

Self-management and support needs of chronically ill people

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Self-management and support needs of chronically ill people

**Zelfmanagement en ondersteuningsbehoeften van
mensen met een chronische ziekte
(met een samenvatting in het Nederlands)**

PROEFSCHRIFT

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1

General introduction

General introduction

People with chronic illness (and their families) face a wide range of adaptive tasks related to the nature and course of their illness and developments in their personal life. For instance, a person with a chronic illness might need to learn new technical skills such as measuring blood pressure, he might also need to lose weight, find ways to cope with a limited amount of energy, and deal with new complications as the illness progresses. All these different tasks can be referred to as self-management. Self-management includes managing symptoms, treating the condition, making lifestyle changes and coping with the physical and psychosocial consequences of having a chronic condition [1-4]. Given the comprehensive nature of chronic diseases, it is not surprising that many chronically ill people find it difficult to achieve optimal self-management [5,6]. To manage the impact of their chronic condition successfully, chronically ill people need adequate support from healthcare providers, in addition to support from their informal network.

Self-management support involves a patient-centred collaborative approach to care and enhances patients' self-management by promoting patient activation, self-efficacy, education, and empowerment [7,8]. "Self-management support expands the role of healthcare professionals from delivering information and traditional patient education to include helping patients build confidence and make choices that lead to improved self-management and better outcomes" [1]. Optimal self-management is the product of a collaboration between chronically ill individuals, their family, and their healthcare providers [8].

However, one of the challenges of providing effective self-management support is that the group of people with chronic conditions is very diverse, so an effective approach for one person may not work for someone else. Currently, there is a lack of knowledge about which chronically ill people benefit from which type of support [9]. Only little attention has been paid to differences in support needs between patients in different stages of their life or illness process, and between patients with different preferences and competences. This lack of knowledge may result in healthcare providers offering support that may be 'too much' for some and 'too little' for others, with obviously negative consequences regarding effectiveness. The purpose of this thesis is to gain insight into chronically ill people's self-management and

their needs for self-management support during different stages of their illness and throughout different phases of life.

This first chapter starts with background information on chronic illness care, chronically ill patients' self-management and support needs. Next, the theoretical background and framework for this study will be presented, followed by a description of the impact of the course of illness and the course of life on patients' self-management and related support needs. Subsequently, the research questions and design of this study will be described. The chapter ends with the outline of this thesis.

Background

Changes in healthcare and the rise of attention to self-management

With an aging population and changing lifestyles, the incidence and prevalence of chronic diseases such as diabetes, cardiovascular disease and chronic lung disease are increasing worldwide. The number of chronically ill people is expected to continue to rise worldwide during the coming decades [10,11]. This growing number of people with chronic illness has resulted in a rising demand for and use of (prolonged and complex) healthcare. The increasing demand for care has led to the development of new service delivery models of care.

Historically, western healthcare systems are built around an acute, episodic model of care, in which healthcare providers are seen as the main actors and patients as passive recipients of care. This approach to care does not suit the reality for most patients with chronic illnesses [12]. For the most part, living with a chronic illness occurs out of sight of healthcare professionals. Chronically ill people therefore play a crucial role in the management of their own illness [13]. It is the patient who makes daily decisions and takes actions that may result in better (or worse) health and quality of life outcomes. Recognising the importance of patients own beliefs and behaviour, there has been a shift in western healthcare systems towards models of care in which patients have a more active role and healthcare providers and patients are considered equally important partners in chronic illness management [9,14,15]. One well-known, and perhaps the most influential, model is the Chronic Care Model (CCM), developed by Wagner and colleagues [16]. This

model was developed as a guide for chronic care improvement [17]. According to the CCM, high-quality chronic illness care is characterised by productive interactions between well-informed and activated patients and multidisciplinary teams of healthcare providers, involving assessment, self-management support, optimisation of therapy and follow-up [18].

Both self-management and self-management support became top priorities in chronic illness care to improve the quality of the healthcare system. It has been estimated that 70–80% of people living with chronic illness could reduce the illness burden and costs by appropriate self-management [19]. This would slow down or postpone disease progression, and the development of complications and comorbidities, resulting in decreased hospital admissions. Self-management support has been associated with improvements in health outcomes, functional status and quality of life [20]. This increasing attention to self-management is also reflected in the new definition of health in which health is defined as ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges’ [21].

In the Netherlands, self-management has also played an important role in healthcare policies. In 2008, the Dutch government aimed to improve the quality of chronic illness care by adopting a nationwide chronic disease management approach [22]. This included proactive, coordinated care and support provided by multidisciplinary care teams, a central role for self-management by patients and the strengthening of the link between prevention and cure, with nationally developed care standards being the main instrument for implementation of this policy [22].

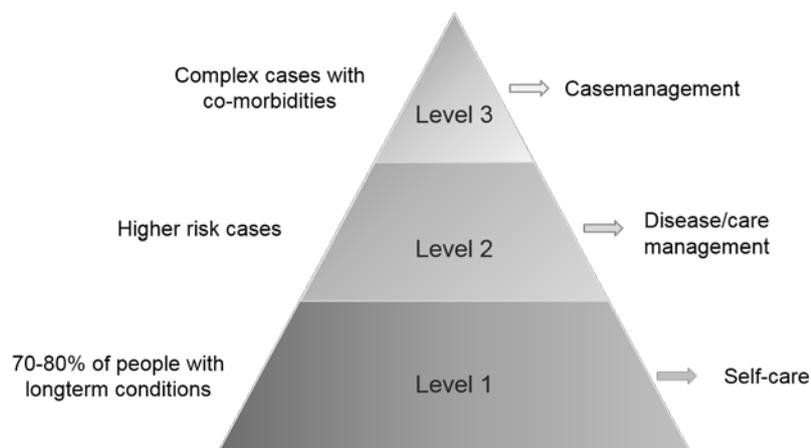
Self-management support needs

Achieving effective self-management is, however, complex, as chronically ill people have to deal with a variety of symptoms, often both medical and non-medical treatments, different healthcare providers, and physical, emotional and social consequences of being chronically ill [1]. In addition, people need to incorporate the management of their chronic illness into their daily life. Studies have shown that chronically ill people experience stress caused by managing and controlling their chronic illness, while trying to maintain ‘normal lives’ [23-25]. Appropriate support is therefore very important.

The question is which people with a chronic illness need which type of support with self-management? The Kaiser Permanente pyramid divides the

population of chronically ill people into three groups [26, 27]. Patients at level 1 (about 70-80%) have their chronic condition reasonably under control and are themselves the main contributors to healthcare; the role of healthcare professionals is primarily one of supporting patients. Patients at level 2 (about 15-20%) are considered to be at increased risk, because their condition is unstable, or because it could deteriorate unless they have structured support through disease management. Professional support from various disciplines is needed at this level. Level 3 (about 3-5%) includes individuals with highly complex needs who require comprehensive (case) management.

Figure 1: Chronic illness care: relative contribution of patients and professionals



Despite its potential, the pyramid in figure 1 also has its limitations. First, it suggests that the role of self-management and patients' support needs depend almost exclusively on characteristics of the patient's health condition. However, the lives of chronically ill people do not solely consist of taking care of their chronic illness. Self-management takes place in chronically ill people's life context and will therefore be defined by it [28]. A second limitation is that this pyramid does not show that managing chronic illness is a dynamic process in which the patient's role may develop throughout the course of illness and throughout the course of life. Each phase of the illness

process will bring about new self-management tasks and require other knowledge and skills from chronically ill people. For instance, people who have recently been diagnosed with a chronic illness may need support to cope with this new and stressful situation, while people in a later stage of the illness may need support to cope with other stressors such as advanced physical complications. At the same time, patients' personal lives change as well. Managing chronic illness might be quite a different story at the age of forty than at the age of eighty.

Theoretical framework

Considering the complex nature of self-management, two perspectives on chronic illness from, respectively, health psychology and medical sociology will be considered. Based on these two perspectives, we constructed a new framework. The aim of this new framework is two folded, as we want to explain: 1. differences in self-management support needs between chronically ill people; and 2. changes in these support needs over time. This framework focuses on the burden of illness, personal goals and resources of chronically ill people, to understand why the needs for self-management support are not the same for every person with a chronic condition. Individual changes over time are linked to the course of illness and the course of life.

Chronic illness as a continuous stressor

Chronic illness can be considered a continuous stressor, characterised both by a series of life events and by daily hassles, which threatens people's physical health and well-being [29,30]. According to stress-coping theory [31], people respond to a stressor by evaluating its potential harmfulness to their well-being, as well as by evaluating what can be done to overcome or prevent the harm (appraisal of the stressor). People vary in the ways in which they appraise potential stressful events [32]. Stress is, therefore, not an imbalance between objective demands and response potential, but relates to the individual's perception. Subsequently, people will respond by performing cognitive or behavioural activities aimed at reduction of the stress (coping). Coping can be defined as constantly changing efforts to manage the demands of a specific situation that are appraised as potentially taxing or exceeding a

person's resources. Coping can address existing situations that are perceived as stressful, but it can also address situations that might be considered potentially stressful in the future, usually referred to as proactive coping [32]. Stress-coping theory has not been developed to specifically explain how people cope with chronic illness. However, self-management can be seen as a specific type of coping with (illness-related) stressors. Considering this, the theory can be useful to explain the diversity in how people manage a chronic illness. First of all, stress-coping theory shows that how people appraise a situation or event varies. So, whether and to what extent people perceive their chronic illness or illness-related symptoms as a threat to their well-being will differ per individual. In effect, the way they will react to this threat will also differ. For instance, when new symptoms arise, some people might go to the doctor, while others might look on the internet for information or decide to ignore it. Second, coping is a continuous process, as it is a function of ongoing appraisal and reappraisal of the shifting person-environment relationships [34]. As chronically ill people's lives change as well as their chronic condition, they have to continuously adapt their coping responses to the stressful situation that is appraised at that moment. This shows that self-management is a dynamic process and that needs for support can change over time. Third, coping is an interaction between an individual's resources and environmental demands [31]. Whether people are capable of managing their chronic illness properly will not only depend on their burden of illness, but also on the resources they have at their disposal. Finally, this theory shows that people can also react to a situation that might occur in the future. This proactive approach is also an important element of self-management. As chronic illness often deteriorates over time, anticipating future developments and taking proactive action may be crucial to maintain a satisfactory quality of life.

Chronic illness as a biographical disruption

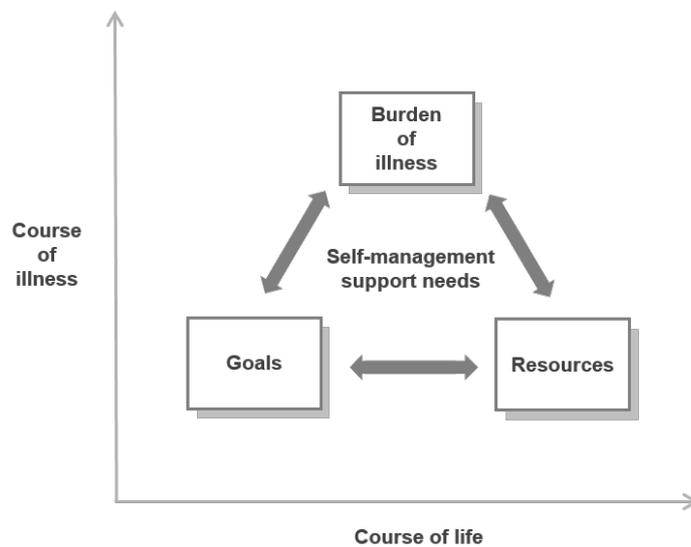
The idea of chronic illness as a biographical disruption stems from medical sociology [35]. The emphasis here is on patients' life course and how this is influenced by experiences related to the onset and development of a chronic disease. It is not only the biomedical condition that influences a person's life, but also how this interferes with this person's life expectations, social roles and the demands he or she experiences from society. The social side of chronic illness deals with the lay experience of illness, and its focus is on

disruptions experienced in multiple domains of life, including financial, emotional, sexual, social and vocational domains [36]. Chronic illness is considered a threat to the individual's self-image and his/her social identity. This perspective also shows that self-management is a continuous process that is determined by the individual context. However, from this perspective, being chronically ill is also a threat to people's identity. This allows us to see chronic illness self-management in a new light. Successful self-management does not mean that a person with chronic illness 'only' needs to perform medical management activities, it also means that this person might need to adjust his or her self-image. This theory shows that self-management is related to people's personal goals and how they see themselves. How do they want to live their lives and do the things they want to do in spite of the symptoms of their chronic illness and their effects?

Theoretical framework of this study

Based on the two perspectives discussed above, we constructed a theoretical framework to explain variation in self-management support needs. This framework is based on three concepts, namely the burden of illness that chronically ill people experience, the goals they set in their lives, and the resources they have at their disposal. Our basic assumption is that chronically ill people need (more) support with self-management when their burden of illness, goals, and (natural) resources are out of balance (Figure 2). The greater the imbalance, the higher the need for support.

Figure 2: Self-management support needs of people with chronic illness



The burden of illness refers to the perception people have of their chronic illness. It is related to e.g. type of disease and treatment, disease severity or stage and other objective disease characteristics, but reflects chronically ill people’s perceptions. As Leventhal and colleagues state, rather than the objective characteristics of a chronic disease, its subjective perceptions will encourage health-related behaviour in chronically ill people [37,38]. In effect, people with similar chronic conditions may have different illness perceptions, and subsequently have different responses to their illness.

The disruption of personal goals gives having a chronic illness its significance [43]. The goals people have in their lives are strongly linked to their individual life course, and are determined by their identity and the social roles they play. Personal goals may differ from medical goals, even when the patient and physician (or other healthcare provider) are communicating about the same health problem [39]. Chronically ill people might need to adjust their goals, which is more difficult when these goals are an integral part of their identity. Resources determine a person’s potential to manage his/her illness properly. Resources can be divided into two types, namely internal and external resources. Internal resources represent characteristics such as a person’s

knowledge, beliefs and competencies [40], whereas external resources represent characteristics that are linked to the external world, such as a person's social network or environmental conditions [41]. For chronically ill people, the professional healthcare they receive is an important external resource. Nowadays, healthcare providers are expected to enable chronically ill patients to make daily decisions and take planned actions that result in optimal health and quality of life outcomes. Whether or not healthcare providers take up such a supportive and coaching role towards their chronically ill patients may vary between healthcare providers, depending on their knowledge, attitudes and competencies.

Chronically ill people's burden of illness, goals and resources are intertwined and influence each other. Changes in one of these factors have direct consequences for the others. Therefore, chronically ill people constantly try to balance their burden of illness, and their goals and resources. This balance can be achieved through compensation or alteration. For instance, when people experience a high burden of illness, they can use more resources (compensation), or when people have fewer resources at their disposal, they might need to alter their goals (alteration).

Changes in self-management support needs over time

Achieving and maintaining balance is complicated as the burden of illness, goals and resources are not static, but change over time. As a result, balancing the burden of illness, goals and resources is an ongoing process. Subsequently, the need for self-management support can change, both quantitatively and qualitatively, during the course of illness and the course of life; as do the type of self-management activities people with chronic illness need to perform. At one moment, people need support with medication adherence, and at another moment they need support to better cope with a limited amount of energy, to change diet or to understand the information that has been given during medical consultations.

The course of illness refers to the development of an illness starting from the onset of symptoms. The way a chronic illness develops differs. The course of illness can be constant, progressive or episodic [42]. A constant course of illness is one in which the course stabilises after the initial crisis event, such as a stroke. A progressive course of illness is usually symptomatic and deteriorative. This course is characteristic of diseases such as arthritis and

COPD. An episodic course of illness implicates that stable periods alternate with periods of relapse, exacerbation or flare-up. Examples of diseases with a more episodic course are asthma or Crohn's disease. The way the illness develops influences the challenges patients encounter in their daily management. Both episodic and progressive courses of illness require constant adaptation and alteration of patients' health regimens to control symptoms, which can cause patients to experience uncertainty and stress [42]. In addition, during the course of illness, patients encounter several critical moments, which may threaten their well-being [43]. Examples of critical moments are the moment of diagnosis, a relapse, a complication, or the onset of a comorbid disease. Schipper and colleagues found that critical moments are not always consecutive; several critical moments can occur at the same time. This may require a lot from a person's ability to adapt [43].

The life course refers to "a sequence of socially defined events and roles that the individual enacts over time" [44]. The individual life course is composed of multiple, interdependent trajectories, such as a school career, work career or a career as a parent [45]. During the life course, people go through a series of transitions, whereby some roles are left behind and new roles are adopted. For example, when employees reach retirement, they leave the role of wage-earner and adopt the role of retiree. These social roles are associated with expectations of certain behaviour and with socially defined resources [46]. Transitions, such as health changes, often bring about adjustments in existing trajectories [47]. As a result, becoming chronically ill can affect the social roles people have in their lives.

Chronically ill people's life context determines the way they experience their chronic illness. Expectations and goals which people have in their lives depend on the phase of life. For instance, research of Gignac and colleagues [48] showed that younger people with osteoarthritis reported more distress and frustrations when managing the disease, because having osteoarthritis was not seen as normal in this age group. In addition, the resources people have to cope with a chronic illness are related to their phase of life. For instance, financial resources initially seem to increase with age and then often decrease after people (partly) stop working [49], and social resources may decrease at old age because of illness and the death of family and friends of the same age.

Current study

As stated at the beginning of this chapter, the purpose of this thesis is to gain insight into chronically ill people's self-management and their needs for self-management support during different stages of their illness and throughout different phases of life. However, the care chronically ill people receive is, as an external resource, also very important for their self-management and related support needs. Research has shown that several elements of high-quality chronic illness care, such as patient-centred communication [50], self-management support [51], regular follow-up and collaborative decision making [52] are associated with greater patient satisfaction, improved health status and increased care efficiency. Therefore, we decided that we should also take the healthcare chronically people receive into account, as it may influence the need for self-management support.

Research questions

In this thesis the following research questions will be addressed:

1. To what extent can chronically ill people's self-management and related support needs be explained by the type and course of their chronic illness?

The self-management tasks people with chronic illness perceive for themselves and the support they need performing these tasks may differ according to the type of chronic disease. However, we expect that the nature of self-management may be similar across different chronic diseases, and that there will be few differences between the perceived self-management tasks and support needs of people with different chronic diseases. To explain variation in self-management support needs, differences in the course of illness may be more relevant. As chronic illnesses change over time, people with chronic illness continuously have to adapt to an altered situation, which might influence their need for self-management support.

Hypotheses:

- Variation in the perceived self-management tasks and related support needs among people with chronic illness relates to the individual course of illness rather than to the type of their chronic disease.
 - Self-management support needs of people with chronic illness are higher when the course of illness is unstable (progressive and/or episodic) than when the course of illness is stable.
2. To what extent can chronically ill people's self-management and related support needs be explained by their life context?

Older people with chronic illness have a different life context than younger people with chronic illness, and as a result their perceptions of what self-management tasks they need to perform, as well as their need for self-management support, will be different. Moreover, what might complicate achieving optimal self-management is the fact that the lives of chronically ill people not solely consist of taking care of their chronic illness. We expect that having problems in everyday life, such as financial, marital or housing problems, will complicate achieving optimal self-management.

Hypotheses:

- Differences between older and younger people regarding their perceived self-management tasks and related support needs can be explained by differences in their life context.
 - Having basic or social problems in everyday life hinders chronically ill people's self-management.
3. To what extent can chronically ill people's self-management and related support needs be explained by the chronic illness care they receive?

The healthcare which chronically ill people receive could be an important resource for their self-management. Healthcare providers can help patients understand their central role in managing their illness, help patients to make informed choices by providing information about their illness and treatment, and engage in healthy behaviour. In accordance with the Chronic Care Model, high-quality chronic illness care can be defined as a patient-centred

collaborative approach to care [53] and is characterised by collaborative goal setting, support for self-management, optimisation of therapy, and intensive follow-up [54]. Receiving high-quality care that is patient-centred and tailored to patients' individual situation, will improve chronically ill people's self-management.

Hypothesis:

- Receiving high-quality chronic illness care (as experienced by chronically ill people) contributes to better self-management.

Data collection

All studies in this thesis made use of survey data provided by members of the National Panel of people with Chronic illness or Disability (NPCD). NPCD is a nationwide prospective panel-study in the Netherlands and provides information about chronically ill (or disabled) people's experiences and perceived consequences of living with chronic illness or disability [55]. All panel members are diagnosed with a somatic chronic disease and/or experience moderate to severe physical disability. In the studies described in this thesis, only panel members with a (medically diagnosed) chronic disease were included. Examples of chronic diseases are diabetes, COPD, asthma or arthritis. To avoid test effects, members participate for a maximum of four years. Annually, 500 new panel members are selected via a standardised procedure to replace drop-outs and members who reached the maximum participation term. Panel members with chronic illness are recruited from general practices based on their medical diagnoses (annual random samples of general practices drawn from the Dutch register of General Practices [56]); there is no possibility for people to sign up for the panel on their own initiative. The NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of the Authority.

For the main part of this thesis, quantitative data collected by self-report questionnaires sent to members of the NPCD were analysed. These questionnaires provide information about chronically ill people's perceived self-management and support needs in general. In addition, we wanted to explore how chronically ill people perceive their life with a chronic illness from their own words. For this purpose, three focus group sessions were held

with 30 (former) members of the NPCD. The information from the focus groups has been used for this thesis to illustrate the quantitative findings, and help understand and interpret these findings.

Outline of this thesis

After this Introduction chapter, this thesis first provides an illustration of how self-management is perceived by chronically ill people and which self-management activities they perform in daily life, based on the focus group sessions held with people with chronic illness. This thesis then continues with three main parts: (1) self-management and course of illness, (2) self-management and life context, and (3) self-management and healthcare.

The first part focuses on chronically ill people's self-management tasks and support needs related to their type and course of illness. **Chapter 2** describes which self-management tasks and support needs chronically ill people have and whether these tasks and related support needs are disease-specific or generic. Do people with different chronic diseases perceive the same tasks as part of their daily management and do they have similar support needs? **Chapter 3** explores the association between chronically ill people's self-management support needs and their individual course of illness. This part ends with an illustration of the findings discussed in chapter 2 and 3. This illustration, once again, is based on the qualitative data collected in the focus group sessions.

The second part describes how chronically ill people's self-management and support needs are determined by their life context. **Chapter 4** focuses on age-related differences in self-management tasks and support needs. The aim of this chapter is to gain understanding of the nature of these age-related differences by looking at the life context of younger and older chronically ill people. **Chapter 5** describes to what extent having basic or social problems in everyday life interferes with chronically ill people's self-management. This part also ends with an illustration of the findings based on the data collected with the focus group sessions.

The third part reports on whether chronic illness care in the Netherlands contributes to chronically ill people's self-management. **Chapter 6** describes how chronically ill people perceive the quality of the chronic illness care they

received and whether or not this perceived quality of care is related to better self-management. Findings of chapter 6 will also be illustrated with narratives of chronically ill people collected in the focus group sessions.

In the final chapter of this thesis (**Chapter 7**) the results of the previous chapters are summarised and discussed. This chapter addresses furthermore some methodological considerations related to the studies performed, and implications for clinical practice and future research are considered as well.

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Illustration

Self-management in daily practice

The term self-management is currently often used in health policies and research on chronic illness care. This section illustrates how chronically ill people themselves define their own self-management and what self-management activities they perform in daily life, based on focus group sessions held with people with chronic illness (more information about the focus group sessions and the analysis of the data can be found in the Appendix). In the studies described in this thesis, we distinguish four types of self-management activities which chronically ill people need to perform according to scientific literature, namely: medical management of the illness, making lifestyle changes, communication with healthcare providers and coping with the consequences of being chronically ill. This illustration is aimed to understand what living with a chronic illness entails.

Medical management

When asked about their chronic illness and the effects it has on their daily lives, people with chronic illness participating in our focus group sessions all mention that they have to take medication. It is almost the first thing people mention. Having to take medication seems to be the most obvious activity related to having a chronic illness. For some participants taking medication is seen as a way to control the chronic illness.

“I’ve had type 2 diabetes since two years. How does this impact my daily life? Well, I just have to take two of those tablets every evening.”

“I just have to swallow a heap of those pills every day. That’s all.”

“I can control it reasonably well, as long as I take my pills on time.”

“Easily treated with medication.”

For many patients, being able to decrease the amount of medication they need to take seems to be an (implicit) goal to strive for.

“I’m also seeing a physiotherapist because I have COPD. I’m taking 500 mg paracetamol 8 times a day. But with my physiotherapist, with manual therapy, it’s gone. I urge everyone to go see a good physiotherapist.”

“I’ve completely stopped taking medication, since I’m losing so much weight.”

“This has been going on for about half a year now, me being in pain 24 hours a day. With medication I can keep a check on it. Thing is, though, we keep having to increase the amount of medication. You know, you can kind of feel that the kick has slowly gone out of it.”

Interestingly, none of the participants mentioned other forms of medical management, such as self-monitoring of symptoms or doing exercises. This does not mean that they did not perform such activities. However, it does indicate that, according to chronically ill people, medical management is strongly dominated by taking medication.

Making lifestyle changes

Another aspect of self-management that was mentioned several times during the focus group sessions is making lifestyle changes. Many participants felt that they could control their chronic illness by changing their lifestyle. Especially exercising regularly and a healthy diet are seen as ways to manage their chronic illness.

“I’ve had it for a long time, of course, but I know I have to pay attention, especially to food and exercise. If I do, things go well.”

“But I have been exercising a lot since three months, and I’ve started to change my eating habits.”

Smoking was more often referred to in a negative way. Participants were aware that they needed to stop smoking, but were not able or willing to actually stop.

“And I also have a bit of COPD due to smoking, which I haven’t quit doing yet, but that aside.”

“Yes, I smoke. Yes, I carry on.”

Communication with healthcare providers

Communication with healthcare providers is an inevitable aspect of chronically ill people's management of their illness. All participants had regular contacts with healthcare providers, they all communicated with their healthcare providers about their treatment and they all asked for help when needed. However, the self-management aspect of communication with healthcare providers particularly relates to the degree in which chronically ill people are actively involved in (decision-making related to) their care. Do they take decisions regarding their care and treatment together with their healthcare provider, rather than just doing what healthcare providers tell them they should do?

Most participants showed active involvement regarding the frequency in which they visit their healthcare provider. Some had regular check-ups with their healthcare provider because they wanted to know that they are doing well, while others only had contact with their healthcare provider when their health condition deteriorated or new symptoms arose.

“When you have asthma, you go to the asthma nurse for check-ups. I don't feel like you have to go there every three months, when everything's fine [...] Then she'll be like: “What do you want to do? Six months, three months?” We discuss what's best, it's my decision.”

“There was a time when I regularly went to the neurologist. Then everything went fine for a while, and I didn't go back there for a few years. And then I had a relapse, and since then I go once or twice every year.”

Some participants mentioned that they made decisions about their treatment together with their healthcare provider.

“I've ditched all my medication [...] I did consult my healthcare provider before doing that [...] I also didn't need any high blood pressure pills any more. I had the blood pressure of a young girl: 130/60.”

“My GP really helps me think about solutions, and when I suggest something, he's often quite open to it. Then we look into it together to see if it's a path that I could take. That's what happened in the last three years...”

I've had 8 or 9 different pain treatments, or pain control treatments so far. And every time I tried something new, a new combination of medicines, he is open-minded about those things, and he also offers them to me. That's rather nice, I think."

The importance of being actively involved, was emphasised by some of the participants. They had a feeling that they needed to be alert to make sure that they received appropriate care, because their healthcare provider would not do it for them. However, some participants felt like healthcare providers did not appreciate it when patients tried to express their own opinion during the consultation.

"Just do it yourself. Take matters in your own hands, guys, really! They'll send you from pillar to post if you don't."

"A few months ago I contacted them myself, because my husband had been suffering from rashes for about three or four years in a row. Such big patches on his back. He had to go into one of those light therapy boxes for two/three years to get rid of the itch and the pain. And at a certain moment, I just started to read the information leaflet for his high blood pressure pills. Turns out that's been the cause all along."

"Yet, I do believe that a few healthcare providers do feel like they're superior, and they're not really open to conversation or ideas. If you have your own ideas about things, a healthcare provider like that will be like 'yes, but....' and then they start passing the buck. So, no, my experiences in that area are not 100% positive, no."

Coping with consequences of being chronically ill

All people in the focus group sessions did things to make living with a chronic illness easier. These things were very diverse as coping with the consequences of living with a chronic illness can be different for every person. We could identify three types of coping, namely accepting the chronic illness, changing life and behaviour, and mobilising resources.

Accepting the fact that you have a chronic illness, that your life has changed and that you cannot do all the things you used to do is a major issue in the

lives of chronically ill people. Some people found a way to accept it, while others were struggling to do so.

“The essence of the book is: do not focus on your symptoms. That’s what I’ve told myself to do, and that’s what I always try. And it helps, in a way. I try to be there for those close to me, metaphorically, to make my life useful.”

“The biggest handicap that comes with my diabetes is that I can’t seem to accept it, or something. I have these immense tantrums whenever I feel like I’m hindered in what I want to do.... And that is what I feel. I feel like it restricts me from living my daily life the way I want to.”

“You’ve been hearing this for more than 11 years, people saying like ‘Come on, just learn to live with it.’ That’s what they say, so you try to make it happen. Only problem is, you’re young and you don’t want to accept that.”

The second strategy we identified is changing one’s life and behaviour. Many participants had to find new ways of doing things, due to a limited amount of energy, physical limitations, or pain. They needed to anticipate the new situation and change their behaviour.

“These are the limitations: I start off really enthusiastically, but then after half an hour, forty-five minutes, ooff, then you just have to finish it in the afternoon, you know. Then I drink a cup of coffee, do a jigsaw puzzle, or a crossword and then after twenty minutes I get going again.

“One of the things I did was join a society that organises city walks, and I really notice that that’s tough for me. I really have to plan ahead all the time. I did some odd jobs around the house on Thursday, and that means I already have to take extra medication on Tuesday. I really take that into account.”

The third strategy we identified was that participants used their resources in order to maintain a normal life. Most participants referred to social resources, such as support from family, friends and neighbours, but in some cases they also mentioned material resources such as money or tools/equipment.

“I can call upon people who have a car when the weather’s really bad, like the last few winters. People who will be there when I need to do my shopping.”

P: “I can drive for, say, twenty minutes or half an hour, so if I have to go further than that I have to ask around among that limited group of friends and acquaintances. That can be tough sometimes.”

I: “How do you deal with that now? Do you call upon those friends and acquaintances?”

P: “I do, as far as that’s possible, at least, and otherwise I have to hire someone. Which I do, if I need to.”

“I also can’t sit normally anymore, because I got terrible bed sores from being in the hospital for so long, and those never heal. So, I can’t sit in a normal chair anymore, but I have a very comfortable one from Prominent.”

