected applications for inclusion in the intervention based on feasibility and the needs identified in Step 1. Techniques from Motivational Interviewing (MI) (Dekker, Kanter, & Rueb, 2015) were used to promote motivation. Principles of Solution Focused Brief Therapy (SFBT) (Ratner, George, & Iveson, 2012) were used for the goal and action oriented change objectives. SFBT is goal-directed, future-focused and addresses solutions rather than problems. These key concepts make SFBT particularly useful to actively involve patients during nursing consultations. Furthermore, the social cognitive theories from which determinants of POs were selected were also the source of behaviour change methods. The methods were translated into practical applications or strategies which were integrated in the intervention protocol. Table 3 shows examples of the theoretical methods and practical applications incorporated into the intervention.

Table 3: Examples of the theoretical methods and practical applications incorporated into the intervention

Change objectives	Determinant	Theoretical method	Practical application/ strategy
Patient becomes aware of and acknowledges problems in various areas of life	Awareness (PAPM/TPB)	Awareness raising providing feedback using visualization	Patients evaluate their life based on the Self-Management Web.
NPs become aware of problems in patients' life on other than medical domains and the benefits of assessing psychosocial areas			<u>*Self-Management Web*</u> *NPs assesses patients' life based on the self-management web*
Patients belief in their own capabilities to optimize self-management behaviour	Self-efficacy (SCT)	Mastery experiences Attribution of failure and success	Patients are asked to evaluate and appoint successes to stable, internal factors and failure to external, unstable factors. When the patient experiences success, the NP will emphasize the role of the patient in the success.
NPs feel self-efficacious about carrying out intervention		*Modelling*	*NPs received training in which role-plays took place as an example*
Patients implement new actions to reach goals and break through habits	Habits (TAB)	Implementation intentions	Patients need to specify if-then, when, where, how, what and where they are going to perform goal related actions

*PAPM: Precaution Adoption Process Model; TPB: Theory of Planned Behaviour; SCT: Social Cognitive Theory; TAB: Theory of Automatic Behaviour

Step 4 Program Production

In Step 4, the actual program was developed. This step contains the determination of program components, the creation of the program scope and sequence, and the development of program materials. Representatives of the steering group and patient committee were presented the concept program and their feedback guided final adjustments.

<u>*Intervention Scope*</u>

The main theme of the program is optimizing self-management based on the principles of self-regulation theories: evaluating areas of life, establishing and setting goals, planning/preparing strategies for achieving the personal goals and actively pursuing goals, monitoring and evaluating goal progress and preparing strategies for relapse prevention. Throughout the intervention, these steps are combined with principles of SFBT to stimulate patients to generate solutions rather than focusing on their problems. The final intervention was called ZENN, an acronym derived from the Dutch translation of Self-Management After Kidney Transplantation (ZElfmanagement Na Niertransplantatie).

Intervention Sequence

The final program consists of four 15-minute sessions with a NP combined with regular appointments in the outpatient clinic. The frequency of intervention sessions is determined by the frequency of consultations within standard care. Therefore, the period between the sessions can range from two weeks to several months. If the time period between session 1 and 2 is over one month, a telephone consultation with the NP is scheduled. During the first session, the emphasis is on assessment: raising awareness, evaluating areas of life, goal setting and preliminary preparation of an action plan. Also, motivation and self-efficacy are discussed using visual analogue scales ranging from 0 to 10. The second and third session are used to monitor and evaluate the progression on goal attainment during the past weeks and discuss outcome expectations. Throughout the second and third session, the action plan is further customized, self-efficacy is positively encouraged and outcome expectations are discussed. During the fourth session, goal progress, relapse prevention and generalization of learned skills to other challenges are discussed (see Figure 2).

Self-Management Web

A visual communication aid called the Self-Management Web (Figure 3) was developed to facilitate achievement of the first change objective. The Self-Management Web is used to standardize the assessment of fourteen life areas and offer a visual overview to guide the conversation between professional and patient. This tool ensures a holistic view, since multiple areas of life are represented in the Web and it enhances intrinsic motivation as patients determine the area they prefer to focus on. The discussion about goals results in shared-decision making between nurse and patient.

During the first session, NPs encourage the patients to evaluate their life domains and assess if they are doing well (1-green), neither good /nor bad (2-orange) or bad (3-red) on each domain. The patient marks the answer on the web to visualize domains with difficulties, which contributes to awareness. When patients report a 2 or 3 the NP asks open questions to clarify the problem. When multiple areas are rated as ‘bad’, the NP invites the patient to prioritize and select the area of life he/she wants to work on after which the other steps of the intervention are carried out.

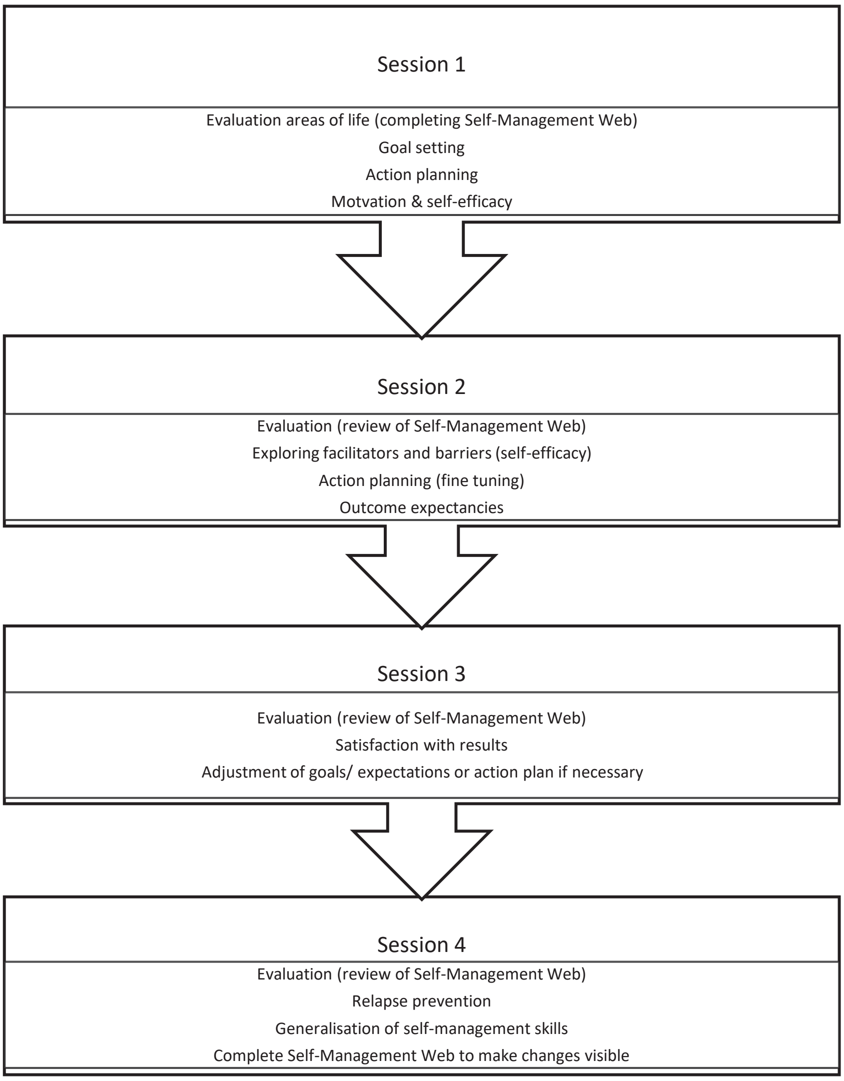


Figure 2 The key components of each session in the intervention

Intervention materials

An intervention protocol was written for the NPs, containing specific guidelines per session on how to approach the patients and which topics to discuss together with suggestions about how to phrase specific questions. To support implementation and adherence to the protocol, a checklist was developed for NPs to report on the steps executed per session per patient. Prior to beginning the intervention, nurses were trained in the delivery. A syllabus was developed which the NPs received in advance of a training regarding the intervention.

Step 5 Adoption and implementation

The effectiveness of an intervention is partially attributable to the quality of the implementation. To promote implementation and ensure fidelity to the intervention, NPs received two training sessions before the implementation of the intervention. During

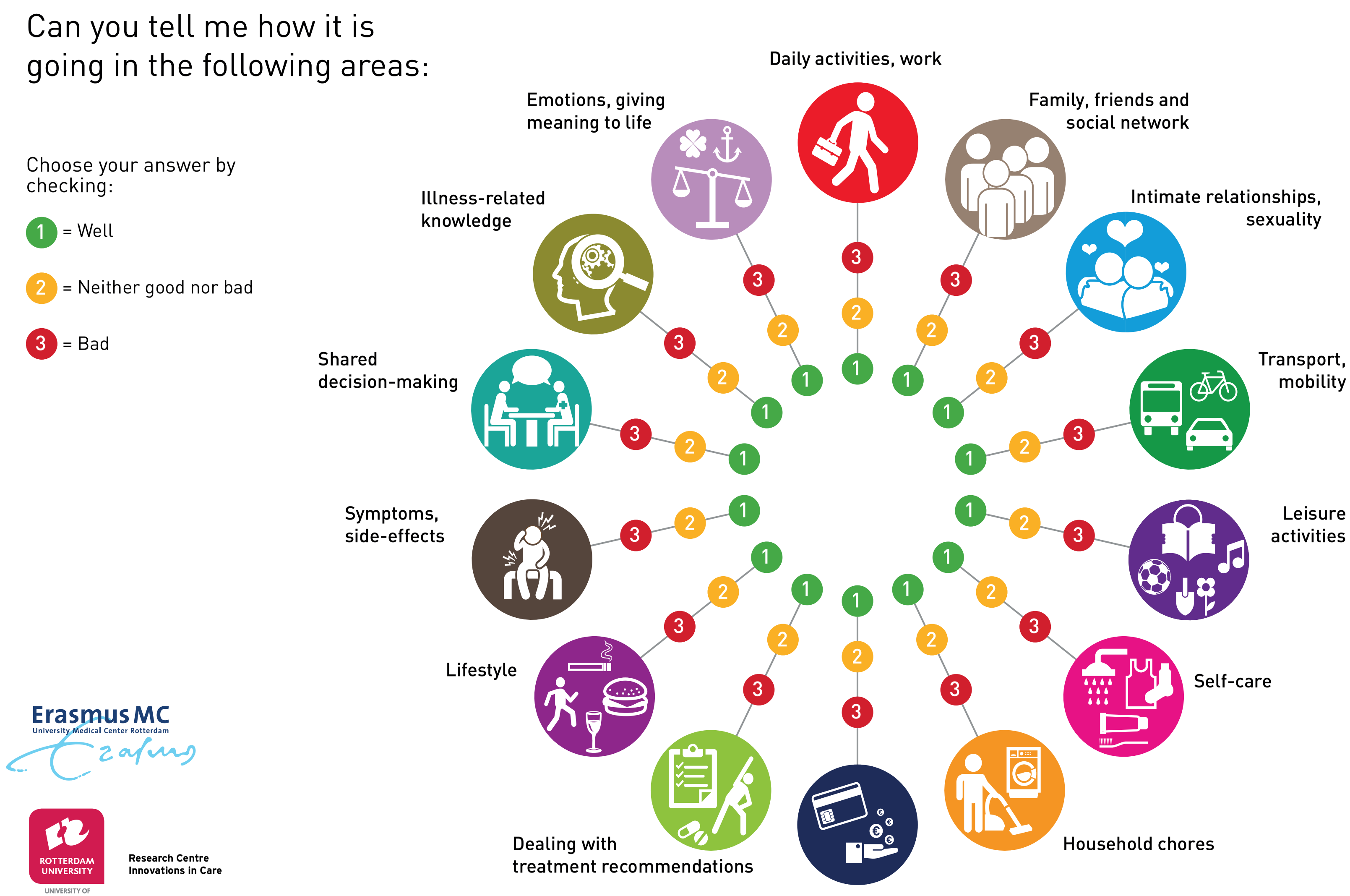


Figure 3. Self-Management Web

the implementation of the intervention the NPs received booster sessions. The training was provided by an experienced psychotherapist (AvtS) and a psychologist (DB).

The training had a dual-purpose; on the one hand it comprised an explanation on how to carry out the intervention protocol, on the other hand NPs were trained in using techniques from SFBT and MI. The training was divided over two 3-hour sessions. After explaining the theories upon which the intervention was based and techniques to be employed during consultations, trainers performed a role play to show the steps (modeling). Subsequently, NPs were invited to participate in role plays with the trainers (mastery experiences). Anticipated problems were thoroughly discussed. At the end of the training, the topics discussed were summarised and the training was evaluated.

Throughout the implementation period, the NPs received booster sessions during which problems encountered could be discussed and techniques practiced. Furthermore, video recordings were made as part of the evaluation of the intervention. NPs received feedback based on the video recordings.

Step 6

In a mixed-methods design, feasibility and preliminary effects of this intervention are currently being assessed. The outcomes of this step fall outside the scope of this article.

DISCUSSION

The development of the current intervention responds to the need for practical and effective interventions to optimise SMS after transplantation, in which tailoring, a holistic approach, shared-decision making, and patient empowerment are incorporated. Additionally, this intervention is in line with the vision of the WHO which stipulates that the healthcare system should be addressed when improving SMS (Sabate, 2003) and with recommendations regarding enhancing self-regulation skills among kidney transplant recipients for optimizing psychological wellbeing (de Vries et al., 2017).

Although findings indicate the importance of anticipating the individual needs of each patient to enhance effectiveness, most current interventions fail to do so (De Bleser et al., 2009; De Geest, Dobbels, Fluri, Paris, & Troosters, 2005; Low et al., 2015). It has been suggested that variance in effectiveness of SMS could be due to the mismatch between the individual's needs and the offered intervention (Trappenburg et al., 2013). To improve the fit, the Self-Management Web was used to assess in which areas of post-transplant life the recipient was experiencing challenges. This ensured standardization of the assessment but allowed room for a personalised approach. To improve the fit, the Self-Management Web was used to assess in which areas of post-transplant life the

recipient was experiencing challenges. This ensured standardization of the assessment but allowed room for a personalised approach.

Our intervention also responded to the tendency for SMS interventions to focus mainly on medical management to the detriment of psychological and social aspects. This emerged from the needs assessment wherein recipients reported the need for psychosocial support in addition to medical guidance, while nurses/NPs acknowledged the shortcomings of their current approach. Studies have shown that psychosocial (e.g. depression, anxiety) and behavioural factors could negatively affect self-management and are therefore important targets for SMS interventions (De Bleser et al., 2009; De Geest et al., 2005; Lorig & Holman, 2003; Low et al., 2015).

Additionally, it has been suggested that interventions should be developed based on theory and evidence-based methods (Bartholomew et al., 2011; De Bleser et al., 2009; Low et al., 2015; Sabate, 2003). There is an increasing emphasis on reporting specific behaviour change techniques used in interventions to increase quality and replicability (Michie et al., 2015). The IM protocol helped to integrate theory and evidence-based methods as well as the needs of the kidney recipients and nurses into the intervention. Behavioural science offers several useful theories and strategies that enhance the effectiveness of interventions used in health behaviours (Sabate, 2003). A realist review demonstrated that self-management support interventions focusing on intrinsic processes were most successful in behaviour change (van Hooft et al., 2016). This emulates earlier authors who have emphasised that education alone it insufficient for health behaviour change Examples of these processes were self-efficacy and (intrinsic) motivation, which were in the backbone of the current intervention. The Self-Management Web provides the basis upon which important personal goals can be set which ensures intrinsic motivation. Self-determination theory (Deci & Ryan, 2000) stipulates that intrinsic motivation is an important factor for effective behaviour change (Maes & Karoly, 2005). The intervention protocol encourages motivation during the intervention, but also emphasises increasing self-efficacy. Studies among kidney transplant recipients have stipulated the importance of promoting self-efficacy when supporting self-management in kidney transplant recipients (Jamieson et al., 2015; Weng et al., 2010). In summary, the strengths of the intervention include tailoring, a holistic approach, focus on intrinsic processes and promotion of shared-decision making.

Limitations

Although the intervention is based on health behaviour change theories and the methods incorporated are evidence-based, this does not guarantee effectiveness in the context of kidney transplantation. The association with health (outcomes) and all life areas addressed in the Self-Management Web may not be clear for patients and professionals alike. Goals attained in the intervention maybe too far removed from the health domain to directly relate to positive health outcomes. In contrast, one could also argue that problems in life areas other than health, often do impact health and thus self-management due to the stress they generate. Effectiveness of the intervention is currently under investigation and results will be presented and discussed elsewhere.

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PART III

Evaluation of self-management support interventions

CHAPTER 7

Is a smartphone application useful for self-management support in patients with a rheumatic disease?

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Submitted

ABSTRACT

Aims

This study 1) investigates whether the use of an app improved patients' self-management 2) investigates which factors are associated with the use of the RD-app, 3) explored patients' experiences with this RD-app.

Background

Self-management is an important aspect in the care for patients with a rheumatic disease (RD). To support patients' self-management, we developed and implemented a smartphone-application (RD-app).

Design

A prospective before-after study was performed among patients with a RD.

Methods

The primary outcome was patients' self-management measured with the Partners in Health-scale (PIH). Survey questions addressed whether the RD-app had contributed to get more hold on the disease and how. A paired t-test was used to evaluate changes in the PIH-scale score after three months. Logistic regression analyses served to investigate variables that are important for using the RD-app.

Results

Of the 1511 eligible patients, 397 completed both the baseline and the follow-up surveys. Participants with positive expectations of the RD-app for getting hold on the disease were more likely to use the RD-app. 114 participants used the RD-app, of which forty-two percent of the app-users perceived that use of the RD-App had contributed to get more hold on the disease. This percentage was higher for those who used the RD-app more frequently ($p=0.04$). The PIH-scale score in the app-users group had not changed after 3 months. Receiving tips, information on exercises and gaining insight in self-reported disease activity contributed to get more hold on the disease.

Conclusion

Almost one third used the RD-app. If they used the RD-app, almost half experienced more hold on the disease. Positive expectations are an important factor for the use of the app.

Relevance to clinical practice

The RD-app can be useful for additional self-management support in a clinical practice.

INTRODUCTION

Patients with rheumatic disease (RD) can face several physical (e.g. pain, stiffness, disability and fatigue) and psychosocial problems that might influence their activities in daily life (Abraido-Lanza & Revenson, 2006). Sometimes emotional, psychosocial adjustments and behavioral changes are needed (Dures et al., 2014; Homer, 2005). This might require a great effort; patients daily have to make decisions to self-manage the disease and are expected to take an active role in this process. Self-management is considered highly in chronic care and it needs to be integrated in a patient's life (Anderson & Funnell, 2005; Glasgow, Jeon, Kraus, & Pearce-Brown, 2008; Wagner et al., 2001).

Self-management is not clearly defined; a commonly used definition is: 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition' (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). Effective self-management approaches might result in physical and psychosocial benefits and improve quality of life (Barlow et al., 2002; Lorig & Holman, 2003). Self-management in RD has primarily been seen as patient's own task, although receiving support to optimise self-management behaviour is appreciated (Been-Dahmen et al., 2017; Dwarswaard, Bakker, van Staa, & Boeije, 2016; van Eijk-Hustings et al., 2013)

Self-management support can be defined as the provision of interventions to increase patients' skills and confidence in managing their chronic condition (Institute of Medicine Committee on Identifying Priority Areas for Quality, 2003). Patients are activated and facilitated to play an active role concerning living with a chronic disease. Besides the support given by nurses in daily care, an additional way to assist self-management support is by using a health-related application (App).

Background

Apps are becoming a part of the nursing practice and it has been suggested that 'nurses must be able to recommend and integrate apps into their clinical practice' (Ferguson & Jackson, 2017). Health-related apps might contribute to assisting self-management by providing information, advice, support, encouragement and tools for monitoring the disease activity and might overcome several barriers like time and distance (Garabedian, Ross-Degnan, & Wharam, 2015; Patrick, Griswold, Raab, & Intille, 2008; Whitehead & Seaton, 2016). Furthermore, apps can provide efficient and individual tailored information at the time suitable for patients (Azevedo, de Sousa, Monteiro, & Lima, 2015; Wang et al., 2014), and a way for patients to become more involved with their self-management of the disease (Grainger, Townsley, White, Langlotz & Taylor, 2017).

