BEING CREATIVE AND RESOURCEFUL

Individuals’ abilities and possibilities for self-management of chronic illness

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“Hospitals are only an intermediate stage of civilization, never intended, at all events, to take in the whole sick population.”
Florence Nightingale (McDonald, 2004, p218)

To Vidar and Kettil, who keep teaching me more about self-management. In memory of Karin Bjermert, who never became a nurse.
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ABSTRACT

Individuals’ self-management styles are crucial for how they manage to live with illness. Commonly investigated factors include social support, self-efficacy, health beliefs, and demographics. There is a gap in the literature with regard to in-depth studies of how those factors actually influence an individual’s self-management.

The aim of this thesis was to investigate the underlying mechanisms of self-management from the perspective of individuals living with chronic illness.

Interviews were conducted with 47 individuals with various chronic illnesses, some of them repeatedly over two and a half years (a total of 107 interviews). The material was analysed with; constructive grounded theory, content analysis, phenomenography, and interpretive description.

The Self-management Support Model identified aspects that influenced participants’ self-management: economic and social situation, social support, views and perspectives on illness, attribution of responsibility, and ability to integrate self-management into an overall life situation. For example, individuals with a life-oriented or disease-oriented perspective on illness prioritized different aspects of self-management. People who attributed internal responsibility performed a more complex self-management regimen than individuals who attributed external responsibility. In conclusion, individuals who were creative and resourceful had a better chance of tailoring a self-management regimen that suited them well. People in more disadvantaged positions (e.g., financial strain, limited support, or severe intrusive illness) experienced difficulty in finding a method of self-management that fit their life situation.
These findings can inspire healthcare providers to initiate a reflective dialogue about self-management with their patients.

Keywords: Self-management, self-care, chronic illness, chronic disease, qualitative research, life conditions, beliefs and values, self-management integration, longitudinal
SVENSK SAMMANFATTNING


Syftet med denna avhandling är att undersöka hur olika livs faktorer, värderingar och processer påverkar individens egenvård av kronisk sjukdom.


I avhandlingen presenteras en modell över aspekter som samverkar till att påverka deltagarnas egenvård. I modellen visas att deltagarnas livsvillkor och social omgivning avgjorde möjligheterna för vilken egenvård deltagarna kunde utveckla.

Deltagare som var kreativa och resursstarka hade goda förutsättningar att utveckla en anpassad egenvård. Till exempel hade personer med ekonomiska resurser större möjligheter att välja egenvård, sociala resurser kunde motivera egenvård och ge praktisk hjälp, kunskaps resurser medverkade till att deltagare fann egenvårdsstrategier som passade deras livssituation. Kreativitet påverkade också egenvård på många plan; kreativa deltagare kunde mobilisera resurser, navigera sjukvårdsystemet, betrakta egenvård från olika perspektiv och finna innovativa lösningar för att anpassa sin egenvård till sin livssituation. Medan personer i mer utsatta situationer (exempelvis med ansträngd ekonomi, arbetslöshet eller en sjukdom som påverkade stora delar av livet) hade svårare att finna lämplig och effektiv egenvård.

Möjligheterna att diskutera egenvård på svenska är begränsad. Delvis beroende på att varken egenvård eller sjukdomshantering är ord som används i dagligt tal, dessutom används ordet egenvård med olika definitioner i skilda sammanhang.
Sedan hanterar de flesta personer sina sjukdomar utan att reflektera över sina strategier. Många personer saknar ord och begrepp för att diskutera hur de hanterar eller skulle vilja hantera sin situation.

Enligt denna forskning informerar vårdpersonal främst om medicinering och livsstilsförändringar. Vårdpersonal skulle kunna informera om fler former av egenvård, hjälpa sina patienter att identifiera hinder och stödja hur deras patienter integrerar egenvård i sina liv. Avhandlingen presenterar ett kommunikationsverktyg som kan inspirera vårdpersonal att utveckla en reflektiv dialog om egenvård med sina patienter.

Nyckelord: Egenvård, sjukdomshantering, kronisk sjukdom, kvalitativ forskning, livsvillkor, värderingar, egenvårds integrering, hantering, anpassning.
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LIST OF PAPERS

The thesis is based on the following papers, which are referred to in the text by their Roman numerals:


1. INTRODUCTION

The woman looked accusingly at me. Couldn’t I do anything for her, give her something? Couldn’t I give her a magic drug that would take away all her troublesome, but not life-threatening, symptoms? And I did nothing for her. I told myself there was nothing neither I nor her physician could do. She was a problematic ‘frequent flyer’ who believed that the healthcare sector could help her. Her strategy for managing her symptoms was to seek acute healthcare; she lacked strategies to manage her symptoms by herself. And I lacked a way to support her...