Reflection

The theoretical distinction of four types of self-management activities made in this thesis is reflected by the activities that chronically ill people report on using to manage their illness in daily life. However, the focus group sessions showed that medical management and making lifestyle changes are explicitly mentioned as activities to manage the chronic illness, whereas communication with healthcare providers and coping with the consequences of being chronically ill are not explicitly mentioned as self-management activities; the latter two types of activities seem to be considered inevitable consequences of being ill. Chronically ill people cannot decide not to communicate or not to cope with the consequences of being chronically ill. However they can decide on how to communicate and how to cope. It is, therefore, more interesting to gain insight into the degree of active involvement of chronically ill people in decision-making about their treatment, and into the degree these people use specific coping strategies such as acceptance of their chronic illness, adjustment of their life and behaviour, and making use of specific resources.

2

Patient-perceived self-management tasks and support needs of people with chronic illness: Generic or disease specific?

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^a Author contribution: LvH, MR and PG designed research; LvH and MH collected data; LvH and MR planned the data analysis; LvH performed data analysis; LvH wrote the paper with input from MR, MH and PG.

ABSTRACT

Background

Self-management is widely accepted as an essential component of chronic care. Nevertheless, little is known about patients' perceptions of self-management.

Purpose

This study aims to explore which self-management tasks and support needs people with chronic illness perceive for themselves, and to establish whether these tasks and support needs are disease specific.

Methods

A nationwide representative sample of 2,064 people with chronic disease filled in the Patient Assessment of Self-management Tasks questionnaire.

Results

Many respondents perceive self-management tasks in the daily management of their condition, although few indicate a need for support. Respondents who feel a need for support in one aspect of self-management are likely to feel a need for support in other aspects as well. Type of disease has a small effect on self-management tasks and even smaller on support needs.

Conclusion

Although the self-management tasks patients perceive may be partly disease specific, self-management support does not necessarily need to be disease specific.

Introduction

The prevalence of chronic diseases such as heart disease, chronic obstructive pulmonary disease (COPD), and diabetes type II is increasing worldwide [1, 2]. In 2008, 63 % of all deaths were caused by chronic diseases. Good care can help control a chronic disease [2]. As patients are largely responsible for the day-to-day care of their chronic illness, self-management is an essential part of chronic illness care. Self-management involves not only the medical management of a condition but also maintaining, changing and creating new meaningful behaviours or life roles, and coping with the psychosocial consequences of chronic illness [3–6]. Successful self-management can avoid preventable mortality and morbidity, improve the quality of life of individuals and families, and boost economic productivity [7].

Unfortunately, many people with chronic illness find it difficult to self-manage successfully [8, 9]. Appropriate support is therefore very important. During the last decades, numerous programs to support self-management have been developed for chronically ill people [10–12]. These programs generally show positive effects on at least some of the outcome variables, but the effects are usually only modest [13, 14]. For instance, self-management education programs may lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management, and exercise [13]. In addition, still little knowledge exists about effective components and long-term effects of these programs [12, 14–17]. Tailoring self-management support to patients' self-defined needs might improve the effectiveness of these programs [18]. However, until now most research on self-management has focused on how people perform self-management tasks or how effective a certain self-management support program is; patients' perspective on what self-management entails for themselves and their related needs have been neglected. For example, do people with chronic illness perceive that taking medication as prescribed is one of their tasks, that monitoring their symptoms is something they should do or that they need to change their diet? And what support needs do they have in this respect?

Patients' perceptions of their illness and treatment are a major determining factor of how they cope with their illness [19–23]. According to stress-coping theory [24], people evaluate whether a situation is potentially harmful to their wellbeing and, if so, what can be done to overcome or prevent the harm

(stress appraisal). Assuming that patients' perceptions of self-management tasks provide an indication of the stress they experience, a generally greater need for support could be expected among patients who perceive more self-management tasks for themselves.

Heijmans and colleagues [25] demonstrated that patients with different chronic conditions perceive many resembling stressors (or adaptive tasks). More specifically, Clark et al. [4] showed that the essential nature of self-management may be similar across different diseases. However, when considering the existing self-management support programs, it appears that only a few start from a generic perspective on chronic illness. An example of such a program is the Chronic Disease Self-Management Program, developed at Stanford University [26]. Most self-management support programs, however, focus on one particular disease, for example COPD or diabetes. A limitation of such programs is that they are not always available for patients with less prevalent chronic diseases.

Moreover, disease-specific programs do not meet the needs of the many patients who nowadays suffer from multi-morbidity [27]. Hence, establishing to what extent self-management tasks and their related support needs are disease specific or of a more generic kind could provide insights to improve self-management support. Therefore, the present study aims to answer the following questions:

1. Which self-management tasks do people with chronic illness perceive for themselves?
2. Which support needs do people with chronic illness have in this respect?
3. Are there differences in the perceived self-management tasks and support needs according to the type of chronic disease(s) people suffer from?

Before answering these questions, the factor structure and the internal consistency of the self-developed questionnaire to assess patient-perceived self-management tasks and support needs will be examined.

Method

Participants

For the purpose of this study, data were used from people diagnosed with one (or more) chronic disease(s) who were participating in the National Panel of people with Chronic illness or Disability (NPCD), a nationwide prospective-panel study in the Netherlands [28, 29]. NPCD was set up in 2005 to provide information about the experiences and consequences of living with chronic illness or disability from the patient's perspective.

NPCD participants with chronic diseases are recruited from (a random sample of) general practices in the Netherlands according to the following criteria: a diagnosis of a somatic chronic disease by a certified medical practitioner, aged ≥ 15 years, not being institutionalized, being aware of the diagnosis, not being terminally ill [life expectancy > 6 months according to the general practitioner (GP)], being mentally able to participate, and having sufficient mastery of the Dutch language [28, 29]. Each year, 500 new panel members are selected via the standardized procedure to replace panel members who withdrew or who had participated for the maximum term of 4 years. Panel members fill in self-reported questionnaires at home twice a year. NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of the Authority.

Data Collection

At the start of panel membership, NPCD participants received a questionnaire on their socio-demographic characteristics. In addition, GPs provided (with patients' permission) medical information about panel members. In April 2011, a self-administered questionnaire about self-management tasks and related support needs was sent by post to 2,542 panel members diagnosed with a chronic disease. To increase the response, a postal reminder was sent to panel members who had not responded yet. The closing date of the questionnaire was late June 2011. A total of 2,064 people completed this questionnaire (81 %).

Operationalization

Self-Management Tasks and Support Needs

To assess patients' perceived self-management tasks and support needs, the authors developed the Patient Assessment of Self-management Tasks

questionnaire (PAST). In accordance with the description of self-management activities by Bayliss et al. [30], four dimensions of self-management tasks and support needs were distinguished: (1) medical management, e.g., taking medication correctly or monitoring symptoms; (2) communication with healthcare providers, e.g., visiting healthcare providers and understanding information given by healthcare providers; (3) coping with the consequences of the illness, e.g., coping with pain, emotions, and an uncertain future; and (4) making lifestyle changes, e.g., exercising sufficiently or eating a healthy diet. To operationalize the four dimensions, information from the international literature as well as from focus groups held with COPD and diabetes patients was used. In the focus groups, patients discussed the activities/tasks they encounter in their daily life related to their chronic illness. Subsequently, the tasks that were identified through the focus groups were reformulated from COPD- or diabetes-specific descriptions to more generic descriptions. The experiences with self-management of people with COPD and diabetes gave a good idea of the wide range of self-management tasks chronically ill people have to perform in their daily lives, as COPD and diabetes differ both in nature (e.g., symptoms, causes) and in course of illness (e.g., intermittent, progressive deterioration). In addition, patients with diabetes or COPD might have more experiences with self-management as there are advanced disease management programs for these two diseases. The appendix illustrates the 19 items formulated to assess the four theoretically distinguished dimensions (see Appendix1).

The PAST assesses to what extent patients feel they need to perform different self-management tasks in their daily lives and to what extent they feel a need for support with these tasks, both answered on a four-point scale ranging from 0 (never) to 3 (always). For example, how often do you need to take medication as prescribed and how often do you need support with this? In the introduction of the questionnaire, it was stated that “support could be seen as help from a healthcare provider but also from family or friends”. Patients who do not perceive a specific self-management task for themselves did not have to report their need for support with this task. The scales of self-management tasks (four scales) and support needs (four scales) were constructed by summing the scores on the separate items belonging to the scale. Participants had to fill in at least three items per scale to get a scale score.

Illness Characteristics

The chronic diseases of participants were registered by their GP using the International Classification of Primary Care [31]. Examples of registered diseases are heart failure, Crohn's disease, and multiple sclerosis. Multimorbidity was defined as the presence of more than one chronic somatic disease. In addition, illness duration was derived from the date of diagnosis of the (first) chronic disease as registered in the GP file.

Socio-demographic Characteristics

The following patient characteristics were included in the study: age, gender, and education level [highest level of completed education, classified as low (primary education, lower secondary and lower vocational education), moderate (intermediate secondary and intermediate vocational education), and high (higher vocational education and university)].

Statistical Analysis

First, descriptive statistics were computed to get information on the characteristics of the study sample.

Next, the factor structure of the questionnaire was examined. First, we performed an exploratory factor analysis to see how the items cluster together. The results of this analysis are shown in the appendix (Appendix 2). Second, a series of confirmatory factor analyses were performed to test the theoretically assumed four-factor structure of the PAST (perceived self-management tasks) questionnaire. The fit of the four-factor model was compared with two other models: a null model assuming no relationship between the items of the PAST and an one-factor model assuming that all items make up one single all-encompassing dimension. The extent to which the models fit the data was assessed by chi-square goodness-of-fit statistics. Non-significant chi-squares suggest a satisfactory fit for the tested model [32, 33]. However, chi-square statistics will nearly always reject the model when large sample sizes are used [33]. Therefore, other measures that are less affected by sample size were computed, namely the non-normed fit index (NNFI), the comparative fit index (CFI), the standardized root mean square residual (SRMR), and the root mean square error of approximation (RMSEA). NNFI and CFI values ≥ 0.95 , SRMR ≤ 0.08 , and RMSEA values ≤ 0.06 were considered indicative of good model fit [34]. In addition, the modification

indices provided by the analysis to establish whether an item assumed to relate to a certain factor better fits one of the other factors were examined. For the factor analysis, only cases that had no missing values were included (n=1,743). Subsequently, the internal consistency of the various self-management tasks and needs scales was computed using Cronbach's alpha.

Descriptive statistics were computed to provide information on what patients perceive as their self-management tasks and what support needs they have in this respect (research questions 1 and 2). In addition, to explore the interrelationships between the self-management tasks and the support needs, Pearson correlation coefficients were computed. To explore whether self-management tasks and support needs relate to the type of chronic illness at stake (research question 3), the effects of disease type on self-management tasks and support needs were estimated by multiple linear regression analyses, controlling for the effects of age, gender, education level, and multi-morbidity.

Because intra-class correlations showed hardly any clustering of support needs within general practices (mean 0.01) and the likelihood ratio test did not show that multilevel analyses had an advantage over ordinary regression analyses, single level regression analyses were conducted. All analyses, except the confirmatory factor analyses, were performed using Stata 12.0. Confirmatory factor analyses were performed using LISREL 8.8.

Results

Characteristics of the Study Sample

Table 1 presents the socio-demographic and illness characteristics of the study sample. The mean age of the respondents was 59 years and more than half were female (56 %). A third (34 %) had a low education level, 42 % had been moderately educated, and 24 % had a high education level. Cardiovascular disease (23 %), asthma (23 %), diabetes (19 %), and COPD (18 %) were the most common chronic diseases within the sample. Almost half of the respondents (43 %) had been diagnosed with more than one chronic disease. On average, the illness duration was 11 years, but there was a wide variety in illness duration (from recently diagnosed through diagnosed during the first year of life).

Table 1: Respondents' socio-demographic and illness characteristics
(n=2,064)

	n	Percentage	Mean	Range	S.D.
Patient characteristics					
Age	2,064		59.3	15-93	16.0
Female	1,156	56%			
Education level					
Lower	690	34%			
Intermediate	849	42%			
Higher	482	24%			
Illness characteristics					
Diagnosis disease					
Cardiovascular disease	475	23%			
Asthma	478	23%			
Chronic obstructive pulmonary disease	371	18%			
Other chronic respiratory disease	140	7%			
Arthritis	240	12%			
Other chronic musculoskeletal disorder	151	7%			
Cancer	141	7%			
Diabetes mellitus	384	19%			
Thyroid dysfunction	147	7%			
Migraine	83	4%			
Neurological disease	106	5%			
Chronic digestive disease	140	6%			
Chronic skin disease	163	8%			
Other chronic disease	232	11%			
Multi-morbidity present	894	43%			
Illness duration (years post-diagnosis)			11.3	0-87	9.0
Less than 5 years	409	21%			
5 to 10 years	714	35%			
10 years or longer	916	44%			

Factor Structure of the PAST Questionnaire

Table 2 shows the results of the confirmatory factor analyses. As the modification indices related to the test of the four-factor model fit showed that item 12 is associated with all four factors and not one in particular, the authors decided to test an additional model: a four-factor model without item 12. Item 12 refers to the use of technical aids, such as an inhaler or blood pressure pump. Only a small fraction of the population of people with chronic illness use such technical aids (<10 % [35]), which justifies the decision to eliminate item 12.

Chi-square tests were significant for all four models, but this might be related to the large sample size used in this study. The CFI and SRMR score of respectively 0.95 and 0.05 indicated a good fit of the final model and the NNFI and RMSEA score of respectively 0.94 and 0.07 indicated a reasonable fit of the final model. The authors therefore considered the model fit as confirmation of the four dimensionality of the PAST (perceived self-management tasks) questionnaire.

Cronbach's alphas were lower for the self-management tasks scales (medical, 0.59; communication, 0.67; coping, 0.82; lifestyle, 0.60) than for the support needs scales (medical, communication, and lifestyle, all 0.79; coping, 0.83), but all indicated an acceptable internal consistency reliability.

Table 2: Measures of fit of four different models of the PAST questionnaire (n=1743)

Sample and model	Chi ²	df	NNFI ¹	CFI ²	SRMR ³	RMSEA ⁴
null model	24281.32*	171				
1-factor model	2549.99*	152	0.90	0.91	0.07	0.10*
4-factor model	1621.31*	146	0.93	0.91	0.06	0.08*
4-factor model without item 12	1235.35*	129	0.94	0.95	0.05	0.07*

* Significant at p<.01

¹ NNFI= Non-Normed Fit Index

² CFI= Comparative Fit Index

³ SRMR= Standardized Root Mean Square Residual

⁴ RMSEA= Root Mean Square Error of Approximation

Patient-Perceived Self-Management Tasks and Support Needs

On average, people with chronic illness perceived a moderate amount of self-management tasks for themselves (mean scores between 1.07 and 1.64 on a scale from 0 to 3; Table 3). They faced more tasks (in number and frequency) in medical management and making lifestyle changes than in communication with healthcare providers and coping with the consequences of chronic illness. The results regarding the needs for self-management support were quite different. Overall, participants reported fairly low needs for self-management support, whereas the highest needs for support were found in the domains communication with healthcare providers and coping with the consequences of chronic illness.

Correlations between the scales for self-management tasks ranged from 0.36 to 0.60 (not in table). The correlations between the scales for support needs were higher, ranging from 0.54 to 0.73. This indicated that participants who reported a need for support in one particular domain of self-management were more likely to report a need for support in other domains of self-management as well. Furthermore, the correlations between the tasks scales and the support needs scales were low to moderate (range 0.11–0.51), indicating that perceiving a particular self-management task did not necessarily imply a related support need.

Table 3: Patient perceived self-management tasks and support needs (scale 0-3)

	Self-management tasks			Self-management support needs		
	n	Mean	Std. Dev	n	Mean	Std. Dev
Medical management	1998	1.64	0.69	1202	0.41	0.51
Communication with healthcare providers	1983	1.07	0.63	1110	0.64	0.59
Coping with the consequences	1990	1.13	0.74	1338	0.64	0.58
Making lifestyle changes	1978	1.57	0.74	1230	0.48	0.60

Perceived Self-Management Tasks and Support Needs According to Disease Type Table 4 shows that the type of chronic disease participants were suffering from related to some extent to the self-management tasks they perceived as part of their daily management. However, the effects of disease

types varied for the four domains of self-management. For instance, people suffering from arthritis perceived more self-management tasks for themselves (compared to people with other types of chronic diseases) regarding communication with healthcare providers and coping with the consequences of their illness, but not regarding medical management tasks and making lifestyle changes. Two disease types had a substantial effect on the extent to which people perceived tasks as part of their daily management. Having diabetes had a strong effect on perceiving more tasks in the domains of medical management, communication, and lifestyle, and having a neurological disease had a strong effect on communication and coping. With regard to the needs for self-management support, disease types less often had significant effects. A diagnosis of a neurological disease, musculoskeletal disorder, diabetes, COPD, or cancer (reference—no such diagnosis) had significant positive effects on the need for self-management (in one or more domains), but in general these effects were small (and smaller than the effects of disease types on the perceived self-management tasks). Furthermore, being older, female, or low educated related to a perception of more tasks as part of the daily management of a chronic illness and to higher needs for self-management support. These effects also differed for the four domains of self-management. Having more than one chronic illness related to the amount of self-management tasks people perceive for themselves regarding medical management.

Table 4: Multiple linear regression analyses testing the effect of type of illness on perceived self-management tasks and support needs of patients with chronic illness (regression coefficient and standard error)

	Self-management tasks				Self-management support needs			
	Medical (n=1966)	Communication (n=1945)	Coping (n=1953)	Lifestyle (n=1941)	Medical (n=1776)	Communication (n=1086)	Coping (n=1313)	Lifestyle (n=1268)
Cons	.82 (.099)	-.43 (.091)	.30 (.107)	1.01 (.116)	.21 (.098)	.11 (.114)	-.29 (.107)	.50 (.119)
Type of illness ¹								
Cardiovascular	.11 (.049) *	.10 (.045) *	.12 (.053) **	.09 (.054)	.07 (.046)	.09 (.054)	.04 (.050)	.06 (.056)
Asthma	.03 (.046)	-.01 (.042)	.00 (.050)	.03 (.051)	.01 (.044)	.01 (.052)	-.05 (.048)	-.06 (.054)
COPD	.06 (.050)	.13 (.045) **	.18 (.054) **	.11 (.055)	.01 (.047)	.13 (.057) *	.08 (.052)	.11 (.058)
Respira. disease	-.02 (.067)	-.01 (.061)	.05 (.072)	-.10 (.074)	.05 (.067)	.10 (.079)	.09 (.074)	-.06 (.079)
Arthritis	.08 (.054)	.14 (.050) **	.21 (.059) **	-.05 (.060)	.10 (.051)	.09 (.061)	.09 (.056)	-.01 (.067)
Muscul. disorder	-.05 (.065)	.12 (.058) *	.19 (.065) **	.08 (.070)	.08 (.061)	.18 (.068) **	.13 (.064) *	.21 (.075) **
Cancer	.03 (.063)	.19 (.059) **	.23 (.070) **	.12 (.072)	.12 (.063)	.18 (.072) *	.10 (.067)	.04 (.077)
Diabetes	.38 (.048) **	.32 (.044) **	.06 (.052)	.34 (.053) **	.09 (.044) *	-.00 (.052)	-.01 (.051)	.12 (.054) *
Thyroid dysf.	.03 (.064)	.04 (.058)	.00 (.069)	.06 (.071)	.03 (.065)	-.01 (.069)	.04 (.066)	.00 (.075)
Migraine	-.11 (.086)	-.02 (.074)	-.00 (.087)	-.07 (.086)	-.03 (.075)	-.03 (.090)	.02 (.086)	-.04 (.092)
Neurol. disease	.12 (.072)	.29 (.066) **	.54 (.078) **	-.07 (.086)	.24 (.071) **	-.24 (.075) **	.23 (.072) **	.12 (.089)
Diges. disorder	.02 (.065)	.12 (.059)	.21 (.070) **	-.04 (.072)	.11 (.062)	.04 (.070)	.08 (.065)	.06 (.071)
Skin disease	-.11 (.062)	.03 (.057)	-.02 (.067)	.00 (.068)	-.06 (.060)	.02 (.070)	.04 (.065)	.02 (.063)
Other disease	-.02 (.055)	.08 (.050)	.03 (.059)	.03 (.061)	.08 (.052)	.11 (.063)	.05 (.058)	.02 (.056)
Age	.01 (.001) **	.01 (.001) **	.01 (.001) **	.01 (.001) **	.00 (.001) **	.01 (.001) **	.00 (.001) *	-.00 (.001)
Gender ²	.11 (.032) **	.11 (.039) **	.19 (.034) **	.08 (.035) *	-.02 (.031) **	.10 (.037) **	.10 (.034) **	.03 (.037)
Educational level ³								
Middle	-.00 (.035)	-.08 (.032) *	-.03 (.038)	-.01 (.039)	-.09 (.035) *	-.16 (.041) **	-.06 (.038)	-.08 (.041) *
Higher	.06 (.041)	-.08 (.038) *	.02 (.044)	.04 (.045)	-.15 (.039) **	-.25 (.046) **	-.09 (.043) *	-.10 (.047) *
Multimorbidity ⁴	.11 (.052) *	.02 (.048)	.02 (.057)	.05 (.058)	-.02 (.050)	-.05 (.059)	.00 (.053)	-.01 (.060)
R ²	13%	13%	10%	8%	7%	12%	4%	3%

* Significant at p<.05
 ** Significant at p<.01
¹ Reference group: people who do not have that specific type of chronic illness. For example, people with COPD were compared with people who have another chronic disease(s).
² Reference group: male
³ Reference group: people with lower educational level
⁴ Reference group: people with one chronic disease

Discussion

This study shows that people with chronic illness perceive a moderate amount of self-management tasks for themselves. Especially in the domains of medical management and making lifestyle changes, they perceive more self-management tasks. People with chronic illness who face (more) tasks in one domain of self-management do not necessarily face (more) tasks in other domains as well. Moreover, people who perceive more self-management tasks do not automatically indicate a higher need for support. Overall, people with chronic illness indicated a fairly low need for self-management support, but people who report a need for support in one domain of self-management probably also need support in other domains of self-management.

The generally low need for self-management support that people with chronic illness reported in this study may be somewhat surprising. It may be explained by the fact that this study assessed the unmet needs for support of the participants, thus not their needs for self-management support that had already been met by the support they received from informal carers and professional care providers. The reason for this is that the actual amount of support people already receive cannot be reliably estimated by self-report, as people who receive similar levels of support may experience the provided support differently. In addition, the authors believe that information on the still existing (unmet) needs is most relevant to improve self-management support for people with chronic illness. Furthermore, the fact that people with chronic illness report a low need for support does not necessarily mean that they will not benefit from support. People with chronic illness may not always explicitly state their needs for support.

People with chronic illness report the highest levels of perceived self-management tasks in the domains of medical management and making lifestyle changes, whereas they report the lowest needs for support with respect to these domains. Findings of Elissen and colleagues [36] showed that self-management support provided by healthcare providers tend to focus mainly on medical and behavioural management of an illness and less on helping patients deal with the emotional consequences of being chronically ill. Because of the emphasis healthcare providers put on the medical and behavioural aspects, patients may perceive the medical management of their illness and making lifestyle changes more often as their self-management

tasks than coping with the consequences of chronic illness for their daily life. The focus on medical and behavioural aspects of self-management in healthcare may also explain why people report a lower need for support in these domains: they already receive sufficient support from healthcare providers in this respect. Moreover, self-management tasks in the medical and lifestyle domains may be more concrete and straightforward than tasks concerning complex processes such as adaptation to a life with chronic illness, resulting in higher support needs regarding coping tasks.

Previous research indicated that there are commonalities in the nature of self-management tasks across different types of diseases [4, 25]. The current study found that self-management tasks are partly generic and partly disease specific. Most types of chronic disease had only a small effect on the number and frequencies of perceived self-management tasks. However, having diabetes or a neurological disease did have a strong effect on the extent to which people perceive tasks as part of their daily management. In many European countries, there are advanced disease management programs for diabetes and not (yet) or only recently for other chronic diseases [27]. It could be that this has led diabetes patients to be more aware of their own role in the management of diabetes, resulting in these patients perceiving more tasks as part of their daily self-management. Neurological diseases, such as Parkinson's disease and multiple sclerosis, are in general progressive diseases that strongly affect people's cognitive and physical functioning. This might explain why having a neurological disease had especially a strong effect on the perceived self-management tasks concerning communication and coping with the chronic disease.

Moreover, this study does show that there are similarities in the self-management support needs for the different diseases. The effects of the different types of diseases on self-management support needs were small and explained only a small proportion of the variation in support needs of chronically ill people. This is an important finding as the type of chronic disease is for many self-management support programs the most important inclusion criterion. This study indicates that developing generic self-management support programs with disease-specific modules that can be added could help optimize the outcomes of these programs. These programs would also better meet the needs of the many patients that suffer from more than one chronic disease. This study only focused on having one or more

chronic diseases. The effect of combinations of specific types of chronic diseases on self-management tasks and support needs was not taken into account. It would be interesting to examine the effect of multi-morbidity on self-management support needs more thoroughly. In addition, further research should focus on the self-management support needs of different target groups to establish how self-management programs can be tailored to the individual needs of patients.

Strengths and Limitations of the Study

This is, to the best of our knowledge, one of the first studies that evaluates self-management tasks and support needs from the perspective of people with chronic illness themselves and the only study that uses quantitative data from a large study population. The use of data from a nationwide representative sample of (medically diagnosed) chronically ill people provides unique insights into the perceptions of people with chronic illness. For this study, a self-developed questionnaire was used and therefore some aspects of the psychometric quality of the questionnaire were tested: its factor structure and (internal consistency) reliability. Our results indicate that the PAST questionnaire supports the theoretically presumed multi-dimensionality of the concept of self-management. The four-factor model fits the data reasonably well. Furthermore, the internal consistency of the tasks and support scales are acceptable. The somewhat low alpha for the medical management scale might be explained by the diversity of the tasks involved. Some people will have to perform self-care tasks, such as putting on elastic stockings and some people might need to monitor their blood pressure, but the fact that someone needs to perform one type of medical task does not directly imply the need to perform the other tasks as well. Nevertheless, all these tasks involve medical management. The same principle applies to the lifestyle scale. For some patients, making lifestyle changes will mean losing weight and for others stopping smoking. In addition, people tend to compensate unhealthy behaviour with healthy behaviour [37]. For instance, “If I exercise sufficiently, I am allowed to eat fast food”. This might explain the slightly low alpha for the lifestyle scale. However, test–retest reliability and construct validity of the questionnaire need to be further examined. In addition, the factor structure of the questionnaire should also be tested in different data samples. If the PAST questionnaire proves sufficiently reliable

and valid, it could be useful for tailoring self-management programs to the individual needs of chronically ill people. Healthcare providers could use the questionnaire to assess patients' unmet support needs.

Conclusion

Although people with chronic illness perceive a moderate amount of self-management tasks for themselves, they do not indicate an explicit need for self-management support. The need for self-management support of people with chronic illness is not strongly related to the extent to which they perceive more or less self-management tasks for themselves, nor can it be satisfactorily explained by the specific type of chronic disease they are diagnosed with. This indicates that though the self-management tasks patients see for themselves may be partly disease specific, self-management support does not necessarily need to be disease specific. Support programs could use a more generic approach and should not only focus on medical management of the illness and making lifestyle changes but also pay attention to coping with the consequences of living with a chronic illness.

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Appendix 1: PAST Questionnaire

How often do you have to.... (1= never, 2= sometimes, 3= mostly, 4= always)
And how often do you need (extra) support with these tasks? (1= never, 2= sometimes, 3= mostly, 4= always) Support can be seen as help from a health-care provider but also from a family or friends.

1. Cope with pain or limitations (Cp)
2. Take medicines as prescribed for you (M)
3. Visit doctors and other healthcare providers (Cm)
4. Take care of what you eat (L)
5. Exercise sufficiently (L)
6. Live a healthy lifestyle (stop smoking, not much alcohol) (L)
7. Cope with the limited amount of energy you have (Cp)
8. Cope with emotions and stress (Cp)
9. Ask for help if needed (Cm)
10. Abandon unhealthy habits (L)
11. Do exercises at home (M)
12. Use technical aids (M)
13. Understand the information of doctors and other healthcare providers (Cm)
14. Cope with limitations in, for example, going out, going on holiday, etc. (Cp)
15. Monitor your complaints and symptoms yourself (M)
16. Perform self-care tasks, like taking care of wounds, putting on elasticated stockings, taking your medicines (M)
17. Monitor your own health by, for example, monitoring your glucose or blood pressure (M)
18. Contact and talk with healthcare providers (Cm)
19. Cope with an uncertain future (Cp)

M = Medical management
Cm = Communication with healthcare providers
Cp = Coping with consequences
L = Making lifestyle changes

Appendix 2: Explorative factor analysis of PAST questionnaire

An exploratory factor analysis using principal component extraction with varimax rotation was conducted to examine the factor structure of the PAST questionnaire. In this analysis, a four factor solution was given (Table 5). Values of the items should be at least .40 on one factor and lower than .35 on the other factors to be included in a particular factor. Based on this rule of thumb, the first factor consists merely out of items we considerate as coping (items 1, 7, 9, 12, 14 and 19). The second factor was less clear. Only item 17 clearly loaded on this factor. The third factor we considered a lifestyle factor (items 5, 6 and 10) and the fourth factor a medical factor (items 2, 15 and 16). The items that we considered as communication related loaded on more than one factor. This might be explained by the fact that communication is the basis for medical management, coping and making lifestyle changes.

Table 5: Explorative factor analysis of the PAST questionnaire (all items)

Variable	Factor 1	Factor 2	Factor 3	Factor 4
Coping with the consequences				
1. Cope with pain or limitations	.7765	.0249	.0631	.1372
7. Cope with the limited amount of energy you have	.7695	.0670	.1910	.1523
8. Cope with emotions and stress	.5422	.1259	.1947	.0182
14. Cope with limitations in, for example, going out, going on holiday	.7686	.0999	.0511	.1309
19. Cope with an uncertain future	.6866	.1635	.0950	.1922
Making lifestyle changes				
4. Take care of what you eat	.1402	.5334	.4118	.0986
5. Exercise sufficiently	-.0128	.0272	.7256	.1836
6. Live a healthy lifestyle (stop smoking, not much alcohol)	.1198	.0111	.7320	.1226
10. Abandon unhealthy habits	.2373	.2768	.5428	-.1333
Medical management				
2. Take medicines as prescribed for you	.0700	.1738	.1504	.7192
11. Do exercises at home	.4132	.2551	.3552	-.1307
12. Use technical aids	.6314	.1658	-.0878	.0327
15. Monitor your complaints and symptoms yourself	.3295	.0925	.2954	.4792
16. Perform self-care tasks, like taking care of wounds, putting on elasticated stockings, taking your medicines	.1957	.1567	.0283	.7341
17. Monitor your own health by, for example, monitoring your glucose or blood pressure	.0134	.7481	.0677	.1958
Communication with healthcare providers				
3. Visit doctors and other healthcare providers	.3455	.4539	.0954	.2885
9. Ask for help if needed	.6211	.3392	.0533	-.0975
13. Understand the information of doctors and other healthcare providers	.3467	.4249	.2473	.1591
18. Contact and talk with healthcare providers	.3867	.5917	-.0945	.1758

Therefore, a second exploratory principal components analysis was conducted, leaving out the items that we considered as communication with healthcare providers. Then we found a three factor solution (Table 6). This solution corresponded with our theoretical framework, with the exception of item 12 and item 11. Item 12 refers to the use of technical aids, such as an inhaler or blood pressure pump. Only a small fraction of the population of people with chronic illness use such technical aids (<10%), therefore we decided to delete this item (also in the final confirmatory factor analysis described in the manuscript). Item 11 refers to doing exercises at home and had a low factor loading on all three factors. We consider item 11 to refer to

medical management (assuming that patients do exercises at home – like they take medication – as part of their treatment; for instance, as advised by a medical doctor or physiotherapist), but it could be argued that item 11 fits one of the other factors as well (for instance, when doing exercises is considered by the patient as healthy behaviour (lifestyle) or a way to reduce stress (coping)).