There are many commercial health-apps available, however, most of the apps have a paucity of high-quality and the content is not evidence based (Bhattarai, Newton-John,

& Phillips, 2018; Grainger et al., 2017). Only a few studies have been done on health-apps for patients suffering from a RD (Nishiguchi et al., 2014; Yamada et al., 2012). These studies showed that apps can be useful to assess gait pattern in rheumatoid arthritis patients (Yamada et al., 2012) and to predict the disease activity by combining subjective measurements of joint symptoms, degree of disability and objective gait balance measurements (Nishiguchi et al., 2014; Yamada et al., 2012). Patients with rheumatoid arthritis stated they would certainly use an app for self-management support (Azevedo, Bernardes, Fonseca, & Lima, 2015).

In 2015, the Rheumatology department in the Erasmus University Medical Center, Rotterdam, the Netherlands, developed and implemented an app for patients with a RD with the purpose of assisting patients get more hold on the disease. The aim of this study was 1) to investigate whether the implementation of this newly developed RD-app can help improve self-management of patients with a RD and 2) to investigate which factors are associated with use of the RD-app, 3) to explore patients' experiences with this RD-app.

METHODS

Design and data-collection

A before-after study was designed to measure the effects of use of the RD-app on patients' self-management behavior after implementation of the RD-app.

We recruited patients with RD from the outpatient rheumatology clinic of the Erasmus University Medical Center in Rotterdam between August 2015-July 2016. All eligible patients whose email address was noted in the electronic patient record received an invitation by email to participate in this study (n=1511) (figure 1). After they confirmed to be willing to participate, they received a questionnaire before (baseline) the launch of the RD-app. All patients who participated at baseline received a second questionnaire three months after the launch of the RD-app. Reminders to return the questionnaire were sent after one and two weeks at baseline and after the second questionnaire by email. At baseline, demographic data, working status, diagnosis and time since diagnosis were obtained.

No extra instructions were given on how to use the app, as we thought it was self-explanatory. Furthermore, no instructions were provided to the (minimum) number of times participants had to use the app nor which categories they had to use specifically.

The study protocol was approved by the Medical Ethical Committee of the University Medical Center Rotterdam (MEC-2015-317). All participants gave written informed consent before completing the baseline questionnaire.

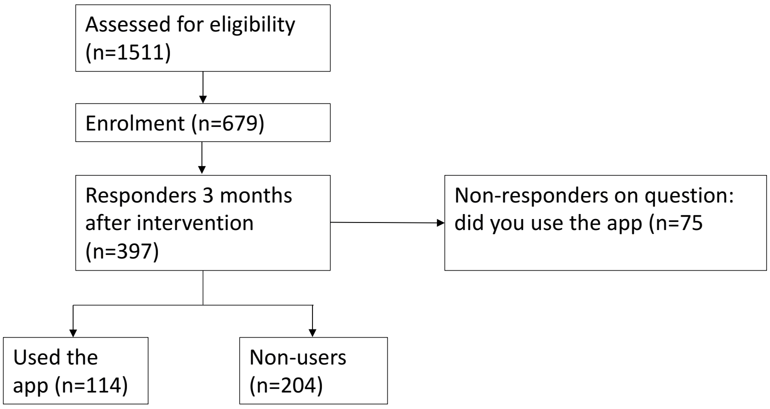

Figure 1. Flowchart inclusion

Development of the RD-app

The RD-app was developed by a team of specialist nurses, rheumatologists, a professional software developer and patients. Different self-management components were incorporated, such as education with disease-specific information, self-monitoring and medication tools, as suggested by studies on self-management interventions (Barlow, Wright, Sheasby, Turner, Hainsworth 2002). The development of the app started by creating a functional design by the team mentioned above. To make sure the design fulfilled the needs and expectations of patients with a RD, a total of 61 patients completed a questionnaire asking for their opinions. This design process resulted in a definitive design consisting of the following six functionalities:

1. Patients can monitor the disease activity using specific self-reported outcomes (e.g. Rheumatoid Arthritis Disease Activity Index, Bath Ankylosing Spondylitis Disease Activity Index, Health Assessment Questionnaire). Thus, this category can be used for self-monitoring the disease.
2. Overall wellbeing and activity level are each rated on a visual analog scale (VAS). The ratings over the last week or months can be visualized. This category is trying to gain more insight information on the course of the overall wellbeing in combination with perceived physical activity level.
3. Different physical exercises, explained with video's, are provided to stimulate activity. Promoting healthy moving by evidence based exercises might be helpful for patients to change their physical activity.
4. The app also provides reminders for medication intake and appointments. With this category the adherence of medication as well as appointments are addressed.
5. A game was developed to increase patients' knowledge about the process of inflammation. Education and understanding the disease is a part of self-management.
6. Tips and health information form the last category. To tailor this app, information categories (tips and health information) can be switched on or off. This tailored evidence-based information is divided into 10 categories: exercises for joints, fatigue,

more hold on the disease, medication, pain, sexuality, tips using hands, holidays, working tips and pregnancy. To perform in daily life and incorporate the disease many tips are provided monthly.

Feedback of the patients was used to develop the app and therefore this is an user driven approached app. Thereafter, a prototype of the app was used for the test rounds, to get feedback on the functionality and missing topics, in two rounds, by 30 and 40 patients, respectively. The first test round resulted in modifications in functionality, minor additions and textual adjustments. After the second test round no more adjustments were made. This app does not include a feedback function, due to privacy legislation.

The RD-app was incorporated in the usual nursing care: patients received information and explanation about this app during nursing consultations, were given written information and received a newsletter from the department of rheumatology to inform them about the app. Furthermore, the app was launched on several different (social) media platforms. The RD-App (Dutch: Reuma app) is freely available from both the iOS and the Android store, thus not only for patients treated in this hospital.

Outcome measures

The primary outcome of this study was the self-management knowledge and behavior as measured by a generic validated 12-item self-rated scale, the Partners in Health scale (PIH scale), with total score ranging from 12 to 96 points. Higher scores indicate better self-management behavior (Battersby & Markwick, 2003; Petkov, Harvey, & Battersby, 2010; Smith, Harvey, Lawn, Harris, & Battersby, 2017). The PIH scale is a reliable and valid instrument for measuring self-management of chronic conditions, including arthritis. Additionally, participants were asked if the app helped them to get more hold on their disease with one dichotomised question, yes or no.

The secondary outcomes were health-related quality of life (HRQOL), self-efficacy, pain, fatigue, and experiences with the app. HRQOL was scored with the validated SF-36 (range score 0-100). A higher score indicates a better HRQOL. It assesses eight health concepts: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions, which are summarised in a physical component summary and mental component summary score (Ware & Sherbourne, 1992). Self-efficacy was measured with the validated Dutch version of the arthritis self-efficacy scale, which consists of two subscales related to self-efficacy to deal with pain and to deal with other symptoms (depression, fatigue, frustration) (Taal et al., 1993). Self-efficacy is 'the belief of patients in their own capability to perform activities to produce a desired outcome' (Bandura, 2001). Pain and fatigue were each measured with a visual analogue scale (VAS) ranging from 0-10, where higher scores are regarded as more fatigue or pain. The VAS scale is valid to detect changes in pain and fatigue in RD patients (Hewlett, Dures, & Almeida, 2011; Wolfe, 2004).

Experiences with the app

To measure experiences of the participants who used the RD-app (app-users) an open-ended question was asked: How did the app help you to gain more hold on your disease? Participants who did not use the app (non-users) were asked to state the reason why they did not use the app.

Statistical analysis

Quantitative data

We used descriptive statistics to describe the study sample. Because not all participants used the RD-App, we divided the participants in two groups: app-users and non-users. A paired T-test was used to investigate whether the use of the RD-app had contributed to an increase in the PIH-scale score and other patient reported outcomes (PROs).

Logistic regression analyses served to investigate variables that are important for using the RD-app. First, univariate analyses were performed. All significant variables were put in the full models; thereafter backward elimination was performed. Results were considered statistically significant when the p-values were less than 0.05. STATA version 13.0 was used to analyze data.

Qualitative data

Answers to the open questions about the experience of the app were labeled and grouped. Two researchers (JB, MW) independently analyzed answers to the open-ended question. Differences were discussed until consensus was reached.

RESULTS

At baseline, 679 of the 1511 eligible patients, participated (response rate 43%). Of those 679 participants, 397 also filled in the second questionnaire. The latter were older ($p<0.01$), more often unemployed ($p=0.04$), had higher expectations the app would help them to get more hold on their disease ($p=0.01$), and had higher scores on the PIH scale ($p=0.08$) than those who responded only at baseline. All other baseline characteristics and PRO did not show differences.

Participants who completed questionnaires ($n=397$) at both periods were most frequently diagnosed with RA, 65% was female, the mean age was 52.0 (SD15.6) years and 71% was higher educated (table 1). Almost all participants had a smartphone (89%). At baseline, 70% thought they would use the RD-app for self-management support and 63% expected it would give them more hold on the disease (table 1).

Of the 397 participants, 19% (n=75) had missing data regarding the question "did you use the app?". Of those participants who missed this question 72% (n=54) did not possess a smartphone. Furthermore, there was a difference between the participants who did or did not answer this question, participants with the missing data worked less often (p=<0.001) and were less highly educated (p=0.006). Further analysis did not show differences on demographics and patients reported outcomes (PROs).

Table 1. Demographics baseline of participants who filled in both questionnaires, app-users, non-users

	Total n=397	
Age (mean, SD)	52.0	(15.6)
Gender (Female) (n; %)	258	(65)
Education (College or higher) (n; %)	284	(71)
Employed (yes) (n; %)	180	(45)
Diagnosis (n; %)		
Rheumatoid arthritis	163	(41.2)
Spondyloarthritis	23	(5.8)
Systemic Lupus Erythematosus	15	(3.8)
Juvenile arthritis	9	(2.2)
Fibromyalgia	24	(6.1)
Osteo-arthritis	37	(9.3)
Gout	20	(5.0)
Arthritis psoriatic	54	(13.6)
Other (e.g. PMR, arthritis eci, sarcoidose)	51	(12.9)
Time since diagnosis (n; %)		
<6 months	7	(1.8)
6 months-1 year	20	(5.0)
1-2 years	46	(11.6)
2-5 years	69	(17.4)
>5 years	254	(64.1)
Nationality (Netherlands) (n; %)	383	(96.4)
Smartphone present (Yes) (n; %)	344	(89.3)
Intend to use the app (Yes) (n; %)	242	(70.4)
Expect the app will increase the self-management skills (Yes) (n; %)	242	(62.7)

App users

After three months, almost one third (n=114) of the participants used the app. App-users had a mean age of 51.3 (SD 16.4). Eighty-eight percent of the app-users (n=98) who had responded positively to the baseline question "do you think you will use the app", actually used it after three months. App-users who used the app five times or more were younger (44.4 vs. 52.1; p=0.03) and were higher educated (p=0.001). Eighty-two percent of the app users would recommend this app to others. Almost all who used the app five times or more (96%) recommended this app to others.

To investigate who did use the RD-app univariate analysis showed a role for gender, positive expectations of the RD-app, help needed to get more hold on the disease and the VAS global as associated factors with actually using the RD-app. In the multivariate analysis only expectations of the RD-app remained significantly associated with actually using the RD-app (p=<0.001) (table 2). Thus, if participants had positive expectations of the RD-app for getting more hold on the disease, they were more likely to use the RD-app compared to those who did not believe the RD-app would help them to get more hold on their disease.

Evolution of self-management and PRO over time

One hundred eleven app-users completed the PIH-scale at baseline and after three months. After three months, the mean score and the subscale scores had not significantly changed (p=0.8) (table 3). Forty-two percent of the app-users agreed the app had contributed to get more hold on the disease. This percentage was significantly higher for app-users who used the app five times or more compared to those who used it less frequently (59% vs. 37%; p=0.04).

Table 2. Prediction model for using the RD-app

Used the RD-app	Uni variate			Multi variate		
	Coef.	95% CI	P value	Coef.	95% CI	P value
Age	-0.0008	-0.004-0.002	0.62			
Gender	0.11	0.008-0.22	0.03	0.09	0.01-0.20	0.1
Time since diagnosis	0.01	-0.03-0.06	0.60			
Employed	0.02	-0.08-0.12	0.42			
Education	-0.04	-0.16-0.07	0.42			
Self-efficacy	0.03	-0.29-0.09	0.31			
Expectations of RD-app	0.21	0.11-0.32	<0.001	0.20	0.10-0.31	<0.001
VAS global	-0.02	-0.05-0.0002	0.05			
SF-36 PCS	-0.003	-0.008-0.0005	0.08			
SF-36 MCS	-0.002	-0.008-0.002	0.25			
Partners in Health scale	-0.0005	-0.005-0.004	0.82			
No help needed	-0.11	-0.22- -0.007	0.03			

*VAS: Visual Analog Scale; SF-36: 36-Item Short Form Survey; PCS: Physical Component Summary; MCS: Mental Component Summary.

The secondary outcomes self-efficacy, VAS pain and VAS fatigue, and SF-36 also did not change over time (table 3).

Experiences with the app

The answers to the question: How has the app helped you getting more hold on the disease, could be divided into three categories: 1) receiving tips, 2) information on exercises and 3) gaining insight into the self-reported disease activity.

Table 3. Patients reported outcome at baseline and after 3 months

Outcome variables	App Users (n=114)		
	Baseline	Post test	P-value
Partners in Health scale (12-96)	79.47 (11.75)	79.20 (11.55)	0.8
VAS fatigue (0-10)	6.07 (2.39)	6.03 (2.22)	0.8
VAS pain (0-10)	4.96 (2.25)	4.97 (2.18)	0.9
SF-36 PCS (0-100)	36.44 (11.39)	36.73 (11.12)	0.7
SF-36 MCS (0-100)	48.44 (10.64)	48.37 (10.72)	0.9
Self-efficacy (1-5)	2.55 (0.83)	2.48 (0.77)	0.1
More grip on Rheumatic disease due to app (yes, %)		42% (48)	
Recommended app to others		82% (94)	

* PIH: Partners in Health Scale; VAS: Visual Analog Scale; SF-36: 36-Item Short Form Survey; PCS: Physical Component Summary; MCS: Mental Component Summary

App-users stated that practical tips were helpful, for example to learn more about the disease and how to gain more control in daily life, and how to deal with fatigue or devices in daily life. Some app-users mentioned that they could use the tips whenever necessary. App-users mentioned that video instruction on physical exercises stimulated them to do more exercises. Lastly, app-users appreciated that the evolution of their self-reported disease activity could be visualized.

Reasons for not using the app

Non-users (n=208) mentioned different reasons for not using the RD-app. The most stated reasons were 'no interest at all' or 'low disease activity. Other reasons were; 'not any added value due to e.g. online information sources', 'not wishing to be confronted with the disease', and 'no time for downloading the app'. Although, some of them stated they want to download the app later on. Some non-users struggled with technical issues as they did not know how to download or did not have enough remaining space on their phone.

DISCUSSION

This study aimed to evaluate if the RD-App had a positive effect on patients' self-management behavior. It appeared that use of the app helped 42% to get more hold on the disease by the provided tips, exercises and the insight in self-reported disease activity. This percentage was even higher for those used the app more frequently. However, a beneficial effect on self-management behavior three months after the launch of the RD-App could not be shown.

Self-management is a complex concept and the assessment of interventions on self-management is complex as well (Nolte & Osborne, 2013). A review on evaluation of self-management support by using apps in chronic illnesses showed conflicting results: only three out of the nine studies demonstrated an improvement in symptom management through self-management when the intervention comprised an app only, thus without a feedback tool integrated in the app (Whitehead & Seaton, 2016). Another review showed that apps were rarely successful in improving self-efficacy or quality of life (Garabedian et al., 2015). In the present study, of the absence of improvement in the PIH scale might be explained by app-users being convinced they had sufficient self-management skills, since most of them had an established RD. On the other hand, it cannot be excluded that the PIH scale fails to pick up any changes important for a patient's experience to get more hold on the disease. Interestingly, almost half of the app-users, even those with an established RD, responded positively to the question: "Did the RD-app help you to get more hold on the disease". Thus, the perception of more hold on the disease increased by using this RD-app. Therefore, this RD-app must not be dismissed as it might be useful for self-management support from the perspective of the users, which is something that is not picked up in the used questionnaires. Besides, app-users appreciated the received tips and information on exercises and gaining insight into the self-reported disease activity. This is in line with a study on users' perceptions of apps, which found that personalised and tailored information was a motivator for using apps (Peng, Kanthawala, Yuan, & Hussain, 2016).

The second aim of the study was to investigate which factors were associated with the use of the RD-app. In the multivariate analysis, only having positive expectations beforehand was found to be associated with actually using the RD-app. This is in line with other studies on smartphone apps, they found that positive expectations and a positive attitude were of great importance for the utilization of apps (Huygens et al., 2016; Wang et al., 2014). Nurses may play a role here by recommending, integrating and communicating positively about the app. However, assessing the quality of existing apps can be difficult (Grainger, Townsley, White, Langlotz, & Taylor, 2017). Nurses can take the lead in integrating technological possibilities, like health-related apps, and using them to improve care targeted at supporting self-management.

In this study, we found a remarkable discrepancy in the willingness to use the app and the actual use. At baseline, 70% of all participants indicated they would use the app. This compares well with a study in patients with epilepsy, in which 65% were willing to use an app for self-management support (Liu, Wang, Zhou, & Hong, 2016). This percentage was higher in a study of willingness of using apps for patients with RA (85%), even if they had to pay for it (Azevedo et al., 2015). In the present study, however, only one third of the participants did actually use the app after three months. A similar gap was seen in a study in patients with diabetes (Frandes, Deiac, Timar, & Lungeanu, 2017), which identified a lack of time and insufficient technological skills as influential factors (Frandes et al., 2017). These factors were also mentioned by the non-users in our study. But, non-users also stated, in the qualitative analysis, that they did not need an app because they had already received enough information. This finding was confirmed in the univariate analysis, an association for the use of the RD-app was found if participant did not need help at all. Similarly, in a study investigating the needs of patients toward self-management and eHealth for self-management, patients had already received most information from health professionals (Huygens et al., 2016).

Some limitations of this study need to be addressed. First, we had missing data, with regard to the question "did you use the app?". This might have affected the outcomes. However, of those who missed this question almost three quaters did not possess a smartphone. After adding these participants to the non-users group, no different outcomes were found for the prediction of the use of the RD-app. The other participants who missed this question had similar results on the of the PIH scale and expectations compared to the other participants. Second, we additionally used a dichotomous question for measuring the feeling of getting more hold on the disease. Self-management is a difficult construct and moreover it is difficult what outcomes must be used (Bykerk, Lie, Bartlett, Alten, Boonen, Christensen, Furst, Hewlett et al.,2014; Trappenburg et al., 2013). Patient reported outcomes should provide key information of the perspective of the patient of getting more grip on the RD. The use of a one single question provided an overall image of the feeling of more grip on the RD, while an extended questionnaire may be useful to address more specific issues. Therefore, we feel that the used single item question is informative to measure how patients perceived hold on their disease. Finally, the effects of the app were measured three months after it was launched. This period may have been too short to detect changes in complex outcomes like self-management. App-users who used the app more often than average found they were getting more hold on the disease. Thus, more long-term evaluation, after 6 and 12 months for example, might show changes in outcomes.

Relevance to clinical practice

Although patients feel self-management has been seen as patient's own task, patients appreciate support on self-management. The RD-app can be useful for additional self-management support in clinical practice. The results are important as they help understand how new technology can improve patients' self-management in daily care.