In recent years, the treatment possibilities for many chronic diseases (e.g., diabetes, rheumatism, multiple sclerosis, and asthma) have changed the lives for millions of people (World Health Organization, 2005). However, there are a lot of symptoms and life challenges that lack sufficient medical treatment options (e.g., pruritus, fatigue, or emotional distress related to living with a chronic disease). Healthcare providers can often treat the pathophysiological aspects of the disease, but they have limited tools for supporting an individual’s self-management of illness. For example, current treatment of people with rheumatoid arthritis involves drugs that are effective for prevention of joint destruction (Haraoui & Pope, 2011). However, many people with rheumatoid arthritis receive little support when struggling with pain management (Shariff et al., 2009). Research has revealed that healthcare providers sometimes find it difficult to address self-management during consultations (Blakeman, Bower, Reeves, & Chew-Graham, 2010). Part of this difficulty is related to their lack of strategies for discussing self-management issues (Bodenheimer, 2007; Wagner, Austin, & von Korff, 1996).

The existing literature concerning self-management of chronic illness has predominantly focused upon self-management of a single diagnosis (e.g., diabetes, asthma, or heart failure) (Bayliss, Steiner, Fernald, Crane, & Main, 2003). Previous research has also emphasized certain elements of self-management, such as taking medication or lifestyle changes. Seldom has self-management of chronic illness been investigated as a whole (Kralik, Price, & Telford, 2010). Research has identified a large number of factors that influence self-management, whereas few studies have explored interactions among those factors or the underlying mechanisms of how they influence self-management. This thesis intends to fill this gap by providing a model for understanding self-management, emphasizing aspects often overlooked in self-management research (e.g., complexity of self-management, attribution of responsibility, and self-management integration), and
showing how those aspects influence self-management. These findings can be used by healthcare providers to initiate a nuanced, reflective dialogue about self-management with their patients.

The introduction continues with a brief description about the research position underlying my work and later follows some concept definitions. The background consists of the following three parts: the first describes chronic disease and self-management from a societal perspective, the second accounts for the individual’s perspective on chronic illness and self-management, and the third is a literature review of identified barriers to and facilitators of self-management.

1.1. Research position

My ontological and epistemological perspective is grounded in critical realism. Critical realism was developed as an answer to the differentiation between natural and social sciences. The philosophy of critical realism suggests a shared ontology and epistemology for the natural and social sciences, challenging the notion of causation and acknowledging the fact that interpretation is necessary in understanding social life (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998).

The reality of critical realism is stratified into three domains: the actual (observable events and objects), the real (underlying structures), and the empirical (humans perceptions, experiences, and scientific knowledge) (Sayer, 2000). According to critical realism, the world is complex, and every event is influenced by countless factors. In order to explain why events occur, the focus should be on all three domains of reality to identify patterns of mechanisms and their way of functioning (e.g., triggers and circumstances), instead of regularities (A.M. Clark, Lissel, & Davis, 2008). A critical realism perspective does not attest to solely qualitative or quantitative research methods. The most important thing is that the research method corresponds with the research question, and different approaches can be used in combination. This theory relies on the notion that the world is complex, and different domains of reality must be researched using different methods (A.M. Clark et al., 2008; Sayer, 2000).

In the following section, I explain some assumptions that have provided a basis for my work. First and foremost, this thesis concerns people who have chronic disease, not patients. Individuals are only patients in relation to healthcare providers, and chronic illness self-management is performed in relation to almost all aspects of a person’s life. Second, I believe that people act in a logical way that depends upon how they understand their world. People understand their world in different ways, and therefore, two individuals may act differently in a similar situation (cf.
Fishbein, 2008). The third assumption is that I do not attempt to judge an individual’s behavior as good or bad. Accordingly, certain self-management regimens should not be judged as better than others. Nonetheless, behavior can be deemed more or less successful at improving health and controlling illness. At times, I have used the terms ‘more or less’ to describe self-management, and this terminology only refers to how often a behavior is performed and how many self-management behaviors an individual performs overall. More self-management is not necessarily better. Rather, ‘sufficient’ self-management is a self-management regimen that is tailored to benefit both the individual’s health and his or hers life goals.