Table 6: Explorative factor analysis of the PAST questionnaire (without communication related items)

Variable	Factor 1	Factor 2	Factor 3
Coping with the consequences			
1. Cope with pain or limitations	.7867	.0408	.1148
7. Cope with the limited amount of energy you have	.7749	.1853	.1297
8. Cope with emotions and stress	.5457	.2437	.0313
14. Cope with limitations in, for example, going out, going on holiday	.7866	.0489	.1264
19. Cope with an uncertain future	.7035	.1360	.1863
Making lifestyle changes			
4. Take care of what you eat	.2063	.5066	.3421
5. Exercise sufficiently	-.0285	.6942	.1496
6. Live a healthy lifestyle (stop smoking, not much alcohol)	.0879	.7022	.0774
10. Abandon unhealthy habits	.2444	.6030	-.0034
Medical management			
2. Take medicines as prescribed for you	.0767	.1184	.7121
11. Do exercises at home	.4450	.4059	-.0351
12. Use technical aids	.6642	-.0721	.0948
15. Monitor your complaints and symptoms yourself	.3128	.2726	.4567
16. Perform self-care tasks, like taking care of wounds, putting on elasticated stockings, taking your medicines	.2107	.0003	.5082
17. Monitor your own health by, for example, monitoring your glucose or blood pressure	.1193	.2128	.5371

3

Self-management support needs of patients with chronic illness: Do needs for support differ according to the course of illness?

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^a Author contribution: LvH, MR and PG designed research; LvH and MH collected data; LvH, MR and PG planned the data analysis; LvH performed data analysis; LvH wrote the paper with input from MR, MH and PG.

ABSTRACT

Objective:

To determine whether chronically ill patients' needs for self-management support depend on their course of illness.

Methods:

Cross-sectional and longitudinal linear regression analyses were conducted using data from 1300 patients with chronic disease(s) who participated in a nationwide Dutch panel-study. Self-management support needs were assessed by the Patient Assessment of Self-management Tasks questionnaire (PAST). Course of illness was operationalized as: illness duration, patients' perception of the course of illness and changes in self-rated general health (RAND-36).

Results:

Self-management support needs are not related to illness duration. Patients who perceive their illness as episodic and/or progressively deteriorating have greater self-management support needs than patients who perceive their illness as stable. Deterioration of self-rated health is related to increased support needs. The effect of the course of illness on support needs depends on the type of self-management activities.

Conclusion:

How chronically ill patients perceive the course of illness and actual changes in self-rated health are predictive for their need for support for self-management activities. Illness duration is not. Practice implications: Helping patients to self-manage should not be confined to the first years after diagnosis. Healthcare providers should be alert to patients' own perceptions of their course of illness and health status.

Introduction

Self-management of chronic illness has been widely recognized as an essential part of chronic illness care, as it empowers patients and improves health outcomes [1,2]. Effective self-management consists of monitoring one's condition and adapting cognitive, behavioral and emotional responses to maintain a satisfactory quality of life [3]. However, many patients have difficulty managing their chronic illness properly [4]. Recognition of these difficulties has led to the development of many self-management support programs over recent decades [4-6]. Nevertheless, evaluating how successful these programs are generally shows only modest positive effects [4-8]. One of the difficulties of developing effective self-management support is that the population of patients with chronic conditions is very diverse. As a result, some patients might need support taking medication as prescribed, while others need support exercising sufficiently. Understanding patients' needs for self-management support might improve the effectiveness of self-management support. So far, research on chronically ill patients' needs for self-management support has been scarce.

The need for self-management support can be studied from the perspective of coping with stressful situations. This perspective views chronic illness as a major life event characterized by a number of recurrent stressful situations that pose serious challenges to adaptation [9-12]. As chronic illnesses change over time, patients with chronic conditions continuously have to adapt to the stressful situation that is appraised at that moment [10]. These constant adaptations trigger the need for support. A better understanding of the individual course of illness could be helpful in determining the support needs of chronically ill patients. The purpose of this study is therefore to examine chronically ill patients' needs for self-management support through the course of their illness.

There are several ways to describe an individual's course of illness. First, the course of illness can be described by the duration of a patient's chronic illness, for instance the time since diagnosis. A second, more subjective way is starting from patients' own perceptions of their course of illness. According to the Common Sense Model of Leventhal and colleagues, subjective perceptions of a chronic disease rather than its objective characteristics will encourage health-related behavior of patients [13,14]. Therefore, how patients

perceive their course of illness might be a good indicator of their self-management support needs. A third way is describing changes in self-rated health over time. As mentioned before, patients with chronic conditions continuously have to adapt to stressful situations, which may trigger the need for support [10,11]. Changes in self-rated health could be considered an indication of the stress they experience.

In this study, we will examine to what extent the course of a chronic illness, operationalized in the three ways described above, relates to chronically ill patients' needs for support for various self-management activities. Our research questions are:

1. How does illness duration relate to the needs for self-management support of chronically ill patients?
2. How does the patients' perceived course of illness relate to the needs for self-management support of chronically ill patients?
3. How do changes in self-rated health (over one year) relate to the needs for self-management support of chronically ill patients?

In line with a broad definition of self-management, e.g. [3,15], we assume that self-management comprises a variety of activities. Therefore, we distinguish, in accordance with Bayliss and colleagues, four types of self-management activities patients might need support with, namely medical management, communication with healthcare providers, coping with the consequences of having a chronic illness, and making lifestyle changes [16]. Because of the different challenges involved, we will study the extent to which patients perceive a need for support separately for these four types of activities.

To guide our research, we formulated three hypotheses.

- (1) Based on focus group sessions we held over the last years with several groups of patients with chronic diseases (e.g. diabetes, COPD), we noticed that self-management support seems to be provided mainly during the first years after diagnosis of a chronic disease. However, a longer illness duration can provoke new stressful situations. The Chronic Illness Trajectory Framework shows that symptoms can become uncontrollable over time, forcing patients to change their adaptive regimen [17,18].

Support may therefore be equally necessary later, as patients proceed through the course of illness. The first hypothesis in our study is that the need for support is not smaller for patients who were diagnosed longer ago than for patients who have more recently been diagnosed with a chronic disease (0–3 years).

- (2) The perceived course of illness may be stable, episodic and/or progressive [19]. Patients who experience their illness as stable may not feel a need to change the way they manage their illness, whereas patients who perceive their illness as episodic and/or progressively deteriorating may need to alter their health regimen continuously, which can bring uncertainty and stress [18]. Previous research has demonstrated an association between poor functioning and the believe that the illness has a cyclical character [20]. We expect that perceiving the course of illness as episodic and/or progressively deteriorating relates to a greater need for self-management support than a course of illness perceived as stable.
- (3) Furthermore, changes in self-rated health demand a great deal from patients' adaptive abilities [21–23]. A relapse or complication may cause stress and subsequently create a need for support, whereas an experienced improvement in health may reduce the need for self-management support. We hypothesized that deterioration in self-rated general health relates to increased self-management support needs, whereas improvement relates to decreased self-management support needs.

Methods

Participants

Data were analyzed from the National Panel of people with chronic illness or disability (NPCD), a nationwide prospective panel study on the consequences of chronic illness in the Netherlands [24,25]. Participants with chronic disease were recruited from more than a hundred general practices (random samples of general practices drawn from the Dutch registration of general practices [26]). Patients were selected using the following criteria: diagnosis of a somatic chronic disease by a certified medical practitioner, aged 2:15 years, not permanently institutionalized, aware of the diagnosis, not terminally ill (life expectancy >6 months according to the GP), mentally

capable of participating, and sufficient mastery of Dutch [24,25]. Annually, 500 new panel members are selected via the standardized procedure to replace panel members who withdrew or who had participated for the maximum term of four years. NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of the Authority.

Data collection

We used data that were collected at three different points in time. In April 2012, a questionnaire about the needs for self-management support and self-perceived general health was sent to the panel members. A total of 1688 patients diagnosed with a chronic disease completed this questionnaire (response = 82%). Socio-demographic information and patients' perception of their course of illness was assessed at inclusion as well as medical data of panel members as provided by their GPs. To answer our final question, we also used data about the needs for self-management support and self-perceived general health from the questionnaire of April 2011. In total, 1300 participants filled in the questionnaire of 2011 as well as the questionnaire of 2012.

Operationalization

Course of illness

Illness duration (in years) was calculated based on the date of diagnosis of the (first) chronic disease, which was extracted from the GP files. For our analyses, we divided illness duration into six categories (0–3 years, 3–5 years, 5–10 years, 10–15 years, 15–20 years and 20 years or more). We did not use age as a continuous variable, as we did not expect support needs to change gradually for each additional year.

How patients perceive their course of illness was based on two questions posed at inclusion: whether patients considered their course of illness as episodic and whether they considered it as progressively deteriorating. Both items were scored on a 3-point scale (1 = 'not at all', 2 = 'to some extent' and 3 = 'to a large extent'). For the analyses, the categories 'to some extent' and 'to a large extent' were combined. Based on these two items the variable 'patient perceived course of illness' was created with four values: (1) stable (respondents who answered 'not at all' for both items); (2) episodic; (3)

progressively deteriorating; and (4) episodic and progressively deteriorating. Patients' self-rated general health was measured by the general health scale of the RAND-36 Short Health Status Survey [27]. The scale score was calculated based on five items and rescored to range from low (1 = poor general health) to high (100 = excellent health). Cronbach's alpha for the general health scale was .81 in both 2011 and 2012. Changes in self-rated general health were calculated by subtracting the individual score for 2011 from the individual 2012 score. This score was divided into three categories based on half the standard deviation [28]: "deteriorated health" (-100 to -7), "no change in health" (-7 to 7) and "improved health" (7-100).

Self-management support needs

To assess patients' need for self-management support, we used the Patient Assessment of Self-management Tasks questionnaire (PAST) [29]. In this questionnaire, patients indicate to what extent they feel they need to perform several self-management tasks and to what extent they feel a need for support with these tasks, both answered on a 4-point scale ranging from 0 (never) to 3 (always). For example, how often do you need to take medication as prescribed and how often do you need support with this? Patients who do not consider a specific self-management task are assumed to have no need for support in this task. In accordance with the description of self-management activities by Bayliss and colleagues [16], we distinguished four types of self-management activities people might need support with: (1) medical management (5 items), e.g. taking medication correctly or self-monitoring of symptoms; (2) communication with healthcare providers (4 items), e.g. understanding information given by healthcare providers and participating in decision making; (3) coping with the consequences of the illness (5 items), e.g. coping with pain and an uncertain future; and (4) making lifestyle changes (4 items), e.g. exercising sufficiently or eating healthily. The scales were constructed by summing the scores on the separate items belonging to the scale. Participants had to fill in at least three items per scale in order to get a scale score. Needs for self-management support were assessed in the questionnaires of 2011 and 2012. Cronbach's alphas for the four scales were .72 and .73 (medical management in 2011 and 2012 respectively), .80 (communication), .83 (coping) and .72 (making lifestyle changes, all both years).

Socio-demographic and illness characteristics

We included the following socio-demographic characteristics: age, gender, highest level of education and living situation. In addition, we included the type of chronic disease and the presence of more than one chronic disease (multi-morbidity). The chronic diseases of participants were registered by their GPs using the International Classification of Primary Care [30]. Examples of registered diseases are heart failure, COPD and multiple sclerosis.

Statistical analyses

Descriptive analyses were performed to provide information on the characteristics of the study sample. Associations between illness duration, patient perceived course of illness and self-rated general health were explored by linear regression analyses and one-way ANOVA, followed by a Bonferroni post hoc test.

To test the first two hypotheses, we conducted linear regression analyses. The first model tested the effects of several socio-demographic and illness characteristics (see Section Socio-demographic and illness characteristics) on the needs for self-management support (dependent variable). The second model tested the effect of illness duration (independent variable) on self-management support needs (dependent variable), controlling for the socio-demographic and illness characteristics. The third model tested the effect of patient-perceived course of illness (independent variable) on self-management support needs (dependent variable) controlling for the socio-demographic and illness characteristics. We tested these models for all four support needs scales.

To test the third hypothesis, we also conducted linear regression analyses. First, we tested the effect of the change in self-rated general health between 2011 and 2012 (independent variable) on the change in the need for self-management support (dependent variable). As we expected that the initial self-rated health might influence this relation, we also conducted analyses which included the interaction term of self-rated general health in 2011 and changes in self-rated general health between 2011 and 2012 as an independent variable. In these analyses we did not control for socio-demographic and illness characteristics, as we measured these variables only once (at inclusion). Again, we tested these models for all four support needs scales separately.

We conducted single-level regression analyses instead of multilevel analyses, since intra-class correlations showed hardly any clustering of support needs within general practices, the original sampling framework (mean .01). In addition, the likelihood ratio test did not show that multilevel analyses had an advantage over ordinary regression analyses. All analyses were performed using Stata 12.0.

Results

The study population

Table 1 presents socio-demographic and illness characteristics of the study population in 2012. The mean age of the respondents was 61 years. Asthma (15%), COPD (15%), diabetes (12%) and cardiovascular disease (12%) were the most common chronic diseases within the sample. Almost half the respondents (48%) had been diagnosed with more than one chronic disease. Four percent of the respondents were diagnosed less than three years ago, 12% three to five years ago, one third (34%) five to ten years ago and almost half (48%) ten years or longer ago. More than a third of the respondents (38%) perceived the course of their illness as stable. The others perceived their illness as episodic (21%), progressively deteriorating (10%) or both (31%). The mean general health score of the study population was 53.6 in 2011 and 52.1 in 2012. The mean change in self-rated health scores was small (-1.7), but the wide standard deviation (14.0) indicates that the perceived general progressively deteriorating reported the lowest perceived health score (37.9). Furthermore, patients' self-rated health was related to illness duration; the longer patients were ill, the lower their perceived health score was. Changes in self-rated health over one year were neither related to illness duration nor to patients' perceived course of illness.

Table 1: Descriptive characteristics of the study population 2012

		<i>n</i>	<i>Percentage</i>	<i>Mean</i>	<i>Range</i>	<i>S.D.</i>
Patients characteristics	Age	1684		61.2	16-93	15.1
	Female	1684	54%			
	Cohabiting	1673	77%			
	Education level	1639				
	Lower ¹		34%			
	Intermediate ²		43%			
	Higher ³		23%			
Objective disease characteristics	Diagnosis index disease	1684				
	Cardiovascular disease		12%			
	Asthma		15%			
	COPD		15%			
	Musculoskeletal disorder		12%			
	Cancer		5%			
	Diabetes mellitus		12%			
	Neurological disease		7%			
	Gastrointestinal disease		4%			
	Other chronic disease		19%			
	Multi-morbidity present	1684	48%			
	Illness duration (years post-diagnosis)	1659		12.0	0.4-66	8.9
	Less than 3 years		4%			
	3 to 5 years		12%			
5 to 10 years		34%				
10 to 15 years		25%				
15 to 20 years		12%				
20 years or longer		13%				
Patient-reported illness characteristics	Patient's perceived course of illness	1468				
	Stable		38%			
	Episodic		21%			
	Progressive deterioration		10%			
	Episodic & progressive		31%			
	Perceived health in 2011	1217		53.8	0-100	20.7
	Perceived health in 2012	1538		52.1	0-100	20.5
	Change in perceived health 2011-2012	1138		-1.7	-55-60	13.99
Deteriorated		31%				
No change		46%				
Improved		23%				

¹ Lower= primary school or only vocational training.

² Intermediate= high school or intermediate vocational training.

³ Higher= college or university.

Effects of illness duration and patients' perceived course of illness on the need for self-management support

Model 1 in Table 2 demonstrates that older people, women, lower educated people, people who live alone and people who have more than one chronic disease had higher support needs. These effects differed for the four types of

self-management activities. Model 2 shows that when comparing patients who have been diagnosed relatively recently (0–3 years) to patients who were diagnosed longer ago, no differences were found in their needs for support. This applied to all four types of self-management activities.

Model 3 shows a significant positive effect of patients' perceived course of illness on the needs for self-management support. This implies that the need for support with all types of self-management tasks was greater for patients who perceived their illness as episodic and/or progressively deteriorating than for those who perceived their illness as stable. In particular, patients who perceived the course of their illness to be both episodic and progressively deteriorating reported a greater need for self-management support. The effects of perceiving one's illness as episodic and/or progressively deteriorating were greatest for the need for support in coping. The adjusted R^2 shows that model 3 explained substantially more of the variance in the needs for self-management support than the first two models.

Table 2: Regression analyses testing the effect of illness duration and patient's perceived course of illness on self-management support needs of patients with chronic illness 2012

Self-management support needs 2012	Medical management			Communication			Coping			Lifestyle		
	Model 1 β	Model 2 β	Model 3 β	Model 1 β	Model 2 β	Model 3 β	Model 1 β	Model 2 β	Model 3 β	Model 1 β	Model 2 β	Model 3 β
Age	.13**	.13**	.12**	.17**	.17**	.17**	.08**	.08**	.08**	-.00	-.00	.01
Gender (ref= male)	.01	.01	-.01	.08**	.08**	.06*	.12**	.12**	.09**	.01	.00	-.01
Educational level												
Low (ref)												
Intermediate	-.07*	-.07*	-.05	-.09**	-.09**	-.06	-.02	-.02	.02	-.02	-.01	-.00
Higher	-.10**	-.10**	-.11**	-.12**	-.12**	-.12**	-.01	-.01	-.02	-.06	-.06	-.07*
Living situation (ref= living alone)												
Multi-morbidity (ref= one disease)	-.02	-.02	-.01	-.05	-.05	-.03	-.08**	-.08**	-.07**	-.06*	-.07*	-.05
Index disease	.07*	.07*	.07*	.06*	.04	.04	.06*	.04	.04	.04	.06	.05
Cardiovascular disease (ref)												
Asthma	-.00	-.01	.01	-.03	-.04	-.03	-.04	-.05	-.03	-.03	-.03	-.03
COPD	-.04	-.04	-.04	-.01	-.01	-.03	.01	.01	-.01	.03	.02	.02
Musculoskeletal disorder	-.01	-.01	-.03	.01	.00	-.03	.05	.05	.02	-.01	-.01	-.03
Cancer	-.02	.02	.03	-.03	.03	.04	.02	.02	.02	-.01	-.01	.01
Diabetes mellitus	.06	.05	.03	.03	.03	.01	.03	.02	.02	.08*	.08*	.06
Neurological disease	.07*	.06	.06	.07*	.06	.05	.11**	.10**	.10**	.03	.04	.02
Gastrointestinal disease	-.02	-.02	-.03	-.01	-.01	-.02	-.02	-.02	.01	.01	.01	-.01
Other chronic disease	-.01	-.01	-.00	-.03	-.03	-.03	-.01	-.02	.01	-.01	-.01	-.00
Duration of illness												
0 to 3 years (ref)												
3 to 5 years		.02			-.00			.02			-.04	
5 to 10 years		.07			.08			.09			-.06	
10 to 15 years		.03			.03			.05			-.11	
15 to 20 years		.05			.05			.09			-.08	
20 years or longer		.05			.08			.08			-.05	
Patient's perceived course of illness												
Stable (ref)												
Episodic			.09**			.14**						.16**
Progressive deterioration			.08**			.10**						.12**
Episodic & progressive			.27**			.33**						.24**
Adjusted R ₂	.04**	.03**	.09**	.06**	.06**	.15**	.04**	.04**	.18**	.01*	.01*	.06**

* Significant difference at $p < .05$. ** Significant difference at $p < .01$.

Effects of changes in self-rated health on changes in support needs

On average, the needs for self-management support of chronically ill patients barely changed between 2011 and 2012, but the wide ranges suggest that the support needs did change substantially for some patients (Table 3). Table 4 (model 1) shows that self-management support needs increased when the self-rated general health deteriorated over the last year, while support needs decreased when perceived general health improved. This effect is illustrated in Fig. 1. The effects of changes in perceived health were the highest for support needs related to 'coping' and the lowest for support needs related to 'medical management' and 'lifestyle changes'. The percentages of variance explained by the change in self-rated health were low. The second model in Table 4 shows that there was no significant interaction effect of patients' initial self-rated health score in 2011. This means that the relationship between changes in self-rated health and changes in needs for self-management support was linear.

Table 3: Description of the changes in self-management support needs between 2011 and 2012

Changes in self-management support needs 2011-2012	<i>N</i>	<i>Mean</i>	<i>Std. Dev.</i>	<i>Min</i>	<i>Max</i>
Medical management	1022	.002	.40	-2.2	2.35
Communication	993	.002	.43	-1.75	2.25
Coping with consequences	1030	-.009	.40	-2.2	2.2
Lifestyle changes	969	.002	.49	-2.25	2.25

Table 4: Regression analyses testing the effect of changes in perceived general health on changes in self-management support needs of patients with chronic illness between 2011 and 2012

Changes in self-management support needs 2011-2012	Medical management	Communication	Coping	Lifestyle
Model 1	β	β	β	β
Changes in perceived health	-.08	-.11 **	-.14**	-.08 *
Adjusted R²	.00	.01 **	.02**	.01 *
Model 2	β	β	β	β
Changes in perceived health	-.14	-.26 **	-.30**	-.02
Perceived health in 2011	.01	.08 *	.03	.02
Change*in health in 2011	.07	.19	.17	-.05
Adjusted R²	.00	.02 **	.02**	.00

* Significant at $p < .05$ ** Significant at $p < .01$.

Discussion and conclusion

Discussion

Patients with chronic illness have different needs for self- management support. The purpose of this study was to examine whether the needs for self-management support of chronically ill patients depend on their individual course of illness. Consistent with our first hypothesis, we found that the needs for self- management support are not lower for patients who have been diagnosed many years ago than for recently diagnosed patients. This can be explained by the fact that the manifestation of a chronic illness often changes over time, which may involve continuously altering self-management tasks. Adaptation to a new health regimen is therefore not only a characteristic of the first phase of illness but also of later phases. This is in accordance with findings of other studies that showed that the demands of the situation when living with a chronic illness vary from one illness stage to another [22,23].

Furthermore, patients' perceptions of the course of their illness relate to their self-management support needs. Patients who perceive their course of illness as episodic and/or progressively deteriorating have greater needs for self-management support than patients who perceive their illness as stable. This is

in line with our second hypothesis. Other studies have shown that an unpredictable course of illness leads to feelings of lower self-efficacy [31,32]. Patients might experience their self-management as failing. The impact on patients' self-efficacy beliefs may be one of the mechanisms through which patients' perceived course of illness influences their need for self-management support.

In line with our third hypothesis, we found a significant effect of a change in self-rated health over one year on changes in self-management support needs. Deterioration of self-rated health relates to increasing self-management support needs, while improvement relates to a decrease. Other studies demonstrated that patients' perceived health status influences their ability to perform self-management. For example, physical limitations and symptoms, such as pain and fatigue, are common barriers to self-management for people with chronic conditions [33,34]. In addition, deterioration of health might cause feelings of loss of control as patients feel that their self-management strategies have failed, whereas experiencing health improvement could affirm patients' self-management.

Interestingly, the effects of patients' perceived course of illness and change in their self-rated health on the need for self-management support differ depending on the type of self-management activities involved. In particular, the need for support in coping with the consequences of chronic illness and in communicating satisfactorily with healthcare providers depend more on patients' perceived course of illness and changes in their perceived health than support needs related to medical management and making lifestyle changes. It might be that more subjective measures of the course of illness (patients' perceptions) impact more on psychological aspects of self-management such as coping and communicating than on more practical aspects such as medical management and making lifestyle changes.

To the best of our knowledge, this is the first study that explores chronically ill patients' needs for self-management support as a function of their individual course of illness. Although this study was primarily cross-sectional, we also performed longitudinal analyses (over a period of one year) to explain changes in the needs for self-management support of patients with chronic illness. One year is however a short period of time for changes to occur. This might explain why, in general, the changes in self-rated health and in the needs for self-management support were moderate, and the explained variation in the

changes in support needs was low. We are aware that a longer follow-up period would have been better. Nevertheless, by combining the cross-sectional results with the results of the longitudinal analyses this study provides relevant insights into the self-management support needs of chronically ill patients.

Furthermore, we did not control for the type and amount of self-management support that patients already received. In the questionnaire we asked respondents to report whether they needed '(extra) support' with certain self-management tasks. Therefore, the fact that people report a need for support cannot be interpreted as that they did not receive any support. We can only conclude that they still have unmet support needs. Unfortunately, it is not possible to get a reliable estimate of the actual amount of support patients receive, as patients experience the provided support differently.

Another limitation is that we assessed patient's perceived course of illness at inclusion, while the needs for self-management support were assessed in April 2011 and 2012. The time between inclusion of the respondent and the data collection of April 2012 varies between 17 days and 4 years (mean 2.0). Knowing that illness perceptions are mainly shaped in the first period of illness [35,36] and that most of our respondents were already ill for a substantial amount of years at inclusion (mean 12.0 years), we assume that their perceptions about the course of illness had become quite stable at that time. Furthermore, patient's perceived course of illness was assessed with only two, self-developed items. Despite this, we used these items because of their ability to distinguish four different 'courses' of chronic illness: stable, episodic, progressive and both. An indication of the validity of the two combined items was found by the significant association with the IPQ-R timeline scale [37] included in the questionnaire of April 2012: people who perceive their illness as episodic or both episodic and progressive reported a significantly stronger cyclical timeline than people who perceived their course of illness as progressive or stable.

Finally, this study only partly explains the variation in self-management support needs of patients with chronic illness. The results show that several aspects of patients' lives that are related to different social roles and resources, such as their age, gender, education and living situation, are important as well. Further research is needed to explore how patients' course of life and their everyday activities interfere with their needs for self-

management support. This may provide more insight into the mechanisms that underlie the self-management support needs of patients with chronic illness.

Conclusion

Chronically ill patients' own perceptions on the course of their illness as well as actual changes in self-rated health are predictive for their needs for support for several self-management activities, whereas illness duration is not. Both the amount of self-management support and the type of self-management activities patients need support with are related to the individual course of illness.

Practical implications

First, healthcare providers need to be aware that self-management support needs of patients with chronic illness can arise or increase at any moment as the illness progresses. Healthcare providers should therefore pay attention continuously to patients' perceptions of their course of illness and their perceptions of health. Second, health-care providers need to have knowledge about self-management support. Support should not only include practical help and advice regarding the medical management of chronic disease and lifestyle issues, but also support for effective communication with healthcare providers and patients' coping with their chronic illness in daily life. This is especially important for patients whose illness is characterized by progressive deterioration and/or by episodic fluctuations in the frequency and severity of symptoms. Finally, the variation in self-management support needs shows that there is an urge for tailored interventions, which take the changeability of patients' support needs into account.

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Illustration

Self-management according to type and course of illness

Chronically ill people need to perform all sorts of activities to manage their illness in daily life. The type of self-management tasks people need to perform, and the support they need to perform these tasks may differ according to the type of chronic disease. For instance, people with diabetes might need to monitor their glucose level and change their diet, while people with arthritis might need to do physical exercises to stay flexible. However, our previous study showed that although the self-management tasks chronically ill people perform may be partly disease specific, self-management support does not necessarily need to be disease specific (Chapter 2). To explain variation in self-management support needs, differences in the course of illness may be more relevant. As chronic illnesses change over time, people with chronic illness continuously have to adapt to an altered situation, which might impact their need for self-management support. Patients who perceive their illness as episodic and/or progressively deteriorating have greater self-management support needs than patients who perceive their illness as stable (Chapter 3). This section illustrates our previous findings with data from focus group sessions held with chronically ill people (more information about the focus group sessions and the analysis of the data can be found in Appendix).

Type of chronic illness and self-management

Type of chronic illness not an issue

The participants of the focus group sessions had a broad range of different chronic diseases, such as asthma, diabetes type II, COPD, multiple sclerosis, cancer or arthritis. Many participants had more than one chronic disease. Although the participants had different types of chronic diseases, their experiences did not differentiate much because of differences between specific chronic diseases. The participants did sometimes disagree with one another, but their type of illness was almost never the reason for their disagreement. On the other hand, similarities between the different types of chronic diseases were also not discussed explicitly. It seems that the type of chronic illness was did not influence the participants' willingness to share and explain their experiences.

Two types of support

Although the type of chronic illness was not an issue, it became clear that people with different types of chronic diseases needed and received different

types of healthcare. We could distinguish two groups. The first group consisted of participants who had been diagnosed with COPD, asthma or diabetes. These participants had regular appointments with their GP or practice nurse. During these consultations their health status was checked and goals were set. Most participants appreciated the regular check-ups, so that they were kept informed of their health status, glucose level or lung function. These appointments assured them that everything was going fine.

“Well, if you’re diabetic you have to go for a check-up every three months. That’s a given. And there’s a special diabetes nurse, a very nice woman. And I do like the fact that she checks up on me. [...] But you do have to go for these check-ups every three months, and it’s good they keep track of that. Other than that, you have to do everything on your own.”

“Well, I rather like having these regular check-ups. To know everything, and to know everything’s still where it should be [...] You want that reassurance, to know that that’s really the case.”

The second group consisted of participants with diseases such as neurological diseases, cardiovascular diseases, or musculoskeletal disorders. These participants did not feel a need for regular check-ups. The care of their chronic condition was usually provided by a medical specialist. Most of these participants decided together with their doctor to stop their regular follow-up visits and only come when needed.

“But when the rheumatologist said ‘I can’t do anything for you any more’, it was really over for me. I didn’t have any pain either. So what do you do? You just get on with your life.”

“There was a time when I regularly went to the neurologist. Then everything went fine for a while, and I didn’t go back there for a few years. And then I suffered a relapse, and since then I go once or twice every year.”

This distinction between the two groups also becomes evident when discussing individual care plans. Only one participant had actually a individual care plan. The individual care plan as a tool to manage chronic

illness seems to appeal more to the first group of participants, especially to people with diabetes, than to the second one.

“If I want to lose weight and I want no-carb or low-carb diet; then that could be really effective, but it takes enormous self-discipline. Well, that’s what they do, they help you to maintain that self-discipline. You just agree on the following: check in every week, send us your values, and we’ll look over your shoulder, every week, and as soon as we notice you’re not sending us anything anymore, then we’ll know something’s wrong and we will send you a reminder. Those kind of mechanisms, they’re part of it, and I really don’t mind at all.”