CONCLUSION

The RD-app seemed to be of benefit to participants in their need to get more hold on the disease. Positive expectations are an important factor for the use of the app, which might increase by better communication about the app.

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CHAPTER 8

Evaluating the feasibility and preliminary results of a nurse-led self-management support intervention for kidney transplant recipients

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ABSTRACT

Background

To support effective SM after kidney transplantation, a holistic nurse-led self-management support intervention was developed using the Intervention Mapping approach. This pilot study aimed to evaluate the feasibility and preliminary results of the intervention for kidney transplant recipients and professionals.

Methods

A controlled baseline-follow-up mixed-methods study was conducted in 2015-2017 to evaluate the intervention. Nurse Practitioners (NP) guided recipients in assessing 14 life areas using the Self-Management Web. Participants were supported in developing self-regulation skills which can be applied to self-management of the illness. Strategies included goal setting, action planning, and promotion of motivation and self-efficacy. Adult recipients from an outpatient clinic of a Dutch University Hospital who underwent their transplant at least one month ago, were invited to participate. NPs, nephrologists and recipients were interviewed to assess feasibility, fidelity and implementation experience. Consultations were videoed and analysed to assess fidelity. To assess the preliminary effects, the intervention group completed baseline (T0) and follow-up (T1) questionnaires on self-management behavior, self-efficacy, quality of life and quality of care. A historical control group of kidney transplant recipients completed the same questionnaires at T1.

Results

Twenty-seven recipients agreed to participate in the intervention group, of which 24 completed the intervention and 16 completed baseline and follow-up surveys. The control group consisted of 33 recipients. Professionals and recipients appraised the open, holistic focus of the intervention as a welcome addition to traditional care and felt that this helped to build a relationship of trust. Recipients also felt they became more competent in problem-solving skills. The within-group analysis showed no significant differences in patients' self-management behavior. A significant difference was found in between groups (C-T1) in self-reported adherence to immunosuppressive medication (P=0.03; G=0.81). The between-group analysis showed a significantly higher perceived quality of care (P=0.02) in the intervention group (T0-T1).

Conclusion

This holistic nurse-led self-management support intervention was found to be feasible and acceptable by professionals and recipients alike. The initial pilot had a small sample and more extensive investigation is needed into the potential effects on self-management behavior and well-being of transplant recipients.

Trial registration

ISRCTN15057632

BACKGROUND

Kidney transplantation is the preferred treatment for patients with end stage renal disease because of better quality of life and survival compared to dialysis (Wolfe et al., 1999; Wyld, Morton, Hayen, Howard, & Webster, 2012). After transplantation, recipients need to learn to adapt to lifestyle recommendations, the medication regimen, changing social roles and emotional challenges (Gordon, Prohaska, Gallant, & Siminoff, 2009; Jamieson et al., 2016). As patients live longer with chronic conditions and often multiple comorbidities, there is and increasing focus on effective self-management and optimizing quality of life (Anderson & Funnell, 2005; Wagner et al., 2001). Self-management has been defined as managing the medical, emotional and social challenges of a chronic condition in daily life with the aim of achieving optimal quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Optimal self-management can indirectly improve the quality of life of kidney transplant recipients (Weng, Dai, Huang, & Chiang, 2010).

One of the core tasks of nurses and nurse practitioners is to support self-management in the post-transplant period, and by doing so promote optimal medical and psychosocial outcomes (Elissen et al., 2013; Lorig & Holman, 2003). In the post-transplant period, self-management support interventions often focus on promoting recipients' medication adherence and self-monitoring through information provision (De Bleser, Matteson, Dobbels, Russell, & De Geest, 2009; De Geest et al., 2014; Low, Williams, Manias, & Crawford, 2015; van Lint et al., 2017), even though it is known that providing information is not enough to change behavior (van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2017). This narrow focus neglects the psychological and social tasks reported by recipients (Been-Dahmen et al., 2018; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). This narrow focus neglects the psychological and social tasks reported by recipients (van Hooft et al., 2017). Support focusing on people's intrinsic motivation and self-efficacy seems to be effective to ensure persistence and performance of new behavior (Bandura, 2001; van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2016). However, holistic and tailored SMS interventions for kidney transplant recipients are scarce. In order to meet these needs, a holistic nurse-led SMS intervention was developed with the Intervention Mapping approach (Bartholomew, Parcel, & Kok, 1998).

This study aims to (1) gain insight into the feasibility and fidelity of a nurse-led self-management (support) intervention for kidney transplant recipients (process evaluation); and (2) make a preliminary assessment of the effects of this intervention on self-management behavior, self-efficacy, quality of life and quality of care. Table 1 provides an overview of the research questions.

METHODS

Study design

A controlled baseline- follow-up study with a mixed-methods design was conducted. Recipients in the intervention group completed the T0 questionnaire before the start of the intervention and their T1 questionnaire after their last session. A historical control group was used because it was not possible for NPs to not use the communication techniques learned in a training during their other consultations. The control group completed the T1 questionnaire 5-12 months after transplantation.

Sample and participants

Intervention group

Recipients

A total sampling approach was used to select kidney transplant recipients aged 18 years and older, who had a functioning graft and underwent their transplant one to eight months ago. Recipients who visited the outpatient post-transplantation clinic of a Dutch University Hospital, between December 2015 and September 2016, were invited to participate. Recipients with cognitive limitations, acute psychiatric problems, who did not speak the Dutch language, with more than two previous consultations with a NP after their transplantation, who underwent treatment in isolation, participated in other studies, or who were undergoing dialysis or were expected to start with dialysis within three months were excluded. No limitations were set to the type of donor or prior renal replacement therapy. A purposive selection of recipients, selected in order of completion of the intervention, were asked to participate in an individual interview and/or observation.

Professionals

The two nurse practitioners (NPs) and nephrologists with whom they work in the post-transplant outpatient clinics were invited to participate in the interviews to evaluate implementation of the intervention.

Control group

Data from the historical control group was collected prior to implementation of the intervention. A total sampling approach was used to select recipients who visited the outpatient post-transplantation clinic of a Dutch University Hospital and who were transplanted between 5 and 12 months earlier. The inclusion and exclusion criteria were the same as to those of the intervention group.

Nurse-led self-management Intervention

The intervention was developed using the Intervention Mapping approach (Bartholomew et al., 1998). First, recipients' and nurses' needs were assessed through individual interviews and focus group, an observational study, a realist review, a qualitative synthesis, and a Q-methodological study (Been-Dahmen et al., 2015; Been-Dahmen et al., 2017; Been-Dahmen et al., 2018; Dwarswaard, Bakker, van Staa, & Boeije, 2016; Grijpma et al., 2016; Ter Maten-Speksnijder et al., 2016; van Hooft et al., 2017) (step 1). Subsequently, change objectives for the self-management support intervention were formulated (step 2). In step 3, theory-based intervention methods were selected and translated into practical implications. Theoretical guidance came from the Self-regulation Theory (Maes & Karoly, 2005), techniques from Motivational Interviewing (Miller & Rollnick, 2013), and Solution-Focused Brief Therapy (SFBT) (Ratner, George, & Iveson, 2012). Thereafter, the intervention protocol, training syllabus, implementation checklist and the Self-Management Web were developed (step 4). Finally, the intervention was implemented in 2015 as a pilot study (step 5). The intervention was called ZENN, an acronym derived from the Dutch translation of Self-Management After Kidney Transplantation (ZElfmanagement Na Niertransplantatie). A full description of the intervention development is available elsewhere (Beck et al., 2018).

The following key elements were included in the intervention: opportunities for tailoring within a general structure; open assessment of patients' needs and preferences using a holistic approach; principles of shared-decision making; and patient empowerment/ in the lead. The overall goal was to enhance recipients' self-management skills in order to integrate treatment and life goals and subsequently optimize recipients' quality of life and health-related outcomes. The steps of the intervention were divided over four sessions. In the first session, self-management challenges were assessed with the so-called Self-Management Web (Figure 1). This visual communication aid offers an overview of fourteen life areas (e.g. work, emotional well-being, sexuality, and transport and mobility), thereby structuring the consultation and opening the range of topics the recipient and NP could address. Recipients evaluate each area by indicating whether they are doing well (1=green), neither good /nor bad (2=orange) or bad (3=red). When multiple areas were red the NP encouraged the patient to rank them according to priority and impact on post-transplant health. Once the challenges had been identified by the recipient, the NPs employed solution-focused communication techniques to discuss recipients' desired outcomes, self-efficacy, to encourage them to set SMART-goals and to make an action plan. A SMART-goal was defined as one that is specific, measurable, achievable, result-focused, and time-bound. Progression on goal attainment and outcome expectations were discussed in the second and third session. Goal progress, relapse prevention and generalization of learned skills to other challenges were discussed

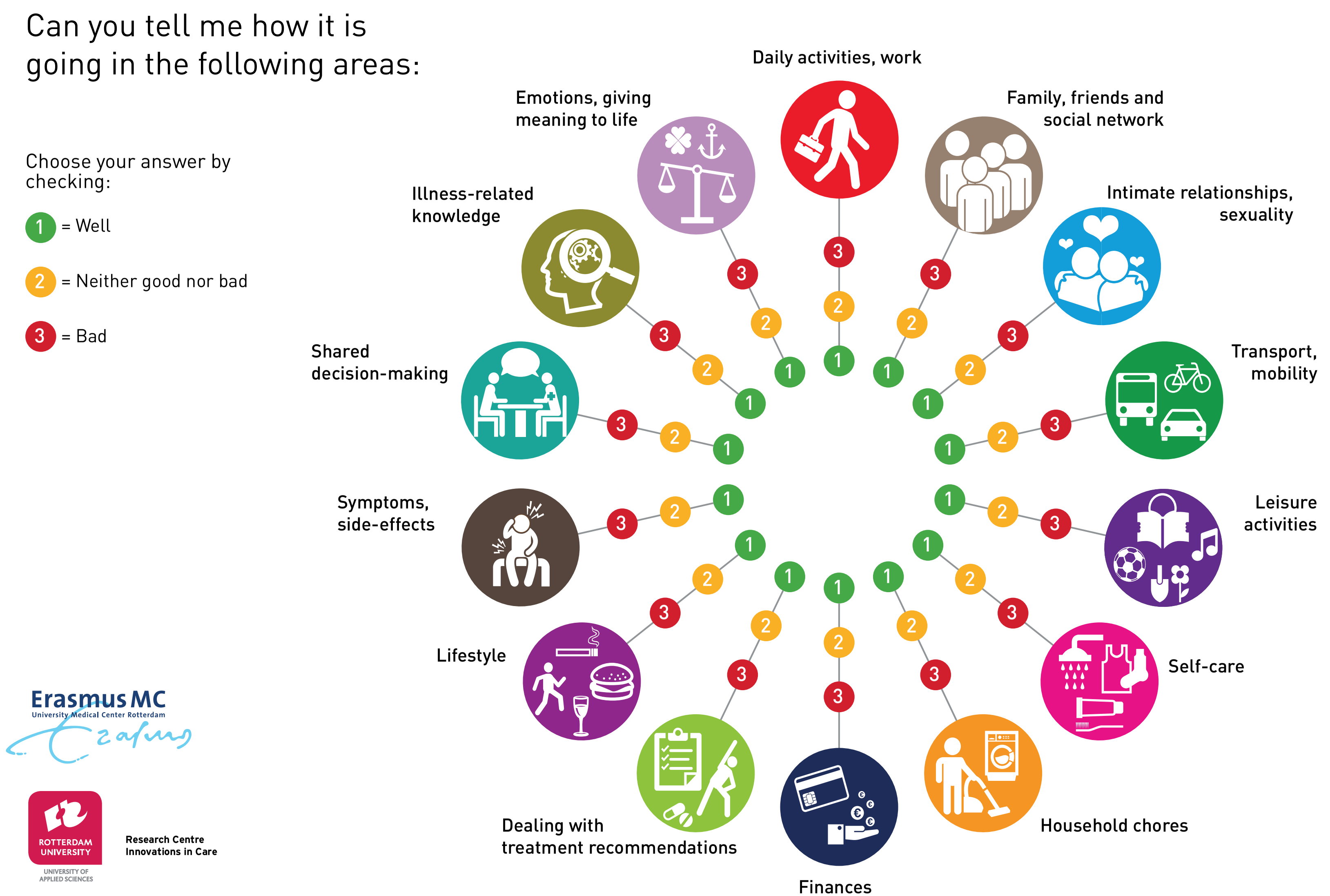

Figure 1. Self-Management Web

in the fourth session. Over the course of these sessions NPs and recipients re-assessed the original 14 life areas to detect other emerging issues and assess priorities.

During the intervention, double appointments were made for recipients (30 minutes rather than 15 minutes) with the NPs at the outpatient clinic. In the first 15 minutes NPs focused on recipients' medical situation and in the second part the intervention was implemented. Time between the sessions ranged from two weeks to several months, depending on time since transplantation and recipients' medical situation. If the period between session 1 and 2 was over a month, a telephone consult with the NP was scheduled.

Two NPs received two half-day training sessions, an intervention protocol and a booster session during which problems encountered could be discussed and techniques practiced. An experienced psychotherapist (AvtS) and a psychologist (DB) provided the training.

Data-collection

Table 1 provides an overview of the data-collection methods per research question.

Table 1. Research questions and data-collection methods

Research questions	Data-collection techniques				
	Quantitative	N intervention group (T0/ T1)	N control group (T1)	Qualitative	N
1. To what extent did the NPs carry out the SMS intervention as described in the protocol? (fidelity)	Therapy Adherence Measurement (TAM-score)	16[a]		Observations	6
2. What are the experiences of recipients and professionals regarding the applicability, usability and acceptability of the nurse-led self-management intervention? (feasibility)	Questionnaire to rate areas recipients perceived to be important and which areas were addressed during the consultation with the nurse	16	33	Individual interviews with patients	11
				Individual interviews with Nurse Practitioners	2
				Individual interviews with doctors	2
3. What are the differences in primary and secondary outcomes of recipients within the intervention group?	Questionnaire (T0-T1)	16			
4. What are the differences in primary and secondary outcomes between recipients in the control and intervention group?	Questionnaire (T1 intervention –control)	16	33		

[a] Only measured at T1.

Qualitative data

In order to analyse professionals' fidelity, six consultations were video recorded (sessions 2-4) and analysed using a semi-structured observation protocol (JB & DB) between September 2016 and November 2016. The first consultation was not filmed to avoid interrupting the process of building trust between the NP and recipient.

To assess applicability, usability and acceptability, semi-structured interviews with recipients, NPs, and nephrologists were conducted by JB, DB and EI between September 2016 and March 2017. Recipients who completed the intervention were purposefully invited to participate in a semi-structured interview using an interview guide. Interview questions focused on: the holistic focus; intervention aspects; patient-activation; use of the intervention at home; and logistics. The interviews with professionals focused on barriers and facilitators of the intervention, intervention aspects, the holistic focus, NPs´ competency to perform the intervention. All interviews were audio-recorded and transcribed.

Quantitative data

Baseline questionnaires were completed by the intervention group before the first session of the intervention (T0) and follow-up questionnaires were completed after the last session (T1). Recipients in the control group only filled in a T1 questionnaire. The intervention group also filled in the therapy adherence measurement (TAM) questionnaire. JB or DB gave the questionnaires to recipients to complete either in the waiting room or at home.

Outcome measures

Table 2 provides an overview of the outcome measures and questionnaires.

The primary outcome of this study was recipients' self-management knowledge and behaviour measured with the 12-item Partners in Health Scale (Lenferink et al., 2016; Petkov, Harvey, & Battersby, 2010; Battersby, Ask, M Reece, J Markwick, & Collins, 2003). Recipients scored on a self-rated 8 point Likert scale (where 1 indicates poor self-management and 8 good self-management) (Lenferink et al., 2016). While the original Australian PIH had a four-subscale structure (α=.82), the Dutch version consists of a two-subscale structure: 1) knowledge and coping; 2) recognition and management of symptoms, and adherence to treatment. The Cronbach's alphas of the subscales were 0.80 and 0.72 respectively. The correlation between the subscales was 0.43 (Lenferink et al., 2016).

Secondary outcomes were quality of life, general health, self-efficacy, experienced pain and fatigue, responses of transplant recipients to receipt of an organ, quality of nurse-led care, social support, and NPs' fidelity. Quality of life was assessed with the SF-36 (range score 0-100) (Aaronson et al., 1998). Four subscales were used: role limitations

Table 2. Outcome measures and questionnaires

Primary outcome	*Secondary outcomes*	*Questionnaire*
Self-management knowledge and behaviour		- Partners in Health Scale (PIH) (Lenferink et al., 2016; Petkov et al., 2010; W Battersby et al., 2003)
	Quality of life	- 36-Item Short Form Survey (SF-36) (Aaronson et al., 1998) - The World Health Organization Quality of Life - brief version (WHOQol-BREF) (Cheung et al., 2017)
	Self-efficacy	- Visual Analogue Scales (VAS) - Self-Efficacy for Managing Chronic Disease 6-item Scale (SECD6) (Brady, 2011; Lorig et al., 2001)
	Feelings after kidney transplantation	- The Transplant Effects Questionnaire (TxEQ) (Annema et al., 2013; Ziegelmann et al., 2002)
	Quality of nurse-led care	- American Consumer Assessment of Health Plan Surveys (CAHPS) (Arah et al., 2006; Delnoij et al., 2006; van Staa & Sattoe, 2014)
	Social support	- Health Education Impact Questionnaire (heiQ) (Osborne et al., 2007)
	NPs' fidelity to intervention protocol	- Therapy Adherence Measurement (TAM) (Osborne et al., 2007)
	Importance vs actual attention to topic during nurse-led consultation session	- Self-developed questionnaire

due to physical health problems (RP), vitality (VT), role limitations due to emotional problems (RE), and general mental health (MH). A higher score indicates a better quality of life. The Cronbach's alphas of the Dutch version for the four subscales RP, VT, RE and MH were, respectively, α=0.88, α=0.83, α=0.83, and α=0.86. Two questions of the World Health Organization Quality of life Instrument (WHOQol-Bref), validated in English (Cheung, Yeo, Chong, Khoo, & Wee, 2017), were used to measure recipients' general quality of life: "How would you rate your quality of life" and "How satisfied are you with your health". These questions had a 5-point Likert scale (1 indicating poor and 5 good quality of life) (World Health Organization, 1996).

Self-efficacy was measured with the Self-Efficacy for Managing Chronic Disease 6-item scale (SECD-6) (Brady, 2011; Lorig et al., 2001). Recipients scored on a self-rated 10-point Likert scale, with 1 indicating not at all confident and 10 total confidence. The Cronbach's alpha of the English scale is α=0.91 (Brady, 2011; Lorig et al., 2001). Our research group translated the scale into Dutch, but it has not been validated.

Recipients scored their general health, experienced pain and fatigue on a ten-point visual analogue scale (VAS). Higher scores indicated better health, more fatigue, or pain. To assess recipients' responses to the receipt of an organ, The Transplant Effects Questionnaire (TxEQ) was used (Ziegelmann et al., 2002). The TxEQ encompasses 23 items in five subscales: worries about the transplant, feelings of guilt towards the donor, disclosure about having a transplant, feelings and behaviour regarding medication adherence, and perceived responsibility to others (Ziegelmann et al., 2002). Recipients scored items on a 5-point Likert scale (1= strongly disagree to 5 = strongly agree). The Cronbach's alphas of the Dutch version of the TxEQ range from 0.66 to 0.79 (Annema, Roodbol, Stewart, & Ranchor, 2013).

Recipients' perceived quality of nursing care was measured with the subscale 'patient-centeredness' of the American Consumer Assessment of Health Plan Surveys (CAHPS). This subscale of the CAHPS consists of 5 questions using a 5-point Likert scale (from 1= no, definitely not to 4= yes, definitely). The scale is validated for use in the Dutch context (α=0.90) (Arah et al., 2006; Delnoij et al., 2006; van Staa & Sattoe, 2014).