1.2. Definitions

1.2.1. Chronic disease and chronic illness

Research literature uses the following concepts for chronic illness, often interchangeably: chronic illness, chronic disease, chronic condition, and long-term medical condition (Wellard, 2010). In this thesis, the concept of ‘disease’ represents the traditional perspective held by healthcare providers, which focuses on a pathological physical process and diagnoses (cf. Kleinman, 1988). Consequently, chronic disease is defined as a condition not curable by medical intervention and requiring periodic monitoring and supportive care in order to reduce illness and facilitate functioning (cf. Donelly, 1993). In contrast, chronic illness is the individual’s perception and experience of living with a chronic disease (cf. Toombs, 1992). The term ‘chronic’ is not ideal, as many diseases can have long periods of remission, and some conditions are defined as chronic by healthcare providers but might be perceived as temporary by the people involved (e.g., ischemic heart disease or asthma) (e.g., Halm, Mora, & Leventhal, 2006). Nevertheless, I will use the term ‘chronic’ only to indicate the temporal nature of the disease. This thesis was built upon interviews with people with chronic diseases of a medical character, including the following: rheumatic diseases, inflammatory bowel disease, diabetes, multiple sclerosis, chronic kidney insufficiency, and ischemic heart disease. Therefore, when using the term ‘chronic disease’, I am referring to medical conditions similar to the aforementioned diagnoses.

Health has traditionally been understood as the absence of disease or pathological test results. However, that definition is problematic for people living with a chronic disease because it means that they can never again be seen as healthy. Here, health will be referred to as a subjective experience of wellness (cf. Mechanic, 1999).
1.2.2. Self-management

Self-management and self-care are often used interchangeably. However, Orem (2001) defines self-care as “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (p43), which includes eating, washing, and interacting with others. Meanwhile, self-management involves activities strategies a person performs to live well with illness (cf. Battersby, Lawn, & Pols, 2010). Self-management includes taking medication, exercising, following a diet, seeking healthcare, managing pain or other symptoms, managing emotions, and adapting household and leisure activities to one’s current capabilities (cf. N.M. Clark et al., 1991). There exist several definitions of self-management in the literature, and the differences are mostly due to how researchers position themselves towards the following issues: i) if self-management can be self-initiated or must be performed in collaboration with healthcare providers (e.g., N.M. Clark et al., 1991; Kralik et al., 2010) ii) if self-management can be performed by the individual or in collaboration with a significant other (cf. Wagner, Bennett, Austin, Greene, Schaefer, & von Korff, 2005), and iii) if self-management is viewed solely as a mediator in controlling disease (Kralik et al., 2010) or also as a way to manage living with illness (Kralik, Koch, Price, & Howard, 2004). I hold that self-management i) can either be in collaboration with healthcare providers or be self-initiated, ii) can be in collaboration with a significant other (e.g., a partner giving an insulin injection), and iii) self-management includes strategies to both control disease and live well with illness. When I use the term ‘self-management regimen’, I mean a general self-management plan, like when an individual has decided to exercise two times a week. In the individual papers I have investigated additional terms (e.g., illness perspectives, self-management integration), and they are defined in Table 1.

There are similarities between coping (Lazarus & Folkman, 1996) and self-management. Coping is used to mediate all kinds of stressful events, and self-management aims to manage health and wellness. In previous research, many elements of self-management have been investigated separately and using different terms. As a result, research using various terms has been included in the literature review (e.g., self-medication (De Bolle et al., 2008), self-treatment (Stevenson, Britten, Barry, Bradley, & Barber, 2003), compliance and adherence (Trostle, 1988), lifestyle changes (Condon & McCarthy, 2006), and coping with chronic illness (N.M. Clark et al., 1991; De Ridder, Geenen, Kuijer, & van Middendrop, 2008).
### Table 1. Concept definitions used in the individual papers.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper I Self-management negotiation</td>
<td>An inner ongoing process where the pros and cons of self-management are compared with each other.</td>
</tr>
<tr>
<td>Paper II Responsibility attribution</td>
<td>Beliefs the individual holds concerning if he/she is responsible for certain events or actions. Individuals are responsible for many things but this study refers to perceived responsibility for self-management and health status.</td>
</tr>
<tr>
<td>Paper III Illness perspectives</td>
<td>Perspectives that includes the individual’s attitudes, beliefs, and values about living with a disease.</td>
</tr>
<tr>
<td>Paper IV Self-management integration</td>
<td>A process in which self-management activities are assimilated into the individual’s life situation.</td>
</tr>
</tbody>
</table>
2. BACKGROUND

2.1. Chronic disease and self-management – a societal perspective

“It is vital that the increasing importance of chronic disease is anticipated, understood and acted upon urgently. This requires a new approach by national leaders who are in a position to strengthen chronic disease prevention and control efforts, and by the international public health community.” (WHO, 2005, p.1)

Chronic disease is a growing problem all around the world. In 2005, chronic disease, such as heart failure, diabetes, chronic respiratory disease, and cancer, accounted for 60% of all deaths (35 million) (WHO, 2005). However, these figures do not account for the major expense of chronic illness to society or the individual’s suffering.