“I think that might be the case for diabetes, but for my rheumatism symptoms, I’m like, yeah, I’m not really waiting for someone to tell what I can and can’t do. I know that by now. And if things are not going well, then I adjust, no problem.”

The question arises whether the differences between these groups are the result of their type of illness or of the way their care is provided. The third part of this thesis provides a more in-depth analysis of how self-management support needs relate to the chronic illness care in the Netherlands.

Course of illness and self-management

Illness duration

All participants in our focus groups sessions had been diagnosed with their chronic illness several years ago and most felt they had become experts in their own chronic illness. They felt they knew what medicine they needed to take, what symptoms they needed to monitor and how to manage these illness-related symptoms. However, even though they had years of experience, many of them still felt a need for support to manage their chronic illness. New symptoms could arise, and some participants began to feel the long term effects of their chronic illness, or new ideas about treatments could emerge.

“I’m a care consumer. I like to keep in touch with the diabetes nurse, GP, etc. Just to tell them how things are going, but also to ask them things, to gather information.”

Course of illness

All participants are dealing with their illness on a daily basis. However, the degree to which people need to perform specific self-management activities depends for a considerable part on the course of their illness. Some participants had (at the moment of the focus group session) a stable course of illness; their symptoms were under control and the deterioration of their illness was only limited. Other participants felt their chronic illness was getting worse and that they therefore needed to take more action. There was also a group of people whose course of illness was characterised by periods in which their symptoms were more intense than in other periods.

“I’ve had type 2 diabetes since two years. How does this influences my daily life? Well, I just have to take two of those tablets every evening, I have become very aware of what I eat, though, and I have a very critical attitude towards the packaging, and the ingredients and all that.”

“I’m suffering from Kahler’s disease, aka Multiple myeloma. It’s a form of bone marrow cancer, and this is the second time I’m in deep, complete remission due to medication. Anyway, the illness will eventually just come back and then everything starts over again. During the time that I’m getting treated, I’m just limited in my possibilities.”

I: “Does your illness occupy all your time, every day?”

P: “No, just periodically. When things are not going well, like with this weather, damp weather. Then it’s like ‘oh, right, now I remember’.”

“This has been going on for about half a year now, me being in pain 24 hours a day. With medication I can keep a check on it. Thing is, though, we keep having to increase the amount of medication. You know, you can kind of feel that the kick has slowly gone out of it.”

The course of the illness is partly related to the type of illness, especially in the cases of an episodic course of illness, such as asthma. However, some people with the same chronic disease have different perceptions on the severity and course of their illness. For some participants their diabetes was stable and under control, while others with diabetes felt their illness was deteriorating.

Reflection

When talking about their chronic illness, received healthcare and the way people cope with the consequences of being chronically ill, there are a lot of familiarities between people with different chronic diseases. However, there seems to be a difference between people with specific diseases, whose care is characterised by regular check-ups and goal setting (probably guided by standards of care), and people with other diseases, whose use of care depends more on a personally felt need. Chronically ill people become experts of their own chronic illness and related care, as the years pass. However, this does not mean that these 'expert-patients' do not need support with their self-management. Chronic illness as well as its treatment and care will change over time. The way the individual course of illness develops seem to be a good indicator of the extent to which chronically ill people feel a need for more (or other types of) self-management support provided by healthcare professionals.

4

Age-related differences in self-management tasks and support needs among people with chronic illness explained by their life context

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^a Author contribution: LvH, MR, TH and PG designed research; LvH and MH collected data; LvH, MR and PG planned the data analysis; LvH performed data analysis; LvH wrote the paper with input from MR, TH, MH and PG.

ABSTRACT

Purpose

Intervention programs to support chronically ill people's self-management have proven to be only modestly successful. This may be due to a neglect of the impact of people's age and related life context. The purpose of this study is to gain understanding of the nature of age-related differences in self-management tasks and support needs.

Methods

Data from surveys among 1,782 people with chronic diseases participating in a nationwide Dutch panel-study were analysed by means of regression analyses.

Results

Older people perceive more self-management tasks for themselves and are more likely to need support due to a more severe physical condition. This relation is tempered, as younger people perceive a bigger threat of their chronic illness and have a stronger believe in their personal control over their illness than older people.

Conclusion

The life context of chronically ill people has an additional value to physical condition in explaining age-related differences in self-management tasks and support needs.

Introduction

Background

Over the past decade, self-management by patients has been recognized an important aspect of chronic illness care, as it can help avoid preventable mortality and morbidity and improve the quality of life of patients and their families [1-3]. Self-management requires patients to contribute not only to the medical management of their condition, but also to maintain, change and create new meaningful behaviours or life roles, and to cope with the psychosocial consequences of their illness [4-6]. Bayliss et al. [7] describe the following components of day-to-day self-management: engaging in activities that promote physical and psychological health, interacting with healthcare providers, monitoring health status and managing the impact of the illness on physical, psychological and social functioning.

Since people with chronic conditions often find it difficult to perform effective self-management [8], many self-management support programs have been developed to help patients manage their illness [9-11]. How successful these support programmes are is however debatable, as they generally show only modest positive effects [10,12]. One possible explanation for these modest effects may be the 'one size fits all' approach of many support programs [13]. Usually the only inclusion criterion for these programs is having a (specific) chronic disease, while our previous study showed that there are similarities in the self-management support needs for the different diseases [14]. Little attention has been paid to patients' age and related life context.

Our previous studies did demonstrate a positive relationship between the needs for self-management support and chronically ill people's age, suggesting that older people are more in need of self-management support [14, 15]. This is in line with findings of other studies that showed that older people in particular are at risk of poor self-management [16]. As health declines with aging, the physical condition of older people will be worse. For instance, older people have a higher risk of multi-morbidity [17], which can result in multiple medication issues, complex recommendations for lifestyle changes and competing demands of seemingly incompatible self-management tasks [7]. Furthermore, functional abilities decline with age [18], causing older people to have more difficulties performing mobility tasks and activities of daily living. As a result, older people will need to perform more (complex) self-

management tasks and are more likely to need support performing these tasks.

However, there are also studies that suggest the opposite. For instance, younger patients with osteoarthritis report more distress and frustration managing their illness than older patients [19], and young people with asthma have more difficulty complying with their self-care regimen [20]. These inconclusive findings indicate that the mechanisms that underlie age-related differences in chronically ill people's self-management support needs might be more complicated. Age is not only a biological process of physiological development. There is also a social component to age, as age is related to a person's life expectations, social roles and the demands he or she experiences from society [21]. Therefore, the impact of the chronic illness and the ability to manage this impact might be different for younger people than for older people, resulting in different self-management tasks and related support needs.

The aim of this study is to gain more understanding of the nature of the age-related differences in self-management tasks and related support needs. As it is common sense that older chronically ill people will have a worse physical condition than younger chronically ill people, we will not focus on this aspect in this study. We rather examine whether there are other factors related to the individual life context that can shed light on the age-related differences in self-management tasks and related support needs of people with chronic illness.

Theoretical framework

Living with chronic illness imposes many challenges to people's everyday life such as managing symptoms, dealing with pain or limited energy, changing lifestyle behaviour and dealing with uncertainties about the future [22]. In terms of stress-coping theory [23], chronic illness can be considered a continuous stressor, characterized both by a series of life events and by daily hassles, which threatens people's physical health and well-being. People respond to a stressor by evaluating its potential harmfulness to their health and well-being as well as by evaluating what can be done to overcome or prevent the harm (appraisal of the stressor). In this study, we assume that people with chronic illness will evaluate which self-management activities they need to perform in daily life to minimize deterioration of their physical

health and maintain well-being. Stress-coping theory also states that, based on their appraisal of the stressor, people will respond by cognitive or behavioural activities aimed at reduction of the stress they experience (coping). We assume that people with chronic illness perform self-management activities or tasks, if they consider these tasks necessary to prevent or minimize harm and if they feel able to perform these tasks. When chronically ill people perceive certain self-management tasks for themselves but do not feel able to adequately perform these tasks, they will feel a need for support.

Self-management tasks

Whether chronically ill people believe that they need to perform certain self-management tasks depends on whether they perceive the chronic illness to be a threat to their well-being and whether they feel they can affect the course of illness by self-management. The extent to which a chronic illness is a threat to chronically ill people's well-being depends on both the physiological presentation of the chronic condition and the consequences of the chronic condition on their functioning. Health declines with aging, older people may need to perform more self-management tasks, as a result of a worse physical condition. However, the perceived consequences of being chronically ill on physical, social and psychological functioning may be more severe for younger people (subjective burden of illness). Physical decline is part of aging and being chronically ill might be more accepted by older people, while younger people may find it harder to accept that they cannot do all the things their peers can. According to Burry [24], it is not only the biomedical condition that impacts on a person's life, but rather how this interferes with the person's life expectations, social roles and the demands he or she experiences from society. Being chronically ill might be a bigger threat to the individual's self-image and his/her social identity when people are young. Therefore, young people with a similar physical condition as older people might experience a greater impact on their daily life, and subsequently, perceive more self-management tasks as part of their daily management than older chronically ill people.

Secondary appraisal of the stressor refers to the feeling of chronically ill people that they can affect or control their chronic illness. This might also differ according to age. Older people might feel that becoming chronically ill is inevitable, while younger people might feel that they can personally control

their chronic condition. Study of Ross, Walker, and MacLeod [25] showed that older patients with hypertension had a lower belief in personal control than younger hypertension patients. Believing that one can control one's chronic illness, might indicate that one is also more inclined to perform self-management tasks. Therefore, we expect that younger chronically ill people also perceive more self-management tasks for themselves than older chronically ill people with a similar physical condition, as their belief in personal control over the illness is greater.

Hypotheses:

1. Younger people perceive the threat of their chronic illness on their well-being greater than older people with a similar physical condition.
2. Younger people perceive their personal control over their chronic illness greater than older people with a similar physical condition.
3. Younger people perceive more self-management tasks for themselves than older people with a similar physical condition (as the perceived threat of the chronic illness and the belief in personal control over the illness is greater for younger chronically ill people).

Self-management support needs

When chronically ill people feel that their chronic illness is a threat to their well-being and that self-management behaviour can change the impact of the chronic illness, but they do not feel able to adequately perform the self-management tasks perceived as required, they may feel a need for support. The resources chronically ill people have at their disposal determine their ability to manage their chronic illness. Research indicates that resources to manage illness are lower among older people. For instance, the ability to read, understand and use healthcare information (i.e. health literacy) is generally lower among older aged people [26, 27], financial resources initially seem to increase with age and then decrease after people (partly) stop working [28], and social resources decrease at old age because of illness and the death of people from their generation [29, 30]. As a result, older people might have fewer resources available to manage their illness than younger people and will subsequently have a higher need for self-management support. However, the need for self-management support also depends on the appraisal of the stressor. If chronically ill people do not perceive their chronic illness as a

threat and they do not think that their behaviour can influence their course of illness, it will be unlikely that they need support with self-management. As we stated above, we expect that older people are less likely to perceive their illness as a threat and belief in their personal control if they have a similar physical condition as younger people, and therefore it will also be possible that older people have a lower need for support with self-management. Because these two trends are contradictory, we expect that overall the support needs do not differ that much between younger and older chronically ill people when they have similar physical symptoms.

Hypotheses:

4. Older chronically ill people have less resources to manage their chronic illness than younger chronically ill people.
5. Older people do not have a higher need for self-management support than younger people with a similar physical condition, as older people have less resources to manage their illness, but younger people higher appraisal of the stressor due to higher perceived threat of the chronic illness and belief in personal control.

Methods

Study sample

The sample of the study consisted of members of the National Panel of people with Chronic illness or Disability (NPCD), a nationwide prospective panel-study on the consequences of chronic illness in the Netherlands [31]. Participants with chronic disease have been recruited from more than a hundred family practices (random samples of family practices drawn from the Dutch register of Family Practices [32]). As (almost) all people in the Netherlands are registered with a family physician and family physicians keep lifelong patient files, these practices form an excellent sampling frame. Patients were selected according to the following criteria: a diagnosis of a somatic chronic disease by a certified medical physician (family physician or medical specialist), aged 15, not being permanently institutionalized, being aware of the diagnosis, not being terminally ill (life expectancy > 6 months according to the family physician), being mentally able to participate, and

having sufficient mastery of the Dutch language. Five hundred new panel members are selected annually via the standardized procedure to replace panel members who withdrew or who had participated for the maximum term of four years. Panel members fill in self-report questionnaires at home twice a year, in April and October. NPCD is registered with the Dutch Data Protection Authority; all data is collected and handled in accordance with the privacy protection guidelines of the Authority.

Apart from medical data that had been provided by the family physicians of the panel members (with their permission), all data was derived from patient surveys. In April 2012, a survey with questions about self-management tasks and related needs for support, consequences of the chronic condition, personal control and income was sent to the panel members. A total of 1,688 people diagnosed with chronic diseases completed this questionnaire (response= 82%). In addition, we used data about health literacy from the questionnaire of April 2011. For the purpose of this study, we only included people aged 25 or older.

Measurement

Age-groups

We distinguish four age groups, namely 25-49, 50-64, 65-74 and 75 plus [33]. We decided to compare these four age groups, as we expected that the life context, perceived self-management tasks and related support needs might differ more according to stages of life rather than over single years.

Perceived self-management tasks and self-management support needs

To assess patients' perceived self-management tasks and related needs for support, we used the Patient Assessment of Self-management Tasks questionnaire (PAST) [14]. In accordance with the description of self-management activities by Bayliss et al. [7], the PAST distinguishes four types of self-management activities: 1) medical management (5 items), e.g. taking medication correctly or self-monitoring of symptoms; 2) communication with healthcare providers (4 items), e.g. understanding information given by healthcare providers and participating in decision-making; 3) coping with the consequences of the illness (5 items), e.g. coping with pain and an uncertain future; and 4) making lifestyle changes (4 items), e.g. exercising sufficiently or eating healthily. People with chronic illness indicate to what extent they feel

they need to perform several self-management tasks and to what extent they feel a need for support in these tasks on a 4-point scale ranging from 0 (never) to 3 (always). People who do not consider a specific self-management task are assumed to have no need for support in that task. The introduction to the questionnaire stated that 'support means not only help from a healthcare provider but also from family or friends'. The scales for self-management tasks and support needs were both constructed by summing the scores for the individual items belonging to the scale. Participants had to fill in at least three items per scale in order to get a scale score.

Physical condition

We used five indicators to measure the physical condition: type of chronic disease, the presence of more than one chronic disease (multi-morbidity), whether the health status is life-threatening or progressively deteriorating and the severity of physical limitations. The chronic diseases of participants were registered by their GPs using the International Classification of Primary Care [34]. In addition, the family physicians indicated to what extent the patient's health status was life-threatening and progressively deteriorating (two separate items answered on a 3-point scale: 1- to a great extent; 2- average; and 3- to a lesser extent). The severity of physical limitations was assessed by the SCP physical disability indicator [35], a self-reported questionnaire distinguishing four levels: none, mild, moderate and severe.

Consequences of chronic illness and personal control

To assess the threat chronically ill people feel for their well-being and their perception of control over their chronic illness, we used respectively the consequences and personal control scale of the Illness Perception Questionnaire (IPQ) developed by Weinman et al. [36]. Both scales consist of five items that could be answered on a five point scale. High scores on the consequences scale represent strongly held beliefs about the negative consequences of the illness on physical, social and psychological functioning, and high scores on the personal control scale represent positive beliefs about the controllability of the illness and a personal understanding of the condition.

Resources

We assessed three types of resources, namely having a partner, health literacy and income. We selected these variables, because these resources will probably differ according to age, and will influence the need for support with self-management. Having a partner was operationalized as living with spouse or partner. Health literacy was assessed using three brief screening questions (scored 0-4) with established validity for identifying people with limited and marginal health literacy skills [37]. The method of Fransen, Van Schaik, Twickler, and Essink-Bot [38] was used to categorize the sum scores as sufficient (> 2) or insufficient (≤ 2) health literacy. Income was defined as the sum of the monthly net incomes (regardless of source) of all household members, corrected for household composition. In order to be able to compare the net incomes of subjects with different household compositions, the total net income of the household was converted into an equivalent net income for a single person's household. This method is commonly used by Statistics Netherlands [39].

Statistical analyses

All hypotheses are based on the condition that younger and older chronically ill people have a similar physical condition. In reality, this is not the case. In this study, we strived to limit the effect of the physical condition by controlling for the five indicators of physical condition described above. This does, however, not mean that people actually have a similar physical condition.

First, descriptive analyses were performed to provide information on physical condition of the four age groups. Differences between the four age groups were tested by chi-squared tests. To examine whether younger chronically ill people perceive the threat of their chronic illness on their well-being (hypothesis 1) and their personal control greater (hypothesis 2) than older people with a similar physical condition, we performed two linear regression analyses with respectively perceived consequences and personal control as dependent variables and age as independent variable, while controlling for the five indicators of physical condition. We performed a chi-squared tests and an one-way ANOVA, followed by a Bonferroni post-hoc test, to examine whether older chronically ill people have less resources than younger chronically ill people (hypothesis 4).

Both hypothesis 3 and 5 consists of two aspects, namely; 1. whether self-management tasks or support needs would be higher, lower or similar between younger and older chronically ill people if they have a similar physical condition, and 2. an explanation why self-management tasks or support needs are higher, lower or similar. Therefore, we needed to perform several linear regression analyses to test both aspects of the hypotheses separately. In the first model, we tested the relation between age and self-management tasks or support needs. In the second model, we controlled for the physical condition in order to check if our first part of the hypotheses is correct. Next, we added variables to the models that can explain why self-management tasks or support needs are higher, lower or similar between younger and older chronically ill people. For self-management tasks, we added perceived consequences and personal control to the model. For self-management support needs, we added perceived consequences, personal control and resources to the model. As we expected that adding perceived consequences and personal control to have a different effect on the relation between age and support needs than resources, we first added perceived consequences and personal control to the model, before we added resources. All analyses were performed using Stata 13.0.

Results

Life context according to age

Younger people are more often diagnosed with asthma, gastrointestinal and neurological diseases, whereas older people are more often diagnosed with COPD, cardiovascular disease, diabetes and musculoskeletal disorders (Table 1). The older people are, the higher the percentage of people with multi-morbidity and severe physical limitations, and the more often the health status is considered by their GP as life-threatening or progressively deteriorating. This indicates that the severity of the physical condition increases with age.

Table 2 shows that chronically ill people older than 65 years perceive less consequences of their chronic conditions on their physical, social and psychological functioning than chronically ill people in the age-group 25-49 years, while controlling for their physical condition. Chronically ill people

who are 75 or older also perceive their personal control over their chronic condition worse than chronically ill people in the youngest age-group. This indicates that the threat of being chronically ill as well as the belief that their behaviour can influence the impact of the chronic illness is greater for younger chronically ill people than older chronically ill people if we control for physical condition.

The percentage of people having a partner was quite similar for the first three age groups (between 76% and 77%), but substantially lower for people who were 75 or older (62%). Almost all participants had a high level of health literacy, but the level of health literacy was more likely to be insufficient in the older age groups. Income did not significantly differ between the four age groups. Overall, table 2 shows that resources are especially lower in the oldest age group compared to the youngest age-group.

Table 1: Differences in pathology of chronic condition according to age-group

	Four age groups				p-value
	25-49 (n=310)	50-64 (n=559)	65-74 (n=468)	75+ (n=316)	
Physical condition					
Type of chronic disease					
Cardiovascular disease	2%	16%	26%	33%	<.001
Asthma	31%	13%	8%	8%	<.001
COPD	3%	14%	15%	23%	<.001
Musculoskeletal disorder	5%	18%	18%	21%	<.001
Cancer	2%	6%	8%	9%	<.001
Diabetes mellitus	5%	14%	19%	18%	<.001
Neurological disease	12%	8%	6%	3%	<.001
Gastrointestinal disease	10%	5%	4%	4%	<.001
Other chronic disease	38%	23%	22%	21%	<.001
Multi-morbidity present	29%	44%	54%	65%	<.001
Life-threatening					
To a lesser extent	89%	78%	76%	72%	<.001
Neutral	10%	15%	20%	25%	
To a greater extent	1%	7%	4%	4%	
Progressive deterioration					
To a lesser extent	77%	60%	55%	48%	<.001
Neutral	19%	28%	34%	39%	
To a greater extent	5%	13%	11%	12%	
Physical limitations					
No limitations	64%	40%	44%	19%	<.001
Slight limitations	22%	28%	31%	34%	
Moderate limitations	12%	25%	17%	34%	
Severe limitations	2%	7%	9%	14%	
Resources					
Having a partner	76%	77%	77%	62%	<.001
Health literacy	98%	93%	93%	90%	<.001
Income	1528.5	1483.6	1557.2	1488.1	n.s.

Table 2: Linear regression analyses assessing the relation between age and the consequences of the chronic illness on functioning and age and personal control of chronic illness, controlling for physical condition.

	Consequences (n=1443)	Personal control (n=1442)
25-49 years	ref.	ref.
50-64 years	-.03	-.05
65-74 years	-.09 **	-.07
75 years and older	-.21 **	-.08 *

* Significant at $p < .05$ ** Significant at $p < .01$.

Self-management tasks

As chronically ill people age, they perceive more self-management tasks necessary (Model 1; Table 3). The second model in Table 3 shows that controlling for the physical condition, reduces the effect of age on perceived self-management tasks for medical management, communication with healthcare providers and making lifestyle changes, and even reversed the effect for coping, although this effect was not significant. This suggests that older people perceive more self-management tasks as part of their daily self-management because they have a more severe physical condition.

The final model shows that the perceived consequences of being chronically ill have a positive association with self-management tasks, indicating that when people experience more consequences of their chronic illness they will perceive more tasks as part of their daily management. The association between perceived personal control and self-management tasks differs per domain. Personal control is positively associated with medical management and making lifestyle changes, while it is negatively associated with coping. When adding the perceived consequences of being chronically ill and personal control, differences between the oldest and the youngest age-group became bigger again. This indicates that the perceived consequences of being chronically ill and personal control temper the relation between age and self-management tasks.

Table 3: Linear regression analyses assessing the relation between age and self-management tasks.

	Self-management tasks			
	Medical management (n=1424)	Communication (n=1419)	Coping (n=1421)	Lifestyle (n=1417)
Model 1				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.14 **	.09 **	.13 **	.08 *
65-74 years	.19 **	.12 **	.06	.10 **
75 years and older	.24 **	.25 **	.17 **	.16 **
Model 2 (controlling for physical condition)				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.05	-.03	-.01	.03
65-74 years	.09 *	.02	-.04	.04
75 years and older	.10 **	.08 *	-.05	.08 *
Model 3 (controlling for physical condition)				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.06	-.01	.00	.04
65-74 years	.13 **	.05	.00	.07
75 years and older	.17 **	.15 **	.05	.13 **
Consequences	.29 **	.35 **	.51 **	.18 **
Personal control	.09 **	.01	-.05 **	.14 **

* Significant at $p < .05$ ** Significant at $p < .01$.

Self-management support needs

The relation between age and the need for self-management support differ between the four types of self-management tasks (Model 1; Table 5). The older chronically ill people are, the more likely it is that they need support with their self-management regarding medical management and communication with healthcare providers. Chronically ill people in the age groups 50-64 and 75 or older also have a higher need for support regarding coping with the consequences of being chronically ill than the youngest age group. Interestingly, there are no significant differences in support needs between the chronically ill people within the age of 25 and 49 and chronically ill people within the age of 65 and 74. Moreover, there are no differences in the need for support with making lifestyle changes between the four age groups.

The second model shows that the effect of age on self-management support needs diminishes, when we control for the physical condition. The effect of

age on support needs regarding making lifestyle changes even reverses. This indicates that older chronically ill people need more support due to a more severe physical condition.

The third model shows that the more people believe that their illness has negative consequences for their well-being, the more likely it is that they will need support with these tasks. Chronically ill people's belief in their personal control was only positively related to the need for support with making lifestyle changes. Adding perceived consequences and personal control to the model increases age-related differences in self-management support needs, especially for the oldest age group. This indicates that the perceived consequences of being chronically ill and personal control also temper the relation between age and self-management support needs.

The final model shows that having an adequate level of health literacy has a negative effect on the need for self-management support. Income only has a negative effect on the support needs regarding medical management and having a partner has no effect on self-management support needs in all four domains. Adding resources to the model barely changes the relation between age and support needs.

Table 4: Linear regression analyses assessing the relation between age and self-management support needs.

	Self-management support needs			
	Medical management (n=949)	Communication (n=932)	Coping (n=961)	Lifestyle (n=911)
Model 1				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.13 **	.13 **	.08 *	.02
65-74 years	.15 **	.15 **	.04	-.03
75 years and older	.20 **	.26 **	.12 **	.04
Model 2 (controlling for physical condition)				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.06	.04	-.02	-.07
65-74 years	.11 *	.09 *	-.01	-.10 *
75 years and older	.11 *	.14 **	-.01	-.09 *
Model 3 (controlling for physical condition)				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.07	.05	-.01	-.06
65-74 years	.12 **	.12 **	.02	-.08
75 years and older	.15 **	.19 **	.05	-.05
Consequences	.26 **	.31 **	.40 **	.25 **
Personal control	.03	.02	-.04	.07 *
Model 4 (controlling for physical condition)				
25-49 years	ref.	ref.	ref.	ref.
50-64 years	.05	.04	-.01	-.06
65-74 years	.12 **	.11 **	.03	-.08
75 years and older	.14 **	.18 **	.06	-.04
Consequences	.26 **	.31 **	.40 **	.25 **
Personal control	.03	.01	-.04	.07 *
Having a partner	.03	.01	-.05	-.05
Health literacy	-.14 **	-.18 **	-.13 **	-.10 **
Income	-.02	.01	-.02	-.01

* Significant at $p < .05$ ** Significant at $p < .01$.

Discussion

Overall, the older chronically ill people are, the more self-management tasks they perceive as part of their daily management and the more likely it is that they need support with these tasks, due to a more severe physical condition.

Chances to have more than one chronic condition, severe physical limitations, and a life-threatening or progressively deteriorating health status increase with age. Other studies also showed that older people have more difficulty managing their chronic illness [14-16]. However, the relationship between age and self-management tasks and related support needs is not as strong as one might expect based on the differences in physical condition. The reason for this is that there are also some contradictive trends that temper the effect of age on self-management tasks and support needs. This study shows that age-related differences in self-management tasks and support needs also depend on the meaning that the chronic illness has for chronically ill people depending on their personal life context.

First of all, younger chronically ill people perceive the threat of their chronic illness on their well-being greater than older chronically ill people when we control for physical condition, which is in line with our first hypothesis. This indicates that being chronically ill might be more disruptive and harder to accept for younger people than for older people. Research of Gignac et al. [19] showed that younger participants with osteoarthritis reported more distress and frustrations managing the disease, because having this disease did not fit with their identity of being young and was viewed as more disruptive for future plans. This finding is also in line with the theory of Bury [24] that chronic illness can be seen as a biographical disruption.

Secondly, younger people with chronic illness also have a stronger belief that their behaviour can affect the impact of their chronic condition. This finding confirms our second hypothesis. Especially, people of 75 and older are less convinced that they can influence the impact of their chronic condition with their behaviour. This is in line with previous studies that showed a positive relation between age and personal control [25]. If people are not convinced that their behaviour can affect the impact of their chronic illness, they will be less likely to actually perform self-management tasks.

Thirdly, resources are lower among older people than younger people. Although, the differences are small between the four age groups. Only chronically ill people, who were 75 or older, were more likely to have an inadequate level of health literacy and to have no partner to help them with the management of their chronic illness. Income did not differ according to age. The age-related differences in resources are smaller than expected (hypothesis 4) and smaller compared to the existing literature [26-30]. This

might be related to methodological differences in how we measured the resources and age (as categorical variable instead of continuous).

As mentioned at the beginning of the discussion, older people perceive more self-management tasks for themselves than younger people, due to a more severe physical condition. When we controlled for the physical condition, the effect of age on perceived self-management tasks did become smaller. However, the influence of the physical condition was not strong enough to reverse the relation between age and self-management tasks, as we expected in the third hypothesis. The relation between age and perceived self-management tasks is however tempered by the fact that younger people perceive the threat of their chronic illness as more severe and their level of personal control higher. Therefore our third hypothesis is partly confirmed.

In addition, older chronically ill people are also more likely to need support with self-management, due to a more severe physical condition. Differences in self-management support needs between the age groups were small when we controlled for physical condition, which is in line with our final hypothesis. However, our assumed explanation why the support needs would be similar across age groups was not completely in line with our findings. Personal control and resources barely explained age-related differences in support needs. Personal control only had a positive effect on the need for making lifestyle changes, and the only resource that was associated with self-management support needs was health literacy. However, the perceived threat of the chronic illness on their well-being did temper the relation between age and self-management support needs, indicating that the differences between older and younger chronically ill people would be bigger if their perceived threat of the chronic illness on their well-being were similar.

Interestingly, the effect of age on self-management tasks and related support needs as well as the mediating effect of consequences, personal control and resources differed for the four domains of self-management. This suggests that the reasons why chronically ill people need support with their self-management not only depend on their personal life context, but also on the type of self-management activities they need to perform. These different effects might also explain why findings of other studies on the relationship between age and the need for support with self-management were contradictory.

Strengths, limitations and further research

To the best of our knowledge, this is the first study that explores age-related differences in self-management support needs according to people's life context. The use of data from a nationwide representative sample of chronically ill people provides unique insights into the perceptions of people with chronic illness. Another strength of this study is that it showed that age-related differences in self-management tasks and support needs are complicated to explain and that there is more to it than just the differences in physical condition.

One limitation of our study is that we could not include social support in this study. Having a partner can be an indicator of social support as the partner is one of the most important people to give social support. However, having a partner does not automatically mean that chronically ill people receive social support. Further research should examine the effect of social support on the need for support. Another limitation of this study is that it only gives us scant information on how self-management support needs arises and why some people need support while others do not. Even though we have taken a lot of factors into account, the reality of daily life is too complex and complicated to cover in full. In addition, it was not possible to fulfil the condition that younger and older people with chronic illness have a similar physical condition. In this study, we could only limit the effect of the five indicators of physical condition. Furthermore, the study was cross-sectional which makes it difficult to determine causality. Further research should use a longitudinal perspective in order to comprehend age-related differences in self-management tasks and related support needs.

Conclusion

This study shows that the life context has an important contribution to physical condition in explaining age-related differences in self-management tasks and related support needs. How chronically ill people perceive the impact of their chronic illness as well as their ability to manage their illness, differs according to age. The results of this study confirm that there is a need for tailored interventions, which take the individual life context into account. For instance, interventions for younger people might focus more on coping

with the consequences of having a chronic illness, while interventions for older people might focus more gaining personal control. Healthcare providers should be aware that the reason why chronically ill people need support might differ according to age.

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5

Do everyday problems of people with chronic illness interfere with their disease management?

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ABSTRACT

Background:

Being chronically ill is a continuous process of balancing the demands of the illness and the demands of everyday life. Understanding how everyday life affects self-management might help to provide better professional support. However, little attention has been paid to the influence of everyday life on self-management. The purpose of this study is to examine to what extent problems in everyday life interfere with the self-management of people with chronic illness, i.e. their knowledge and ability to manage their disease.

