

Introduction

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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, & Gijssen, 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 patients¹ 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 &

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; Stiggebout 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, Lambergts, 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 I 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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