No summarized statistics exist for how many people live with chronic disease in Sweden. However, about 6% of the Swedish population has diabetes (Socialstyrelsen, 2010), over 1% has rheumatoid arthritis or another inflammatory rheumatic disease (Lindblad, Essén, & Stawiarz, 2010). About 17,000 people in Sweden live with multiple sclerosis (Svenska MS-registret, 2011), and over 8,000 are in treatment for chronic kidney insufficiency (Svenskt njurregister, 2011).

The treatment options for people living with chronic diseases have improved over the past 50 years. Due to medical developments, some diseases are no longer considered to be lethal (e.g., diabetes, HIV), and disability caused by disease can either be prevented (e.g., rheumatoid arthritis) or postponed (e.g., multiple sclerosis) (cf. Cluff, 1981). However, many of the treatment regimens are complex and demanding. For example, a treatment regimen may require that a person lives a structured daily life, performs regular monitoring (N.M. Clark et al., 1991), and takes on responsibility for the treatment (Hibbard, Mahoney, Stock, & Tusler, 2007). At the same time, the cost of treatment to society has increased, and the decisions concerning who gets which treatment can be arbitrary (Silwer, 2007). Not all individuals receive treatment, some are undertreated, or some do not take their medication. Other troublesome aspects of living with a chronic disease (e.g., pain, fatigue, impairments) are still not easily treated or even possible to treat with currently available medications, and these aspects demand other kinds of interventions (Lorig et al., 2006).
2.1.1. Does self-management lead to better health?

Self-management has been shown to influence disease prognosis, leading to better functional ability, fewer symptoms, and fewer complications (De Ridder et al., 2008). Self-management’s positive effects on disease control have been described in people with diabetes (Hansen et al., 2009; Heisler, Cole, Weir, Kerr, & Hayward, 2007; Toljamo & Hentinen, 2001), heart failure (Schnell-Hoehn, Naimark, & Tate, 2009), and Cohn’s disease (Tanaka et al., 2006). However, most studies that aim to investigate the medical outcomes of self-management use a medical definition of self-management, predominantly investigating adherence to medications, healthful dieting, exercising, and attending healthcare follow-up visits.

The likelihood of influencing a disease prognosis differs depending on the diagnosis, because disease development may be more or less related to lifestyle behaviors and medications. Girdler and colleagues (2010) conducted a randomized, controlled trial to increase self-management among people with visual impairment. They found that participants in the intervention group participated in more life situations, reduced their depression rate, and increased their physical health after the intervention. Similarly, a review by Hibbard (2003) found that people that take a more active role in patient-provider relationship and in self-management had better health outcomes, for example, by increasing functionality and reducing pain. Other studies have found that low levels of self-management are correlated with poor psychological outcomes, such as depression, emotional distress, and low quality of life; however, in what way these variables influence each other needs further investigation (De Ridder et al., 2008).

2.1.2. The ‘self-management movement’

Self-management is not a new phenomenon. People have always tried to control illness by all possible means. In fact, self-management is both older and more widely used than healthcare-initiated care (Rogers, Bury, & Kennedy, 2009). Lorig and Holman (2003) points out that all people take part in self-management because it is impossible to not manage an illness, as to choose to not manage it is also a choice of action.

In recent years, chronic illness self-management has received more attention in response to substantial programs aimed at supporting self-management in Australia (Jordan & Osborne, 2007), Scotland (Douglas Scott, 2010), and England (Wilson & Mayor, 2006). This trend is partially attributable to evolving societal values about the individual’s right to his/her own health and to ideas from the self-help movement (Battersby et al., 2010). In addition, policy-makers in the Western world have also viewed individual self-management of disease as one way of
managing increasing healthcare costs. Policy-makers have concluded that if people performed ‘better’ self-management, they would control their diseases and, thereby, prevent costly complications and seek less healthcare assistance (Rogers et al., 2009; Wellard, 2010).