Methods:

To estimate the effects of having everyday problems on self-management, cross-sectional linear regression analyses with propensity score matching were conducted. Data was used from 1,731 patients with chronic disease(s) who participated in a nationwide Dutch panel-study.

Results:

One third of people with chronic illness encounter basic (e.g. financial, housing, employment) or social (e.g. partner, children, sexual or leisure) problems in their daily life. Younger people, people with poor health and people with physical limitations are more likely to have everyday problems. Experiencing basic problems is related to less active coping behaviour, while experiencing social problems is related to lower levels of symptom management and less active coping behaviour.

Conclusions:

The extent of everyday problems interfering with self-management of people with chronic illness depends on the type of everyday problems encountered, as well as on the type of self-management activities at stake. Healthcare providers should pay attention to the life context of people with chronic illness during consultations, as patients' ability to manage their disease is related to it.

Introduction

Background

Self-management of (chronic) diseases by patients has been promoted by healthcare providers and policymakers in many Western societies as a cornerstone of modern healthcare [1]. Self-management requires people with chronic illness to monitor their health status, take medication as prescribed, interact with healthcare providers and manage the impact of the illness on physical, psychological and social functioning [2]. However, people with chronic conditions often find it difficult to perform effective self-management [3], as indicated by e.g. low rates of medication adherence [4,5], poor levels of disease control [6], and the modest positive effects of self-management interventions [7,8].

Previous studies have shown that people with chronic illness experience tension between managing and controlling their chronic illness while being able to do what they would like to do with their lives [9-11]. As Corbin and Strauss state (1985), the ideal context for self-management would be a controlled environment in which influences of everyday life are minimised [12]. However, in reality, people with chronic illness need to consistently balance the demands of the illness against those of everyday life, as the lives of people do not solely consist of taking care of their chronic illness. People with chronic illness have jobs, partners, children, friends, and hobbies, and experience the delights and concerns that come with them. Moreover, due to their illness they may encounter additional problems in daily life, for instance problems related to living independently (e.g. housing, finances). These problems might be partly the consequence of having a chronic disease, but they might also influence the way people manage their disease.

The Social Production Function theory of Lindenberg and colleagues [13-15] states that people produce well-being by achieving goals, within the set of resources and constraints they face. Based on this theory, we argue that people with chronic illness need to prioritise their goals and decide where their resources such as time, energy, money and social support will go. Facing, for instance, financial, marital or housing problems, people may prioritise coping with these problems as more important than managing their chronic disease. Solving everyday problems requires resources, which can then no longer be used to manage the chronic illness. For example, research of

Townsend *et al.* (2006) indicated that people with chronic conditions sometimes gave priority to maintaining a 'normal' life at the expense of controlling symptoms [11].

"The process of self-management could be eased if the particular circumstances and the broader context in which it takes place are addressed by practitioners" [11]. Understanding how everyday life affects self-management might help to provide better support. Most research, however, focuses on how chronic illness complicates maintaining a normal life. Until now, little attention has been paid to the opposite, namely how everyday life influences the level of self-management of people with a chronic condition. Therefore, the purpose of this study is to examine to what extent problems in everyday life intervene with the level of self-management of people with chronic illness.

Hypotheses

To guide our research, we formulated the following hypotheses:

1. **Recognising and managing symptoms** of a chronic condition requires time and energy. Examples of symptom management are monitoring of glucose level or blood pressure when you have diabetes or cardiovascular diseases, controlling shortness of breath when you have asthma or COPD, or doing exercises to maintain flexible when you have arthritis. We expect that symptom management will be neglected when people have everyday problems that also require their attention. We therefore hypothesise that *experiencing problems in everyday life will be negatively associated with the level of daily symptom management of people with chronic illness.*
2. Being **actively involved in the treatment** of the illness by adhering to treatment regimens, visiting healthcare providers and participating in decision-making will also require time and energy from people with chronic illness. However, these self-management tasks are more likely to be performed within a medical context, in close collaboration with healthcare professionals. Therefore, we expect that the effect of everyday problems on patients' active involvement in the treatment will be limited. In effect, we hypothesise that *experiencing problems in everyday life will be negatively associated with the level of active involvement in treatment of people with chronic illness, but to a lesser extent than their symptom monitoring and management.*

3. Dealing with the consequences of having a chronic illness on physical, emotional and social wellbeing (**coping**) may be particularly complicated when people also have other problems. We expect that this aspect of self-management will be influenced most, as there are many similarities between having to deal with everyday problems and coping with chronic illness. We therefore hypothesise that *experiencing problems in everyday life will be negatively associated with the coping behaviour of people with chronic illness.*

Methods

Study sample

The sample of the present study consisted of members of the National Panel of people with Chronic illness or Disability (NPCD), a nationwide prospective panel-study on the consequences of chronic illness in the Netherlands [16]. For this study, we only included the participants with chronic illness. Participants with chronic illness were recruited from more than a hundred general practices (random samples of general practices drawn from the Dutch registration of General Practices [17]). These panel members were selected according to the following criteria diagnosed with a somatic chronic disease by a certified medical practitioner, aged 15, not permanently institutionalised, aware of the diagnosis, not terminally ill (life expectancy > 6 months according to the general practitioner), mentally capable to participate, and sufficiently proficient in Dutch. Potential panel members received an information letter about the panel and were asked to fill in a reply form whether or not they want to join the panel. If they were interested, they received a questionnaire on their demographic characteristics. When that questionnaire was returned, they were considered members of the panel. Annually, 500 new panel members were selected via the standardised procedure to replace panel members who withdrew or who had participated for the maximum term of four years. NPCD is registered with the Dutch Data Protection Authority; all data were collected and handled in accordance with the privacy protection guidelines of the Authority.

At inclusion, NPCD participants received a questionnaire on their socio-demographic characteristics. In addition, general practitioners (GP) provided

(with patients' permission) medical information about the panel members (chronic diseases diagnosed, dates of diagnoses, health status etc.). In April 2013, a questionnaire about self-management, everyday life problems and perceived general health was sent to the panel members. A total of 1,731 patients diagnosed with a chronic disease completed this questionnaire (response= 80%).

Operationalisation

Self-management

We used the Dutch version of the Partners in Health Scale (PIH-Dutch) to measure patients' self-management knowledge and behaviour. This scale was originally developed as part of the 'Flinders Program of Chronic Care Self-Management [18,19]. The PIH-Dutch scale consists of 12 items, which were answered on a scale ranging from 0 'low self-management' to 8 'high self-management'. Examples of items are: 'I have the ability to take action when my symptoms get worse', 'I have the ability to arrange appointments as recommended by my healthcare provider' and 'I have the ability to manage the impact of the condition on my social life'. As the first answering options of the original scale were all at a very close distance from each other resulting in a distribution very skewed to the right, we recoded the lower scores (0-3=0, 4-5=1, 6=2, 7=3 and 8=4). Four components of self-management were distinguished, namely knowledge (2 items; knowledge about disease and treatment), recognition and management of symptoms (2 items; monitor symptoms and act when symptoms worsen), active involvement in treatment (4 items; taking medications as prescribed, attend appointments, shared decision-making) and coping with consequences (4 items; dealing with effects on physical, emotional and social wellbeing and progress towards healthy life). As we focused in this study solely on self-management behaviour, we did not include the knowledge scale. Scale scores were computed by dividing the sum of respondents' item scores by the number of items filled in, and range from 0 to 4, with higher scores indicating better self-management.

Everyday problems

To assess everyday problems we used the biographical list of problems (BIOPRO), developed by Hosman (1983) [20]. In this questionnaire, respondents were asked to indicate whether or not they have recently (no

specific time frame given) encountered any of the following problems: financial, housing, employment, with partner, with children, with other people, sexual, with leisure time. Based on an exploratory factor analysis using principal component extraction with varimax rotation, we distinguished two types of problems, namely problems related to basic needs (financial, housing, employment) and problems related to social needs (partner, children, other people, sexual, leisure time). Based on this distinction, we constructed two dichotomous variables: basic problems and social problems (both scored into 0 'having no problems' and 1 'having problems').

Socio-demographic, illness and health status characteristics

In our study, we included the following socio-demographic characteristics of the participants: age, gender and highest level of education, classified as low (primary education, lower secondary and lower vocational education), intermediate (intermediate secondary and intermediate vocational education) and high (higher vocational education and university). In addition, we used data provided by their GPs: type of chronic disease(s) diagnosed (coded by means of the International Classification of Primary Care [21] and presence of more than one chronic disease (multi-morbidity). Patients' self-rated general health was measured by the general health scale of the RAND-36 Short Health Status Survey, ranging from 1 'poor health' to 100 'excellent health' [22]. Finally, the severity of physical limitations was assessed by the SCP physical disability indicator [23], a self-report questionnaire distinguishing four levels: none, mild, moderate and severe. This indicator assessed people's ability to perform different tasks and activities, such as the ability to walk for short period of time, walk for a longer period of time, do odd jobs around the house, read the newspaper, hear what is being said during conversations, etc.

Analyses

Descriptive analyses were performed to provide information about the characteristics of the study sample and to describe the everyday problems people with chronic illness encounter. To assess whether having basic or social everyday problems was related to the socio-demographic, illness and health status characteristics of people with chronic illness, we performed two multivariate logistic regression analyses (one with basic problems as

dependent variable and the other with social problems as the dependent variable).

Next, we assessed the relationship between having basic or social problems and level of self-management. The problem in assessing this relationship is that having basic or social problems is not exogenous. Personal and health characteristics are related to self-management and to having problems. This makes it difficult to estimate the relationship of having problems and self-management. In other words, there are confounding variables that might influence both the outcomes (in our study, level of self-management of people with chronic illness) and comparison groups (people having everyday problems versus those not having everyday problems). We used propensity score matching (PSM) to solve this problem as much as possible. The propensity score is a balancing score: conditional on the propensity score, the distribution of observed covariates will be similar between chronically ill people with and without everyday problems [24,25]. Models were adjusted for age, sex, education, comorbidity, perceived general health and physical limitations and we inspected the diagnostics for propensity score analysis (checking for balance in the covariates). PSM is one way of approaching the problem and has its own assumptions that are not perfectly met in our study. Our assumption was that given similar background characteristics having everyday problems (the 'treatment') or not (the 'controls') could be considered as randomly assigned. Therefore, we also conducted multivariate linear regression analyses as a sensitivity analysis of our findings in the propensity score matching. In addition, as we could not include an interaction effect in the PSM analysis between having basic and social problems on the level of self-management, we also conducted a multivariate linear regression analyses in which we included this interaction effect as well.

The panel members were originally selected from general practices, resulting in a hierarchical data structure. Since intra-class correlations showed hardly any clustering of self-management behaviour within general practices (mean 0.01), and the likelihood ratio test did not show that multilevel analyses had an advantage over ordinary regression analyses, single-level regression analyses were conducted. All analyses were performed using Stata 13.0.

Results

Description study sample

The mean age of the study sample was 61.8 years (SD 14.3) and fifty-four percent of the respondents were female. Cardiovascular disease (26%), COPD (22%) and asthma (20%) were the most common chronic diseases within the sample. Half of the study sample (48%) was diagnosed with more than one chronic (somatic) disease. The mean perceived health score of the study sample was 52.8, which is substantially lower than the mean score found in general population samples [26]. Forty-one percent of the respondents had no physical limitations, twenty-nine percent mild limitations, twenty-two percent moderate and eight percent severe limitations.

Problems in everyday life

A third (37%) of the respondents reported recently experiencing one or more problems in their everyday lives. Twenty percent of the study sample encountered basic problems and 28% social problems (Table 1). Only 11% of the respondents had basic problems as well as social problems. Sexual (14%) or financial (12%) problems were mentioned most often.

Table 1: Everyday problems of people with chronic illness

Everyday problems	n	%
No problems	1,087	63%
Basic problems	351	20%
<i>Finances</i>	208	12%
<i>Housing</i>	84	5%
<i>Work</i>	147	9%
Social problems	485	28%
<i>Leisure pursuit</i>	149	9%
<i>Partner</i>	129	8%
<i>Children</i>	89	8%
<i>Friends</i>	138	8%
<i>Sex</i>	238	14%

Both types of everyday problems were negatively associated with age and perceived health (Table 2). These associations indicate that the older people are, or the higher they rate their general health, the less likely it is that they encounter basic and social problems in their everyday life. In addition, respondents who experienced (mild, moderate or severe) physical limitations had significantly higher odds of having everyday problems than people who did not experience physical limitations, except for respondents with severe physical limitations regarding having basic problems.

Table 2: Multivariate logistic regression analyses testing the relation between everyday problems and socio-demographic, illness and health status characteristics (n=1501)

	Everyday problems	
	Basic problems	Social problems
	OR	OR
Socio-demographic characteristics		
Age	.95 **	.97 **
Female	.81	.78
Educational level		
Low	Ref.	Ref.
Intermediate	1.17	1.49 **
High	.90	1.38
Illness characteristics		
Type of disease(s)		
Cardiovascular disease	.81	.90
Asthma	1.08	1.12
COPD	.98	1.07
Musculoskeletal disorder	.69	1.05
Cancer	.79	1.24
Diabetes mellitus	1.00	1.00
Neurological disease	.90	1.05
Gastrointestinal disease	.85	.74
Other chronic disease	.81	1.01
Multi-morbidity	1.04	.99
Health status characteristics		
Perceived general health	.98 **	.98 **
Physical limitations		
No limitations	Ref.	Ref.
Slight limitations	2.05 **	1.98 **
Moderate limitations	2.31 **	2.53 **
Severe limitations	1.35	2.27 **

* Significant at $p < .05$ ** Significant at $p < .01$.

Everyday problems and self-management

Chronically ill people with basic or social problems reported lower levels of self-management than people who did not have everyday problems (Table 3 & Table 4). Adjusting for covariates reduced the differences between the two groups, although some differences remained significant. Regarding basic problems, there was no difference in symptom management (hypothesis 1) and active involvement in treatment (hypothesis 2) between people who have basic problems and people who do not have basic problems. However, people who experienced basic problems were less actively coping with the consequences of their illness than people who did not have those problems (hypothesis 3). Regarding social problems, people who experienced social problems had a lower level of symptom management (hypothesis 1) and were also less active in coping (hypothesis 3). There were no differences between people who had social problems and those who did not regarding symptom management (hypothesis 2).

The sensitivity analyses show similar results (Appendix 1 & 2). We also found that having both basic and social problems had an interaction effect on coping (Appendix 3). This indicates that the negative association of having basic or social problems with the level of coping was stronger when people had both basic and social problems. An interaction effect was not found for the other two domains of self-management.

Table 3: Mean level of self-management comparison between chronically ill people who have no basic problems and chronically ill people who have basic problems, unadjusted means versus PSM adjusted estimates *

	Unadjusted means (n)		Model-based (adjusted) estimates		
	No basic problems	Basic problems	Mean difference	95% CI	p-values
Self-management					
Symptom management	2.97 (1174)	2.91 (301)	.01	-.27 – .28	n.s.
Active involvement	3.37 (1182)	3.21 (299)	-.10	-.23 – .03	n.s.
Coping	2.78 (1183)	2.15 (303)	-.29	-.44 – -.15	0.000

* Models are adjusted for age, sex, education, comorbidity, perceived general health and physical limitations.

Table 4: Mean level of self-management comparison between chronically ill people who have no social problems and chronically ill people who have social problems, unadjusted means versus PSM adjusted estimates *

	Unadjusted means (n)		Model-based (adjusted) estimates		
	No social problems	Social problems	Mean difference	95% CI	p-values
Self-management					
Symptom management	3.01 (1053)	2.83 (422)	-.16	-.31 – -.02	0.026
Active involvement	3.36 (1059)	3.29 (422)	-.06	-.16 – .05	n.s.
Coping	2.86 (1062)	2.13 (424)	-.37	-.48 – -.25	0.000

* Models are adjusted for age, sex, education, comorbidity, perceived general health and physical limitations.

Discussion

Being chronically ill is not a ‘one moment stressful life event’, but a continuous process of balancing the demands of the illness and the demands of everyday life. The basic assumption of this study was that performing self-management activities is more complicated when people have basic and social problems in their everyday life. This study shows that having everyday problems is indeed related to lower levels of self-management. The effect of everyday problems on self-management depends on the type of problems people with chronic illness encounter on a daily basis, as well as on the type of self-management at stake.

One third of the people with chronic illness encounters basic or social problems in their everyday life. Interestingly, having everyday problems is negatively associated with age. Studies show that older adults’ lives are less stressful compared to the lives of middle-aged adults, as they report fewer daily stressors and their routines are less disrupted by stressors [27-29]. Furthermore, people with chronic illness are more likely to experience everyday problems when they have physical limitations and when they perceive their health as poor. This is not surprising as some everyday problems might be a direct consequence of having a chronic illness. For instance, people might have problems with their work because of a limited amount of energy due to the chronic disease.

In line with our first hypothesis, the level of recognition and management of symptoms was lower when people have social problems in their daily life. However, in contrast to what we expected, people who had basic problems, such as financial, housing or work problems, did not display a lower level of symptom management than people who did not have those problems. The reason why only social problems were associated with symptom management may be related to the nature of social problems. Having social problems could be a sign of a lack of social support. Studies have shown that good social support has a positive effect on self-management [30].

In contrast with our second hypothesis, having basic or social problems in everyday life did not have an (small) effect on the level of active involvement in the treatment, such as adhering to treatment regimens, visiting healthcare providers and participating in decision-making. Almost all respondents scored really high on this aspect of self-management, which might indicate that we only measured a basic level of active involvement. In addition, active involvement in treatment will be established in a medical context in close collaboration with healthcare professionals. Therefore, active involvement will not only depend on the patient, but also on the healthcare professional. This probably more easily activates a frame where managing the chronic condition in this respects gets priority.

Finally, we found that having basic and social problems was related to less coping with the consequences of having a chronic disease, such as dealing with the effects of being chronically ill on physical, emotional and social wellbeing. In line with our third hypothesis, coping (from all three self-management dimensions we assessed) appeared to be most affected by having everyday problems. In addition to their negative main effects, having both basic and social problems accumulated in an even lower level of coping. This is an important finding as it might explain why a person with a chronic illness is not able to accept the chronic illness or make the desired lifestyle changes.

Strengths, limitations and future research

A strength of this study is the use of data from a nationwide representative sample of people with chronic illness. This provides unique insights into the perceptions of people with chronic illnesses. In addition, this study is one of the first to examine the effect of everyday problems on the level of self-management of people with chronic illness. We did so by using PSM.

A limitation of this study is that its cross-sectional design means we cannot determine causality; PSM is only an approximation. We aimed to study whether and how everyday problems of people with chronic illness interfere with their self-management, but we cannot reject the reversed effect, namely that poor self-management of a chronic illness results in experiencing (more) everyday problems. We have tried to minimise the problem by using PSM. Another limitation is formed by the fact that we lacked information about the severity of the problems. People could have, for instance, minor financial problems (not being able to go on holiday) or major financial problems (struggling to get by each month). Despite this lack of information about the severity of the problems, we did find a negative association with the level of self-management. This negative association might have been even stronger if we could have included the severity of the problems people with chronic illness encounter.

Longitudinal studies are needed to establish whether and in what way everyday problems result in lower levels of self-management. Further research should examine more precisely which types of everyday problems have an effect on self-management and whether combinations of certain problems have an accumulating effect on self-management. Also, the theoretical idea that people set priorities in which problems to address, given their limited resources, and that these priorities are influenced by how they see their personal situation, needs more research.

Conclusion

It was already known that being chronically ill can be disruptive to people's daily life. However, this study shows that this effect might work both ways and that everyday problems of people with chronic illness interfere with their self-management. The effect of these problems on self-management depends on the type of problems people with chronic illness encounter on a daily basis as well as on the type of self-management at stake. Healthcare providers should therefore actively address the individual (social) circumstances of people with chronic illness and the broader context in which self-management of chronically ill people takes place. Seeing self-management as part of people's individual life context might help to understand the difficulties people with chronic illness might have with self-management and, in many cases, to subsequently resolve them.

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Appendix 1

Table: Linear regression analyses testing the effect of basic problems on self-management, controlling for socio-demographic, illness and health status characteristics

	Symptom management (n=1475) Coef.	Self-management Active involvement (n=1481) Coef.	Coping (n=1486) Coef.
Everyday problems			
Basic problems	-.05	-.11*	-.38**
Covariates			
Age	-.00	.01**	.01**
Female	.19**	.05	-.02
Educational level			
Low	Ref.	Ref.	Ref.
Intermediate	.02	.08	.06
High	-.02	.06	-.00
Multi-morbidity	.06	.07	-.01
Perceived general health	.00	.00	.02**
Physical limitations			
No limitations	Ref.	Ref.	Ref.
Slight limitations	-.08	-.01	-.26**
Moderate limitations	-.14	-.01	-.44**
Severe limitations	-.16	.04	-.74**

* Significant at $p < .05$ ** Significant at $p < .01$.

Appendix 2

Table: Linear regression analyses testing the effect of social problems on self-management, controlling for socio-demographic, illness and health status characteristics

	Self-management		
	Symptom management (n=1475) Coef.	Active involvement (n=1481) Coef.	Coping (n=1486) Coef.
Everyday problems			
Social problems	-.17**	-.04	-.42**
Covariates			
Age	-.00	.01**	.01**
Female	.18**	.06	-.02
Educational level			
Low	Ref.	Ref.	Ref.
Intermediate	.03	.08	.08
High	-.01	.06	.03
Multi-morbidity	.07	.07	-.00
Perceived general health	-.00	.00	.02**
Physical limitations			
No limitations	Ref.	Ref.	Ref.
Slight limitations	-.07	-.02	-.24**
Moderate limitations	-.12	-.02	-.41**
Severe limitations	-.13	.05	-.69**

* Significant at $p < .05$. ** Significant at $p < .01$.

Appendix 3

Table: Linear regression analyses testing the interaction effect of basic and social problems on self-management, controlling for socio-demographic, illness and health status characteristics

	Self-management		
	Symptom management (n=1475) Coef.	Active involvement (n=1481) Coef.	Coping (n=1486) Coef.
Everyday problems			
Basic problems	.00	-.14*	-.17*
Social problems	-.16*	-.03	-.29**
Interaction effect	-.02	.07	-.26*
Covariates			
Age	-.00	.01**	.01*
Female	.18**	.05	-.03
Educational level			
Low	Ref.	Ref.	Ref.
Intermediate	.03	.08	.09
High	-.01	.06	.02
Multi-morbidity	.07	.07	-.01
Perceived general health	-.00	.00	.02**
Physical limitations			
No limitations	Ref.	Ref.	Ref.
Slight limitations	-.07	-.01	-.23**
Moderate limitations	-.12	-.01	-.39**
Severe limitations	-.13	.05	-.69**

* Significant at $p < .05$. ** Significant at $p < .01$.

Illustration

Self-management and life context

Being chronically ill plays a role in all aspects of people's life. The life context will for some part determine to what extent a person is hampered by his or her illness or to what extent he or she experiences limitations due to illness. How people manage their disease might, therefore, depend on the stage of life they are in and related life context. Our previous studies showed that older, chronically ill people have higher needs for self-management support than younger people, as a result of their higher burden of illness and their diminished social roles (Chapter 4), and that having everyday problems is associated with less self-management activities (Chapter 5). In this section, we will illustrate these findings with the personal experiences of chronically ill people based on focus group sessions (more information about the focus group sessions and the analysis of the data can be found in Appendix).

Old versus young

The mean age of the participants of the focus group sessions was 65 years, but the range was very broad. The youngest participant was 35 years and the oldest 86 years. When talking about their chronic illness and their daily hassles, participants often mentioned their age as a reference point. For instance, they mentioned that they felt better or worse compared with someone of the same age. For people above a certain age, physical limitations are more acceptable or expected. What this age is differs between individuals. One participant referred to 'being over 60 years' as a starting point for physical decline, while another referred to 'being over 80 years'.

"The only problem is, you're young and you don't want to accept that."

"Like I already mentioned, I'm almost 81 and I still feel rather good. When you're over eighty it's this one day and that the next, and there have been times when I wanted to see the GP about one thing or another. So that's all part of it. But other than that, I just count my blessings every day."

"I'm 81, but mentally and physically I feel like I'm 65."

Work

The combination of having a job and being chronically ill can be complicated. The consequences of the chronic condition, such as a limited amount of energy, may interfere with chronically ill people's ability to work. As a result, some participants had to either reduce their working hours, stopped working completely, or went into early retirement due to their disease.

“And I'm often very tired when I go to work. I get home at 14:30, 14:45 and then I first have to rest. [...] Well, my energy is gone at that point.”

“It goes alright for a certain amount of time and then it emerges again, and then it's a bit more serious and it limits you in what you can and can't do. And then it's really hard to get up in the morning. The flexibility of your joints also becomes a problem, and that can sometimes restrict you in your job as well.”

“Currently on sickness benefits, but normally I work 38 hours a week.”

“The cardiologist told me: ‘Stop working now’. I was working for an insurance company. ‘Stop working now, otherwise you're not going to last very long’”.

“I have diabetes and arthrosis and that's why I've decided to retire early, because the arthrosis sometimes interfered with my work. Other than that I don't really have any complaints.”

In order to keep working, participants had to make arrangements with their employees and colleagues. These arrangements could vary from adjusting your workplace to making sure that there is someone to replace you when your illness deteriorates.

“Until my pension, I worked at a company which made sure that I had specially adapted furniture for when I was working behind my computer, they arranged everything really nicely.”

“Well, I’ve made some arrangements with my employer. And he always says to me: ‘if you don’t feel well, just go home’. I just go home whenever things are not going well and there are people to support me, someone who will just replace me if I’m not there, and that helps me to keep working as much as possible. And I’m very grateful for that.”

“Yes, I’ve always continued working. Well, I’m next to the window. My colleagues are often cold, ‘but we do have to open the window for a bit.’ Fresh air will do us all good.”

Some participants have experienced that legislation and regulations can make it (more) difficult to continue working due to their chronic disease.

“I have my own company, and I’ve had it for a long time, and I always feel like society is my biggest enemy when it comes to running it. You can’t get insured, banks refuse to give you any money, those kind of things. To me that’s a blatant form of social humiliation, really.”

“And the hospital is willing to cooperate, my employer wants to cooperate, but the UWV (Social Services) doesn’t. They simply say: ‘Based on current laws, sir, you’re just half a percent off. Too bad, sir!’ They don’t even consider the importance of them being able to help someone get back to work.”

Being able to work seems to be an important aspect of participants’ lives. Especially, younger participants did their best to keep working despite their physical limitations. Many participants who were not able to continue their paid job or who were retired, did volunteer work. Working as a volunteer seems to be a way for the participants to remain involved and active, and to contribute to society.

“Well, you only have one goal, really. And as you just said, I was only 21 at the time, and still fighting it, and you really want to work, but on the other hand. I mean, there’s moments when you do feel good. Good enough to work, that is.”

“I’ve stopped working, have started to do a lot of volunteer work [...] And

you can draw so much strength from.. I mean, when you're not working anymore... at first it's not easy, but if you start volunteering, you really start to draw strength from being around other people. It really gives you positive energy. It's such a relief, really."

Family

Many participants indicated that having a chronic condition is not only a burden to them, but also to their family, i.e. partner and children. During all three focus groups sessions, participants expressed their worries about their close relatives. First of all, they are concerned about the emotional impact of the disease. For instance, their family might need to cope with the fear of losing them, or they need to deal with changes in their personality due to the chronic illness. Moreover, participants worried about the heavy burden of caring for them. When they felt unable to manage their illness and life on their own, family members were the first to help them. However, this might be complicated, especially when help is needed structurally and not just occasionally, as partners and children are often busy themselves.

"I feel that, if you have a disability or an illness and you're married or in a relationship, then you both have it. For me, it's of prime importance that you can rely on each other. And if your partner is in good health, you're very lucky. Otherwise, it will be a problem, obviously."

"I've realised that being ill...for me, it's not such a big deal. It's a lot worse for those around you. I just think: 'make the most of it,' but those around me, who have, in my case, witnessed the accident [...] Well, they often say things, like 'are you sure you should be doing that?' Because I always try to do everything I did before."

"Well, just that there's someone there, in the hospital, who tells my family that I'm not the same person as I was when I entered the hospital. I've become this completely different person [...] I can't really tell them what's wrong with me, that's what's so shitty about it. You know you're not quite yourself anymore, but you can't explain what's wrong."

“In my direct environment, I experience things such as that my wife has to care both for me and her mother, who’s still alive but lives in Limburg almost 200 km away. She fell, broke her hip, and then that’s so much extra stress for my wife, because she also has to visit her.”

Combination of problems

When talking about living with a chronic illness, it became clear that being chronically ill not only involves dealing with illness in the medical context. Participants had to deal with a whole range of related problems and challenges. For instance, they needed to deal with all sorts of regulations and legislations in order to keep living independently, to keep their work or to receive disability benefits. All these things together can accumulate in quite a high burden.

“Well, it can be difficult in general, because it’s not just about the medical sector. You have to deal with all sorts of different authorities; an insurance company, or other things. And then it all piles up really quickly, because there’s always so many forms to hand in, and to fill in. And they never agree with you, so you always have to do more work than you’d hoped for. And all those things just pile up and that’s very taxing.”

Furthermore, people might also have other problems in their lives. Sometimes these problems are directly caused by the chronic illness, but this is not always the case. For instance, one participant explained that it was more complicated for him to contract professional support since his divorce. Even though these problems might not be caused by the illness, they can interfere with chronically ill people’s self-management, as time, energy and money need to be spent on solving personal problems. Moreover, problems are sometimes intertwined, which complicates determining causality: does one feel tired as a result of chronic disease or due to personal problems? Important to note is that participants did not directly talk about problems that were not considered illness-related.

“Yes, I could afford it when I was still working fulltime [...] I had the misfortune of getting divorced a few years ago. I really didn’t want that, but those things just happen. Anyway, this also included a financial divorce. So, financially, it’s a bit trickier at the moment. That’s why I’m still working.”

“I assume I feel a bit more tired, but that could also have something to do with my current home situation. My wife has autism, and ME and anxieties, and that requires a lot of support. Other than that, I like to live an active life, and that also costs a lot of energy. So, basically I’m not sure if feeling less energetic is related to my diabetes or not.”

Reflection

What it means to be chronically ill and what it will take to retain a ‘normal’ life differs per person, depending on the individual situation and course of life. For younger people, being chronically ill might be harder to accept. The chronic illness does not tally with their self-image as a young and active person. Older people seem less disturbed by their chronic illness, as many consider it a part of aging. This finding is in line with Bury’s notion of chronic illness as a biographical disruption (Bury, 1982). This theory states that the meaning people give to their chronic condition depends on how it interferes with their individual’s image of the self and their social identity. In the case of young people, chronic illness is more of a threat to their social identity compared to older people, and therefore harder to accept.