Social integration and support was measured with a subscale of the Health Education Impact Questionnaire (HEIQ) (Osborne, Elsworth, & Whitfield, 2007). This subscale measuring social integration and support consist of 5 items scored on a 4-point Likert scale (1= total disagree and 4 = total agree); Cronbach's alpha is 0.86. Higher scores indicate high levels of social interaction, higher sense of support and seeking more support from others. Since our research group translated this subscale into Dutch, it has not yet been validated.

Delivering an intervention as intended, also referred as fidelity (Perepletchikova, Treat, & Kazdin, 2007), is positively associated with better outcomes (Durlak & DuPre, 2008). NPs' fidelity was measured with a self-developed Therapy Adherence Measurement (TAM). The development of the TAM was guided by characteristics as described in the literature (Kazdin, 2007; Perepletchikova et al., 2007; Schoenwald et al., 2011). First, the purpose of this fidelity measurement was established, after which essential elements of the intervention to determine NPs' fidelity were identified (Additional file 1 provides the 16 questions of the TAM).

Our research group developed a questionnaire based on the topics of the Self-Management Web, the conversation tool which is a part of the ZENN intervention. Patients indicated the importance of paying attention to various topics and the actual attention NPs paid to these topics. This scale consists of 15 items scored on a 3-points Likert scale (importance questions: 1= not important, 2 = somewhat important, and 3 = very important; attention questions: 1= no attention, 2= some attention, 3 = much attention). To be able to measure differences, answer options 1 and 2 were recoded as negative and 3 as positive.

Data-analysis

Qualitative analysis

Interviews were transcribed verbatim and imported into Atlas.ti 7.0. Data-driven codes were assigned to text. The results of first coding were discussed in the research team (JB, EI & EM) until agreement was reached. Any disagreements were resolved by discussion.

Thereafter, codes were sorted into categories and further refined during the coding process (Creswell, 2007; Polit & Beck, 2008).

Two researchers (JB & DB) independently observed the videoed consultation sessions using a predetermined observation list based on the essential elements of the intervention protocol. Results were compared, and differences were discussed.

Quantitative analysis

Medians, interquartile ranges (IQR) and proportions were used for descriptive analyses. The Wilcoxon test was used for the baseline - follow-up analysis within the intervention group (T0-T1) and the Wilcoxon test and Chi-square test were used for testing differences of the intervention and control group (T1-C). Effect sizes were calculated for the outcome measures with the bias-correct effect size Hedges (G). Effect sizes were interpreted as small (=0.20), medium (=0.50), or large (=0.80) (Fritz et al., 2012). IBM SPSS Statistics 24.0 was used for statistical analyses. The CONSORT guidelines were followed in reporting the methods and results.

Ethical considerations

Transplant recipients who were eligible for the study were informed about this study by their NP (MT and MB) and received an information letter. DB called recipients to ask whether the information was clear and they were willing to participate. Only those recipients who returned the signed informed consent form participated. An additional informed consent form was signed by recipients participating in the interviews or observations. After completion of the study, participants received a €10 gift voucher. All participants were assured of confidentiality: data were processed anonymously, and medical staff did not have access to the non-anonymous data. The study protocol was approved by the Medical Ethical Committee of the University Medical Center Rotterdam (MEC-2015-317).

RESULTS

Thirty-one kidney transplant recipients were invited to participate in the intervention group, of which 27 agreed to participate. Figure 2 shows the flowchart of the kidney transplant recipients in the intervention group. There were no significant differences between the results of recipients who underwent two or four sessions. For the control group, 48 recipients were invited to participate, 33 returned the follow-up questionnaire. Sample characteristics are shown in Table 3. There were no significant differences between the characteristics of the control group, intervention group and non-responders of the intervention group.

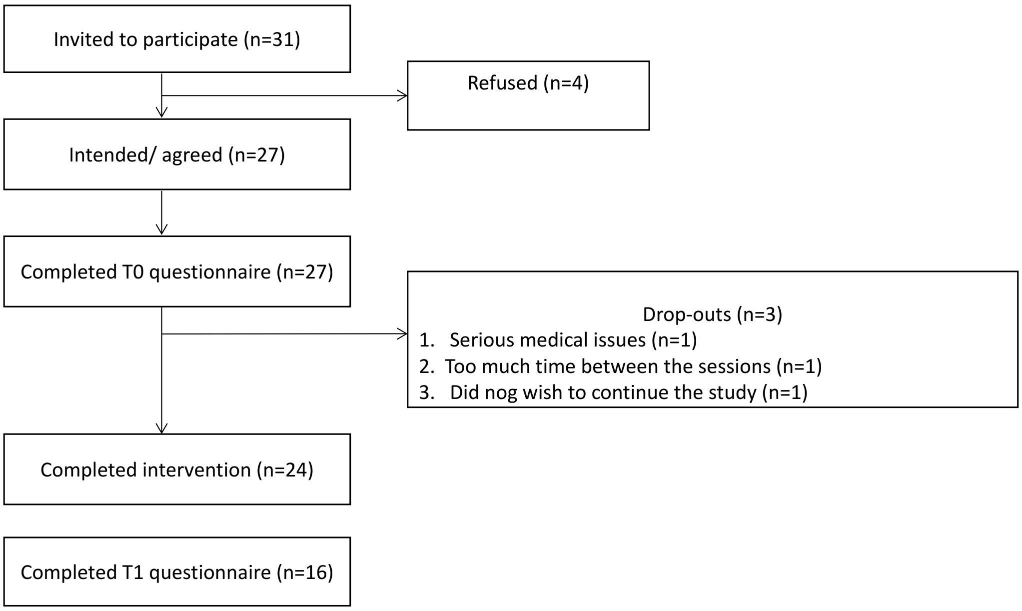

Figure 2. Flowchart of kidney transplant recipients in intervention group

Research question 1: To what extent did the NPs carry out the self-management support intervention as described in the protocol? (fidelity)

Fidelity

Fifteen recipients completed the Therapy Adherence Measurement (TAM). Nine recipients discussed non-medical topics with their NP. Key elements of the protocol e.g. use of the Self-Management Web, goal setting, action planning, self-efficacy, and motivation were reported to be addressed by three quarters of the recipients. Recipients reported the focus on the sessions to be more on problems than solutions. Data are presented in Additional file 1.

Observations of the consultations

Six consultation sessions were filmed and analyzed. In general, both NPs delivered the intervention as intended. Almost all intervention steps were completed, and techniques of Motivational Interviewing and Solution-Focused Brief Therapy were used in all 6 sessions filmed. For example, recipients were asked about their motivation and confidence in pursuing their goal: *"How much confidence do you have in your ability to improve this?"* (NP2). The next session was started by referring to what had been discussed previously: "*How did it go with the goal we set last time?" (NP1)*. NPs discussed recipients' progress on their goal attainment plan, usually by asking recipients to rate their progress on a scale from 0-10. If recipients had not attained their goals, NPs praised recipients for their efforts and discussed the experienced barriers. NPs used the solution-focused approach to stimulate recipients in a positive way:

Table 3. Sample characteristics

Characteristics	*Control group (n=33)*	*Intervention group (n = 24)*
Age (median; IQR)	59.8; IQR 29.4-75.8	59.7; IQR 28.7-72.2
Gender	22 (66.7)	17 (70.8)
Male (n; %)		
Marital status	21 (63,6)	11 (52.4)
married/ living together (Yes) (n; %)		[b]
In paid employment yes; (n; %)	10 (30.3)	9 (37.5)
Highest educational attainment (n; %)	[a]	[b]
None	1 (3.2)	1 (4.8)
Primary school	3 (9.7)	1 (4.8)
Secondary School	9 (29.03)	7 (33.3)
Higher education	18 (58.15)	12 (57.1))
Number of transplantations (n; %)		
1	26 (78.8)	21 (87.5)
2	4 (12.1)	3 (12.5)
3	3 (9.1)	0 (0.0)
Ethnicity (n; %)	[a]	
African	3 (9.7)	5 (20.8)
Asian	4 (12.9)	2 (8.3)
European	22 (71.0))	16 (66.7)
South American	0 (0.0)	1 (4.2)
Turkish	2 (6.4)	0 (0.0)
Dialysis before transplantation (n; %)		
yes	21 (63.6)	17 (70.8)
no	12 (36.4)	7 (29.2)
Comorbidity (n; %)		
Diabetes	9 (27.3)	6 (25.0)
Cardiac Event	6 (18.2)	5 (20.8)
CVA event	5 (15.2)	1 (4.1)
Vascular Event	3 (9.1)	1 (4.1)

[a] – missings (n=2); [b] – missings (n=3).

> *"Given the fact that you've been ill in the meantime, you've actually done really well. Really good that you've doing more, because your fitness had been improving every time." (NP1)*

Alternative strategies for goal attainment were also discussed. Sometimes, recipients set unattainable goals for the next session. Then NPs helped them to reformulate these into small and realistic steps.

Some situations required future exploration of cognitions and emotions that influence recipients' behavior, for example, when a recipient expressed fear of increasing physical activities, the NP talked about this fear with the recipient. Both NPs were able to tailor the intervention to their recipient's specific needs, however some aspects of the protocol were more challenging: for example, asking open questions and encouraging recipients to develop their own solutions instead of offering potential solutions.

Research question 2: What are the experiences of recipients and professionals regarding the applicability, usability and acceptability of the nurse-led self-management intervention? (feasibility)

Recipients' experiences

Eleven recipients, proportional to the distribution of recipients across the NPs, participated in an interview about their experiences with the intervention.

Need for holistic support

Recipients saw transplantation as a major life event and support to deal with these consequences was desirable. The opportunity to discuss medical, emotional and social issues during outpatient consultations with a NP was highly appreciated by recipients. In standard care, they had experienced that healthcare professionals focus on medical issues leaving little time to discuss other topics. One recipient explained that, initially, he was not convinced of the importance of discussing non-medical topics with a NP. However, after some sessions, he realized how beneficial the intervention was:

> *"The first few times I thought, does this make sense? After two or three times we discussed more serious [topics]. We had deep, long conversations. These helped me. It was not just nice small talk. We talked about feelings……This helped me. It helped me to become active." (R2)*

Most recipients expressed that the intervention should be made available for all kidney transplant recipients. One recipient stated no personal need for this holistic support, as he did not wish to discuss personal matters with his doctor or NP. Still, he felt that the intervention could be beneficial for others.

In the T1 questionnaire, recipients were asked to rate which areas they perceived to be important and which areas were addressed during the consultation with the NP. Recipients in the intervention group rated the importance of sexuality (P=0.02), leisure activities (P=0.04), adjusting lifestyle (P=0.04), psychological well-being (P=0.00), dealing with lack of understanding of others (P=0.03); and (re)initiating normal life (P=0.03) significantly higher than recipients in the control group. No significant differences were measured within the intervention group between baseline and follow-up.

At T0, there was a discrepancy between patient-reported areas of importance and these topics being addressed (whereby important topics were not being discussed) in the following areas: social context and relationships; sexuality; personal care; psychological well-being; dealing with lack of understanding of others; and (re)initiating normal life. There was a significant increase within the intervention group in the extent to which important areas were addressed by the healthcare professional: psychological well-being (P=0.03), (re)initiating normal life (P=0.046), being in control with own treatment process (=0.046), and dealing with the chronic condition (P=0.03). These areas were addressed significantly more often in the intervention group than in the historical control group (Table 4).

Evaluation of the intervention components

The Self-Management Web was rated as helpful and understandable, particularly the pictograms. Not all topics were considered relevant for everyone, but recipients did not consider this to be a problem. Recipients felt invited to discuss a wide range of life areas with their NP, including topics they would never have thought about to discuss (e.g. financial problems or sexuality). Recipients appreciated the opportunity to do so. Evaluating and assessing if recipients are doing well on the various life domains helped them to gain an overview of their progress after transplantation:

> *"Well, the difference between the beginning and the end was quite spectacular. In the beginning, I had o lot of domains scored as bad. But at the end, I also had some good scores. Given that I still have medical issues, it was very nice for me to see that I made progress." (R6)*

When a life domain was scored as 'bad', this triggered them to think about possible causes and solutions. Recipients knew NPs could not resolve their problems, but appreciated it that NPs helped them formulate possible solutions. Being encouraged to set concrete and specific goals helped recipients to make a step forward and was experienced as motivating. Some recipients mentioned that after the intervention, they had acquired more knowledge about their illness:

> *"[I learnt] everything about the disease. I am very happy that this kind of program exists. It really helps people after transplantation." (R7)*

A relationship of trust was usually built over several sessions and facilitated in-depth personal discussions. Some recipients stated they had become more competent in problem-solving skills over time. Recipients recognized the importance of intrinsic motivation to work on personal goals:

> *"It has to come from inside. Nobody else could do it for you." (R1)*

The skills learnt may be useful in tackling future problems and issues in daily post-transplant life. Recipients reported being preoccupied with medical complications; they therefore preferred to receive the intervention once these issues had been resolved.

Professionals' experiences

Two NPs and two nephrologists were interviewed about their experiences with the intervention.

Table 4. Importance of paying attention and actual attention paid to various topics

Topics	*Answer options*	*Area perceived to be important (N; %)*					*Answer options*	*Area of importance addressed by NP (N; %)*				
		T0	T1	C	P-value – Wilcoxon test (T0-T1)	P-value – Chi square (C-T1)		T0	T1	C	P-value – Wilcoxon test (T0-T1)	P-value – Chi square (C-T1)
(Unpaid) work or education	Not important	7 (46.7)	5 (31.3)	15 (50.0)	0.380	0.384	Not addressed	7 (53.9)	4 (26.7)	19 (63.3)	0.083	0.012
	Important	8 (53.3)[a]	11 (68.8)	15 (50.0)[c]			Addressed	6 (46.1)[c]	11 (73.3)[a]	11 (36.7)[c]		
Social contacts and relationships	Not important	3 (20.0)	4 (25.0)	13 (43.3)	0.763	0.239	Not addressed	6 (46.1)	4 (26.7)	16 (51.6)	0.052	0.000
	Important	12 (80.0)[a]	12 (75.0)	17 (56.7)[c]			Addressed	7 (53.9)[c]	11 (73.3)[a]	15 (48.4)[b]		
Sexuality	Not important	8 (53.3)	5 (31.3)	21 (70.0)	0.166	0.016	Not addressed	9 (69.2)	6 (40.0)	27 (87.1)	0.096	0.002
	Important	7 (46.7)[a]	11 (56.8)	9 (30.0)[c]			Addressed	4 (30.8)[c]	9 (60.0)[a]	4 (12.9)[b]		
(Adjustment of) leisure activities	Not important	0 (0.0)	2 (12.5)	12 (40.0)	0.527	0.036	Not addressed	2 (16.7)	1 (6.3)	17 (54.8)	0.257	0.002
	Important	15 (100.0)[a]	14 (87.5)	18 (60.0)[c]			Addressed	10 (83.3)[d]	15 (93.7)	14 (45.2)[b]		
Practical matters in daily life (e.g. household)	Not important	4 (26.7)	3 (18.8)	13 (41.9)	0.132	0.088	Not addressed	3 (23.1)	3 (20.0)	21 (72.4)	0.564	0.001
	Important	11 (73.3)[a]	13 (81.2)	18 (58.1)[b]			Addressed	10 (76.9)[c]	12 (80.0)*	8 (27.6)[d]		
Transport and mobility	Not important	5 (33.3)	6 (37.5)	16 (53.3)	0.803	0.455	Not addressed	5 (28.5)	5 (33.3)	21 (72.4)	0.705	0.009
	Important	10 (66.7)[a]	10 (62.5)	14 (46.7)[c]			Addressed	8 (61.5)[c]	10 (66.7)*	8 (27.6)[d]		
Personal care (e.g. washing, dressing)	Not important	7 (46.7)	5 (31.3)	13 (43.3)	0.160	0.671	Not addressed	8 (57.1)	5 (31.3)	20 (66.7)	0.057	0.005
	Important	8 (53.3)[a]	11 (68.7)	17 (56.7)[c]			Addressed	6 (42.9)[b]	11 (68.7)	10 (33.3)[c]		
Adjusting lifestyle (e.g. nutrition, exercise)	Not important	2 (20.0)	1 (6.3)	9 (30.0)	0.527	0.038	Not addressed	4 (30.8)	2 (12.5)	11 (37.9)	0.107	0.009
	Important	13 (80.0)[a]	15 (93.7)	21 (70.0)[c]			Addressed	9 (69.2)[c]	14 (87.5)	18 (62.1)[d]		
Psychological well-being	Not important	1 (6.7)	2 (12.5)	7 (23.3)	0.783	0.003	Not addressed	5 (35.7)	2 (12.5)	16 (55.2)	0.021	0.003
	Important	14 (93.3)[a]	14 (87.5)	23 (76.7)[c]			Addressed	9 (64.3)[b]	14 (87.5)	13 (44.8)[d]		

Table 4. Importance of paying attention and actual attention paid to various topics (*continued*)

Topics	*Answer options*	*Area perceived to be important (N; %)*					*Answer options*	*Area of importance addressed by NP (N; %)*				
		T0	T1	C	P-value – Wilcoxon test (T0-T1)	P-value – Chi square (C-T1)		T0	T1	C	P-value – Wilcoxon test (T0-T1)	P-value – Chi square (C-T1)
Dealing with the chronic condition	Not important	1 (6.7)	1 (6.7)	3 (9.7)	0.564	0.167	Not addressed	2 (14.3)	0 (0.0)	11 (37.9)	0.025	0.001
	Important	14 (93.3)[a]	14 (93.3)[a]	28 (90.3)[b]			Addressed	12 (85.7)[b]	16 (100.0)	18 (62.1)[d]		
Dealing with lack of understanding of others	Not important	5 (33.3)	2 (13.3)	10 (32.3)	0.119	0.015	Not addressed	9 (64.3)	5 (33.3)	21 (72.4)	0.053	0.002
	Important	10 (66.7)[a]	13 (86.7)[a]	21 (67.7)[b]			Addressed	5 (35.7)[b]	10 (66.7)[a]	8 (27.6)[d]		
(re)inting normal life	Not important	1 (6.7)	2 (12.5)	3 (9.7)	1.00	0.030	Not addressed	3 (21.4)	1 (6.3)	12 (40.0)	0.046	0.000
	Important	14 (93.3)[a]	14 (87.5)	28 (90.3)[b]			Addressed	11 (78.6)[b]	15 (93.7)	18 (60.0)[c]		
Medical issues around the condition	Not important	2 (13.3)	1 (6.3)	2 (6.4)	0.564	0.922	Not addressed	2 (14.3)	0 (0)	2 (7.1)	0.157	0.022
	Important	13 (86.7)[a]	15 (93.7)	29 (93.6)[b]			Addressed	12 (85.7)[b]	16 (100.0)	26 (92.9)[e]		
Referral to other health care professionals (if needed)	Not important	5 (33.3)	1 (6.3)	1 (3.1)	0.480	0.446	Not addressed	1 (7.2)	1 (6.3)	8 (26.7)	0.083	0.044
	Important	10 (66.7)[a]	15 (93.7)	31 (96.9)[a]			Addressed	13 (92.9)[b]	15 (93.7)	22 (73.3)[c]		
Being in control with own treatment process	Not important	1 (6.7)	0 (0.0)	1 (3.1)	0.480	0.216	Not addressed	1 (7.2)	1 (6.3)	10 (35.3)	0.046	0.002
	Important	14 (86.7)[a]	16 (100.0)	31 (96.9)[a]			Addressed	13 (92.9)[b]	15 (93.7)	20 (66.7)[c]		

[a] – missing (n=1); [b] – missings (n=2); [c] – missings (n=3); [d] – missings (n=4); [e] - missings (n=5)

Holistic focus

The ability to have deeper conservations with recipients about their daily life was appreciated by both NPs. Before implementing the intervention, they did not have a structured approach to guide the conversation about emotional and social issues:

> *"I really liked this. Especially the Self-Management Web is a nice opening to start the conversation. Discussing all these topics helped me to create a complete picture of my recipients and to get insight into their problems" (NP1)*

Especially for newly transplanted recipients, NPs saw the intervention as a valuable addition to usual care. In their experience, many recipients struggle with emotional problems after transplantation such as guilt, anxiety and even depression. During the intervention, they were surprised that even recipients with many medical problems still wished to talk about emotional and social issues. At the same time, both NPs felt a strong responsibility for monitoring recipients' medical situation. Therefore, they considered it very important to have still enough time to focus on medical aspects. For the nephrologists, it was of added value that NPs were able to address sensitive topics with the recipients that were not discussed with them, such as sexual dysfunction. One of the nephrologists emphasized the added value of providing psychosocial support:

> *"I think that this intervention has an added value for recipients' quality of life. I do not think we get better functioning kidneys, but we will get better functioning recipients." (Nephr1)*

The other nephrologist wondered whether this kind of support was within the scope of medical care. This doctor would rather see that NPs paid more attention to improving recipients' therapy adherence.