In Sweden, no general policy exists regarding self-management support. In other Western countries, the ‘self-management movement’ has been driven by the voluntary sector (Douglas Scott, 2010; Wilson & Mayor, 2006). Sweden does not have a strong voluntary sector that can provide self-management interventions. However, Sweden does have a tradition of a large healthcare sector. Self-management support by healthcare providers in Sweden has never really been explored. One study investigating consultations at a nurse-led asthma clinic found that nurses did not plan the consultations on an individual basis, and they used little time for discussing self-management issues (Österlund Efremsson, Klang, Larsson, Ehrenberg, & Fossum, 2009). Another study showed that although much of the diabetes education was performed according to guidelines, few nurses tailored the education to suit the individual patient (Thors Adolfsson, 2008). In Sweden, a few research groups have developed self-management interventions within the healthcare sector (Adolfsson, Walker-Engström, Smide, & Wikblad, 2007; Amsberg, 2008; Hörnsten, Stenlund, Lundman, & Sandström, 2008; Jönsson, Öhrn, Lindberg, & Oscarson, 2010). Most of the interventions have had positive results regarding clinical test results (Amsberg, 2008; Hörnsten et al., 2008; Jönsson et al., 2010), distress and depression (Amsberg, 2008).

2.2. Chronic Illness and self-management – the individual perspective

“When Nancy was very sick, her illness drained her of energy, pulled her into her physical self, obligated her ability to concentrate, impaired her vision, and robbed her of sleep. Increasing her medications resulted in more symptoms, including lethargy and depression.” (Charmaz, 1997, p.1)

2.2.1. Living with chronic illness

A chronic illness often influences every aspect of an individual’s life, such as identity, leisure activities, financial situation, and social relationships (Charmaz, 1997). A large body of research has investigated the experience and/or meaning of chronic illness. Chronic diseases vary in cause, symptoms, prognosis, and treatment options. Despite this variability, studies investigating the meaning making of chronic illness have identified similar themes across diagnoses. For example, struggling (Clancy, Hallet, & Caress, 2009), adjustment and adaptation
(Lundman & Jansson, 2007; MacDermott, 2002), loss (Lundman & Jansson, 2007), identity threats (Charmaz, 1983; Morse, 1997), body changes (Gullick & Stainton, 2008; Häkanson, Sahlberg-Blom, Nyhlin, & Ternestedt, 2009; Williams, 1996), stigma and normalization (Joachim & Acorn, 2000a; Joachim & Acorn, 2000b), hope (Duggleby et al., 2010; Eriksson, 2010), strength (Dingley & Roux, 2003), and spirituality (van Leeuwen, Tiesinga, & Jochemasen, 2007) have all been described as themes common to various chronic illnesses.

2.2.2. Learning to live with chronic illness

When individuals learn to live with illness, they strive to reconstruct a ‘life as normal’ (Robinson, 1993). A ‘normal life’ is achieved by using various self-management strategies. For example, Whittemore and Dixon (2008) described that integrating diabetes is a complex process involving hindrances, such as symptoms, and changes in body and life. The hindrances can be managed with various strategies, like learning and experiencing, managing illness, and utilizing resources. Similarly, Kralik and colleges (2005) investigated the concept of ‘moving on’ to live a good life with illness. They found that ‘moving on’ consisted of knowing one’s responses to illness, developing inner convictions, refraining from making comparisons, prioritizing what was important, and shifting one’s identity. According to Hörnsten, Jutterström, Audulv, and Lundman (2011) the process of illness integration is intertwined with the process of developing self-management skills. Because illness is ever-changing, defining illness integration as a process with a definite endpoint can be problematic (Paterson, 2001). Instead, recent research has shown that illness integration can be described as an ongoing, circular process (Hörnsten et al., 2011). Paterson has described this notion in ‘The Shifting Perspective Model of Chronic Illness’. The model describes how individuals either focus on a life perspective or an illness perspective. At first, people have a dominant perspective; then, they shift perspective according to their current illness experiences. For example, a worsening of symptoms can make individuals focus more upon their illness and less upon their life experiences. On the contrary, a holiday can make individuals push illness to the background. Charmaz (1997) has described living with chronic illness as including ‘good’ and ‘bad’ days. A ‘good’ day is defined as a day when the illness’s intrusion into life is minimal and the individual can focus upon other things. In contrast, on a ‘bad’ day, the illness cannot be ignored, and symptoms and/or self-management become the focus when the choice of activities is limited; the individual often feels emotionally strained on ‘bad’ days.
2.2.3. Self-management goals

Healthcare providers tend to define health goals using medical terms (e.g., good test results or risk reduction). Individuals living with disease tend to describe their goals of self-management in terms of life goals, such as being independent or being able to perform certain activities (Gorawara-Bhat, Huang, & Chin, 2008; Huang, Gorawara-Bhat, & Chin, 2005). When self-management goals are examined, it is evident that health and well-being have many layers and meanings. Identified self-management advantages and goals are, for example, feeling better physically, being in a happier mood (Hwu & Yu, 2006), feeling independent, preventing further illness and minimizing medications (Huang et al., 2005). Skjutar and Müllerdorf (2010) found that people with chronic pain perceived several often conflicting needs. People needed to find a balance between the painful body and the eager mind, they needed to change their self-identity and lastly find meaningful activities in which they can engage.