Having a chronic illness affects the work situation of chronically ill people. Some might not even be able to work due to their chronic illness, others might need to make arrangements to keep on working. Either way, being chronically ill is not something that can be glossed over when having paid work. The same goes for family. Chronic illness also has a deep impact on their lives as they can be concerned about the effects of illness on their ill relative, or because they have to take care of their ill family member.

Finally, this illustration shows that chronically ill people often have more problems in their lives than their chronic illness alone, such as being divorced, having a spouse with health problems, or having financial problems. It is important for healthcare providers to be aware of chronically ill people’s everyday problems and daily hassles as they also influence their disease management. These problems might explain why a person with a chronic

illness is not able to make the desired lifestyle changes or to accept the chronic illness. Seeing difficulties with self-management as part of patients' individual life context might help to understand these difficulties and, in many cases, to subsequently resolve them.

6

Perceived quality of chronic illness care is associated with self-management: results of a nationwide study in the Netherlands

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^a Author contribution: LvH, MR and PG designed research; LvH and MH collected data; LvH and MR planned the data analysis; LvH performed data analysis; LvH wrote the paper with input from MR, MH and PG.

ABSTRACT

Background: Healthcare providers are increasingly expected to help chronically ill patients understand their own central role in managing their illness. The aim of this study was to determine whether experiencing high-quality chronic illness care and having a nurse involved in their care relate to chronically ill people's self-management.

Methods: Survey data from 699 people diagnosed with chronic diseases who participated in a nationwide Dutch panel-study were analysed using linear regression analysis, to estimate the association between chronic illness care and various aspects of patients' self-management, while controlling for their socio-demographic and illness characteristics.

Results: Chronically ill patients reported that the care they received was of high quality to some extent. Patients who had contact with a practice nurse or specialised nurse perceived the quality of the care they received as better than patients who only had contact with a GP or medical specialist. Patients' perceptions of the quality of care were positively related to all aspects of their self-management, whereas contact with a practice nurse or specialised nurse in itself was not.

Conclusion: Chronically ill patients who have the experience to receive high-quality chronic illness care that focuses on patient activation, decision support, goal setting, problem solving, and coordination of care are better self-managers. Having a nurse involved in their care seems to be positively valued by chronically ill patients, but does not automatically imply better self-management.

Introduction

Nowadays, self-management by patients (and their families) is recognised as an essential part of chronic illness care [1-4]. Self-management is defined as the individual's ability to deal with everything a chronic illness entails [5]. This includes managing symptoms, treating the condition, making lifestyle changes and coping with the physical and psychosocial consequences of having a chronic condition [5,6]. The aim of self-management is to minimise the impact of the chronic disease and maintain a satisfactory quality of life [7,8]. Given the comprehensive nature of their condition, it is not surprising that many patients find it difficult to achieve optimal self-management [9,10]. Healthcare providers are therefore increasingly expected to help patients understand their own central role in managing their illness, make informed choices and engage in healthy behaviour [5,11].

Historically, Western healthcare systems are built on an acute, episodic model of care, which does not suit the comprehensive needs of the chronically ill [6]. Consequently, there has been a move away from models of care in which the healthcare provider is seen as the main actor and the patient as a passive recipient, towards models in which the patient is ascribed a more active role and healthcare providers and patients are considered equally important partners in chronic illness management [12-14]. In accordance with the Chronic Care Model, high-quality chronic illness care can be defined as a patient-centred collaborative approach to care [15], and is characterised by collaborative goal setting, support for self-management, optimisation of therapy, and intensive follow-up [16].

In the Chronic Care Model, the delivery of care by a multidisciplinary care team is considered an important element of high-quality care [17]: patients might benefit from the varied skills and knowledge of the different professionals involved in their care. In many countries, such as the UK, Sweden, Finland, Australia, New Zealand and the Netherlands, nurses have become important actors in the care for patients with chronic illness, as most doctors have neither the training nor the time to engage in behaviour change counselling or to give self-management support [17,18]. Generally, doctors (general practitioners or medical specialists) focus on the process of diagnosing and initiating medical treatment, whereas practice nurses and specialised nurses provide education, monitor treatment outcome, support

behaviour change and coordinate active follow-up [18,19]. Several studies indicate that nurses' involvement leads to improved quality of chronic illness care and improved patient outcomes [20-23].

According to the Chronic Care Model, receiving high-quality chronic illness care should enable patients to actively contribute to (decisions regarding) their care and take actions that result in optimal health and quality of life outcomes. Research has shown that several elements of high-quality chronic illness care, such as patient-centred communication [24], self-management support [25], regular follow-up and collaborative decision making [26], are associated with e.g. greater patient satisfaction, improved health status and increased care efficiency. However, the relationship between (patient-perceived) quality of chronic illness care and patients' self-management is less clear. The limited number of studies that have examined this relationship used a narrow definition of self-management, focusing solely on aspects of medical management and self-care [27,28]. One study found a positive association between high quality chronic illness care and patient activation which is a condition for good self-manage [29]. The effects on coping with the psychosocial consequences of chronic illness in daily life, however, have hardly been studied. This is striking, as findings of Elissen *et al.* [30] show that self-management support provided by healthcare providers tends to focus mainly on medical and behaviour management and less on helping patients deal with the emotional consequences of being chronically ill.

Research focus and context

Considering the important role of the organization of care as illustrated by the Chronic Care Model for chronically ill patients' behaviour and outcomes, we decided to study the relationships between the perceived quality and the involvement of nurses in the care of chronically ill patients in the Netherlands and their self-management. In the Dutch healthcare system, general practitioners (GPs) function as 'gatekeepers', which means that access to medical specialists and hospital care requires a referral from a GP. Practice nurses and specialised nurses have been introduced to reduce the workload of GPs and medical specialists as well as to improve the quality of chronic illness care [17, 31]. In 2008, the Dutch government aimed to stimulate the improvement of the quality of care for patients with chronic conditions by adopting a nationwide chronic disease management approach [32]. This

approach included the delivery of well-coordinated care and support by multidisciplinary care teams embedded in primary care, a central role for self-management by the patient and strengthening of the link between prevention and cure [33], with nationally developed care standards being the main instrument for implementation of this policy [34]. Care standards have been developed and regional care programmes based on these care standards have been implemented for several chronic diseases, starting with diabetes mellitus, COPD and cardiovascular disease. Currently, more care standards have become available, but given their disease-specific nature and the complexity of the delivery and (separate) financing systems of healthcare and social care, chronic illness care in the Netherlands, as in other European countries, seems to be still fragmented[34], and issues of quality and efficiency remain high on the policy agenda.

Given the still actual and pregnant question on the quality of chronic illness care, we will begin our study by exploring the current status of chronic illness care in the Netherlands by examining chronically ill patients' perceptions of the quality of the care they receive and the involvement of nurses in their care. Next, as it is expected that the involvement of nurses contributes to a better quality of care [20,31], we will examine the relationship between nurse involvement and chronically ill patients' perceptions of receiving high-quality chronic illness care. Finally, we will examine the associations between the perceived quality of chronic illness care and nurse involvement on the one hand and aspects of chronically ill patients' self-management on the other.

We aim to answer the following research questions:

- How do chronically ill patients perceive the quality of the chronic illness care they receive, and to what extent are nurses (practice nurses or specialised nurses) involved in chronic illness care in the Netherlands, in addition to general practitioners and/or medical specialists?
- To what extent is the quality of chronic illness care as perceived by patients related to the involvement of a nurse in their care?
- To what extent does the perception of receiving high-quality care and the involvement of a nurse relate to chronically ill patients' self-management?

Methods

Study sample

The sample of the present study consisted of members of the National Panel of people with Chronic illness or Disability (NPCD), used in a nationwide prospective panel study on the consequences of chronic illness in the Netherlands [35]. Participants with chronic illnesses were recruited from more than a hundred general practices (random samples of general practices drawn from the Dutch register of General Practices [36]). These panel members were selected based on the following criteria: they were diagnosed with a somatic chronic disease by a certified medical practitioner, aged ≥ 15 , not permanently institutionalised, aware of the diagnosis, not terminally ill (life expectancy > 6 months according to the general practitioner), mentally capable of participating, and sufficiently proficient in Dutch. Annually, 500 new panel members are selected via the standardised procedure to replace panel members who have withdrawn or who have participated for the maximum term of four years. The NPCD is registered with the Dutch Data Protection Authority; all data is collected and handled in accordance with the privacy protection guidelines of the Authority.

On inclusion, NPCD participants received a questionnaire about their socio-demographic characteristics. In addition, GPs provided (with the patients' permission) medical information about the panel members. In October 2012, a questionnaire about experiences with chronic illness care and healthcare providers was sent to the panel members ($n=1,064$, response=85%) and in April 2013, a questionnaire about self-management ($n=1,227$, response=82%). A total of 699 participants filled in both questionnaires; they constituted the sample of this study. These participants were registered with 35 general practices from all over the country.

Operationalisation

Self-management

To cover a comprehensive range of aspects of self-management (in accordance with Bayliss [12]), we included two measuring instruments. The first was the Dutch version of the Partners in Health Scale (PIH-Dutch), which measures patients' self-management knowledge and behaviour. This PIH scale was originally developed as part of the 'Flinders Program of Chronic Care Self-

Management [37,38]. The PIH-Dutch scale consists of 12 items, which are answered on a nine-point scale with 0 indicating low self-management and 8 high self-management, and is divided into four scales, namely: knowledge, coping with consequences, recognition and management of symptoms, and active involvement in treatment [39]. Scale scores were computed by dividing the sum of participants' item scores by the number of items filled in, with higher scores indicating better self-management.

Since communication with healthcare providers as an aspect of self-management is not addressed sufficiently in the PIH-Dutch, we also included the short version of the Perceived Efficacy in Patient-Provider Interaction (PEPPI-5) scale [40,41]. This scale consists of five items assessing the level of efficacy experienced by patients regarding their interactions with physicians. The items are scored on a scale ranging from 1 (very confident) to 5 (not confident at all). Mean scale scores were used in this study, with higher scores indicating higher levels of perceived efficacy in consultations.

Perceived quality of chronic illness care

We included the short version of the Patient Assessment of Chronic Illness Care questionnaire (PACIC-S) [42-43], to examine patients' perceptions of chronic illness care. The PACIC-S consists of 11 items assessing the extent to which patients experience that the care they received included decision support, goal setting, problem solving, and follow-up/coordination of care. These items are answered on a five-point scale ranging from 1 'almost never' to 5 'almost always'. Mean scale scores were used, with higher scores indicating patients experiencing higher quality of care.

Healthcare providers

Participants were asked whether they had contact with a GP, medical specialist, practice nurse and specialised nurse during the last 12 months. Based on these questions, we computed one dichotomous variable: patients receiving care provided by a GP and/or medical specialist versus those receiving care provided by a GP and/or medical specialist as well as by a practice nurse and/or specialised nurse.

Socio-demographic and illness characteristics

We included the following socio-demographic characteristics of the

participants in our study: age, gender, and highest level of education. In addition, we used data provided by their GPs: the types of chronic disease that had been diagnosed (coded by means of the International Classification of Primary Care [44]), the presence of more than one chronic disease (multi-morbidity), illness duration (time post-diagnosis computed from the month and year of diagnosis of the (first) chronic disease) and whether patients' health status was life-threatening or progressively deteriorating (on a 3-point scale) according to the GP.

Statistical analyses

Descriptive analyses were performed to provide information about the characteristics of the study sample and to describe the perceived quality of chronic illness care and the involvement of different types of doctors and nurses in the care participants received during the last year (question 1). As disease management programmes have been introduced to improve the quality of care but have only been implemented until now for some chronic diseases in the Netherlands, we also wanted to check whether the perceived quality of chronic illness care was different for people with different types of chronic diseases. Therefore, we performed linear regression analyses to check whether the perceived quality of chronic illness care differed for patients with different types of chronic diseases and logistic regression analyses to check whether the odds of having a nurse involved in their care differed between patients with different types of chronic diseases.

T-test for independent samples was used to establish whether the perceived quality of chronic illness care differed between patients who received care from a practice nurse/specialised nurse in addition to the care provided by a GP/medical specialist and patients who only received care from these doctors (question 2).

Finally, we performed linear regression analyses to estimate the associations between patients' perceived quality of chronic illness care and nurse involvement in care (independent variables) and patients' self-management (dependent variables) (question 3). We controlled for the effects of socio-demographic and illness characteristics. We conducted single-level regression analyses instead of multilevel analyses, since intra-class correlations (Appendix 1) showed hardly any clustering of patients' self-management abilities within general practices (which was the original sampling

framework). In addition, the likelihood ratio test did not show that multilevel analyses had an advantage over ordinary regression analyses. All analyses were performed using Stata 13.1.

Results

Characteristics of the study sample

Table 1 shows the socio-demographic and illness characteristics and self-management scores of the study sample. The mean age was 64.4 years and fifty-two percent of the participants were female. Cardiovascular disease (31%), musculoskeletal disorders (25%) and diabetes (23%) were the most common chronic diseases within the sample. Half (53%) of the study sample was diagnosed with more than one chronic (somatic) disease and the mean illness duration (time post-diagnosis) was twelve years. The health status of 79% of the participants was not life-threatening or only to a small extent, and in 61% it was not progressively deteriorating or only to a small extent. Mean scores on the self-management scales were high, indicating that participants generally perceived their self-management to be quite good.

Table 1: Sample characteristics

		N	%	Mean	Range	S.D.
Socio-demographic characteristics	Age	694		64.4	19-92	12.2
	Female	364	52%			
	Educational level					
	Low	241	36%			
	Intermediate	274	41%			
	High	157	23%			
Illness characteristics	Types of disease					
	Cardiovascular disease	213	31%			
	Asthma	85	12%			
	COPD	84	12%			
	Musculoskeletal disorder	170	25%			
	Cancer	95	14%			

		N	%	Mean	Range	S.D.
	Diabetes mellitus	162	23%			
	Neurological disease	83	12%			
	Gastrointestinal disease	51	7%			
	Other chronic disease	248	36%			
	Multi-morbidity present	371	53%			
	Illness duration in years	676		12.4	.9-66	8.9
	Life-threatening					
	To a lesser extent	511	79%			
	Neutral	98	15%			
	To a greater extent	35	5%			
	Progressive deterioration					
	To a lesser extent	376	58%			
	Neutral	200	31%			
	To a greater extent	68	11%			
Self-management	Knowledge	677		6.69	0-8	1.19
	Coping	684		6.36	0-8	1.45
	Symptom management	678		6.73	0-8	1.53
	Active involvement	683		7.20	0-8	1.06
	Perceived efficacy in communication	653		3.98	1-5	0.72

Chronic illness care

The involvement of a GP in their care was reported by almost all participants, followed by the involvement of medical specialists, practice nurses and specialised nurses (Table 2). More than a third (37%) of the participants only received care from a GP and/or medical specialist, whereas 63% also had a practice and/or specialised nurse involved in their care.

Table 2 also shows that participants had a mean score of 2.53 on the PACIC-S. Considering the item scores (not tabulated), most participants perceived their care as well-organised, were regularly asked about health habits and were given choices to think about (mean item scores > 2.99). However, some aspects of high-quality care were reported less often: only a few participants reported having received a copy of their treatment plan, having been contacted after a visit to see how things were going (follow-up care) and

having been encouraged to go to a specific group or class to help them cope with their chronic illness (mean item scores < 2.00).

Both the odds of having a practice nurse or specialised nurse involved in their care and the quality of chronic illness care that patients experienced were related to the type of chronic disease(s) they suffered from (not tabulated). Participants who had been diagnosed with COPD and/or diabetes were more likely to have a practice nurse or specialised nurse involved in their care (OR=2.03, $p<.05$ and OR=6.03 respectively, $p<.01$) and rated the quality of their care higher ($\beta =.11$ and $\beta =.11$ respectively, $p<.05$) than participants who had not been diagnosed with these diseases.

Table 2: Characteristics of received chronic illness care (care providers involved and perceived quality of care)

	N	% or mean	Std. Dev.
Involvement of care providers			
GP	690	88%	
Medical specialist	677	68%	
Practice nurse	671	50%	
Specialised nurse	668	26%	
Patients' perceived quality of chronic illness care (range 1-5)	575	2.53	0.84

Associations between healthcare providers involved and perceived quality of care

How chronic illness care is organised is associated with how patients perceive the quality of their care. Participants who received care from a nurse, in addition to care from a GP and/or medical specialist, rated the quality of their care higher than participants who received their care solely from a GP and/or medical specialist(s) (Table 3). The added value of having a nurse involved in the care process was highest regarding patients' experiences with follow-up care, discussing lifestyle issues and setting goals.

Table 3: Patients' perceived quality of chronic illness care according to the type of healthcare providers involved in their care (N= 528-559)

	Healthcare providers involved		T-test
	Only GP or specialist	Also practice or specialised nurse	
Patients' perceived quality of chronic illness care			-
Over the past 6 months, when I received care for my chronic conditions, I was ...	2.31	2.64	4.54**
... satisfied that my care was well-organised	3.89	4.01	-1.41
... asked questions, either directly or on a survey, about my health habits	2.73	3.28	4.46**
... given choices to think about	2.99	3.01	-0.12
... helped to set specific goals to improve my eating or exercise	2.30	2.81	4.35**
... asked how my chronic illness affects my life	2.31	2.58	-2.31*
... told how my visits to other types of doctors, like the eye doctor or surgeon, helped my treatment	2.08	2.72	5.23**
... helped to make a treatment plan that I could use in my daily life	1.98	2.30	2.84**
... helped to plan ahead so I that could take care of my illness even in hard times	2.01	2.28	-2.51*
... given a copy of my treatment plan	1.66	2.08	3.94**
... contacted after a visit to see how things were going	1.68	2.05	3.63**
... encouraged to go to a specific group/class to help me cope with my illness	1.68	1.89	-2.12*

* Significant at $p < .05$

** Significant at $p < .01$

Associations between chronic illness care and self-management

Participants' perceptions of the quality of chronic illness care were positively related to their self-management (Table 4). The better they perceived the quality of care to be, the higher their level of self-management was. Perceived quality of care had the strongest association with the communication component of self-management and the weakest with patients' knowledge. Having a practice nurse or specialised nurse involved in the care was not associated with a higher level of self-management. Moreover, we have also

conducted a separate regression analysis with nurse involvement included as the only predictor variable, besides the confounders (and thus without the perceived quality of care variable), but this analysis also showed that nurses' involvement in care is not associated with patients' self-management (not tabulated).

Furthermore, table 3 shows that age and being diagnosed with a musculoskeletal disorder have an additional significant effect on participants' level of coping with the consequences of chronic illness, and that gender, education level and being diagnosed with diabetes, musculoskeletal or neurological disorders all had an additional significant effect on participants' confidence in their communication with healthcare providers.

Table 4: Effects of patients' perceived quality of chronic illness care and nurse involvement on aspects of self-management of people with chronic illness (standardised coefficients)

	Knowledge (n=408) β	Coping with consequences (n=469) β	Symptom management (n=469) β	Active involvement (n=469) β	Perceived efficacy in communication (n=458) β
Patients' perceived quality of chronic illness care	.13 **	.17 **	.14 *	.16 **	.21*
Nurse involvement in care	-.05	-.01	.01	.01	-.04
Covariates					
Age	-.02	.13 *	-.04	.08	-.06
Female (ref: male)	-.01	-.08	.06	-.05	-.11*
Educational level (ref: low)					
Intermediate	.00	.05	-.08	.07	.08
High	.04	.06	-.03	.09	.15*
Types of disease ¹					
Cardiovascular disease	-.02	-.01	-.04	-.08	-.09
Asthma	-.02	-.00	.06	.03	-.01
COPD	.02	-.04	-.02	-.01	-.01
Musculoskeletal disorder	-.09	-.11 *	-.05	-.02	-.14†
Cancer	.06	.02	.01	-.01	.01
Diabetes mellitus	-.03	-.03	.01	-.02	-.11*
Neurological disease	.00	-.06	-.08	2	-.10†
Gastrointestinal disease	-.06	-.03	.02	.04	-.02
Other chronic disease	-.03	.03	-.05	-.09	-.05
Multi-morbidity present (ref: no)	.06	-.02	.13	.12	.14
Illness duration	.03	.00	.01	-.02	-.01
Life-threatening (ref: to a lesser extent)					
Neutral	-.01	-.04	.03	-.02	-.09
To a greater extent	.01	-.09	.07	.04	-.06
Progr. deterioration (ref: to a lesser extent)					
Neutral	-.00	-.09	-.09	-.12 †	-.07
To a greater extent	.08	.05	-.06	.01	-.04
R ²	4%	9%	7%	7%	13%

* Significant at p<.05

** Significant at p<.01

† Reference group; people who do not have that specific type of chronic illness. For example, people with COPD were compared with people who have another chronic disease(s).

Discussion

This study provides insight into the current state of chronic illness care in the Netherlands and how this relates to chronically ill patients' self-management. As self-management is nowadays considered a key element in the care for people with chronic illness, it is important that chronic illness care is organised and that healthcare providers provide care in a way that it supports patients to better self-manage their illness. To start with the healthcare providers involved, almost all people with a chronic illness in the Netherlands receive care from a GP and two thirds also receive care from one or more medical specialist(s), but only half of them also had contact with a practice nurse and about a quarter also had a specialised nurse involved in their care. In general, chronically ill patients reported receiving chronic illness care that was of high quality to some extent. In this study, people with chronic illnesses had an average score of 2.53 on the PACIC-S, which was slightly lower than the 2.63 found by Cramm *et al.* [44] who studied the experiences of people with cardiovascular disease who had all been enrolled in a comprehensive disease management programme (which is still not the case for all chronically ill people in the Netherlands). However, some elements of high quality care are implemented better than other aspects. Incorporating patients' social environment into their treatment and more intensive follow-up to assess patients' progress are aspects that need more attention. Other studies also found that the quality of chronic illness care, in both the Netherlands and other European countries, is still inadequate in terms of patient-provider communication, shared decision-making and follow-up between visits [30,45,46].

Furthermore, this study shows that patients with different chronic diseases have different experiences with chronic illness care in the Netherlands. We found that nurses were more often involved in the care for patients with diabetes or COPD, which is in line with the competence profile of practice nurses in the Netherlands [47]. Also, patients diagnosed with diabetes or COPD perceived the quality of care as higher than people with other chronic diseases. This difference in nurse involvement and perceived quality may be a direct result of the introduction of disease-specific chronic disease management programmes

In line with existing literature [20-23], we found that nurses' involvement can

improve the quality of care for chronically ill patients. Compared to patients who only had contact with a GP or medical specialist(s), patients who also had contact with a practice nurse or specialised nurse perceived the quality of their care to be better. This confirms the rationale behind current health policy to promote task delegation, as it should lead to GPs and medical specialists having more time to focus on the diagnostic and medical treatment process, while nurses could spend time on other important elements of high-quality care, such as monitoring treatment outcomes, providing education and support with behaviour change, and active follow-up [18,19,48]. However, nurses' involvement in treatment was not associated with higher levels of self-management. This was also the case when we included nurse involvement as the only predictor variable in the model. One of the explanations for this might be that we do not actually know which care these nurses provided. For instance, nurses might have focused on monitoring the clinical outcomes of medical treatment and organizing follow-up care rather than on providing self-management support. Tension between following clinical guidelines and a patient-centred collaborative approach to care has been previously reported [18]. Another explanation relates to the complicated nature of chronically ill patients' self-management: it has been found to depend on many personal and contextual factors [49, 50] and the involvement of nurses is only one of the many factors in this respect.

Nevertheless, our results indicate that patients who experience a higher quality of care have more knowledge of their illness, are more capable of coping with the consequences of their illness, are more able to recognise and manage their symptoms, are more actively involved in their own treatment and are more confident in their communication with healthcare providers. Previous work has already shown a positive relationship between the (perceived) quality of chronic illness care and patient activation [29] and self-management behaviour such as regular exercise and healthy diet [27,28]. Our study, however, focuses on a broader array of self-management aspects and shows that the perceived quality of care is also associated with coping with the psychosocial consequences of chronic illness in daily life. However, as mentioned above, chronically ill patients' self-management is determined by many personal and contextual factors, and considering the small part of the variation in each of the self-management aspects explained by the perceived quality of chronic illness care, there are indeed many other factors involved.

Strengths, limitations and further research

One of the strengths of this study lies in the use of a nationwide representative sample of (medically diagnosed) chronically ill people. The distribution of the chronic disease categories in our sample was similar to that of a large nationwide database which contains the health data, including the medical diagnoses of chronic diseases, of about 10% of the Dutch population (NIVEL's Primary Care Database [51]). This confirmed our confidence that our sample is a good representation of the total population of people with (somatic) chronic illness in the Netherlands and allowed us to assess to what extent high-quality chronic illness care is implemented in the Netherlands. Another strength of this study lies in the fact that we examined several aspects of self-management instead of solely focusing on the medical or lifestyle aspects of self-management.

The most important limitation of this study is that it is not clear whether receiving high-quality chronic illness care lets patients engage in more self-management behaviour or whether more self-management behaviour, better knowledge or confidence in this respect triggers healthcare providers to deliver higher quality care. It will probably be a combination of both. In addition, as the quality of chronic illness care is patient reported, it may be that patients' self-efficacy might impact their perception of the quality of care. Furthermore, chronic illness care and self-management were not assessed at the same time. Both the healthcare providers involved and the perceived quality of care were assessed six months prior to the assessment of participants' self-management. Since we examined whether there would be support for the hypothesis, derived from the Chronic Care Model, that the way chronic illness care is provided impacts on chronically ill patients' self-management (and not the other way around), we consider it acceptable that participants' self-management was assessed six months later than their report of the healthcare providers involved in their care and their perceptions of the quality of the care they received. Nevertheless, we cannot draw any conclusions about causality in this respect, as the design of our study does not allow to rule out the alternative pathway described above. Longitudinal studies are needed to further study the interaction between the quality of chronic illness care and chronically ill patients' self-management. Future research could also investigate whether some elements of high-quality chronic illness care have more impact on patients' level of self-management than

other elements. Finally, it is recommended that more research is carried out to study the effect of nurses' involvement on the (perceived) quality of chronic illness care, as it is important to know for further improvement of chronic illness care in what way the involvement of nurses contributes to a better quality of care.

Conclusion and practice implications

This study shows that the way chronic illness care is provided is, to some extent, related to patients' self-management knowledge, skills, behaviour and efficacy. Helping patients understand their central role in managing their illness, make informed choices and engage in healthy behaviour is likely to improve chronically ill people's level of self-management. The Dutch health policy to improve the quality of chronic illness care by increasing the role of (practice and specialised) nurses in the care for people with chronic diseases seems to be effective. However, it is questionable whether the disease-specific approach of the Dutch care standards and disease management programmes is appropriate to improve care for all people with chronic illness, including those who suffer from less prevalent chronic diseases or from multimorbidity. Comprehensive chronic illness care that starts from patients individual goals, preferences and competencies ('goal oriented care' [52]) instead of patients' chronic disease type(s) may be a promising way to improve the quality of chronic illness care for all.

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Appendix 1

Table: Intra Class Correlations (ICC) of chronic illness care and level of self-management within general practices

	ICC
Chronic illness care	
Patients' perceived quality of chronic illness care	.02
Nurse involvement in care	.02
Self-management	
Knowledge	.00
Coping with consequences	.04
Symptom management	.00
Active involvement	.02
Perceived efficacy in communication	.02

Illustration

Self-management and healthcare

The healthcare chronically ill people receive is an important resource for their self-management. Healthcare providers can help patients understand their central role in managing their illness, make informed choices by giving patients information about their illness and treatment options, and engage in healthy behaviour. Important elements of high quality chronic illness care are patient centeredness, self-management support, patient activation, goal setting, problem solving, coordination of care and follow-up. Findings of our study described in Chapter 6 show that patients who experience a higher quality of care have a higher level of self-management knowledge and behaviour. This section illustrates our previous findings with data from focus group sessions held with chronically ill people (more information about the focus group sessions and the analysis of this data can be found in Appendix).

Experiences with healthcare in general

Most participants felt that their care is well-organised. When they had a question, there were healthcare providers whom they can phone or send an email to. Many participants reported that they can contact their GP for their problems, but many were also frequently in touch with a practice nurse or specialist nurse they can turn to.

“Anyhow, I contact the nurse practitioner via email. Whenever I have a question or an ache or a thing, I’ll send her an email and she messages me and she discusses it with one of the GPs, or MDs or whatever you want to call it.”

“And in case there are any questions in the meantime, there’s always someone willing to listen to me. Then I just see my nurse practitioner, and if necessary he can discuss it with the GP. He is always available. So, fortunately, that’s no problem. And fortunately, I hardly ever need him, but it’s nice knowing he’s there when I do.”

All participants had several healthcare providers involved in their care. The extent to which healthcare providers cooperate and exchange information about patients varied. Patient experiences with the coordination of care differentiated. It also depended on the complexity of the care needed. If a patient only sees a GP and a practice nurse who work together in the same

practice, the coordination of care was quite simple. However, when people had more than one chronic condition and specialists from different disciplines were involved in their care, it became more complicated.

“Well, I don’t think very highly of it where medical files are concerned. I mean, they’re doing a good job and they do it properly, but they forget a few things.”

“In my case, the GP gets a little note with the results from the blood tests etc. All of that goes very smoothly. And then he calls me on the phone, like: ‘I hear you’re in remission again.’ But that does not include the physiotherapist. I need him from time to time when I want to get back on my feet again, and then it can be tricky to remember exactly which little bone in my back has a lesion, so that he has to be extra careful when massaging my back. And then you have to take great pains to unearth that information, because the GP doesn’t know, so you need a specialist. And nowadays, I should say, I tend to contact my oncological nurse before I contact the specialist. In these sort of cases.”

“I notice this with my daughter, who has several different chronic diseases and who is dependent on two specialists. When there is no one willing to take final responsibility, you’re in real trouble. And then you’re the one with a chronic illness and hugely limited energy. Whereas, in fact, you need 150% of your energy to even be able to sort it out and organise things, because someone else, who is supposed to be doing that, is not doing it.”

Patient’s role in care

The extent to which participants felt like they were in control or wanted to be in control of the care for their chronic disease differed between participants. Some participants thought that healthcare providers were better equipped to decide what type of treatment or medication is needed. Others preferred a more active role; they like to discuss the different treatment options with their healthcare provider and decide together how to continue the treatment. Furthermore, some participants had the feeling that healthcare providers do not always appreciate it when patients have their own opinion about what needs to be done.

I: “Do you feel like you can plan your own care independently? And like you can direct it? Like you also receive the care that you want? Like you yourself really have a say in it?”

P: “Well, partly, but I do believe that a few healthcare providers feel like they’re superior, and they’re not really open to conversation or ideas. If you have your own ideas about things, a healthcare provider like that will be like ‘yes, but...’ and then they start passing the buck. So, no, my experiences in that area are not 100% positive, no.”

“You just mentioned something about directing. That’s one of those things. In theory, the GP is the one who directs and coordinates my care. He has a general overview of things, he can see the big picture. I feel like it’s always the GP who does this.”

“I have diabetes. You have to be mindful of that every day. Because if you don’t, things will go wrong pretty quickly. So that’s my responsibility, I strongly feel that. But in my opinion, my surrounding medical support, yeah, I’ll just call ‘em that; they’re my technical directors. I’m the director, and they’re the director’s assistant or technical director. When I have a specific question about something I don’t understand, then I use their specialist knowledge. That’s what I do.”