Evaluation of intervention components

NPs reported experiencing a learning curve and being challenged to adapt their methods of communication and way of interacting with patients. The intervention required them to shift their focus from problems to solutions and from offering solutions to stimulating patients to generate these themselves.

> *"First, I was dreading it. I was expected to do something I was not used to. I had to get out of my comfort zone." (NP1)*

The Self-Management Web was regarded a useful communication aid to assess issues. According to NPs, recipients felt comfortable to discuss daily life issues and aspects that NPs never discussed before, such as financial problems to visit the outpatient clinic. Still, NPs found it difficult to encourage recipients to set SMART goals and to prevent disappointment.

Another challenge was to end their consult in time, especially during the first session when all life areas were evaluated. The intervention is designed to empower the recipient, which also entails that they select the topics to work on. This sometimes created a dilemma for the NP, when a patient did not select an issue that they considered as an area for change (for example: lifestyle). NPs also considered it difficult when a recipient expressed intrinsic motivation to change behavior without turning it into action:

> *"Someone wished to stop smoking but did not quit. It this situation, it was very hard to say something positive or give him a compliment. At one point, I asked him whether it was the right moment for him to stop smoking. He said: 'Yes, I really want to quit'. Still, he did not show any indication of doing so. I then started to focus on one of his other goals. But every time, he started to discuss he wished to quit."* (NP2)

Some aspects of the intervention were reported to feel as somewhat unnatural or forced: for example, asking about recipients' self-efficacy and discussing recipients' motivation.

The NPs experienced the training as very helpful to learn solution-focused communication skills. Particularly role playing and discussing the filmed consultations sessions were mentioned as helpful. Reinforcement and positive feedback helped them to improve their skills. After the training, both NPs felt competent to deliver the intervention.

The intervention has provided them tools to activate and support recipients in behavioral change. For this, NPs expressed the importance of tailoring the intervention to recipients' own needs. It also helped them to build a relationship of trust with their recipients.

Research question 3 & 4: What are the differences in outcomes of recipients?

Primary outcome

There were no significant differences in recipients' self-management knowledge and behaviour (PIH) within the intervention group (T0 vs T1) and between the intervention and historic control group (T1 vs C) (Table 5).

Secondary outcomes

No significant differences in quality of life between the intervention and historic control group were measured with the SF-36. However, after the intervention, recipients within the intervention group reported a significantly higher Quality of life (P=0.02) with a medium effect size (G=0.78) on the domain Role limitations due to physical health problems. A significant lower Quality of life was reported on the domain Vitality (P = 0.03; G=-0.41). Further, no significant differences were found on the subdomains general quality of life and satisfaction with health on the World Health Quality of Life (WHOQol-Bref) questionnaire. No significant differences in self-efficacy within (P=0.32; G=0.20) and between

Table 5. Medians, interquartile ranges and p-values of the primary and secondary outcomes

Outcomes	Subdomain (questionnaire)	T0		T1		Control group (c)		P-value (Wilcoxon test)		Effect Size	
		N	Median (IQR)	N	Median (IQR)	N	Median (IQR)	C-T1	T0-T1	C-T1	T0-T1
Self-management knowledge and behaviour	Total Score (PIH)	15	88.0 (81.0 – 92.0)	15	88.0 (81.0 - 94.0)	32	85.5 (80.0 - 93.0)	0.54	0.41	0.20	0.24
Self-management knowledge and behaviour	Knowledge and coping (PIH)	15	51.0 (41.0-53.0)	15	51.0 (45.0 - 55.0)	33	47.0 (42.0 - 54.5)	0.47	0.43	0.23	0.27
Self-management knowledge and behaviour	Recognition and management of symptoms, adherence to treatment (PIH)	15	38.0 (36.0-40.0)	15	38.0 (36.0 - 40.0)	32	38.5 (36.0 – 40.0)	0.89	0.69	0.18	0.09
Quality of Life	General quality of life (WHOQol-BREF)	16	4.0 (3.0 – 4.0)	16	4.0 (3.0 - 4.0)	32	4.0 (3.0 - 4.0)	0.73	0.56	0.20	0.22
Quality of Life	Satisfaction with health (WHOQol-BREF)	16	3.0 (2.0 – 4.0)	16	3.5 (3.0 - 4.0)	33	4.0 (3.0 - 4.0)	0.27	0.40	-0.31	0.11
Quality of Life	Role limitations due to physical health problems (SF-36)	15	0.0 (0.0 – 50.0)	15	75.0 (0.0 - 100.0)	30	87.5 (0.0 - 100.0)	0.78	0.02	- 0.11	0.78
Quality of Life	Role limitations due to emotional problems (SF-36)	14	100.0 (0.25 – 100.0)	15	100.0 (50.00 - 100.0)	29	100.0 (66.7 - 100.0)	0.55	0.73	-0.17	0.14
Quality of Life	Vitality (SF-36)	16	50.0 (26.3 – 58.8)	16	32.5 (25.8 - 52.5)	32	42.5 (25.0 - 53.8)	0.58	0.03	- 0.14	-0.41
Quality of Life	General mental health (SF-36)	16	75.5 (61.5 – 88.0)	16	84.0 (70.5 - 92.0)	32	87.5 (64.0 - 92.0)	0.75	0.27	0.11	0.27
Self-efficacy	Total score (SECD6)	16	5.3 (3.2 – 7.2)	16	5.3 (2.8 - 7.6)	30	5.6 (3.8 - 7.3)	0.94	0.32	-0.04	0.20
Self-efficacy	VAS - health	16	60.1 (32.6 – 81.1)	16	66.9 (50.7 - 79.8)	32	70.5 (53.8 - 80.6)	0.70	0.25	-0.13	0.31
Self-efficacy	VAS -pain	16	8.3 (2.5 – 36.0)	16	3.6 (0.4 -25.7)	33	2.9 (0.7 – 14.0)	0.99	0.90	0.05	0.20
Self-efficacy	VAS - fatigue	16	57.2 (9.4 – 74.5)	16	25.7 (19.6 - 65.5)	33	43.9 (8.6 - 61.9)	0.82	0.45	-0.08	0.20
Transplant effects	Worry about the transplan (TxEQ)	14	3.4 (2.5 – 4.0)	16	3.1 (2.6 - 3.5)	29	3.3 (2.7 - 3.7)	0.69	0.69	0.11	0.48

Table 5. Medians, interquartile ranges and p-values of the primary and secondary outcomes (*continued*)

Outcomes	Subdomain (questionnaire)		T0		T1		Control group (c)	P-value (Wilcoxon test)		Effect Size	
Transplant effects	Guilt towards the donor (TxEQ)	16	2.1 (1.8 – 2.6)	16	2.0 (1.6 - 2.2)	33	2.2 (1.8 - 2.8)	0.08	0.07	0.54	0.34
Transplant effects	Disclosure about the transplantation (TxEQ)	16	5.0 (4.0 – 5.0)	16	4.8 (4.4 - 5.0)	32	4.8 (3.7 - 5.0)	0.85	0.07	-0.01	0.31
Transplant effects	Adherence to immunosuppressive medications (TxEQ)	16	4.8 (4.4 – 5.0)	16	5.0 (4.6 - 5.0)	32	4.8 (4.1 - 5.0)	0.03	0.12	0.81	0.43
Transplant effects	Responsibility towards others (TxEQ)	16	3.5 (3.0 – 4.0)	16	3.6 (3.3 - 4.0)	33	3.8 (3.0 - 4.3)	0.86	0.36	0.02	0.20
Social support	Social integration and support (heiQ)	16	18.5 (13.5 – 20.0)	16	19.0 (15.0 - 20.0)	33	18.0 (15.0 - 20.0)	0.78	0.91	-0.09	-0.04
Patient-centred care	Total score (CAHPS)	15	19.0 (18.0 – 20.0)	15	20.0 (20.0 - 20.0)	32	19.5 (18.0 - 20.0)	0.05	0.02	0.56	0.56

* C= control group; T0 = intervention group at baseline T1= intervention group after receiving the intervention.

** PIH - Partners in Health Scale ; WHOQol-BREF - The World Health Organization Quality of Life - brief version; SF-36 - 36-Item Short Form Survey; SECD6 – Self-Efficacy for Managing Chronic Disease 6-item Scale; VAS - Visual Analogue Scales ; TxEQ - The Transplant Effects Questionnaire; heiQ - Health Education Impact Questionnaire; CAHPS - American Consumer Assessment of Health Plan Surveys.

groups (P=0.94; G=-0.04) were found. There were also no significant differences in VAS Health, Pain and Fatigue. A significant difference was found between the historic control group (median 4.8) and the intervention group (median 5.0) in self-reported adherence to immunosuppressive medication (P=0.03; G=0.81). The differences on the other subdomains of the TxEQ were not significant. Moreover, there was a medium effect size on the domain guilt towards the donor between the intervention and historic control group (G=0.54). There was also no significant difference on social integration and support within the intervention group (P=0.91; G=-0.04) and between the intervention and historic control group (P=0.78; G=-0.09). The quality of patient-centered care provided by NPs improved significantly between baseline and follow-up in the intervention group (P=0.02; Median T0=19.0 & T1=20.0), but no significant differences in quality of care were found between groups. The effect size in both groups was medium (G=0.56).

DISCUSSION

This pilot study was conducted to evaluate the feasibility of a newly developed, holistic, nurse-led, self-management intervention. Although several self-management interventions for patients with various chronic conditions have been developed, interventions specifically for kidney transplant recipients are scarce and mostly focus on providing support for medication adherence (De Bleser et al., 2009; De Geest et al., 2014).

The qualitative findings of this study showed that our intervention is feasible and is promising to help kidney transplant recipients deal with post-transplant challenges. According to most professionals and recipients, the holistic focus of the intervention was a welcome addition to traditional care. Prior to the intervention, professionals largely focused on medical support, and overlooked recipients' need for emotional and social support (Been-Dahmen et al., 2015, 2018; Elissen et al., 2013; Ter Maten-Speksnijder et al., 2016). NPs were being challenged to adapt their methods of communication and way of interaction with patients. Sometimes difficulties were experienced in working with this intervention: e.gg ending their consultations in time and accepting that patients not always select an issue that they considered as an area for change.

While the quantitative findings of this pilot showed no significant changes in recipients' self-management behavior, the within-group (T0-T1) analysis indicated a significant improvement in the quality of delivered patient centered care, and quality of life - physical role. Changes in recipients' quality of life- physical role may be explained by gradual improvements in the medical situation and physical health during the recovery period after transplantation. After the intervention, this group reported significantly higher medication adherence than the control group. Before the implementation of the intervention, patients indicated that it was important for professionals to pay attention to psychosocial topics while these were not frequently addressed during consultations. After the intervention, significantly more attention was paid to these topics in the intervention group compared to the control group. This is an indication than the protocol was followed, and that patients' needs were being more sufficiently addressed.

Since recipients consider kidney transplantation to be a major life event, it is relevant that the intervention offered them the opportunity to discuss their daily life challenges and psychosocial issues. Discussing various areas of life with a NP, helped recipients to create awareness in the challenges they face and the progress they made during the intervention. After completing the intervention, recipients felt more competent in problem-solving skills, which should be confirmed by a more extensive investigation into potential effects on self-management behavior and well-being of transplant recipients. For persistence and performance of new behavior, it is important that recipients have the motivation and self-efficacy that they are capable to deal with various situations (van Hooft et al., 2017).

Tailoring was an essential component of the intervention. The need for tailoring can be explained by the variation in kidney transplant recipients attitude, needs and preferences towards self-management support (Grijpma et al., 2016). A personal approach instead of an 'one size fits all' approach for support is desired. Chronically ill patients wish to be seen as individuals with personal needs (Dwarswaard et al., 2016). Because various life areas were addressed using the Self-Management Web in the intervention, professionals were able to assess recipient's challenges individually and to discuss solutions that were suitable for the individual recipient. The open assessment also enables recipients to bring forward their own ideas, needs and preferences, which is seen as an important part of self-management (Anderson & Funnell, 2005; Wagner et al., 2001). It should have been noted that not all recipients wish to receive holistic support (Been-Dahmen et al, 2018) and that a high standard of care demands flexibility from the professional in altering their own style of delivery according to the patient's preferences (van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2014).

In complex interventions, the skills of health care professionals strongly influence the outcomes (Clark, 2013; Disler, Gallagher, & Davidson, 2012). For this reason, the NPs in this study were trained to perform the intervention, including booster sessions during implementation. Some aspects of the intervention were challenging to them, such as asking open questions and encouraging recipients to develop their own solutions rather than offering potential solutions. Respecting recipient's autonomy in selecting life areas to focus on versus reaching optimal health outcomes is an ethical dilemma NP experienced when providing the self-management support intervention (Dwarswaard & van de Bovenkamp, 2015). Nurses tend to support recipients to make the 'right choices' according to standard medical norms (Dwarswaard & van de Bovenkamp, 2015). Training in Solution-Focused Brief Therapy (SFBT) can affect nurses' communication skills positively

(Bowles, Mackintosh, & Torn, 2001). In this study NPs indicated that particularly receiving feedback in booster sessions about their skills helped them to become more competent in performing the SFBT.

In contrast to many self-management interventions (van Hooft et al., 2017), the intervention was developed according to a methodological strong procedure, including techniques of behavioural change that have a strong theoretical and evidence base. Strengths-based interventions such as those using SFBT and MI seem to be promising in supporting recipients' to self-confidence (Gingerich & Eisengart, 2000). Another strong point of this pilot study is the mixed-method design, which is recommended to evaluate complex interventions (Craig et al., 2008). It helped us to gain insight into the various essential elements of this intervention: open assessment of recipients' needs, holistic approach, tailoring advice, patient activation, building confidence and motivation, goal setting, solution focused, shared-decision making, and working on a relationship of trust between the patient and professional. These working mechanisms are in line with the five tasks (*Assess, Advise, Agree, Assist, Arrange*) defined in the Five A's model for health care professionals in self-management support (Glasgow et al., 2002). In line with the aim to promote patient empowerment, the patient was in the lead and encouraged to set the agenda.

In future testing of self-management interventions, researchers should take into consideration that patient reported experiences are important. Paying attention to patient's individual experiences increases the quality of care (van de Bovenkamp & Zuiderent-Jerak, 2015), which advocates for 'context-based practice' instead of evidence based practice (Raad voor Volksgezondheid en Samenleving, 2017). Patients Reported Experience Measures (PREMs), such as the CAHPS questionnaire, are valuable to measure what kind of care is delivered and whether the patient was satisfied with this care (e.g. Did the nurse listen to you?). Such measures can be valuable additions in examining the effects of self-management interventions.

A limitation of this study is that the intervention was evaluated in a single-center, results may therefore not be generalizable to all kidney transplant recipients in other settings. This requires further investigation alongside the potential value for recipients of other organs. There are many challenges for daily living that are common for all chronically ill patients (van Houtum, Rijken, Heijmans, & Groenewegen, 2015), therefore this self-management intervention might be suitable for patients with other chronic conditions and their health care professionals as well. Other limitations include the small sample size, which is inherent to a pilot study, and the fact that the intervention was not completely integrated into standard care.

CONCLUSION

In conclusion, the nurse-led self-management support intervention we evaluated was found to be feasible and acceptable by professionals and recipients alike. Essential elements reported by professionals and recipients were: open assessment of recipients' needs, holistic approach, tailoring advice, patient activation, building confidence and motivation, goal setting, solution focused, shared-decision making, and working on a relationship of trust between the patient and professional. No effects on patients' self-management behaviour were detected, although adherence to immunosuppressive medication improved. This initial pilot had a small sample and a more extensive investigation is needed into the potential effects on self-management behavior and well-being of transplant recipients.

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Additional file 1. Results of the TAM questionnaire

	Total (n = 15) N (%)
Number of sessions followed	
1	0 (0.0)
2	0 (0.0)
3	0 (0.0)
4	12 (85.8))
Others	
6 sessions	1 (7.1)
I do not know	1 (7.1)[a]
How often were non-medical topics discussed?	
Never	5 (35.7)
During 1 session	1 (7.1)
During 2 sessions	0 (0.0)
During 3 sessions	3 (21.5)
During 4 sessions	5 (35.7)[a]
Topics discussed with NP	
Daily activities	9 (60.0)
Social Network	8 (53.3)
Intimate relationships, sexuality	5 (33.3)
Transport, mobility	2 (13.3)
Leisure activities	8 (53.3)
Self-care	9 (60.0)
Household chores	10 (66.7
Finances	2 (13.3)
Following treatment recommendations	9 (60.0)
Lifestyle	7 (46.6)
Symptoms, side-effects	10 (66.7)
Shared decision-making	6 (40.0)
Illness-related knowledge	11 (73.3)
Emotional and spiritual well-being	8 (53.3)
How often was the Self-Management Web discussed?	
Never	1 (7.1)
During 1 session	4 (28.6)
During 2 sessions	3 (21.5)
During 3 sessions	1 (7.1)
During 4 sessions	5 (35.7)[a]
Did you receive the booklet for patients?	
Yes	12 (80.0)
No	3 (20)
How often did you set goals together with the NP?	
Never	2 (14.2)
During 1 session	3 (21.5)
During 2 sessions	3 (21.5)
During 3 sessions	2 (14.2)
During 4 sessions	4 (28.6)[a]
Did the NP discuss your motivation to set a goal?	
Yes	13 (92.8)
No	1 (7.1)[a]

Additional file 1. Results of the TAM questionnaire (*continued*)

	Total (n = 15) N (%)
How often did you create an action plan together with the NP?	
Never	2 (15.4)
During 1 session	2 (15.4)
During 2 sessions	4 (30.8)
During 3 sessions	1 (7.6)
During 4 sessions	4 (30.8)[b]
How often did the NP encourage you to make concrete when, why and with who you are gone work on a goal you set?	
Never	3 (23.1)
During 1 session	0 (0.0)
During 2 sessions	1 (7.6)
During 3 sessions	3 (23.1)
During 4 sessions	6 (46.2)[b]
Did the NP discuss your self-confidence to reach a goal?	
Yes	12 (85.7)
No	2 (14.3)[a]
Did the NP check whether you made progress in the past period?	
Never	2 (15.4)
During 1 session	0 (0.0)
During 2 sessions	4 (30.7%)
During 3 sessions	7 (53.9)
During 4 sessions	0 (0.0)[b]
Did the NP discuss your satisfaction with your progress?	
Yes	12 (85.7)
No	2 (14.3)[a]
If necessary, were your goals adjusted?	
Yes	10 (71.4)
No	1 (7.1)
It was not necessary	3 (21.5)[a]
Did the NP discuss with you how you can deal with problem in the future?	
Yes	10 (71.4)
No	4 (28.6)[a]
What was the consultation with the NP focused on?	
Solutions	2 (15.4)
Problems	8 (61.5)
I do not know	3 (23.1)[b]

[a] – missing (n=1); [b] – missings (n=2)

CHAPTER 9

General Discussion

GENERAL DISCUSSION

The central aim of this thesis was to explore how nurses could effectively support patients with a chronic condition in dealing with the disorder in daily life. This was elaborated in three parts: I) patients' and nurses' experiences with and needs for self-management support; II) development of a self-management support intervention; and III) evaluation of self-management support interventions. In this final chapter, I will reflect on the main findings and provide implications for clinical practice and future directions for research.