2.3. Factors influencing self-management

“For most people, the condition is not their first priority or focus and everyday they make decisions that affect the management of their chronic condition without advice from health professionals.” (Battersby et al., 2010, p.85)

This part of the thesis contains an overview of factors that have been investigated for their influence on an individual’s self-management of chronic illness.

The field of self-management research is fragmented among different diagnoses (Sevick et al., 2007). For example, self-management of diabetes is well-studied, and a search in PubMed generated 8,764 hits for the search terms ‘self-management AND diabetes’. Self-management of other diagnoses has been investigated less; a PubMed search of ‘self-management AND multiple sclerosis’ generated 412 hits, and a search of ‘self-management AND inflammatory bowel disease’ generated 228. Self-management research has traditionally been closely linked to research of compliance and preventive health behaviors, and the connection has not been totally beneficial. Compliance is a somewhat problematic concept, as compliance does not account for the individual’s circumstances or activities that are not advised by healthcare professionals. In turn, preventive health behavior research has traditionally viewed decision-making in the setting of one-time decisions (e.g., taking part in a cancer screening program) and not as an ongoing, everyday task (Paterson, Russell, & Thorne, 2001).
People perform more or less chronic illness self-management in terms of how often and how many kinds of activities they perform. In one study, an overwhelming majority of participants stated that they took their medication and checked their feet daily, but only about 20% reported that they exercised regularly (Gatt & Sammut, 2008). Many people also reported that they wanted to perform more self-management than they are currently (Austrian, Kerns, & Reid, 2005).

A number of factors have been shown to influence self-management. It should be noted that each study identifies factors that fit its own theoretical framework and definition of self-management. For example, studies that define self-management as being equivalent to adherence do not account for healthcare providers’ behavior or for power structures as possible barriers to self-management (Spenceley & Williams, 2006). In addition, various factors influence or interact with one another on different levels. Studies have found that belonging to an ethnic minority is associated with performing less self-management (e.g., Schnell-Hoehn et al., 2009), but this phenomenon may relate to that particular group’s health beliefs, limited financial resources and/or power relations in society that marginalizes the ethnic group. Therefore, belonging to an ethnic minority may not, by itself, be a barrier to self-management (Williams Oladele & Barnett, 2006).

2.3.1. Demographic factors and social structures

Studies have repeatedly investigated demographic factors, such as age, gender, and education, and their association with self-management. According to several studies, older people perform more self-management than younger people (Albright, Parchman, Burge, & the RRNeST Investigators, 2001; Chen & Wang, 2007; Chriss, Sheposh, Carlson, & Riegel, 2004; Hansen et al., 2009). This contrasts with evidence that self-management ability decreases with age (Evans & Wickstrom, 1999) and that older people often experience problems with environmental factors (e.g., transportation) (Austrian et al., 2005).

Gender. The male gender is associated with more self-management (Bai, Chiou, & Chang, 2009; Chriss et al., 2004). Heo, Moser, and Widener (2007) suggested that different mechanisms are behind women’s versus men’s self-management of heart failure. Men’s self-management was related to confidence and perceived control, whereas women’s self-management was associated with poor functional status. Ferrand, Perrin, and Nasarre (2008) found that men and women had different goals for exercise. Women described the social aspects of training in a group and the positive body image as motivators, and men were driven by health benefits, acquisition of skills and disease control.
Social position. Higher education (Bai et al., 2009; Sloan, Padrón, & Platt, 2009) and higher income (Bai et al., 2009) are associated with more self-management. Daniel O Clark et al. (2008) showed that socioeconomically vulnerable adults performed fewer kinds of self-management activities (e.g., mostly taking medication and keeping healthcare visits) than people with insurance. The reasons for not performing self-management included lack of financial resources, more social responsibilities (e.g., tending for grandchildren), priorities other than health, and differences in expectations. Other researchers have agreed, suggesting that life problems (e.g., financial hardship, family problems, addictions) result in a self-management of chronic illness being a low priority (Carbone, Rosal, Torres, Goins, & Bermudez, 2007), and that people with low income often have low confidence in self-management (Wasson, Johanson, & Mackenzie, 2008).