In one focus group sessions, participants made the distinction between having control over medical issues and over life issues. Healthcare providers had control over the type of medication and treatment, while participants had control over how to live their lives.

“There are two types of ‘directing’. You want to direct the course of your own life, but you also want that those medical clowns, that there is someone there to direct them, because he has to be able to see eye to eye with his colleagues in order to provide you with good medical care.”

Problem areas

Talking about healthcare, there was a general feeling that patients need to do a lot themselves, that there is less focus on the patient as a whole person and that the healthcare system has become more complex and rigid.

Doing things yourself

Many participants mentioned that, when it comes to caring for their chronic disease, they need to do a lot of things themselves. On the one hand they felt that that is their responsibility. On the other hand they sometimes felt overwhelmed by all the things they need to do. Some participants pointed out that they continuously needed to make sure that they actually received the care they needed. Some participants were concerned that not every patient is capable of taking on this responsibility.

“But that also means that you always have to be terribly outspoken in order to defend your own interests. Once you can’t do that anymore, you’re royally screwed. Yes, because naturally there are loads of people who just can’t do that anymore, who don’t want to, who’ve had enough of that. So that means that if there’s no one else who is able to do that for them, or wants to do it, or knows what the situation is like...well, then it just doesn’t happen.”

Some participants felt that their GP was really there for them and that there was someone who looked out for them, who had their best interests at heart. Interestingly, participants perceived this type of GP as an exception. They counted themselves lucky to have such an extraordinary GP.

“My GP is that exception to the rule. I’ve known him for at least 50 years. About three months ago, I contracted shingles. My GP kept his promise of calling me on the phone twice a week, just to ask how I was doing. He’s managed to do that for three consecutive weeks. That kind of GP.”

“The real GP doesn’t exist anymore. Like in the old days. Those are just exceptions.”

“Well, it might be unique, but my GP phones me himself. [...]My GP really helps me think about solutions, and when I suggest something, he’s often

quite open to it. Then we look into it together to see if it's a path that I could take."

Caring for the whole patient

Furthermore, many participants felt that healthcare providers focused mainly on curing the disease, and did not always pay enough attention to the person who has the chronic disease. Healthcare providers were not fully aware of patients' personal context. What does being chronically ill mean for this individual? How is his/her life context? Does he or she have a job, a partner they can count on, children that they need to look after?

"Yes, but that means there can only be one conclusion: healthcare no longer puts the patient as a person at the centre of interest. That's what it's all about."

Interviewer: *"According to you, is the GP well-informed about your personal circumstances and how that goes? You're shaking your head. No?"*

Participant: *"I increasingly feel like he isn't. More and more things are handled by the assistant nowadays, that is my experience, in our case. So that means you have to make a separate appointment, while you didn't have to do that before."*

Rigid healthcare system

Participants felt that the healthcare system had become somewhat rigid, which made it difficult to receive optimal care. For instance, the time it took to receive the proper in-home-care or to get the right diagnosis was considered too long. This feeling did not necessarily need to be based on their own experiences regarding chronic illness care, but could also be based on stories they heard from other people, or on their own experiences regarding care for acute conditions.

"I've got some experience with asking for additional support, which we did recently. Via the GP. He is very attentive, he gets everything going, and then the healthcare provider sends you a form. And then you get a week and a half, and before that time's up you have to send it back. Then it says: we'll contact you within 2 weeks. Well, that turns into 4 months. It all takes an

awfully long time. And then after 4 months someone will come to your house to hold an intake interview and then you have to really convince those people that you need the additional support. I understand that. And I have no problem doing that. But then, before they actually send you someone, another 6 or 8 weeks will have passed. And that's very frustrating. Because when you make the request you are already in need of that assistance. But the help you need only arrives about 6 months later. I just find that very frustrating and it doesn't serve the interests of those who are in need of support. It's such a shame, really. I understand why it happens, but I still find it hard to accept.

Other participant: *"I wouldn't be so understanding. This represents about the entire healthcare system, you know!"*

"Yes, you go and see your GP, who refers you to a specialist, and then the waiting begins. And then you go to that specialist, and then they do tests and then the next period of waiting begins. Before you know it, six months have passed and you still don't know anything."

Reflection

It is difficult to state whether or not healthcare providers offer chronically ill people sufficient support with their self-management. It seems that it differs per healthcare provider and per patient. In general, chronically ill people feel that their care is well-organised. However, they also feel that the healthcare system has become more bureaucratic and less focused on the patient as a whole. Chronic illness care is often complex, as many different healthcare providers are involved, such as the GP, practice nurse, medical specialist, physiotherapist or pharmacist, and these healthcare providers do not always cooperate or communicate well with each other. Chronically ill people sometimes feel overwhelmed by all the things they need to do themselves, and feel like they continuously need to make sure they receive the care they need. Healthcare chiefly seems to focus on taking care of the chronic condition, and little attention seems to be paid to the context of patients' lives.

7

General discussion

Chronically ill people face a lot of challenges in their everyday life, such as coping with a limited amount of energy, taking medication correctly, communicating with healthcare providers, etc. However, not all people with a chronic illness are able to perform these tasks properly in order to minimise the impact of the chronic disease and maintain a satisfactory quality of life [1]. The question is why some people are more able to manage their chronic illness, while others struggle to do so? And why do some people need a lot of support from professional caregivers and other do not? Better understanding of why chronically ill people need support with self-management may improve chronic illness care, as support can be tailored to the specific needs of individual people. Therefore, the aim of the study described in this thesis was to gain insight into chronically ill people's self-management and their related needs for self-management support. This thesis consists of three main parts: (1) self-management and the course of illness, (2) self-management and the life context, and (3) self-management and healthcare.

In this chapter the results of our studies are summarised and discussed in view of earlier findings, theory, and research methodology. The chapter concludes with implications for future research and clinical practice.

Main Findings

Self-management is more than medical management and a healthy lifestyle

Nowadays, a broad definition of self-management, in which self-management is more than a patient's contribution to his medical treatment, is most commonly used in both scientific literature and policy documents [2-5]. Findings of this study confirm that self-management is more than medical management and adopting a healthy lifestyle, as chronically ill people also need to communicate effectively with healthcare providers and cope with the consequences of being chronically ill in daily life. However, the focus group sessions showed that there is a clear difference between chronically ill people's perception of the first two types of self-management activities compared to their perceptions of the latter two activities. Medical management and making lifestyle changes are clearly seen by chronically ill people as activities to control the impact of their chronic illness. In contrast, communicating with healthcare providers and coping with the consequences of being chronically ill are not the first things that come to mind when

thinking of self-management. These two types of activities seem to be considered as inevitable consequences of being ill. Chronically ill people cannot decide not to communicate with healthcare providers or not to cope with the consequences of being chronically ill. It is something that they do without considering it as 'purposeful self-management'. However, although people cannot decide whether or not to communicate with healthcare providers and cope with the consequences of being chronically ill, they can decide on how to communicate with healthcare providers and how to cope. Interestingly, chronically ill people report the highest need for support with these latter two types of activities. It seems that communication and coping are addressed less during consultations with healthcare providers. Important to note is that the four types of self-management activities are to some extent related to one another. When chronically ill people need support with one aspect of self-management, they probably also need support with other aspects of self-management.

Self-management and related support needs are not disease specific

In line with our expectations, this study demonstrates that there are a lot of similarities between people with different chronic diseases when it comes to the self-management tasks they perceive. For instance, almost all report the need to take medication, visit a doctor, and incorporate their chronic illness into their daily lives. However, there are some differences between people diagnosed with different diseases. For instance, people who are diagnosed with diabetes perceive more self-management tasks as part of their daily management than people diagnosed with other (somatic) chronic diseases. These differences might relate to the nature of the chronic disease and/or the care chronically ill people receive. In the Netherlands, as in many European countries, there have been advanced disease management programs for diabetes for several years now, and not (yet) or more recently for other chronic diseases [6]. It could be that the emphasis on self-management in these programmes has led diabetes patients to be more aware of their own role in the management of diabetes, resulting in these patients perceiving more tasks as part of their daily self-management.

Findings of this study show that there are even less differences between people with different chronic diseases in the needs they have for support with their self-management. Why some people need support with self-

management and others do not, can hardly be explained by the type of disease, which was also in line with our expectations. We found only people diagnosed with neurological disease or musculoskeletal disorders to have a slightly higher need for support than other people diagnosed with chronic disease. Neurological diseases and musculoskeletal disorders strongly affect people's physical functioning, which might complicate performing self-management tasks. The severity of physical disabilities is one of the most influential factors for determining a need for support.

The need for self-management support changes during the course of illness

As the years pass, chronically ill people become experts of their own illness and related care. However, this does not mean that these 'expert-patients' do not need support with their self-management. Our results show that the needs for support with self-management are as high for people who have been diagnosed with their disease for a short period of time as for people who have been diagnosed for a long period of time. This implies that the need for support can emerge during every phase of the illness. Previous studies also found that new stressful situations can occur at any given time during the course of illness [7-9]. For instance, new symptoms may arise or people start to feel the long term effects of their chronic illness, which may increase the need for self-management support.

As we expected, this study demonstrated that the way the individual course of illness develops is a better predictor of self-management support needs than illness duration. People who experience an episodic and/or progressively deteriorating course of illness have higher needs for self-management support than chronically ill people who perceive their course of illness as stable. Moreover, perceived health also has an effect on the needs for self-management support. When self-reported health deteriorates, the need for support increases, and when self-reported health improves, the need for support decreases. Both an unstable course of illness and a perceived deterioration of health may on the one hand complicate the performance of self-management tasks and on the other hand lead to feelings of lower self-efficacy, as people might feel they are not in control and that their self-management is failing. As a result, people will need more support with their self-management.

Self-management is intertwined with the daily lives of chronically ill people

The lives of chronically ill people do not solely consist of taking care of their chronic illness. People might also work, have children, have friends, etc. This means that chronically ill people can also have other challenges in their lives besides managing their illness properly. Our findings show that one third of the people with chronic illness encounters problems in their everyday life, such as financial problems, work-related problems, or problems with their partner, children or other people. These problems can be the result of chronic illness, but this is not always the case. Either way, our study demonstrated that having everyday problems makes it more difficult to manage the chronic disease properly. The reason for this might be that people have other things on their mind and need to divide their attention, time and energy. However, it is important to note that the relation between everyday problems and performing adequate self-management is not as straightforward as we expected. The effect of having everyday problems on self-management depends on the type of problems chronically ill people encounter on a daily basis, as well as on the type of self-management at stake.

In addition, the phase of people's lives also influences how they perceive their chronic illness and determines the need for support with self-management. Findings of our study showed that the older chronically ill people are, the more self-management tasks they perceive and the more support they need performing these tasks. This is partly due to a more severe physical condition as chances of having more than one chronic condition, physical limitations, and a life-threatening or progressively deteriorating health status increase with age. Having a more severe physical condition makes the need to perform activities to control the impact of the illness more eminent, while it complicates at the same time the performance of these activities. However, we also found some contradictive influences that tempered this effect of age.

First of all, our findings demonstrated that younger people feel a greater impact of their illness on their daily lives than older people, when controlled for differences in physical condition. Second, younger people with chronic illness also have a stronger belief that their behaviour can impact their chronic condition than older chronically ill people. These findings suggest that younger people may be more inclined to perform self-management tasks (if we control for the physical condition). The reason for this, might be that

being chronically ill has another meaning for younger adult people than older people. Younger people with a chronic illness often need to combine their illness with work and the care for (young) children, while the demands of active parenthood and paid work are relinquished in older age. In addition, being chronically ill does not fit with the idea young people have of their lives and the goals they strive for.

We expected that the resources people have at their disposal might also explain the effect of age on self-management and related support needs. We assumed that the older people are, the less resources they have, which would complicate self-management and therefore enhance the need for support. However, our findings showed only small differences in resources between younger and older chronically ill people.

Chronic illness care can be a resource for good self-management

The chronic illness care people receive can be a resource that facilitates self-management. In accordance with the Chronic Care Model, good chronic illness care is characterised by patients and healthcare providers working together in a team, setting goals together and optimising the therapy [5]. Patients receive support with self-management from their healthcare providers and there is an intensive follow-up. In our study, almost all people with a chronic illness receive care from a GP and two thirds also receive care from one or more medical specialist(s), but only half of them also had contact with a practice nurse and about a quarter also had a specialised nurse involved in their care. In addition, chronically ill people reported to receive to some extent high-quality chronic illness care. However, involving patients' social network in their care and proactive follow-up to monitor patients' progress are aspects that need more attention.

In addition, our study showed that the care chronically ill people receive differs depending on the type of chronic disease. People diagnosed with diabetes or COPD often have, next to their appointments with their medical specialist, regular consultations with their practice nurse, in which their health status is checked and treatment goals are set. In contrast, people with diseases such as neurological diseases or musculoskeletal disorders usually do not have such consultations with a practice nurse. This difference in provided care could be explained by the disease management programs that have been developed and implemented for diabetes and COPD, but not yet on a large

scale for those other chronic diseases.

How chronic illness care is organised is associated with how patients perceive the quality of their care. Our study showed that chronically ill people who have contact with a practice nurse or specialised nurse, next to their regular visits with the GP or medical specialist, perceive the quality of their care to be better compared to chronically ill people who only have contact with a GP or medical specialist. This finding might be explained by the fact that practice nurses or specialised nurses are often the main contact person for chronically ill people. In addition, practice nurses or specialised nurses may have more time during consultations. However, nurses' involvement in treatment was not associated with higher levels of self-management. One of the explanations for this might be that we do not actually know which care these nurses provided. Tension between following clinical guidelines and a patient-centred collaborative approach to care has been previously reported [18].

In line with our expectations, this study shows that the way chronic illness care is provided is likely to improve chronically ill people's self-management. Findings of this study indicated that people who experience a higher quality of care have more knowledge of their chronic illness, are more capable of coping with the consequences of their illness, are more able to recognise and manage their symptoms, are more actively involved in their own treatment and are more confident in their communication with healthcare providers. However, the perceived quality of chronic illness care only explained a small proportion of the variance in chronically ill people's self-management in our study. This indicates that the quality of the care chronically ill people receive is one of the many factors that have impact on patient's self-management, but it is certainly not the only factor.

Discussion

Theoretical reflections

In order to explain variation in self-management support needs of people with chronic illness, we constructed a theoretical framework. This framework guided our reflection process during this study. The question we wish to address here is whether this framework helped us gain a better understanding of self-management support needs and whether all the elements of this

framework contributed to the explanation why some people need support with self-management while other do not.

Our basic assumption was that chronically ill people need (more) support with self-management when the burden of illness (e.g. how people perceive their chronic illness), the goals people strive for in their lives, and the resources people have at their disposal to manage their chronic illness are out of balance. The more the burden of illness, goals and resources are out of balance, the higher the need for self-management support will be.

The findings of this thesis confirm that the three main elements of the framework, burden of illness, goals and resources, play an important role in explaining self-management support needs. These three elements influence each other and it is therefore difficult to examine the effects of these elements separately. For instance, the burden of illness is not the chronic illness in itself, but the perception people have of their illness. This is determined by the type of chronic disease, its severity and course, but also by the goals chronically ill people have, the life phase they are in and the social roles they have in their lives. It is the combination of all these elements that determines the burden of illness. Not everyone with the same chronic disease, physical limitations or course of illness will experience the same burden of illness.

Chronically ill people start to see their chronic illness as a problem and feel a need for self-management as soon as they can feel restricted to live their life as they wanted. As Bury [10] states, the disruption of personal goals gives having a chronic illness its significance. Therefore, some people see their illness only as 'a bit inconvenient'. Some things might take more time or might be a bit of a hassle, but nothing really impales the way they live. Other people have more difficulties with their chronic illness, as they are no longer able to do the things they want to do, such as work, hobbies or even living independently. The possibility that goals might be disrupted in the future due to the consequences of the chronic illness might also force people to perform self-management. For instance, the fear of losing sight and no longer being able to live the live as they want, can trigger people with diabetes to change their diet.

The resources people have at their disposal determine whether chronically ill people are capable of managing their illness properly. Social Production Function Theory states that people can use different resources to reach the same goal [11-13]. For instance, if someone is no longer capable of driving a car,

he can ask friends and family to drive, make use of public transport or order a taxi. The first solution requires a good social network, the second solution requires access to public transport in the neighbourhood and the third solution sufficient money. Compensation is the key here. People who lack a strong social network or access to public transport can compensate that in this example with good financial resources. However, compensation has its limits. The fewer resources people have, the higher the chances that they need support with their self-management. In addition, Hobfoll [15] stated that a loss of resources can lead to the loss of more resources. For instance, the loss of health or the loss of a partner can lead to the loss of financial resources. Overall, the study shows that self-management is a dynamic process and that there is no simple answer to the question why some people need support with their self-management while other do not. It all depends on the moment in time. At what point in their life are people? Do they work fulltime, do they take care of young children, are they retired, etc.? And where are they in their course of illness? Is their course of illness stable, have they just been diagnosed, did new symptoms arise, etc.? This will all influence the burden of illness, the goals people have and the resources people have at their disposal. The framework helped to clarify the complexity of self-management process by focusing on the burden of illness, goals and resources and how these elements are influenced by developments in people's course of illness and life. Knowing how people perceive their burden of illness, which goals they strive for in their lives and which resources they have at their disposal, will give a good impression for their ability to manage their chronic illness and subsequently their need for support.

Methodological reflections

Data

For this thesis, we made use of data from a nationwide representative sample of (medically diagnosed) chronically ill people, and illustrated the quantitative findings with narratives of chronically ill people. The combination of quantitative and qualitative data provides unique insights into the perceptions of people with chronic illness. The NPCD consists of 3,500 people diagnosed with all types of somatic chronic diseases. Therefore, we could include people with various diseases, such as cardiovascular diseases, neurological diseases, diabetes, asthma and COPD instead of focusing solely on one type of chronic

disease. This gave us the chance to look beyond the type of chronic disease. Panel members with chronic illness are recruited from general practices based on their medical diagnoses. People are not able to sign up for the panel on their own initiative. There might be a small selection bias, as not all people with chronic diseases will identify themselves as being chronically ill and therefore decide not to participate in the panel. Especially, people whose chronic illness does not have a big impact on their lives, might feel that the NPCD surveys are not addressed to them. Therefore, it might be that people with more severe chronic diseases are overrepresented in the panel.

Furthermore, although the NPCD provides the opportunity for repeated measurements, we could not fully use this possibility, as we had difficulty to select one measuring instrument that could be used to assess all dimensions of self-management behaviour at several measuring moments. Therefore, it was not possible to examine how self-management of chronically ill people changes over time. The majority of the data used in this thesis was analysed cross-sectional, which makes it impossible to determine causality. However, we were able to examine the effect of changes in perceived health on changes in self-management support needs, although it was only over a two year period. Even though two years is a short period of time, we could establish a relationship between changes in chronically ill people's perceived health and their self-management support needs.

Assessing self-management

A strength of this study lies in the fact that we examined different domains of self-management instead of solely focusing on the medical or lifestyle aspects of self-management. Although a more broad definition of self-management has become the standard, most studies tend to focus on one or two aspects of self-management, mainly medical management and making lifestyle changes. This is one of the few studies that examined more domains of self-management. Therefore, it was difficult to make use of validated instruments to measure self-management. We developed our own questionnaire to assess the various tasks people perceive as part of their daily self-management and the support they need performing these tasks (PAST questionnaire). Although the initial tests to validate this questionnaire were good, further examination of the test-retest reliability and construct validity of the questionnaire are needed. In addition, the factor structure of the questionnaire should also be

tested in different data samples. Furthermore, this questionnaire does not measure what chronically ill people actually do, it rather measures what they perceive they should do and with what activities they need support. Therefore, to measure the actual self-management behaviour, we also used the Partners in Health scale (PIH) [16,17]. This questionnaire measures different aspects of self-management that correspond with the domains in the PAST-questionnaire. However, communication with healthcare providers as an aspect of self-management is not addressed sufficiently in the PIH scale. Therefore, we also made use of the short version of the Perceived Efficacy in Patient-Provider Interaction (PEPPI-5) scale, which assesses the level of efficacy experienced by patients regarding their interactions with physicians [18]. The combination of these questionnaires covers the broad scope of self-management to some extent.

What do we still need to know?

The study described in this thesis gives a good overview on which factors influence chronically ill people's self-management and related support needs. Most hypotheses in this thesis are confirmed by the findings of this study. Regarding the course of illness, it was confirmed that the course of illness explains more variation in self-management tasks and related support needs than the type of chronic disease. In addition, the need for self-management support is lower when people perceive the course of their illness as stable than when people perceive an unstable course of illness. Regarding chronic illness care, it was confirmed that people who experience a higher quality of care are better able to manage their chronic illness properly. Furthermore, nurses' involvement in the care can improve the quality of care for people with chronic illness although, nurses' involvement was not associated with better self-management.

However, not all hypotheses in this study were confirmed. The hypotheses concerning self-management and the life context were partly confirmed by the findings of this study. First of all, differences in perceived self-management tasks and support needs between older and younger people can to some extent be explained by differences in their life context, but the relationships between age and their perceived self-management tasks and related support needs is very complex. Our assumptions why there would be differences between younger and older chronically ill people in their

perceptions of self-management tasks and related support needs were supported by our findings. For instance, younger chronically ill people perceive a greater threat of their chronic illness on their well-being than older chronically ill people, younger people with chronic illness have a stronger belief that their behaviour can affect the impact of their chronic condition, and younger people have more resources to perform self-management tasks. However, when we combined the different somewhat contradictory hypotheses, it became less clear how these different aspects were related.

In addition, the amount of resources people have at their disposal hardly explained any differences between younger and older people in their need for support. One of the reasons why this hypothesis was not confirmed could be the way we measured the resources. We focused on three resources, namely having a partner, health literacy and income. Having a partner could be an indicator of social support as the partner is one of the most important people to give support. However, having a partner does not automatically mean that chronically ill people receive support. Next, we measured health literacy in a confined way, mainly focusing more on the ability to read health information than on the ability to understand and use this information. As most people in the Netherlands are able to read, the average score on this scale was high and little variation between people existed. It is questionable whether the combination of these three resources gives a good indication of the resources that chronically ill people have at their disposal. In addition, it might be that some resources are more valuable to have in order to manage a chronic illness than others.

Second, the everyday problems people have in their lives complicate effective self-management. However, how they actually interfere depends on the type of problems and the type of self-management activities at stake. For instance, having social problems does have a negative effect on the level of symptom management, while having basic problems such as financial or work related problems does not have an effect on symptom management. Thus, the relationship between having everyday problems and the level of self-management is not simple. It is important to know in what way the everyday problems impede people from performing effective self-management.

One of the reasons why these hypotheses related to the life course were only partly confirmed might be that these hypotheses were very complicated and less straightforward than the hypotheses regarding the influence of the course

of illness and the quality of care. Life contexts are very diverse and consist of many different elements that all can influence self-management and related support needs. To make it even more complicated, all these different aspects of the life course are intertwined. This makes it difficult to measure them separately and determine the individual effects of all these aspects. However, although the hypotheses regarding the life course were not completely confirmed by our findings, this study did provide new information on the relationship between chronically ill people's life course/context and self-management support needs.

Recommendations for future research

First, to fully understand why some people manage their chronic illness without big difficulties and others need much more support with their self-management, longitudinal data are needed. In the ideal situation, we would follow a group of chronically ill people over a longer period of time. In this way, we could examine how certain changes in people's life or course of illness affect their self-management and need for support. How does a small change in the burden of illness, goals or resources influence the need for support with self-management? And how do people's burden of illness, goals and resources influence each other? To what extent can people compensate a high burden of illness with their resources? And to what extent are people willing or able to alter their personal goals when confronted with the limitations of being chronically ill?

Second, the resources people have at their disposal to manage their illness have not been given sufficient attention in this thesis. Especially, the role of social support provided by family, friends or neighbours should be examined further, as it is an important resource for self-management. In the focus groups, we did discuss this topic shortly and it became clear that most people receive support from their partner, children, friends or neighbours. However, asking for support every now and then is different from needing intensive support on a regular basis. As a chronic illness is something people have to deal with for the rest of their lives, chronically ill people's need for support is not just temporary and it is the question to what extent people can rely on their social network for the long run. It would be interesting to examine this further.

At last, there is a need for a validated instrument that assesses the quantity and quality of chronically ill people's self-management. This instrument should be based on a broad definition of self-management and should preferably be disease generic. The PAST-questionnaire is one step in the right direction. However, this questionnaire needs to be further validated and only examines what people think they should do with regard to self-management, not what they actually do. Furthermore, it is also important to take into account the difficulty of the different self-management tasks. Some tasks might be harder to accomplish than other tasks.

Implications for practice

It is important for healthcare providers to focus on the patients as a whole instead of focusing mainly on the chronic disease. As a chronic illness cannot be cured, chronically ill people need to incorporate their illness into their lives. Chronically ill people need to take an active role in their treatment and healthcare providers should support them with this. Healthcare providers are more and more expected to coach chronically ill people with their self-management [18, 19]. In order to do this, healthcare providers need to be aware that there is more to chronically ill people than their chronic disease. Problems in people's daily life can complicate self-management. Therefore, the life context should also be discussed during consultations. In order to help people manage their illness properly, healthcare providers should have an understanding of people's personal situation and of the difficulties they might encounter during the daily management of their chronic disease.

In addition, self-management is more than taking medication correctly and adopting a healthy lifestyle. However, it seems that healthcare providers pay most attention to these aspects of self-management. Coping with the consequences of being chronically ill is just as important. Taking medication and making lifestyle changes are more concrete tasks and it may be easier to set goals for these types of tasks, while coping with the consequences of being chronically ill is not so straightforward. It might be helpful to understand what people want with their lives. Is it important for them to have and keep a professional career, to do their own shopping, to have an active social life? And is it possible for them to accomplish these goals? What is standing in their way? A goal-oriented approach rather than a problem-oriented approach

to care may better suit the comprehensive support needs of people with chronic illness.

Furthermore, it is important for healthcare providers to be aware that the need for support can arise at any moment during the course of illness. People do not only need support when they are just diagnosed. The course of the illness can change for instance, as new symptoms arise or people need to deal with the long term effects of the chronic disease, but also the lives of people can change which might make it more difficult to incorporate their chronic illness into their lives. Therefore, healthcare providers need to be aware that self-management is a dynamic process, which changes over time.

Finally, it is questionable whether a disease-specific approach of chronic illness care is appropriate to improve care for all people with chronic illness, including those who suffer from less prevalent chronic diseases or from multi-morbidity. Although some self-management tasks might be disease specific, self-management support in general does not need to be disease specific. Comprehensive chronic illness care that starts from patients individual goals, preferences and competencies instead of patients' chronic disease type(s) may be a promising way to improve the quality of chronic illness care for all.

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Summary

Chronically ill people face many challenges in their everyday life, such as coping with a limited amount of energy, taking medication correctly, communicating with healthcare providers, etc. All these different tasks can be referred to as self-management. Self-management includes managing symptoms, treating the condition, making lifestyle changes and coping with the physical and psychosocial consequences of having a chronic condition. However, not all people with a chronic illness are able to perform self-management properly in order to minimise the impact of the chronic disease and maintain a satisfactory quality of life. The question is why some people are able to manage their chronic illness, while others struggle to do so; and why some people need a lot of support from professional caregivers while others do not? Better understanding of which factors determine chronically ill people's need for support with self-management may improve chronic illness care, as support can be tailored to the specific needs of individual people. The aim of the study described in this thesis was therefore to gain insight into chronically ill people's self-management and their related needs for self-management support.

What might complicate self-management is the fact that self-management is a dynamic process in which the role of chronically ill people develops throughout the course of illness. At the same time, chronically ill people's personal lives may change as well, which determines the context in which self-management takes place. In addition, the professional healthcare they receive is an important resource for chronically ill people. Nowadays, healthcare providers are expected to enable chronically ill patients to make daily decisions and take planned actions that result in optimal health and quality of life outcomes. Whether or not healthcare providers choose to play such a supportive and coaching role in the lives of their chronically ill patients may vary between healthcare providers and depends on their knowledge, attitudes and competencies.

In order to understand variation in self-management behaviour and related support needs, our research was directed by the following questions:

1. To what extent can chronically ill people's self-management and related support needs be explained by the type and course of their chronic illness?

2. To what extent can chronically ill people's self-management and related support needs be explained by their life context?
3. To what extent can chronically ill people's self-management and related support needs be explained by the way chronic illness care is provided?

To answer these questions, the study focused on the perspective of chronically ill people. All data used in this study were provided by members of the National Panel of people with Chronic illness or Disability (NPCD), which is a nationwide prospective panel-study that provides information about people's experiences and perceived consequences of living with chronic illness or disability. For the main part of this thesis, quantitative data collected by self-report questionnaires sent to members of the NPCD were analysed. In addition, information from focus groups with 30 (former) members of the NPCD has been used in this thesis to illustrate the quantitative findings, and to help understand and interpret these findings.

This thesis consists of three main parts: (1) self-management and course of illness (*chapters 2 and 3*), (2) self-management and life context (*chapters 4 and 5*), and (3) self-management and healthcare (*chapter 6*).

This thesis starts with the **Illustration 'Self-management in daily practice'**, which shows how self-management is perceived by chronically ill people and which self-management activities they perform in daily life, based on the focus group sessions held with people with chronic illness. In line with the description of self-management in the literature, participants in the focus groups talked about their experiences with four different types of self-management activities that chronically ill people perform in order to manage their illness in daily life, namely medical management, making lifestyle changes, communication with healthcare providers and coping with the consequences of being chronically ill. The first two types of activities are explicitly mentioned as activities which manage the chronic illness, whereas the latter two types of activities seem to be considered inevitable aspects of being ill. Chronically ill people cannot decide not to communicate or not to cope with the consequences of being chronically ill. However, they can decide on how to communicate and how to cope.

Chapter 2 describes the self-management tasks and support needs people with chronic illness perceive as part of their daily management, and examines whether these tasks and support needs are disease specific. Although chronically ill people perceive a moderate amount of self-management tasks in the daily management of their condition, they do not indicate an explicit need for self-management support. The need for self-management support of people with chronic illness is not strongly related to the extent to which they perceive more or less self-management tasks for themselves. So, perceiving more self-management tasks as part of daily management does not directly imply that people will need more support. However, chronically ill people who feel a need for support in one aspect of self-management are likely to feel a need for support in other aspects as well.

There are a lot of similarities between people with different chronic diseases when it comes to the self-management tasks they perceive. For instance, almost all people report the need to take medication, visit a doctor, and incorporate their chronic illness into their daily lives. However, there are some differences between people who have been diagnosed with different diseases. For instance, people who have been diagnosed with diabetes perceive more self-management tasks as part of their daily management than people diagnosed with other chronic diseases. Regarding self-management support needs, there are even less differences between people with different types of chronic diseases. This indicates that, although the self-management tasks patients feel they have to carry out may be partly disease specific, self-management support does not necessarily need to be disease specific. Support programmes could use a more generic approach and should not only focus on medical management of the illness and making lifestyle changes, but should also pay attention to coping with the consequences of living with a chronic illness.