I) EXPERIENCES WITH AND NEEDS FOR SELF-MANAGEMENT SUPPORT

We established that nurses mostly restricted their self-management support efforts to enabling patients to deal with the medical challenges of the condition. Nurses' views and patients' experiences were confirmed by another study of the NURSE-CC research group, in which nurse practitioners were observed during outpatient consultations (Ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). The three distinct perceptions of nurses about self-management, patient's role and their own support role (Chapter 2) were largely congruent with a Q-study of the NURSE-CC research program, which dealt with nurses' perspectives on the goals of self-management support. Table 1 shows the similarities and differences about nurses' views on self-management between both studies (van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). One of the differences is that, in our study, outpatient nurses seemed unconcerned about reducing healthcare costs, whereas this was the main goal in the '*gatekeeper*' perspective described by van Hooft and colleagues. This is remarkable, since there is an increasing pressure of the Dutch government and insurance companies on healthcare professionals to provide affordable care of high quality (Katon et al., 2010; Schneider, O'Donnell, & Dean, 2009). Differences could be explained by variation in the target group and study design. In contrast to our study, where only outpatient nurses and nurse practitioners (NPs) from one university hospital were interviewed (Chapter 2), van Hooft and colleagues (2015) included nurses with various educational levels working in a variety of healthcare settings (e.g. mental healthcare, home-care and general practice). Also, van Hooft and colleagues (2015) used Q-methodology, a method specifically aimed at enlarging differences in views by searching for contrasts between values and believes (Stephenson, 1935; Watts & Stenner, 2012).

The definition of high quality of care will differ between patients (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Our studies about patients' needs (Chapters 3 & 4) confirmed that people with chronic conditions have various tasks in managing the medical, emotional and social consequences of the condition (Corbin & Strauss, 1988; Lorig & Holman, 2003). At the start of the NURSE-CC research program, we were quite ignorant about what kind of self-management support patients wished to receive – and

Table 1. Similarities and differences between two NURSE-CC studies about nurses' views on self-management support

Been-Dahmen et al. 2015 (Chapter 2)	Van Hooft et al. 2015
'Adhering to medical regimen' - Self-management is the ability of patients to live as healthy as possible - Patients should adhere to prescribed medical regimens - To achieve behavioural change, nurses should provide information about the medical regimens.	*'Clinician'* - The main goal of nurses' support is supporting patients to be able to be treatment adherent. - Nurses holding this view combine education with proposing solutions for problems patients encounter.
'Monitoring symptoms' - Self-management is specified as patients' monitoring of medical symptoms and their ability to take action if things are not going well - Patients should take an active role to be better able to manage their condition - Nurses should provide education to equip patients for monitoring	*'Educator'* - The main goal of nurses' support is to instruct their patients so they will be able to manage their condition - Nurses holding this view found it important that patients are capable to deal with the symptoms and complications of their condition.
'Integrating illness in daily life' - Self-management is the patient's ability to cope with the chronic condition in daily life - Patients are the prime agents in determining how life can be adjusted to a chronic condition - Nurse should provide holistic support and help patients to adapt to their chronic condition	*'Coach'* - The main goal of nurses' support is supporting patients to integrate their chronic condition in daily life - Nurses holding this view have a holistic view on self-management support.
	'Gatekeeper' - The main goal of nurses' self-management support is reducing healthcare costs. - Nurses holding this view stimulated their patients to become less independent of health care professionals

from whom. From the patient's point of view, good self-management support does not only address the medical challenges, but also the emotional and social consequences of having a chronic condition (Chapters 3 & 4). These results were unravelled using the model developed in a qualitative review performed in the NURSE-CC research program, which indicated that patients need to receive *instrumental* (practical support e.g. to deal with medical issues), *psychosocial and relational support* from healthcare professionals, relatives and fellow patients (Dwarswaard, Bakker, van Staa, & Boeije, 2016). We found considerable similarities between the support needs of patients with a rheumatic disorder and those of recipients after kidney transplantation (Chapters 3 & 4). *Instrumental support* should include tailored provision of disease-specific knowledge and instruction. *Psychosocial support* should address the ability to share emotional issues with a nurse. *Relational support* should include the ability to discuss the social consequences of having a chronic condition. Another NURSE-CC study, dealing with the support needs of patients with head and neck cancer regarding the consequences of the disease and its treatment, confirmed these needs (Peeters et al., 2018). Besides generic support needs, also differences between both patient groups were found, confirming that patients have generic and disease-specific support needs (van Houtum, Rijken, Heijmans, & Groenewegen, 2015). For example, patients with a rheumatic disorder wished to learn how to deal with symptoms and fluctuations, needed practical advice for self-managing, and appreciated being helped building self-confidence and empowerment by encouragement and reassurance (Chapter 3). Kidney transplant recipients wanted to be encouraged by positive feedback, receive training to develop self-awareness skills to recognise body signals, and receive support to find new daily life routines (Chapter 4). In contrast to patients with a rheumatic disorder, kidney transplant recipients indicated a more explicit need for sharing experiences with fellow patients. People with rheumatic disorders were of the opinion they had to 'do it themselves'; they saw self-management primarily as a patient's responsibility. Additionally, individuals with head and neck cancer fervently wished to receive support in dealing with the physical problems they experienced after treatment. Besides, they wished to receive support to build self-confidence to move on with their lives (Peeters et al., 2018). Although this could not be confirmed, these differences in self-management support may be related to differences in the nature of these chronic conditions. At least, it can be concluded that the need for holistic support is a common denominator for patients with a chronic condition and that all patients wish for an approach tailored to their condition and experienced challenges.

The results also demonstrated the existence of a significant gap between patients' need to receive holistic support and current nursing practice. Despite the claim of the nursing profession that nurses are experts in care-giving and apply a biopsychosocial perspective (Allen, 2015), providing self-management support from a broad perspective is not self-evident and the biomedical model of healthcare provision still appears to dominate. Above mentioned findings indicate that nurses, and other healthcare professionals, need to comprehend the importance of providing support in a broad perspective. Only when there is understanding changes in work practices can be achieved (World Health Organization, 2005). To achieve such understanding, health professionals should be made aware of the necessity of providing support from the biopsychosocial model of care to outpatients with a chronic condition.

Conclusion 1: Nurses tend to restrict self-management support to the medical challenges of patients with a chronic condition. In contrast, patients wish to receive self-management support that fits their medical, social and emotional needs and contributes to a successful management of everyday challenges.

We found that patients wished that nurses would inform about their individual support needs (Chapters 3 & 4). While the need to receive holistic support is generic, individual support needs still vary. For example, one patient may find it hard to deal with the misunderstanding of relatives, while another patient is struggling to find a balance between work-related activities and rest. A few patients did not want to discuss personal issues with their nurse and only wished to receive medical support. This emphasises again the importance of providing self-management support tailored to patients' individual support needs, which other researchers, too, have pointed out (Bos-Touwen, 2016; Trappenburg et al., 2013). Our research showed that nurses rarely provided tailored support and mostly used a type of traditional (standardised) patient education to promote their patients' self-management (Chapter 2).

Since there is no '*one size fits all approach*', assessing individual needs seems to be the first step in providing effective self-management support. By becoming aware of patients' individual support needs, preferences, values, requirements, and individual characteristics (National Clinical Guideline Centre (UK), 2012), nurses will be able to effectively tailor information, instructions and recommendations. Assessing individual needs is the first of the five phases of the self-management support process and is considered one of the necessary competencies for nurses to provide sufficient self-management support (Duprez et al., 2016; Glasgow, Davis, Funnell, & Beck, 2003; van Hooft, 2017). In addition, nurses must also acquire other competencies in line with the phases of the Five A's model (Glasgow et al., 2003; van Hooft, 2017). After Assesing patients' needs, nurses should tailor their information, instruction and advice to patient's individual needs (Advice phase). Collaborative goal setting (Agree phase) and helping patients to adapt with daily life challenges (Assist phase) are important. If needed, nurses should refer their patients to other healthcare professionals (Arrange phase). Overall, nurses should be able to form partnership with their patients. This also coincides with the current trend in healthcare to deliver person-centred care (Kitson, Marshall, Bassett, & Zeitz, 2013). To conclude, in person-centred care it is the patient who sets the agenda, not the nurse. We therefore need nurses who know how to coach and support their patients to their liking.

Conclusion 2: Tailoring information, instruction and advice is essential in providing adequate self-management support. Therefore, the first step of each self-management support intervention should be assessing patient's individual support needs, which should be repeated regularly as these may change over time.

II) DEVELOPMENT OF A SELF-MANAGEMENT SUPPORT INTERVENTION

In the past decade, the effectiveness of self-management support interventions has been much studied. Most interventions focused on the medical management of a chronic condition. Although many reviews conclude that these interventions are useful in practice, it was not clear what particular components of the intervention contribute to success (Jones, Lekhak, & Kaewluang, 2014; Radhakrishnan, 2012; Wenjing, Guihua, & Shizheng, 2015): for whom do these interventions work and in what circumstances? Many studies examined only one type of intervention (e.g. education), targeted at one specific chronic condition (e.g. diabetes type 2), and not specific developed for the use by nurses (Bentsen, Langeland, & Holm, 2012; Bonner et al., 2014; Kuo, Lin, & Tsai, 2014; Radhakrishnan, 2012; Song, Yong, & Hur, 2014). We added to the knowledge by providing more insight into the working mechanisms of nurse-led self-management support interventions with our Realist Review (Chapter 5). Successful interventions focus on patient's intrinsic processes such as motivation and self-efficacy; making that patients perceive an internal locus of control. While previous reviews have shown that solely providing education is ineffective (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Coster & Norman, 2009), nurses mostly use standardised patient education to improve their patients' self-management skills instead of applying interventions that activate patients (Chapter 2). To change patients' self-management behaviour, nurses should provide tailored information, reinforce their patients and combine patient education with skills enhancement. Involving relatives could enhance the effectiveness of self-management support interventions, too, as also was concluded in a qualitative synthesis about patients' needs in self-management support (Dwarswaard et al., 2016). Another working mechanism that our Realist Review revealed is that homogeneity in the target group of the intervention (condition, extent of motivation, recently diagnosed or not) had a positive effect on recognition and confidence. The above insights indicate that it would be worthwhile to develop holistic self-management support interventions that focus on improving the patient's intrinsic processes. We expect that recognition of these mechanisms will lead to successful self-management support. For this reason, a nurse-led self-management support intervention was developed within the NURSE-CC research program using the Intervention Mapping approach. The assessment of patients' needs was central to this intervention. Given that professionals exert a great influence on the outcomes of interventions (Clark, 2013; Disler, Gallagher, & Davidson, 2012; Macdonald, Rogers, Blakeman, & Bower, 2008), NPs received a two half-days training session before implementation. They learned how to carry out the intervention protocol and through role plays were trained in conversation techniques based on the method of Solution Focused Brief Therapy and Motivational interviewing. During the intervention period, NPs received booster sessions to discuss problems they encountered and practice conversation techniques. Feedback was provided through video recordings. This generic intervention was tailored to the specific needs of individuals with head and neck cancer and kidney transplant recipients. The intervention for kidney transplant recipients was called the ZENN intervention, an acronym derived from the Dutch name (*ZElfmanagement Na Niertransplantatie*), which translates into Self-Management After Kidney Transplantation

The developed self-management support intervention is unique and new because it consists of several elements that, in combination, should lead to success: elements tested before, such as goal setting and motivational interviewing (Maes & Karoly, 2005; Miller & Rollnick, 2013; Ratner, George, & Iveson, 2012)

Conclusion 3: Since providing education alone is not enough to change a patient's behavior, effective self-management support consists of a combination of elements that intends to influence patient's intrinsic processes, such as motivation and self-efficacy.

III) EVALUATION OF A SELF-MANGEMENT SUPPORT INTERVENTION

Evaluating self-management support interventions is a complex affair, as reported before by others (Trappenburg et al., 2013), and it remains difficult to find hard evidence about the effectiveness. In our study, we also found no significant differences in patients' self-management behaviour, self-efficacy, quality of life and social support after completing the intervention (Chapters 7 & 8). This might potentially be ascribed to: the nature of the study design, the intervention itself was not so powerful, the small number of participants and some ceiling effects in the outcome measures (e.g. quality of life and self-efficacy).

In view of the known difficulties in measuring the effectiveness of self-management support intervention, we used a mixed-methods design to evaluate both interventions (The RD-app and ZENN intervention). In contrast to the quantitative results, the qualitative result showed that both had an added value for patients. Tailoring was seen as an important mechanism: patients with rheumatic disorders mentioned that the RD-app helped getting more grip on the disease (Chapter 7) and kidney transplant recipients described that the intervention helped them to develop problem-solving skills (Chapter 8). Other working mechanisms of the ZENN intervention mentioned by kidney transplant recipient were: open assessment of one's broad support needs, activation, building confidence and motivation, goal setting, solution focused approach, shared-decision making, and follow-up. The conversational tool (Self-Management Web) helped nurses engage in deeper conversations with their patients in a more structured way. Similar results were found in another study in the NURSE-CC research program, with patients with head and neck cancer. Our self-management support intervention has a unique composition, which has never been tested elsewhere.

The most difficult and perhaps the most important challenge of our mixed-method research was integrating and evaluating the quantitative and qualitative outcomes (Chapters 7 & 8). This has been acknowledged in previous research (Reams & Twale, 2008; van Staa, 2011). Within the paradigm of evidence based practice it would be customary to value the quantitative results as more important (Mantzoukas, 2008). Nevertheless, as paying attention to a patient's individual experiences will increase the quality of care (van de Bovenkamp & Zuiderent-Jerak, 2015), a plea has been made for 'context-based practice' instead of evidence-based practice (Raad voor Volksgezondheid en Samenleving, 2017). This does not imply that qualitative research is more valuable than randomised clinical trials. When testing medical procedures or medication, clinical trials are far more reliable. But in healthcare research, for example on nursing innovations, this kind of research is not always applicable. For one thing, it is not always possible to blind patients and nurses for the intervention or changes in standard care. Although effectiveness of innovations in nursing care cannot always be demonstrated quantitatively, changes can be of great value for patients. Often these innovations lead to better perceived quality of care from the patient's perspective (Chapter 8). Alternatively, by selecting outcome measures that are more closely related to the patient and the intervention, we may be able to detect changes. For example, if we had asked the patients in our study before and after completing the intervention to rate on a VAS scale (1-10) the extent to which they reached their set goals compared to their self-confidence, we might have measured progress. Or by asking questions such as: "Did the intervention have added value for you in comparison with the standard care?", "Do you recommend this type of care for other patients?" and "Do you think the intervention should be included in the standard care provision", we might have been able to gain more insight into the added value of the self-management intervention for patients and the quality of care.

The above considerations call for a change of perspective in researchers, healthcare professionals and policy makers. Not only 'hard' evidence should be used to measure improvements of quality of delivered care, but we should place more importance on patients' and professionals' opinions of what constitutes high-quality care. Nowadays, healthcare institutions increasingly use what are known as patient reported outcome measures (PROMs) by to gain insight into patients' experiences with delivered care (e.g. how much pain was felt after a certain treatment). Besides PROMs, healthcare institutions are recommended to use patients reported experience measures (PREMs) to measure the quality of the delivered care. In contrast to PROMs, PREMs measure what kind of care professionals delivered and whether the patient was satisfied with this care (e.g. Did the nurse listen to you?) (Bos, Zuidgeest, van Kessel, & de Boer, 2015). In our evaluation studies (Chapters 7 & 8), a subscale of an international PREM scale, the Consumer Assessment of Healthcare Providers and Systems (CAPHS), was used to measure patients' experiences with the self-management support intervention. The results indicated a significant increase in the perceived quality of patient-centred nursing care within the intervention group (T0-T1) (Chapter 8). From both the patients' and professionals' perspective we could conclude that our self-management support intervention was successful and helpful for patients with a chronic condition to deal with daily life challenges. It would thus be a shame if the intervention would not be used in current nursing chronic care due the lack of hard evidence.

Conclusion 4: To detect the added value of innovative self-management interventions, evaluation studies should place more importance on patients' and professionals' opinions of what constitutes high-quality care.

General discussion

In this thesis, we focused specifically on self-management support provided by nurses. It has been advocated, however, that self-management support should be a multidisciplinary team approach (World Health Organization, 2002). Patients in our studies (Chapters 3 & 4) indicated – in line with conclusions from another study in the NURSE-CC research program (Dwarswaard et al., 2016) – a need for professional support, which can be provided by nurses, physicians or other healthcare professionals. However, patients were more inclined to discuss these daily life issues with a nurse because nurses were less pressed for time. These findings are congruent with previous research about patients' preference to discuss medical care with the doctor and receive additional support from a nurse or NP (Laurant et al., 2008).

Lack of time is often mentioned as an obstacle to provide healthcare care with a biopsychosocial focus (Chapters 2 & 8). But is providing biopsychosocial care always more time consuming? A self-management support intervention such as the ZENN intervention indeed requires more consultation time. Nurses in our study had 30 minutes' consultation time instead of the usual 15 minutes. In today's healthcare system, it seems not realistic to expect doctors to extend their consultation sessions. On the other hand, it seems reasonable to expect a doctor to inform about a patient's daily life with a chronic condition and this does not always have to be more time consuming. Consequently, given that nurses are highly trusted by their patients and trained to provide patient-centred care, nurses are in an excellent position to provide support tailored to the specific needs assessed by a doctor. The doctor's role as a medical expert is not a problem; it is important, though, that even the doctor recognises their patients' holistic support needs . Good cooperation and multidisciplinary team work in self-management support (e.g. between doctors, nurses and patients) contributes to a more effective and patient-centred healthcare system (Babiker et al., 2014; Baker, Gustafson, Beaubien, Salas, & Barach, 2006).

TO CONCLUDE….

How can nurses effectively support patients like Mark in the self-management challenges of dealing with their chronic condition(s) in daily life?

People with chronic conditions (like Mark in the case in Chapter 1) wish to receive self-management support from professionals that fits their needs, does not have a limited (biomedical) focus and that addresses all daily life areas that are challenged by their condition(s). Standardised education provision is not sufficient to enable them to deal with their chronic condition in daily life. From Mark's point of view, his nurse would bring added value by regularly assessing the challenges of his everyday life (such as work, relationships, financial aspects, adherence to therapy). Only then, nurses can facilitate developing the problem-solving skills a patient needs to live a satisfactory life despite the illness.

FUTURE DIRECTIONS

Recommendations for clinical practice

- From the patients' point of view, all healthcare professionals should understand the importance of providing self-management support from a broad perspective. Nurses, then, should more often provide self-management support from such a broad perspective. To achieve this, nurses should get a sense of the necessity of providing holistic, tailored support to outpatients with a chronic condition.
- Nurses need to acquire self-management support competencies in line with the phases of the Five A's model: assessing, advice, agree, assist and arrange. In all phases, nurses should strive to form partnership with their patients.
- Nurses, and other healthcare professionals, should refrain from providing solely education to promote their patient's self-management behaviour. They should use interventions that focus on improving patient's intrinsic processes like self-efficacy and motivation. Using conversational tools, such as the 'Self-management Web', can help them to identify and assess a patient's individual support needs. In addition, practical self-management interventions that enable nurses to coach a patient's self-management should be implemented.
- Nurses and other healthcare professionals should cooperate more often in providing self-management support: a multi-disciplinary approach is required.

Recommendations for future research

- Future research should continue with evaluating the open, tailored and holistic self-management support intervention, provided to patients with various types of chronic condition. It would be encouraging to choose outcome measures closely related to the patient and intervention. More importance should be given to patients' and professionals' opinions about the added value of interventions aimed to improve the quality of care.

- In current research articles, it is not clear to what components of an intervention success or failure can be ascribed, for whom these interventions work and in what circumstances. Researchers should not only evaluate the effectiveness of interventions but explain working mechanisms by using mixed-method designs.