Ethnicity. Belonging to an ethnic minority seems to be a barrier for chronic illness self-management; for example among aboriginals in Canada (Schnell-Hoehn et al., 2009), Bangladeshi people in United Kingdom (Choudhury, Brophy, & Williams, 2009), Puerto Ricans in the United States (Carbone et al., 2007). This barrier is partially due to the fact that people of different backgrounds prioritize different self-management behaviors (Darr, Astin & Atkin., 2008), but people from ethnic minorities may also have limited access to medical information (Choudhury et al., 2009). Another explanation is that cultural values can restrict the individual’s acting space (Carbone et al., 2007), and the individual may hold treatment beliefs that differ from the medical model of Western societies (Wang & Matthews, 2010). Another explanation is offered by Williams Oladele and Barnett (2006), who found that ethnicity (white, Hispanic or African American) was not associated with self-management after controlling for socioeconomic class. A possible conclusion is that the association between ethnic minorities and self-management only holds when people belonging to an ethnic minority are socially disadvantaged.

Religion and spirituality. Religious beliefs can influence self-management; for example, people with Buddhist values (Sowattanangoon, Kochabhakdi, & Petrie, 2008) and non-religious participants (Bai et al., 2009) have been shown to perform more self-management. Polzer and Miles (2007) investigated African Americans’ relationship with God and self-management. They found that some participants were supported by the spiritual relationship, while others put faith in God’s healing powers, the later made self-management unnecessary.

Environmental factors. Environmental factors are often described by participants in qualitative research as being important for self-management. However, such factors have been investigated less in quantitative studies. For example, access to a
training center has been described as a factor that facilitates exercise (Kärner, Tingström, Abrandt-Dahlgren, & Bergdahl, 2005), while bad weather can be a barrier to exercise (Austrian et al., 2005). Other factors, like transportation facilities or urban planning, can both facilitate and hinder self-management (e.g., whether or not a park is safe to walk in, food stores accessible with a wheelchair) (Duncan, Heath, Trevoy, & Clark, 2009).

2.3.2. Social support
Social support is a well-investigated variable in chronic illness self-management; a search of ‘social support AND self-management’ generated 11,122 hits in PubMed. However, there are inconsistencies in the evidence for the influence of social support on self-management. Some studies have reported positive associations between social support and self-management (Albright et al., 2001; Chen & Wang, 2007), while others have not found any relationships (Chlebowy & Garvin, 2006), and some have found that social support is related to some self-management tasks but not others (Rosland et al., 2008). In a study with individuals’ having diabetes and heart failure, a majority reported that their family supported self-management, while about one-fourth stated that their family was a hindrance to self-management. Women reported less support and more hindrances (Rosland, Heisler, Choi, Silveira, & Piette, 2010). Samuel-Hodge et al. (2000) showed that women’s multiple social responsibilities impeded their self-management. Furthermore, social support was predominantly provided by daughters and other adult females.

Social support from significant others can influence self-management on different levels, like by providing instrumental help and making daily life easier (e.g., reminders for medication, helping with household work and transportation) (Samuel-Hodge et al., 2000) or by setting a standard for the social norm (Gatt & Sammut, 2008). Munir, Randall, Yarker, and Nielsen (2009) found that employers’ support influenced employees’ self-management at work. Individuals described that having friends with a similar illness was helpful, as they could provide tips and emotional support (Malcomson, Lowe-Strong, & Dunwoody, 2008).

2.3.3. The role of healthcare providers
Healthcare providers play an essential role as the primary source of information for individuals with chronic illness (cf. Richard & Engebretson, 2010). However, only about half of all patients have understood the physician’s advice and recommendations when leaving the physician’s office (Bodenheimer, 2007). Individuals that report good communication with their physician and shared decision-making performed more diabetes self-management (Heisler et al., 2007)
and had higher confidence in their self-management skills (Wasson et al., 2008). People describe that healthcare providers who take an empathic approach to their patients, encourage involvement in decision-making, and provide practical and individualized information motivate self-management of diabetes (Oftedal, Karlsen, & Bru, 2010). Meanwhile, healthcare providers’ behaviors hindered self-management in cases of unmet needs and expectations, mistrust (Jallinoja et al., 2007), or when individuals felt that they were being lectured or blamed (Matthews, Peden, & Rowles, 2009). In addition, the patient’s role in the patient-provider relationship is also important for self-management. Hibbard showed that a positive change in patient activation has been associated with more self-management behaviors (Hibbard et al., 2007).