Chapter 3 examines whether chronically ill people's needs for self-management support depend on their course of illness. Self-management support needs are not related to illness duration. The needs for support with self-management are as high for people who have been diagnosed with their disease for a short period of time as for people who have been diagnosed for a long period of time. This implies that the need for support can emerge during every phase of the illness. The way the individual course of illness develops is

a better indicator of self-management support needs. People who have an episodic and/or progressively deteriorating course of illness have higher needs for self-management support than chronically ill people who perceive their course of illness as stable. Moreover, changes in perceived health also have an effect on the needs for self-management support. When self-reported health deteriorates, the need for support increases, and when health improves, the need for support decreases. Consequently, helping patients to self-manage should not be confined to the first years after diagnosis. Healthcare providers should pay attention to/ be aware of patients' own perceptions of their course of illness and health status.

The **Illustration 'Self-management according to type and course of illness'** confirmed that there are a lot of similarities between people with different chronic diseases. However, there seems to be a difference between people with specific diseases whose care is characterised by regular check-ups and goal setting (probably guided by standards of care), and people with other diseases, whose use of care depends more on a personally felt need. As the years pass, chronically ill people become experts on their own chronic illness and related care. However, this does not mean that these 'expert-patients' do not need support with their self-management. Chronic illness, as well as its treatment and care, will change over time. The way the individual course of illness develops seems to be a good indicator of the extent to which chronically ill people feel a need for more (or other types of) self-management support provided by healthcare professionals.

Chapter 4 evaluates the nature of age-related differences in self-management tasks and support needs. Older people perceive more self-management tasks for themselves and are more likely to need support due to a more severe physical condition. This effect of age on self-management is tempered, as younger people see their chronic illness as a bigger threat and have a stronger belief in their personal control over their illness than older people. This suggests that younger people are more inclined to perform self-management tasks if we control for the physical condition. The reason for this might be that being chronically ill means something different to younger adult people than to older people. In addition, being chronically ill does not tie in with the idea young people have of their lives and the goals they strive for. Overall, the

life context of chronically ill people has an additional value to physical condition in explaining age-related differences in self-management tasks and support needs. Consequently, the individual life context needs to be taken into account when tailoring self-management support to chronically ill people's specific needs.

Chapter 5 studies to what extent everyday problems interfere with chronically ill people's self-management. One third of people with chronic illness encounter basic (e.g. financial, housing, employment) or social (e.g. partner, children, sexual or leisure) problems in their daily life. Younger people, people with poor health and people with physical limitations are more likely to have everyday problems. Having everyday problems makes it more difficult to manage the chronic disease properly. The effect of everyday problems on self-management depends on the type of problems chronically ill people encounter on a daily basis, as well as on the type of self-management at stake. For instance, experiencing basic problems is related to less active coping behaviour, while experiencing social problems is related to lower levels of symptom management and less active coping behaviour. It is very important that healthcare providers actively address the individual (social) circumstances of people with chronic illness and the broader context in which self-management of chronically ill patients takes place, as it determines patients' ability to manage their disease.

The **Illustration 'Self-management and the life context'** shows that what it means to be chronically ill and what it takes to retain a 'normal' life differs per person, depending on the individual situation and course of life. For younger people, being chronically ill may be harder to accept, while older people seem less disturbed by their chronic illness, as many consider it a part of aging. Having a chronic illness affects the work situation of chronically ill people. Some might not be able to work due to their chronic illness; others might need to make arrangements to keep on working. Either way, being chronically ill is not something that can be glossed over when having paid work. The same goes for family members. Chronic illness also has a deep impact on their lives as they can be concerned about the effects of the illness on their ill family member, or because they have to take care of their ill family member. Finally, chronically ill people may have more problems in their lives

than their chronic illness alone, such as being divorced, having a spouse with health problems, or having financial problems. Seeing difficulties with self-management as part of patients' individual life context might help to understand why a person with a chronic illness is not able or motivated to make the desired lifestyle changes or to accept the chronic illness.

Chapter 6 examines whether receiving high-quality chronic illness care contributes to chronically ill people's self-management. Chronically ill people reported that they received high-quality chronic illness care. However, involving patients' social environment with their care and intensive follow-up to assess patients' progress are aspects that need more attention in chronic illness care. The care chronically ill people receive differs per type of disease. People diagnosed with diabetes or COPD have, next to their appointments with their medical specialist, regular check-ups with a practice nurse or specialised nurse, in which their health status is checked and treatment goals are set. In contrast, people with diseases such as neurological diseases or musculoskeletal disorders usually do not have contact with a practice nurse. The way chronic illness care is provided is related to patients' self-management knowledge and behaviour. Helping patients understand their central role in managing their illness, make informed choices and engage in healthy behaviour is likely to improve chronically ill people's level of self-management. The findings in this chapter suggest that nurses are qualified to provide high-quality chronic illness care and could therefore be seen as valuable contributors to this mission. However, the quality of the care chronically ill people receive is one of the many factors that have an impact on patients' self-management, but it is certainly not the only factor.

The **Illustration 'Self-management and received healthcare'** illustrates that the support chronically ill people experience with their self-management differs per healthcare provider and per patient. This makes it difficult to state whether or not healthcare providers offer chronically ill people sufficient support with their self-management. In general, chronically ill people feel that their care is well-organised. However, they also feel that the healthcare system has become more bureaucratic and less focused on the patient as a whole. Chronic illness care is often complex, as many different healthcare providers are involved, such as the GP, practice nurse, medical specialist,

physiotherapist or pharmacist, and these healthcare providers do not always cooperate or communicate well with each other. Chronically ill people sometimes feel overwhelmed by all the things they need to do, and feel like they continuously need to make sure they receive the care they need. Healthcare chiefly seems to focus on taking care of the chronic condition, and less attention seems to be paid to the context of patients' lives.

Conclusion

Self-management of people with chronic illness encompasses more than medical management and making lifestyle changes. Self-management also involves communicating properly and actively with healthcare providers and coping with the consequences of being chronically ill in daily life. Support from healthcare providers should focus on all these different aspects of self-management, as they are all related to each other. For instance, someone who is able to communicate in an effective manner with healthcare providers, will probably understand his or her medical treatment better and will consequently be more likely to take his or her medication as prescribed.

Self-management takes place in the individual context of someone's personal life. Self-management and related support needs are therefore determined by this life context. To better understand the difficulties chronically ill people encounter with self-management, one should have an understanding of their life context. Is a person still working full time and how are things at work, does he or she have a relationship and how is this relationship or does a person have children and how are these children doing?

The needs of chronically ill people for self-management support change over time. The support needs at one moment in time can change completely within the space of few months. These changes can be related to changes in the course of the illness, in personal life context, or in both. Either way, self-management is a dynamic process that requires support throughout the whole process and not just during the first months or years of the chronic illness. Finally, it is questionable whether a disease-specific approach of chronic illness care is appropriate to improve care for all people with chronic illness, including those who suffer from less prevalent chronic diseases or from multimorbidity. Although some self-management tasks might be disease specific, self-management support in general does not need to be disease specific. Comprehensive chronic illness care that starts from patients individual goals,

preferences and competencies instead of patients' chronic disease type(s) may be a promising way to improve the quality of chronic illness care for all.

Samenvatting (summary in Dutch)

Mensen met een chronische ziekte hebben veel uitdagingen in hun dagelijkse leven, zoals omgaan met een beperkte hoeveelheid energie, het correct gebruik van medicatie, effectief communiceren met zorgverleners, etc. Deze verschillende taken worden ook wel zelfmanagement genoemd. Zelfmanagement bestaat uit het omgaan met symptomen, behandelen van de ziekte, maken van leefstijlveranderingen en omgaan met de fysieke en psychosociale gevolgen van de chronische ziekte. Het doel van zelfmanagement is om de impact van de chronische ziekte op het dagelijks leven te minimaliseren om zo een goede kwaliteit van leven te behouden. Echter niet alle mensen met een chronische ziekte zijn in staat om zelfmanagementtaken uit te voeren. De vraag is waarom sommige mensen wel in staat zijn om goed om te gaan met hun ziekte, terwijl anderen hiermee worstelen? Waarom hebben sommige mensen veel ondersteuning nodig van zorgverleners, terwijl anderen weinig ondersteuning nodig hebben? Om de zorg voor mensen met chronische ziekte te verbeteren, is het nodig om te begrijpen hoe ondersteuningsbehoeften bij zelfmanagement ontstaan. Op die manier kan de zorg worden aangepast aan de specifieke individuele behoeften van mensen met een chronische ziekte. Doel van deze studie is om inzicht te krijgen in de zelfmanagementtaken van mensen met een chronische ziekte en hun behoeften aan ondersteuning bij zelfmanagement.

Wat zelfmanagement zo complex maakt, is dat zelfmanagement en de daaraan gerelateerde zorgbehoeften worden beïnvloed door veel verschillende aspecten van het leven van mensen met een chronische ziekte. Allereerst is de ziekte en het ziekteverloop hierop van invloed. Mensen met COPD moeten hele andere zelfmanagementtaken uitvoeren dan mensen met diabetes en het is waarschijnlijk veel moeilijker om goed met je chronische ziekte om te gaan wanneer deze verslechtert dan wanneer deze stabiel is. Ten tweede, vindt zelfmanagement plaats in de individuele context van mensen hun persoonlijke leven. Omgaan met een chronische ziekte is heel anders wanneer je jong bent, fulltime werkt en de zorg voor jonge kinderen hebt, dan wanneer je gepensioneerd bent en geen zorg voor kleine kinderen meer hebt. Verder is de professionele zorg die mensen ontvangen een belangrijke bron voor zelfmanagement. Tegenwoordig wordt van zorgverleners verwacht dat zij mensen met een chronische ziekte in staat stellen om beslissingen te nemen in de dagelijkse zorg voor hun ziekte. In hoeverre zorgverleners ervoor kiezen

om een ondersteunende en coachende rol op zich te nemen verschilt per zorgverlener en hangt af van hun kennis, houding en vaardigheden.

Om een beter begrip te krijgen van de variatie in zelfmanagementgedrag en daaraan gerelateerde ondersteuningsbehoeften, zal in dit onderzoek worden gefocust op de volgende vragen:

1. In hoeverre kan het zelfmanagement van mensen met een chronische ziekte en daaraan gerelateerde ondersteuningsbehoeften worden verklaard door het type ziekte en het ziekteverloop?
2. In hoeverre kan het zelfmanagement van mensen met een chronische ziekte en daaraan gerelateerde ondersteuningsbehoeften worden verklaard door hun levensfase?
3. In hoeverre kan het zelfmanagement van mensen met een chronische ziekte en daaraan gerelateerde ondersteuningsbehoeften worden verklaard door de manier waarop zorg aan mensen met een chronische ziekte wordt verleend?

Om een antwoord te krijgen op deze vragen richt deze studie zich op het perspectief van mensen met een chronische ziekte. Alle data die is gebruikt in dit proefschrift is afkomstig van mensen uit het Nationaal Panel Chronisch Zieken en Gehandicapten (NPCG). Dit is een landelijk representatieve panel waarin mensen bevraagd worden over hun ervaringen met en de gevolgen van leven met een chronische ziekte of beperking. In deze studie is gebruik gemaakt van zowel kwantitatieve als kwalitatieve onderzoeksmethoden. Data zijn verzameld door middel van vragenlijsten en focusgroepen met mensen met een chronische ziekte. De informatie uit de focusgroepen is gebruikt ter illustratie van de kwantitatieve bevindingen om zo deze bevindingen beter te begrijpen en interpreteren.

Dit proefschrift bestaat uit drie delen: (1) zelfmanagement en ziekteverloop (*hoofdstuk 2 en 3*), (2) zelfmanagement en levensfase (*hoofdstuk 4 en 5*), en (3) zelfmanagement en gezondheidszorg (*hoofdstuk 6*).

Het proefschrift begint met een illustratie van zelfmanagement in de dagelijkse praktijk, gebaseerd op de focusgroep gesprekken met mensen met een chronische ziekte (**Illustration 'Self-management in daily practice'**). In deze illustratie wordt beschreven wat mensen met een chronische ziekte zelf onder zelfmanagement verstaan en welke zelfmanagementactiviteiten zij in

hun dagelijks leven moeten uitvoeren. De verdeling die in de literatuur en in de studie wordt gemaakt tussen verschillende zelfmanagementtaken, zoals medische management, het maken van leefstijlveranderingen, communicatie met zorgverleners en omgaan met de gevolgen van chronisch ziek zijn, komt terug in de verhalen van mensen met een chronische ziekte. Medisch management en het maken van leefstijlveranderingen worden expliciet genoemd door mensen als taken om de chronische ziekte onder controle te krijgen. Communicatie met zorgverleners en omgaan met de gevolgen van een chronische ziekte in het dagelijks leven worden juist gezien als onvermijdelijke aspecten van het chronisch ziek zijn. Mensen met een chronische ziekte kunnen er niet voor kiezen om *niet* te communiceren met zorgverleners of om *niet* om te gaan met de gevolgen van hun ziekte. Maar ze kunnen wel beslissen *hoe* ze communiceren met zorgverleners en *hoe* ze omgaan met de gevolgen van hun ziekte.

Hoofdstuk 2 beschrijft de zelfmanagementtaken en ondersteuningsbehoeften van mensen met een chronische ziekte en onderzoekt in hoeverre deze bepaald worden door het type ziekte waarmee mensen zijn gediagnosticeerd. Hoewel mensen met een chronische ziekte behoorlijk wat zelfmanagementtaken voor zichzelf zien weggelegd, hebben zij over het algemeen niet een expliciete behoefte aan zelfmanagementondersteuning. De behoefte aan ondersteuning is niet sterk gerelateerd aan de hoeveelheid taken die mensen voor zich zelf zien weggelegd. Dus wanneer mensen meer taken moeten uitvoeren, betekent dit niet dat zij ook meer ondersteuning nodig hebben. Wel is er een samenhang tussen de ondersteuningsbehoeften op verschillende aspecten van zelfmanagement. Mensen die behoefte hebben aan ondersteuning op één bepaald aspect van zelfmanagement, bijvoorbeeld met medisch management, hebben waarschijnlijk ook behoefte aan ondersteuning op een ander aspect van zelfmanagement.

Er zijn veel overeenkomsten in de zelfmanagementtaken van mensen met verschillende soorten ziektes. Bijna alle mensen met een chronische ziekte nemen medicijnen, bezoeken regelmatig een arts en moeten een manier vinden om de chronische ziekte in hun leven te passen. Toch zijn er ook verschillen tussen mensen met verschillende ziektes. Mensen gediagnosticeerd met diabetes of mensen met een neurologische aandoening zien bijvoorbeeld meer taken voor zichzelf weggelegd in hun dagelijkse

omgang met hun chronische ziekte dan mensen die zijn gediagnosticeerd met andere ziektes. De ondersteuningsbehoeften van mensen met een chronische ziekte bij zelfmanagement verschillen minder per type ziekte. Dus ondanks dat de zelfmanagementtaken deels ziekte specifiek zijn, betekent dit nog niet dat de ondersteuning bij zelfmanagement ziekte specifiek moet zijn. Ondersteuningsprogramma's bij zelfmanagement kunnen een meer generieke aanpak gebruiken. Ook moeten ondersteuningsprogramma's zich niet alleen focussen op de medische en leefstijl aspecten van zelfmanagement, maar ook op de communicatie met zorgverleners en het omgaan met de gevolgen van de chronische ziekte.

Hoofdstuk 3 beschrijft in hoeverre ondersteuningsbehoeften van mensen met een chronische ziekte bij zelfmanagement afhangen van hun ziekteverloop. Behoeften aan zelfmanagementondersteuning zijn niet afhankelijk van de duur van de ziekte. De behoeften aan ondersteuning zijn even hoog voor mensen die nog maar net zijn gediagnosticeerd met een chronische ziekte als voor mensen die al langere tijd een chronische ziekte hebben. Dit suggereert dat ondersteuningsbehoeften kunnen ontstaan op elk moment in het ziekteproces. De manier waarop de ziekte zich ontwikkelt is een betere indicatie voor ondersteuningsbehoeften bij zelfmanagement. Mensen, die het verloop van hun ziekte ervaren als episodisch of progressief verslechterend, hebben meer behoefte aan ondersteuning dan mensen, die hun ziekteverloop ervaren als stabiel. Ook veranderingen in de ervaren gezondheid hebben een effect op de ondersteuningsbehoeften van mensen met een chronische ziekte. Wanneer de ervaren gezondheid verslechtert, neemt de behoefte aan ondersteuning toe en wanneer de ervaren gezondheid verbetert, neemt de behoefte aan ondersteuning af. Deze bevindingen laten zien dat ondersteuning bij zelfmanagement niet alleen moet worden gegeven in de eerste jaren na de diagnose. Verder moeten zorgverleners meer aandacht besteden aan de percepties van patiënten over hun ziekteverloop en hun gezondheid.

De tweede illustratie in dit proefschrift (**Illustration 'Self-management according to type and course of illness'**) bevestigt dat er veel overeenkomsten zijn tussen mensen met verschillende ziektes. Wel kwam in de focusgroepen naar voren dat er verschillen zijn in de zorg die mensen met

verschillende ziektes krijgen. De zorg voor mensen met ziektes, zoals diabetes, COPD en astma, wordt gekenmerkt door regelmatige controles en het maken van behandeldoelen. De zorg voor mensen met andere ziektes, zoals artritis of reuma, lijkt juist veel meer af te hangen van de behoeften die mensen hebben aan zorg. Bij deze groep staan de afspraken niet per jaar vast, maar worden gaandeweg ingevuld. Over de jaren heen worden mensen met een chronische ziekte een expert wat betreft hun chronische ziekte en de zorg daarvoor. Dit betekent niet dat deze 'expert patiënten' geen behoefte hebben aan ondersteuning. Zowel chronische ziektes als hun behandeling en zorg veranderen in de loop der jaren. De manier waarop de ziekte verloopt, kan een goede indicatie zijn voor de ondersteuningsbehoefte van mensen met een chronische ziekte bij zelfmanagement.

In **hoofdstuk 4** wordt aandacht besteed aan leeftijd gerelateerde verschillen in zelfmanagement taken en ondersteuningsbehoeften. Oudere mensen zien meer taken voor zichzelf weggelegd in de dagelijkse omgang met hun ziekte dan jongere mensen. Ook hebben zij vaker behoefte aan ondersteuning bij zelfmanagement. Dit komt deels doordat oudere mensen veelal meerdere ziektes hebben, hun fysieke beperkingen ernstiger zijn en hun gezondheidstoestand vaker levensbedreigender is dan bij jongere mensen. Dit effect van leeftijd op zelfmanagement wordt verminderd doordat jongeren vaker hun chronische ziekte als een bedreiging zien en doordat jongeren sterker het gevoel hebben dat zij controle uit te kunnen oefenen op hun ziekte dan ouderen. Dit impliceert dat wanneer rekening wordt gehouden met de verschillen in de fysieke toestand tussen jongeren en ouderen, jongeren meer bereid zullen zijn om zelfmanagementtaken uit te voeren dan ouderen. Dit kan worden verklaard doordat chronisch ziek zijn iets anders betekent voor jongeren dan voor ouderen. Het hebben van een chronische ziekte past niet in het beeld dat jongere mensen hebben van hun leven en bij de doelen die zij nastreven. Terwijl ouderen het hebben van een chronische ziekte vaak zien als een onvermijdelijk onderdeel van ouder worden. Kortom, de fase van leven waarin mensen met een chronische ziekte zich bevinden, heeft een toegevoegde waarde bij het verklaren van leeftijd gerelateerde verschillen in zelfmanagementtaken en ondersteuningsbehoeften. Daarom moet de persoonlijke situatie van mensen met een chronische ziekte mee worden genomen in de ondersteuning bij zelfmanagement.

Hoofdstuk 5 beschrijft in hoeverre zelfmanagement wordt belemmerd door alledaagse problemen. Een derde van de mensen met een chronische ziekte heeft problemen in hun alledaagse leven. Dit kunnen basis problemen zijn, zoals financiële problemen, problemen met huisvesting of problemen op werk, maar het kunnen ook sociale problemen zijn, zoals problemen met partner of kinderen, seksuele problemen of problemen met vrijetijdsbesteding. Jongere mensen, mensen met een slechte gezondheid of mensen met fysieke beperkingen hebben meer kans op het hebben van alledaagse problemen. Het hebben van alledaagse problemen maakt het moeilijker om goed om te gaan met een chronische ziekte. Dit komt doordat mensen met alledaagse problemen minder tijd, energie of motivatie hebben voor optimaal zelfmanagement. Het effect van alledaagse problemen hangt af van het soort problemen dat mensen hebben en van de zelfmanagementactiviteit die mensen moeten uitvoeren. Bijvoorbeeld, het hebben van basis problemen hangt samen met minder actief coping gedrag, terwijl het hebben van sociale problemen samenhangt een lager niveau van symptoom management. Het is belangrijk dat zorgverleners de persoonlijke omstandigheden van mensen met een chronische ziekte betrekken in het consult, aangezien deze omstandigheden mede bepalen in hoeverre mensen in staat zijn goed om te gaan met hun ziekte.

De volgende illustratie (**Illustration ‘Self-management and the life context’**) laat zien wat chronisch ziek zijn betekent voor mensen en wat er allemaal nodig is om een zo ‘normaal’ mogelijk leven te kunnen leiden. Dit hangt af van de individuele situatie en de levensloop van mensen. Voor jongere mensen is het moeilijker om te accepteren dat ze een chronische ziekte hebben. Oudere mensen daarentegen lijken minder gehinderd te worden door de chronische ziekte, doordat zij het als een onvermijdelijk aspect van ouder worden beschouwen. Het hebben van een chronische ziekte beïnvloedt de werksituatie van mensen met een chronische ziekte. Sommigen zijn niet langer meer in staat om te werken door hun ziekte, andere mensen moeten allerlei regelingen met de werkgever treffen om te kunnen blijven werken. Hoe dan ook, je kunt een chronische ziekte niet negeren wanneer je een betaalde baan hebt. Hetzelfde geldt voor familie. De chronische ziekte heeft ook een grote invloed op de levens van familieleden. Zij kunnen bezorgd

zijn over de gevolgen van de chronische ziekte en zij zijn ook vaak degenen die meehelpen in de zorg voor de chronische ziekte. Tot slot, mensen met een chronische ziekte hebben meer problemen in hun leven dan alleen de zorg voor hun ziekte. Zo kunnen ze in een scheiding liggen, een partner hebben met gezondheidsproblemen, of financiële problemen hebben. Wanneer zorgverleners zelfmanagement zien als een onderdeel van het leven van patiënten, is het wellicht beter te begrijpen waarom sommige mensen met een chronische ziekte niet in staat of gemotiveerd zijn om bijvoorbeeld de gewenste leefstijlaanpassingen te doen of om hun ziekte te accepteren.

Hoofdstuk 6 besteedt aandacht aan de mate waarin de kwaliteit van de zorg voor chronische zieken bijdraagt aan het niveau van zelfmanagement. Mensen met een chronische ziekte zijn redelijk tevreden met de kwaliteit van de zorg die zij ontvangen. Al zijn er nog aspecten van de zorg die meer aandacht verdienen, zoals het betrekken van de omgeving van de patiënt bij de zorg en intensieve nazorg waarbij de voortgang van patiënten goed wordt gemonitord. De zorg die mensen met een chronische ziekte ontvangen verschilt per soort ziekte. Mensen gediagnosticeerd met diabetes of COPD hebben vaker regelmatige controles bij een praktijkondersteuner (POH) of gespecialiseerde verpleegkundige naast de afspraken die ze met hun huisarts voor medisch specialist hebben. In tegenstelling, mensen met neurologische ziektes of spieraandoeningen hebben over het algemeen geen contact met een POH of gespecialiseerde verpleegkundige. De manier waarop zorg wordt verleend is van invloed op de kennis van patiënten over zelfmanagement en hun zelfmanagementgedrag. Door patiënten te helpen bij het begrijpen van hun centrale rol in de zorg voor hun chronische ziekte, het maken van beslissingen in de zorg en het bevorderen van een gezonde leefstijl zal hun niveau van zelfmanagement stijgen. De bevindingen van deze studie laten zien dat POH's en gespecialiseerde verpleegkundigen zeer geschikt zijn om dit soort zorg te verlenen en daarmee de kwaliteit van zorg te verbeteren.

De laatste illustratie (**Illustration 'Self-management and received healthcare'**) laat zien dat de ervaringen van mensen met een chronische ziekte met professionele ondersteuning bij zelfmanagement verschillen per patiënt en per zorgverlener. Dit maakt het moeilijk om algemene uitspraken te doen over het niveau van zelfmanagementondersteuning in zorg. Wel is

duidelijk dat de meeste mensen met een chronische ziekte het gevoel hebben dat hun zorg goed is georganiseerd. Ze hebben echter ook het gevoel dat de gezondheidszorg steeds bureaucratischer is geworden en steeds minder gericht is op de patiënt als een geheel. Verder blijkt dat de zorg bij een chronische ziekte vaak erg complex is, omdat er meerdere zorgverleners bij betrokken zijn, zoals de huisarts, POH, medisch specialist, fysiotherapeut of apotheker. Deze verschillende zorgverleners werken niet altijd goed samen en de informatie over de patiënt wordt vaak niet met elkaar gedeeld. Al met al hebben mensen met een chronische ziekte regelmatig het gevoel dat zij alles zelf moeten doen en dat zij regelmatig moeten checken of alles wel goed gaat in de zorg voor hun ziekte. Zorgverleners lijken zich vooral op de ziekte te focussen en weinig aandacht te geven aan de context waarin mensen met een chronische ziekte zich in bevinden.

Conclusie

Allereerst, zelfmanagement van mensen met een chronische ziekte omvat meer dan alleen medisch management en het maken van leefstijlaanpassingen. Zelfmanagement draait ook om communicatie met zorgverleners en omgaan met de gevolgen van de ziekte in het alledaagse leven. Deze verschillende aspecten van zelfmanagement staan niet los van elkaar. Bijvoorbeeld, als iemand in staat is om op een effectieve manier te praten met zijn zorgverleners dan zal diegene waarschijnlijk ook beter begrijpen wat zijn medische behandeling inhoudt en daarmee ook beter in staat zijn om zijn medicatie correct in te nemen. Daarom is het belangrijk dat zorgverleners ondersteuning bieden op alle aspecten van zelfmanagement.

Ten tweede, zelfmanagement vindt plaats in het alledaagse leven van mensen met een chronische ziekte. Om de moeilijkheden in kaart te brengen die mensen met een chronische ziekte tegenkomen bij zelfmanagement, is begrip van de persoonlijke leefomstandigheden nodig. Werkt iemand nog fulltime en hoe is de situatie op de werkvloer? Heeft iemand een relatie en is dit een stabiele relatie of zijn er problemen? Heeft iemand kinderen en gaat alles goed met deze kinderen? Hoe het leven van mensen met chronische ziekte is ingevuld, welke doelen zij nastreven en welke problemen zij hebben in hun alledaagse leven, bepalen in hoeverre ze in staat zijn om zelfmanagement activiteiten uit te voeren.

Ten derde, de ondersteuningsbehoeften van mensen met een chronische

ziekte bij zelfmanagement veranderen in de loop der tijd. De ondersteuningsbehoeften die mensen nu hebben, kunnen binnen enkele maanden compleet anders zijn. Deze veranderingen in ondersteuningsbehoeften worden beïnvloed door veranderingen in het ziekteverloop, het leven van mensen met een chronische ziekte of in beide. Wat deze veranderingen ook teweeg brengt, belangrijk is om er van bewust te zijn dat zelfmanagement een dynamisch proces is waarbij ondersteuning nodig is gedurende het gehele ziekteproces en niet alleen in de eerste periode na de diagnose.

Ten slotte, is het de vraag of een ziekte specifieke aanpak van de zorg voor chronisch zieken de beste manier is om de zorg voor alle mensen met een chronische ziekte te verbeteren. Vooral mensen met een zeldzame ziekte of met meerdere chronische ziektes lopen het risico om buiten de boot te vallen bij deze aanpak. Deze studie laat zien dat ondersteuning bij zelfmanagement over het algemeen generiek geven kan worden, ondanks de (kleine) verschillen in zelfmanagementtaken tussen mensen met verschillende ziektes. De individuele doelen, voorkeuren en competenties van mensen met een chronische ziekte vormen een beter startpunt voor ondersteuning dan de chronische ziekte die mensen hebben.

Appendix

Methodology of focus group sessions

To illustrate the quantitative findings, we used data collected during focus group sessions held with chronically ill people in September 2013. For these meetings, we recruited participants among chronically ill people living nearby Utrecht (location of the focus group sessions) who were no longer a member of the National Panel of people with Chronic illness or Disability (NPCD), but indicated that were interested in participating in future research. In total, 269 chronically ill people were invited. A quarter of these people replied, of which 37 people (14%) were willing to participate. Reasons for not participating were diverse, but no time and not being able to come due to physical limitations were mentioned most often. In the end, thirty chronically ill people participated in the focus group meetings (8-12 participants per meeting). Two thirds of the participants was male and one third female. The average age was 63 years and varied from 35 to 86 years.

All three focus group meetings took place at NIVEL in Utrecht and the duration of the meetings was 2 hours, including a 15 minute break. The meetings were led by an experienced moderator and observed by the PhD student. The focus group meetings started with a short round of introductions in which the participants explained what living with a chronic conditions entails for them. The focus group meetings were guided by a semi-structured topic list and participants were encouraged to bring forward any other relevant information. This list covered the following topics: definition of the concept self-management, self-management behaviour, difficulties with self-management, self-management support, self-management support needs and individual care plans. Discussions were audio-taped (with the participants' informed consent) and complete transcripts were produced.

The two researchers who guided the sessions read all transcripts and independently wrote a memo for all three focus groups in which the most important or remarkable outcomes were described. These memos were subsequently compared and discussed. Moreover, the PhD student systematically coded the transcripts. Examples of these codes are 'self-management', 'chronic illness', 'medical management', and 'coping'. The process of ordering and coding was assisted by MaxQda.

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Curriculum vitae

Lieke van Houtum was born on the 25th of October 1984 in Haarlem, the Netherlands. After finishing secondary education (atheneum) at Sancta Maria in Haarlem in 2003, she studied Interdisciplinary Social Science at the University of Amsterdam. In 2009, she obtained her Master's degree in Medical Anthropology and Sociology at the University of Amsterdam as well as her Master's degree in Social Policy and Social Interventions.

In 2009, she started working at NIVEL, the Netherlands Institute for Health Services Research. She worked on several projects within the research program 'Care demand of chronically ill and disabled'. In 2010, she started with the research described in this PhD thesis, under the supervision of prof. dr. Peter Groenewegen and dr. Mieke Rijken. During that time, she published several research articles in international journals and presented her work at several national and international conferences.

Lieke is currently working at the Dutch Diabetes Research Foundation, where she monitors several research projects regarding the quality of life of people with diabetes and complications related to diabetes.

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