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CHAPTER 10

Summary

Samenvatting

SUMMARY

Living with a chronic condition requires ongoing adjustment to physical, psychological and social demands. To date, patients are expected to be flexible and to take an active role in their disease management in the form of self-management. No generally accepted definition of self-management exists; often its meaning is reduced to adherence to a medical regimen. In this thesis, the holistic definition of Barlow et al (2002 p.178) is used: *'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.'*

To be able to take an active role, patients must possess certain skills to solve problems, make decisions, find and utilise resources, form partnership with their healthcare professionals, and take action. Given these requirements, most patients they will need support from healthcare professionals. Nurses are in an excellent position to play a significant role in self-management support. They are highly trusted by their patients and trained to provide patient-centred care. Still, they need to be properly equipped with new competencies, adequate training and sufficient interventions. Many practical self-management interventions have been developed to guide nurses; hard evidence about the effectiveness is lacking however. It is not clear what particular components contribute to the success or failure of self-management interventions and how self-management support can be optimised to the patient's perspective.

Therefore, the **central aim** of this thesis was to explore how nurses could effectively support patients with chronic conditions in dealing with the disorder in daily life.

PART I) EXPERIENCES WITH AND NEEDS FOR SELF-MANAGEMENT SUPPORT

Chapter 2 describes a qualitative study with 27 nurses/ nurse practitioners working in outpatient clinics of a university hospital in the Netherlands. This study aimed to unravel nurses' views on the self-management role of people with chronic conditions in, nurses' own support role and to establish how these views relate to nurse-led self-management support. Three distinct views on the patient's role emerged, ranging from a biomedical to a wider biopsychosocial focus: *adhering to a medical regimen; monitoring symptoms; and integrating illness into daily life*. Nurses holding the view *'adhering to a medical regimen'* interpreted self-management as the patient's ability to live as healthy as possible. Patients were considered good self-managers if they adhered to the treatment and lifestyle rules. Nurses adhering to the *'monitoring symptoms'* view specified self-management as the regular monitoring of medical symptoms and the ability to take action if things are not going well. Nurses holding the *'integrating the illness into daily life'* view defined self-management as patient's ability to cope with the chronic condition in everyday life. Despite the fact that all outpatient nurses recognised the importance of self-management and providing support, most of them had a limited focus on the concept – addressing the medical management of a chronic condition only. Social and emotional tasks of living with a chronic condition were overlooked.

To gain insight in the self-management challenges and support needs of outpatients with a chronic condition, two qualitative studies with another patient group were conducted. Both studies made use of focus groups and individual interviews, and interview data was analysed with the Directed Content Analysis method and coded with predetermined codes derived from our model about support needs of chronically ill patients. This model distinguished three types of support: instrumental, psychosocial and relational support. **Chapter 3** identified the self-management support needs of outpatients with rheumatic disorders. Fourteen patients participated in two focus group interviews and six were interviewed individually. Patients saw self-management primarily as a task for themselves but nevertheless appreciated help to achieve this. Above all, they wanted to be seen as experts-by-experience of living with a rheumatic disorder. Only a few patients appreciated psychosocial support from fellow patients. Preferred support givers were professionals, such as nurses, and relatives. Professional's self-management support should be focused on coaching patients in developing problem-solving skills for managing the medical, emotional and social challenges of dealing with a rheumatic disorder in daily life. Important elements of self-management support were: learning how to deal with symptoms and fluctuations, talking about emotional aspects, discussing daily life issues and sharing disease-related information. It was considered crucial that support be tailored to individual needs and expertise. **Chapter 4** revealed kidney transplant recipients' self-management challenges and support needs. Thirty-two recipients participated in four focus groups and nine were interviewed individually. Challenges after transplantation included becoming an expert patient, adjusting daily life activities, dealing with medical regimen, forming relationships with nurses, dealing with social consequences, dealing with emotions related to transplantation and the donor, and improving self-image. To deal with these challenges, participants wished to receive disease-specific knowledge and instruction, share personal experiences with fellow patients, share and discuss not only medical but also emotional and social issues with nurses, and be encouraged through positive feedback. 'One-size fits all' education failed to meet their needs. Current support from nurses tended to ignore emotional and social support needs

To connect to patients' daily life challenges, nurses should assess patients' individual support needs and tailor their support accordingly. Self-management support should be focused on coaching patients in developing problem-solving skills, for which practical tools and training are needed.

PART II) DEVELOPMENT OF A SELF-MANAGEMENT SUPPORT INTERVENTION

We conducted a Realist Review to discover how nurse-led self-management interventions for patients with chronic conditions work and in what context they work successfully (**Chapter 5**). Theories-in-use (how the intervention actually worked) and pathways the interventions followed were determined. Most interventions consisted of counselling and education (face-to-face or in groups); some included physical exercises or self-monitoring. Three working mechanisms were found: increasing patients' knowledge, skills enhancement and motivation. Interventions focusing on patients' self-efficacy and motivation (intrinsic processes) were most successful. Importantly, for new behaviour to be performed and sustained, patients must perceive internal locus of control. Less successful were interventions that focused on education only to change behaviour. In contrast, re-enforcement of education, tailoring information to individual needs, and combining education with skills enhancement are successful intervention elements to achieve behavioural changes. Involving relatives could positively influence the effectiveness of interventions. Homogeneity in the intervention group (e.g. condition, extent of motivation, recently diagnosed or not) had a positive effect on recognition and patients' confidence. Insight in working mechanisms may help nurses to decide what self-management support intervention they can best use in a specific setting and patient group. Preferably, interventions aimed at increasing a patient's intrinsic process will be selected.

Chapter 6 describes the systematic development of a nurse-led self-management support intervention with the use of the Intervention Mapping (IM) approach. The result was a generic intervention that incorporates patients' and nurses' needs, and that is based on relevant theories and evidence-based methods. The intervention included the following key elements: (1) opportunities for tailoring within a general structure; (2) a holistic approach; (3) principles of shared-decision making; and (4) patient empowerment. The overall goal was to enhance the self-management skills needed to integrate treatment- and life goals and subsequently optimise one's quality of life and health-related outcomes. Nurse practitioners (NP) guided patients in assessing 14 life areas using the Self-Management Web, setting priorities, setting SMART goals, making action plans, promoting motivation and self-efficacy, and generalization of skills to new goals. The NPs had been trained in communication techniques based on the principles of Solution-Focused Brief Therapy.

This generic intervention was tailored to the specific needs of kidney transplant recipients and individuals with head and neck cancer. The intervention for kidney transplant recipients was called the ZENN intervention, an acronym derived from the Dutch name (*ZElfmanagement Na Niertransplantatie*), which translates as Self-Management After Kidney Transplantation.

PART III) EVALUATION OF A SELF-MANAGEMENT SUPPORT INTERVENTION

A prospective before-after study **in Chapter 7** investigated whether the use of a smartphone-application improved the self-management behaviour of patients with a rheumatic disease (RD), identified factors associated with the use, and unravelled patients' experiences with the app. The RD-app was developed by specialist nurses, rheumatologists, an app developer and patients with a RD. Different components were incorporated: (tailored) disease-specific information, self-monitoring, physical exercises, and medication tools. Patients were informed about the RD-app during nursing consultations and received a newsletter about the launch. The RD-app was actually used by 114 of the 397 patients involved in the evaluation. Forty-two percent of the app-users mentioned that the use of the RD-app had helped them to get more grip on the disease. This percentage was higher for those who used the RD-app more frequently (P=0.04). Patients with positive expectations beforehand were more likely to actually use the RD-app. Patients' self-management behaviour did not change significantly. Receiving tips, information on exercises and gaining insight in self-reported disease activity were mentioned as elements with an added value. Reasons for not using the RD-app were, for example, no interest at all, low disease activity, not any added value due to e.g. access to online sources, and not wishing to be confronted with the disease. We concluded that although the app was not used very often and no significant behaviour changes were detected, it seemed to help getting more grip on the disease.

Chapter 8 describes a controlled before-after mixed-methods study to evaluate the self-management support intervention ZENN. Adult kidney transplant recipients who had received the transplant more than one month ago were invited to participate. NPs, nephrologists and recipients were interviewed to assess feasibility, fidelity and implementation experience. Consultations were videotaped and analysed to assess protocol adherence. To assess the preliminary effects, the intervention group completed baseline and follow-up questionnaires on self-management behaviour, self-efficacy, quality of life and quality of care. A historical control group of kidney transplant recipients completed the same questionnaires at follow-up.

Twenty-eight recipients agreed to participate in the intervention group, of whom 24 completed the intervention and 16 filled out both baseline and follow-up surveys. The historic control group consisted of 33 recipients. Both NPs delivered the intervention as intended. Professionals and recipients appraised the open, holistic focus of the intervention as a welcome addition to traditional care and felt that this helped to build a trusting relationship between recipient and professional. Recipients also felt becoming more competent in problem-solving skills. The analysis showed a significant improvement of the perceived quality of nursing care (P=0.02) in the intervention. Between groups (C-T1) a significant difference was found in self-reported adherence to immunosuppressive medication (P=0.03). This self-management support intervention was appreciated feasible and judged as having added value by professionals and recipients alike. To gain more insight into the potential effects of the intervention, more research with relevant outcome measures is needed.

CONCLUSION

The findings from the studies in this thesis contributed to more understanding as to how nurses could support patients in the self-management challenges they experience in dealing with a chronic condition in daily life. These patients wish to receive self-management support that fits with their needs, does not have a limited (biomedical) focus and that addresses all daily life areas challenged by the disease. Receiving standardised education is not sufficient.

From the patients' and professionals' points of view, the newly developed self-management intervention seems to be feasible. Regularly assessing the daily-life challenges with the Self-Management Web (related, among other things, to work, (intimate) relationships, financial aspects, adherence to therapy) and tailoring support accordingly had an added value for both. It helped nurses to facilitate their patients to develop the problem-solving skills needed to live a satisfactory life despite the illness.

SAMENVATTING

Patiënten met een chronische aandoening staan continu voor de uitdaging om hun dagelijks leven aan te passen aan de lichamelijke, psychologische en sociale consequenties daarvan. Hierbij wordt verwacht dat zij een flexibele houding aannemen en een actieve rol spelen. Dit wordt ook wel aangeduid als zelfmanagement. Een algemeen geaccepteerde definitie van zelfmanagement ontbreekt tot op heden. Vaak wordt het concept gereduceerd tot medisch management, maar soms worden ook bredere definities gehanteerd waarin sociale en emotionele aspecten worden meegenomen. In dit proefschrift werd de brede definitie van Barlow en collega's gebruikt (2002): 'Zelfmanagement verwijst naar de mogelijkheden van individuen om te gaan met de symptomen, behandeling, lichamelijke en psychische consequenties en leefstijlveranderingen die inherent zijn aan het hebben van een chronische aandoening. Effectief zelfmanagement gaat uit van individuele mogelijkheden om een aandoening te monitoren en invloed uit te oefenen op cognitieve, gedragsmatige en emotionele reacties, wat nodig is voor het handhaven van een bevredigende kwaliteit van leven. Op deze manier ontstaat een dynamisch en continue proces van zelfregulatie.'

Om patiënten in staat te stellen een actieve rol te spelen bij het managen van hun aandoening, is het belangrijk dat ze probleemoplossende vaardigheden aangeleerd krijgen, in staat zijn beslissingen te nemen, hulpbronnen weten te vinden en aan te spreken, partnerschap met professionals kunnen vormen en actie kunnen ondernemen. Gezien de eisen die dit stelt, hebben de meeste patiënten hierbij ondersteuning van professionals nodig. Verpleegkundigen worden gezien als een beroepsgroep met een excellente positie voor het bieden van zelfmanagementondersteuning. Onder andere omdat ze getraind zijn in het verlenen van patiëntgerichte zorg en patiënten over het algemeen een groot vertrouwen in hen hebben. Wel moeten ze worden uitgerust met nieuwe competenties, adequate training en passende interventies. Hoewel inmiddels al verschillende zelfmanagementinterventies zijn ontwikkeld, is de wetenschappelijke basis beperkt. Vaak is niet duidelijk welke specifieke componenten van verpleegkundige zelfmanagementinterventies bijdragen aan het succes of het falen hiervan en hoe zelfmanagementondersteuning vanuit het perspectief van patiënten kan worden geoptimaliseerd. De **centrale doelstelling** van dit proefschrift was daarom het in kaart brengen van de wijze waarop verpleegkundigen patiënten met een chronische aandoening effectief kunnen ondersteunen bij het omgaan met hun aandoening in het dagelijks leven.

DEEL 1) ERVARINGEN MET EN BEHOEFTEN AAN ZELFMANAGEMENT-ONDERSTEUNING

Hoofstuk 2 beschrijft een kwalitatieve studie onder 27 verpleegkundigen en verpleegkundig specialisten, die werkzaam zijn op verschillende poliklinieken van het Erasmus MC in Rotterdam. Deze studie heeft (1) de visies van verpleegkundigen op de rol van patiënten bij zelfmanagement, (2) hun eigen ondersteuningsrol en (3) hoe hun visie samenhing met de wijze waarop ze zelfmanagementondersteuning boden in kaart gebracht. Er werden drie verschillende visies gevonden, variërend van het biomedische tot het bio-psychosociale perspectief: *trouw aan het medische regime, monitoren van symptomen* en *integreren van de chronische aandoening in het dagelijks leven*. Verpleegkundigen die de visie '*trouw aan het medische regime*' aanhingen, interpreteerde zelfmanagement als de mogelijkheid van patiënten om zo gezond mogelijk te leven. In hun ogen doen patiënten het goed als ze trouw zijn aan de behandeling en de leefstijladviezen van professionals. Verpleegkundigen met de visie '*monitoren van symptomen*' beschreven zelfmanagement als het regulier monitoren van symptomen en in staat zijn om actie te ondernemen als het even wat minder goed gaat. Verpleegkundigen die de visie '*integreren van de aandoening in het dagelijks leven*' aanhielden definieerden zelfmanagement als de mogelijkheid van patiënten om te gaan met de aandoening in het dagelijks leven. Hoewel zelfmanagement door de geïnterviewde verpleegkundigen als iets belangrijks werd gezien, hadden veel van hen een beperkte focus. Vaak werd alleen ondersteuning geboden bij medische problemen en werden de sociale en emotionele uitdagingen van patiënten met een chronische aandoening onderschat.

Om inzicht te krijgen in de uitdagingen en ondersteuningsbehoeften van poliklinische patiënten met een chronische aandoening werden twee kwalitatieve studies (Hoofdstuk 3 & 4) bij verschillende patiëntengroepen uitgevoerd. Beide studies verzamelden data met focusgroepen en individuele interviews. Data werden gecodeerd met vooral gedefinieerde codes die waren gebaseerd op een model van de onderzoeksgroep NURSE-CC (NUrsing Research into Self-management support into Chronic Care) over zelfmanagementondersteuningsbehoeften van patiënten. Dit model beschrijft drie types ondersteuning: instrumentele, psychosociale en relationele ondersteuning.

Hoofdstuk 3 geeft de behoefte van poliklinische patiënten met een reumatische aandoening weer bij zelfmanagementondersteuning. Veertien patiënten namen deel in twee focusgroepen en zes patiënten werden individueel geïnterviewd. Zelfmanagement werd door de patiënten voornamelijk gezien als een taak voor henzelf. Ze wilden gezien worden als ervaringsexperts. Desalniettemin was hulp nodig om dit te bereiken. Bij voorkeur ontvingen patiënten ondersteuning van naasten en professionals zoals verpleegkundigen. De ondersteuning van professionals zou gericht moeten zijn op het coachen van patiënten bij het ontwikkelen van probleemoplossende vaardigheden voor het omgaan met de medische, emotionele en sociale uitdagingen van het leven met een reumatische aandoening. Belangrijke elementen van zelfmanagementondersteuning waren: leren hoe om te gaan met symptomen en fluctuaties, bespreken van emotionele aspecten, in gesprek gaan over problemen die ervaren worden in het dagelijks leven en het delen van ziekte specifieke informatie. Hierbij werd het afstemmen van ondersteuning op individuele behoeftes van patiënten als zeer belangrijk gezien. Slechts een aantal patiënten hadden behoefte aan psychosociale ondersteuning van medepatiënten.

Hoofdstuk 4 beschrijft de uitdagingen en ondersteuningsbehoeften van niertransplantatiepatiënten. Tweeëndertig patiënten hebben deelgenomen aan vier focusgroepen en negen patiënten werden individueel geïnterviewd. Uitdagingen die patiënten ervoeren na een niertransplantatie waren: expert worden, aanpassen van activiteiten in het dagelijks leven, omgaan met medische regimes, aangaan van een relatie met verpleegkundigen, omgaan met de sociale consequenties, omgaan met de emoties die horen bij het ondergaan van een transplantatie en het verbeteren van het zelfbeeld. Om in staat te zijn met deze uitdagingen om te gaan wilden de patiënten vooral ziekte specifieke educatie en instructie ontvangen, de mogelijkheid hebben om persoonlijke ervaringen te bespreken met medepatiënten, in de gelegenheid zijn om naast medische problemen ook sociale en emotionele aspecten met een verpleegkundige te bespreken en aangemoedigd worden met positieve feedback. Gestandaardiseerde educatie sloot niet aan op hun behoefte. Toekomstige zelfmanagementondersteuning zou afgestemd moeten zijn op de individuele ondersteuningsbehoeften van een patiënt.

Door ondersteuningsbehoeften uit te vragen, kunnen verpleegkundigen aansluiten op de individuele ondersteuningsbehoeften van patiënten. Zelfmanagementondersteuning zou zich vervolgens moeten focussen op het coachen van patiënten bij het aanleren van probleemoplossende vaardigheden, waarvoor praktische hulpmiddelen en training nodig zijn.

DEEL 2) DE ONTWIKKELING VAN EEN ZELFMANAGEMENTINTERVENTIE

De realist review in **hoofdstuk 5** onderzocht hoe zelfmanagementinterventies werken bij patiënten met een chronische aandoening en in welke contexten ze succesvol zijn. De theoretische basis en de manier waarop interventies daadwerkelijk werkten werden in kaart gebracht. De meeste interventies bestonden uit advies, instructie en educatie (individueel of in groepsverband). Sommige interventies bestonden ook uit lichamelijke oefeningen en het zelfstanding monitoren van de medische situatie. In deze studie werden drie werkende mechanismen gevonden: het vergroten van de kennis, het verbeteren van de vaardigheden en het vergroten van de motivatie van patiënten. Interventies die gericht waren op de zelfeffectiviteit en motivatie (intrinsieke processen) van patiënten bleken het meest succesvol. Voor het ontwikkelen en handhaven van nieuw gedrag is het belangrijk dat patiënten zelf een gevoel van controle ervaren. Minder succesvol waren de interventies die focusten op het veranderen van gedrag via educatie. Interventies waarin educatie werd gecombineerd met aanmoediging, die afgestemd werd op individuele kennisbehoeften en waarin vaardigheden werden aangeleerd, waren meer succesvol. Deze inzichten in werkzame mechanismen kunnen verpleegkundigen helpen om te beslissen welke interventies ze het beste kunnen gebruiken in een specifieke setting en bij een specifieke patiëntengroep. Bij voorkeur gebruiken verpleegkundigen interventies die als doel hebben de intrinsieke processen van patiënten te versterken.

Hoofdstuk 6 beschrijft de systematische ontwikkeling van een verpleegkundige interventie voor zelfmanagementondersteuning met behulp van de Intervention Mapping (IM) methode. Het resultaat was een interventie die inspeelt op de behoeftes van patiënten en verpleegkundigen, ontwikkeld is op basis van relevante theorieën en gebaseerd is op wetenschappelijk bewezen methodes. De zelfmanagementinterventie bestaat uit de volgende belangrijke elementen: (1) mogelijkheden voor maatwerk binnen een algemene structuur; (2) een holistische benadering; (3) bevat principes van gezamenlijke besluitvorming; (4) versterkt de eigen kracht van patiënten. Het doel van de interventie is het versterken van zelfmanagementvaardigheden die nodig zijn voor het integreren van behandel- en levensdoelen. Daarnaast is het ook gericht op het optimaliseren van de kwaliteit van leven en de gezondheidsuitkomsten van patiënten. Verpleegkundig specialisten ondersteunden patiënten bij het in kaart brengen van 14 levensdomeinen met behulp van een gesprekshulpmiddel genaamd Zelfmanagement Web, het stellen van prioriteiten, het stellen van SMART doelen, het maken van actieplannen, het promoten van motivatie en zelfeffectiviteit en het generaliseren van de geleerde vaardigheden naar nieuwe doelen. Daarnaast werden de verpleegkundig specialisten getraind in communicatietechnieken die gebaseerd zijn op de principes van Solution-Focused Brief Therapy.

Deze generieke interventie is aangepast aan de specifieke ondersteuningsbehoeften van niertransplantatiepatiënten en individuen met hoofd-halstumoren. De interventie voor niertransplantatiepatiënten werd de ‘ZElfmanagement Na Niertransplantatie’ (ZENN) interventie genoemd.

DEEL 3) EVALUATIE VAN ZELFMANAGEMENTINTERVENTIES

Een prospectieve studie met een voor- en nameting werd uitgevoerd in **hoofdstuk 7** om in kaart te brengen: (1) in hoeverre het gebruik van een mobiele applicatie (de Reuma-app) het zelfmanagementgedrag van mensen met een reumatische aandoening positief beïnvloedt; (2) welke factoren het gebruik van de app beïnvloeden; (3) welke ervaringen patiënten met de app hebben. De Reuma-app werd ontwikkeld door specialistische verpleegkundigen, reumatologen, een app-ontwikkelaar en patiënten met reuma. Het omvat verschillende componenten, zoals: (op maat geleverde) ziekte specifieke informatie, een dagboek voor het monitoren van de medische situatie, uitleg over lichamelijke oefeningen en hulpmiddelen voor therapietrouw. Patiënten werden geïnformeerd over de app tijdens verpleegkundige consultaties en ontvingen een nieuwsbrief over de lancering van de app. De Reuma-app werd gebruikt door 114 van de 397 patiënten die betrokken waren bij de evaluatiestudie. Tweeënveertig procent van de app-gebruikers beschreef dat de app hen had geholpen om meer grip op hun aandoening te krijgen. Patiënten met een positieve verwachting waren meer geneigd om de app te gebruiken. Patiënten beschreven het ontvangen van adviezen, het verstrekken van informatie over oefeningen en het krijgen van inzicht in de zelf-gerapporteerde ziekteactiviteit via de app als waardevolle elementen van de interventie. Er was echter geen significante verandering van het zelfmanagementgedrag binnen de interventiegroep. Redenen voor het niet gebruiken van de app waren bijvoorbeeld afwezigheid van interesse, een lage ziekteactiviteit, geen toegevoegde waarde zien ten opzichte van andere online bronnen en niet geconfronteerd willen worden met de ziekte.

Hoofdstuk 8 beschrijft een evaluatiestudie met een voor- en nameting naar de toepasbaarheid van de ZENN-interventie, uit Hoofdstuk 6. Volwassenen die één tot acht maanden geleden een niertransplantatie hadden ondergaan werden uitgenodigd voor deelname. Verpleegkundig specialisten, nefrologen en niertransplantatiepatiënten werden geïnterviewd over de uitvoerbaarheid, de trouw aan het protocol en hun ervaringen met de implementatie. Enkele consultatiesessies werden opgenomen op video en geanalyseerd om de trouw aan het protocol in kaart te brengen. Voor de evaluatie werd een interventiegroep uitgenodigd om een voor- en nameting in te vullen. Vragenlijsten over onder andere zelfmanagementgedrag, zelfeffectiviteit, kwaliteit van leven en de kwaliteit van de verpleegkundige zorg werden meegenomen. Een historische controlegroep heeft dezelfde nameting ingevuld als de interventiegroep. Uiteindelijk hebben 24 patiënten de gehele interventie doorlopen. De historische controle groep bestond uit 33 patiënten. Beide verpleegkundig specialisten hebben de interventie uitgevoerd zoals beschreven in het protocol. Professionals en patiënten waardeerden de open, holistische focus van de interventie en beschreven die als een waardevolle aanvulling op de standaard zorg. De interventie hielp bij het opbouwen van een vertrouwensrelatie. Daarnaast beschreven niertransplantatie patiënten dat ze meer competent werden in probleemoplossende vaardigheden. De analyses lieten binnen de interventiegroep een significante toename in de kwaliteit van de verpleegkundige zorg zien ($P=0.02$). Tussen de groepen (C-T1) werd een significant verschil gevonden in de zelfgerapporteerde therapietrouwheid ($P=0.03$). Deze zelfmanagementinterventie werd gewaardeerd, was uitvoerbaar en van toegevoegde waarde voor niertransplantatie patiënten en professionals.

CONCLUSIE

De resultaten van de studies in dit proefschrift dragen bij aan het verkrijgen van meer inzicht in de wijze waarop verpleegkundigen patiënten met een chronische aandoening kunnen ondersteunen bij de uitdagingen die ze ervaren in het dagelijks leven. Patiënten willen graag zelfmanagementondersteuning ontvangen die aansluit op hun behoeften, geen beperkte (medische) focus kent maar ingaat op alle domeinen van het dagelijks leven. Het ontvangen van gestandaardiseerde educatie is onvoldoende.

Vanuit patiënten- en verpleegkundig perspectief is de nieuwe brede zelfmanagementinterventie uitvoerbaar en van toegevoegde waarde. Het regulier in kaart brengen van dagelijkse uitdagingen met het Zelfmanagement Web (bijvoorbeeld gerelateerd aan werk, relaties en financiële aspecten) en het op maat leveren van ondersteuning werden gewaardeerd als toevoeging op de huidige zorg. Tevens hielp de interventie verpleegkundigen om patiënten probleemoplossende vaardigheden aan te leren, die nodig zijn voor het creëren van een bevredigend leven ondanks de chronische aandoening.

APPENDICES

DANKWOORD

"It often feels like two steps forward, one step back, but if you keep going, before you know it, you have climbed a mountain" (David Williams)

Zoals deze citaat - *mijn elfde stelling* - al suggereert: een promotietraject is een ontwikkelproces dat niet lineair verloopt. Het kent pieken en dalen. Tegenslagen heb je nodig om deze bergtop te bereiken. Mijn promotietraject heb ik ervaren als een leerzaam proces en ik ben dan ook dankbaar voor alle kansen die ik heb gekregen.

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Chantal en Mariëlle, wat ben ik blij dat jullie mijn paranimfen zijn. *Chantal*, mede verplegingswetenschapper, bijzonder om zo'n goede vriendin te hebben met dezelfde interesses. Bedankt dat je altijd zo oprecht betrokken was bij mijn promotietraject. *Mariëlle*, vele uurtjes hebben we samen over NURSE-CC gebrainstormd. Onze koffiemomenten waren niet alleen productief, maar ook ontzettend gezellig. Bedankt dat ik altijd bij je terecht kon voor een luisterend oor. Heel leuk dat we, samen met Susanne, onze NURSE-CC tijd hebben afgesloten op het STTIEC congres in Cambridge. Nu op naar jouw promotie!

Natuurlijk wil ik ook al mijn collega's van de HBO-V, Kenniscentrum Zorginnovatie en het Erasmus MC bedanken. Een paar collega's wil ik apart in het zonnetje zetten. *Susanne*, mede NURSE-CC promovendi, wat was het fijn om tegelijk met iemand aan dit avontuur te beginnen. Bijzonder om jouw promotie van zo dichtbij meegemaakt te hebben. Ik kijk ernaar uit om samen binnen ZM-Doc aan de slag te gaan. *Ada, Cora, Emma, Erica, Denise, Heleen, Hennie, Jan-Willem, Jolanda, Margot, Mariska, Mirjam, Marleen & Wendy,* bedankt voor de fijne samenwerking binnen NURSE-CC. *Jane, Marjolijn, en Stefanie*, wat was het prettig om altijd bij jullie als mede-promovendi terecht te kunnen voor vragen. Onze etentjes waren altijd een gezellige bron van inspiratie! *Elly, Hanneke, Joyce (Erasmus MC) & de rest van het Kenniscentrum secretariaat* bedankt voor alle secretariële ondersteuning. *Ko Hagoort,* jij wist altijd mijn Engelse teksten aan te scherpen. *Els en Marion*, jullie vooral bedankt voor alle ruimte die ik vanuit de HBO-V kreeg voor het doen van mijn promotieonderzoek. *Marleen, Sharon en Corine*, gaaf dat we met elkaar de minor Psychiatrie hebben ontwikkeld. Heerlijk om naast het doen van onderzoek samen met jullie bezig te zijn geweest met het overdragen van ons vak.

Lieve pa en ma, jullie passie voor de gezondheidszorg en pa zijn passie voor de wetenschap zijn mijn basis geweest voor het ontwikkelen van mijn passie voor de verpleegkundige zorg. Dankbaar ben ik dan ook voor alle mogelijkheden en aanmoedigingen die ik van jullie heb gehad om intellectuele uitdagingen aan te gaan. Bijzonder dat jullie mijn promotietraject, in de maanden die we als gezin bij jullie woonden, van zo dichtbij hebben meegemaakt. *Mieke*, wat een gemis voor de gezondheidszorg dat jij dit werkveld achter je hebt gelaten. Ik ben er trots op dat je nieuwe paden in durft te slaan en je dromen achterna durft te gaan. Houd dit vast!

*Lieve To*n, ik heb niet anders dan respect voor de zware bergtocht die u heeft moeten doorstaan. Ik vind het ontzettend jammer dat u mijn promotie niet meer mee kunt maken. Uw vriendelijkheid en nederigheid voor eenieder, zullen altijd mijn voorbeeld zijn. *Cootje*, ik heb er bewondering voor hoe u het leven weer heeft opgepakt. Bedankt dat u altijd zo'n lieve oma bent voor Sarah-Lu en Ezra. Ontzettend fijn dat ze de laatste tijd wat vaker bij u terecht konden, zodat ik wat extra tijd had om mijn proefschrift af te ronden

Lieve *Sarah-Lu en Ezra*, jullie hebben mij geleerd om te relativeren. Zelfs in drukke periodes hielpen jullie altijd bij het vinden van ontspanning. *Sarah-Lu*, wat ontzettend leuk om mijn analytische kant in jou terug te zien. *Ezra*, jouw opgewekte en sociale karakter is een waardevol talent. Ik ben benieuwd wat het leven jullie gaat brengen. Waar jullie ook voor kiezen, ik zal altijd trots op jullie zijn.

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De top van deze berg is in zicht. Ik ben benieuwd wat er nog meer op mijn pad gaat komen.

Janet

PHD Portfolio

Name PhD student: Janet Been-Dahmen
Erasmus MC Department: Rheumatology
PhD period: 2012 – 2018
Promotor: Prof. J.M.W. Hazes
Supervisor: dr. E. Ista
dr. A. van Staa

1. PhD training	**Year**	**Workload** *ECTS*	*(hours)*
General Courses			
- Teaching degree	2013	4.3	(120)
- CPO cursus: *Patient Oriented Research: design, conduct, analysis and clinical implications*	2015	0.3	(8)
- Research integrity	2016	0.3	(8)
- Engels - Cambridge Training	2016-2017	3.6	(100)
Specific courses (e.g. Research school, medical training)			
- Evers Research: Qualitative data-analysis using Atlas.ti	2012	0.6	(16)
- Evers Research: training in focus groups	2014	0.6	(16)
- Evers Research: working with Atlas.ti 7.0 (update)	2014	0.1	(4)
- Multivariate analysis	2015	0.3	(8)
- Applied Multivariate analysis	2015	3.0	(84)
Presentations on national & international conferences			
- Rotterdam, Erasmus MC, VIP2 Conference, workshop Nurse-led self-management support.	2013	0.3	(8)
- Gothenburg, Sweden. *Nurses' experiences with self-management support to outpatients with chronic conditions*. Oral presentation.	2014	1	(28)
- Graz, Austria. *Patient needs and preferences with regard to self-management support in rheumatology: a qualitative study*. Oral presentation	2015	1	(28)
- Utrecht, The Netherlands. *Self-management support by Nurses: How Research Leads to Action and Reflection.* Workshop.	2016	1	(28)
- Groningen, The Netherlands. *Self-management support by nurses: How Research led to Action and Reflection.* Workshop.	2016	1	(28)
- Rotterdam. The Netherlands. *Evaluating the effects of a nurse-led self-management intervention for kidney transplant patients: mixed-method design.*	2017	1	(28)
- Cambridge, United Kingdom. *Evaluating the effects of a nurse-led self-management intervention for kidney transplant patients: mixed-method design.*	2017	1	(28)
Other			
- Research Meetings department Rheumatology	2012-2014	1	(30)
- Intervisie and coaching promovendi, Rotterdam University	2013-2014	0.3	(10)
- Coaching to professionalise teaching skills	2016	0.5	(14)

2. Teaching	**Year**	**Workload (ECTS/hours)**	
Lecturing			
- Workshop "Data collection in qualitative research projects"	2013	0.1	(4)
- Workshop "Data analyse in qualitative research projects"	2013	0.1	(4)
- Project-based learning (minors)	2013-2018	13	(392)
- Social Skills training	2015	1	(29)
- Training: family participation in care for psychiatric patients	2016	0.8	(21)
- Training: rehabilitation in psychiatry	2016-2018	1 .7	(49)
- Actualities in psychiatric care	2017	0.3	(10)
- Psychopathology	2017-2018	0.6	(9)
Developing			
- Developing education module "substance abuse treatment"	2013	1	(28)
- Developing education semester "Psychiatry"	2014	2	(56)
- Developing education module "Psychopathology"	2016	1.4	(40)
Supervising Bachelor theses			
Bachelor of nursing students	2016 -2018	14	(417)
Total		**57.2**	

LIST OF PUBLICATIONS (NOT INCLUDED IN THIS THESIS)

Beck D., Been-Dahmen J.M.J., Staa A.L. van. (2017) Zelfmanagementondersteuning na niertransplantatie: een nieuwe interventie. *Dialyse en nefrologie magazine*: 34-36.

Been-Dahmen, J.M.J. (2014) Van 'verzuiling' naar toegepaste analyse. *Recensie Kwalon*.

Been-Dahmen, J. M. J., Ista, E., & Van Staa, A. (2018). Hoofdstuk 13: Zelfmanagementinterventies: ontwikkeling, evaluatie en implemtatie: In A. Van Staa, L. Mies, & A. J. Ter Maten-Speksnijder (Eds.), *Verpleegkundige ondersteuning bij zelfmanagement en eigen regie*. Houten: Bohn stafleu van loghum.

Peeters, M. A. C., Braat, C., Been-Dahmen, J. M. J., Verduijn, G. M., Oldenmenger, W. H., & Staa, A. v. (2018). Support needs of people with head and neck cancer in dealing with the consequences of their disease and its treatment in daily life: A qualitative study. *Oncology Nursing Forum,* **45**, XXX-XXX

Staa A.L. van, Beck D., Been-Dahmen J.M.J., Massey E.K. (2017) Ondersteuning bij zelfmanagement: een nieuwe verpleegkundige interventie. *De verpleegkundig specialist*. 1: 8-14.

PRESENTATIONS

Been-Dahmen J.M.J., Beck D., Peeters M.A.C., van der Stege H., Grijpma J., Tielen M., van Buren M., Weimar M., Ista E., van Staa A.L., E.K. Massey. (2018) Evaluating the feasibility of a nurse-led self-management intervention for kidney transplant recipients. NTV-BTS Transplantation Congress. Rotterdam, Nederland. *Oral presentation*

Been-Dahmen J.M.J., Beck D., Peeters M.A.C., van der Stege H., Grijpma J., Tielen M., van Buren M., Weimar M., Ista E., van Staa A.L., E.K. Massey. (2018) Evaluating the feasibility of a nurse-led self-management intervention for kidney transplant recipients. STTI 4th European Regional conference. Götenburg, Zweden. *Oral presentation*

Been-Dahmen, J.M.J., Dwarswaard, J.M., Hazes, J.M.W., Ista, E., van Staa, A.L.,. (2015). Nurses' experiences with self-management support to outpatients with chronic conditions; . STTI 2nd European Regional Conference. Götenburg, Zweden. *Oral presentation*

Been-Dahmen, J.M.J., Walter, M.J., Dwarswaard, J.M., Ista, E., van Staa, A.L., Hazes, J.M.W. (2015). Patients' needs and preferences with regard to self-management support in rheumatology: a qualitative study; European Doctoral Conference in Nursing Science. Graz, Oostenrijk. *Oral presentation.*

Dahmen, J. & van Hooft, S. (2013). Verpleegkundigen & Zelfmanagementondersteuning (onderzoeksprogramma NURSE-CC); 'On speaking terms', Verpleegkundig symposium (VIP^2) Erasmus MC. Rotterdam. *Workshop.*

Dahmen, J. & van Hooft, S. (2014). Zelfmanagement in de praktijk; themadag aandachtsvelders wondzorg. Erasmus MC. Rotterdam. *Workshop.*

Van Staa, A.L., Been-Dahmen, J.M.J., Peeters, M.A.C., ter Maten-Speksnijders A.J., Ista, E. Dwarswaard J. (2015) Self-management Support by nurses: How research leads to action and reflection. STTI 3rd European Regional Conference, Utrecht, Nederland, juni 2016. *Workshop.*

Van Staa, A.L., Been-Dahmen, J.M.J., Peeters, M.A.C., ter Maten-Speksnijders A.J., Ista, E. Dwarswaard J. (2015) Self-management Support by nurses: How research leads to action and reflection. Nursing Science congress, Groningen, Nederland. *Workshop*

CURRICULUM VITAE

Janet Been-Dahmen is geboren op 28 september 1987 te Amsterdam. Na het afronden van de HAVO in 2004, is ze aan de Hogeschool Rotterdam gestart met de opleiding tot verpleegkundige. Als duale student was Janet werkzaam op verschillende psychiatrische afdelingen in het Erasmus MC. Na het afronden van deze studie is ze in 2008 als verpleegkundige gaan werken op de Adolescentenkliniek, afdeling Kinder- en Jeugdpsychiatrie van het Erasmus MC. Deze baan heeft ze gecombineerd met de deeltijdopleiding Verplegingswetenschap aan de Universiteit van Utrecht. In 2011 heeft ze deze studie succesvol afgerond.

Binnen Kenniscentrum Zorginnovatie van Hogeschool Rotterdam is ze in 2012 gestart met haar promotieonderzoek. Janet haar promotieonderzoek richtte zich op zelfmanagementondersteuning door verpleegkundigen aan chronisch zieken. Dit onderzoek maakte deel uit van het onderzoeksprogramma “Nursing Research into Self-management and Empowerment in Chronic Care” (NURSE-CC). Naast haar baan als onderzoeker is ze ook werkzaam als docent binnen de opleiding Verpleegkunde; waar ze nauw betrokken is bij de minor Psychiatrie en het afstudeeronderwijs.

Janet Been-Dahmen was born in Amsterdam on the 28th of September 1987. In 2004, she started studying a bachelor degree in Nursing at Rotterdam University of Applied Sciences. She combined her study with working as a nursing student at various psychiatric departments at the Erasmus Medical Center in Rotterdam. After graduation, she started working as a registered nurse at the psychiatric department for adolescents of the Erasmus Medical Center. At the same time, she transferred to Utrecht University to obtain her Master degree in Nursing (2008-2011).

In 2012, Janet started her PhD at Research Centre Innovation in Care, Rotterdam University of Applied Sciences. Her PhD project was part of a big research program called 'Nursing Research into Self-management and Empowerment in Chronic Care' (NURSE-CC). Janet's research focused on the provision of self-management support by nurses to patients with various chronic conditions. Beside doing research, Janet teaches nursing students at Rotterdam University of Applied Sciences.