Studies have provided inconsistent evidence for the influence of healthcare organizations on the individual’s self-management of chronic illness (Kaissi & Parchman, 2009; Parchman, Pugh, Wang, & Romero, 2007). Albright et al. (2001) found associations between an individual’s satisfaction with his/her diabetes care and the performance of more self-management. A qualitative study by Clark Vincent, Zimmer, and Sanchez (2009) found that individuals with diabetes believed that the bureaucracy of the healthcare system caused them stress and had a negative impact on their self-management.

2.3.4. Physical factors

Physical signs of disease can both motivate and impede self-management. Kärner et al. (2005) described how individuals were motivated to maintain lifestyle changes if they either interpreted having fewer symptoms as a sign that self-management worked or if more symptoms were understood as an increased need for self-management (Kärner et al., 2005). Furthermore, Nagelkerk, Reick, and Meengs (2006) described how individuals that tried unsuccessfully to get their blood glucose levels under control often lost self-management motivation. Hwu and Yu (2006) showed that a barrier for exercise among people with chronic pain was their perceived risk that self-management could increase symptoms or cause injury. Hansen et al. (2009) found that more frequent blood glucose monitoring was associated with longer disease duration, having multiple insulin injections per day, having had milder hypoglycemic events recently, but not with diabetes-related complications.

Several studies have shown a negative association between comorbidities and self-management (Egede, Ellis, & Grubaugh, 2009; Kerr et al., 2007; Krein, Heisler, Piette, Makki, & Kerr, 2005; Schnell-Hoehn et al., 2009). This negative association is partially due to the fact that symptoms of or treatments for the condition interact
negatively (Bayliss et al., 2003) or could be difficult to distinguish from each other (Baptist, Deol, Reddy, Nelson, & Clark, 2010) and that individuals with comorbidities are less confident in their self-management abilities (Wasson et al., 2008). Chronic pain can, for example, be such an emotional pressure that it drains energy needed for other engagements, including pain management (Davis, Hiemenz, & White, 2002). Baptist et al. (2010) have shown that individuals with both asthma and heart failure found it difficult to distinguish which symptoms were related to each disease. Consequently, they did not know what strategies to employ when getting short of breath, and many increased both their asthma and their heart failure medications.

2.3.5. Psychological factors – beliefs and knowledge

Knowledge. Knowledge is a necessary basis for self-management, but increased knowledge does not, by itself, lead to changed behavior (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Chen & Wang, 2007). Researchers have identified the following several kinds of knowledge important for self-management: knowledge about symptoms and disease (Lippa, Klein, & Shalin, 2008; Matthews et al., 2009), self-management strategies (Davis et al., 2002), and the healthcare system (Osborne, 2010). Health literacy is, for example, defined as knowing where and when to seek care, having communication skills, being assertive, being literate, and having the capacity to process and retain information (Jordan, Buchbinder, & Osborne, 2010). Individuals with heart failure need to recognize the signs of disease activity in order to know what self-management activities to perform in certain situations (Carlson & Riegel, 2001). People with multiple sclerosis found it empowering to know the latest research, and they stated that medical knowledge granted them with a more realistic view of their illness (Malcomson et al., 2008). It should be noted that disease knowledge in most studies is treated as being equivalent to Western medical knowledge, and researchers tend to have rigid views about what is knowledge and what are ‘misconceptions’.

Health beliefs. The understanding people have about the causes and nature of their illness varies (Hampson, Glasgow, & Foster, 1995). For example, people with arthritis perform little pain management if they believe that arthritis pain is a natural part of aging (Davis et al., 2002). People also consider their different beliefs before they decide to start a medical treatment; for example, some people take into consideration risks of side effects (Gordon, Smith, & Dhillon, 2007) and the belief that physicians may prescribe unnecessary medication (Stack, Elliott, Noyce, & Bundy, 2008).
Loignon, Bedos, Sévigny, and Leduc (2009) identified three self-management regimens related to different ways of understanding asthma and asthma treatment. Individuals that primarily tried to control symptoms used their medication as prescribed. In contrast, people that tried to prevent asthma symptoms from a holistic perspective used alternative treatments. People that tried to tolerate symptoms without treatment sought emergency care when the symptoms became unbearable. Research into health beliefs are often grounded in health behavior theories (e.g., the health belief model, social-cognitive theory, and the theory of reasoned action). These theories have in common the fact that they acknowledge a cognitive aspect in health behavior decision-making, and they assume that health behavior performance relies on an individual’s perceptions, beliefs, and outcome expectations (Munro, Lewin, Swart, & Volmink, 2007).

**Control and responsibility.** The individual’s beliefs regarding control have also been investigated in relation to self-management. The following concepts are closely related in the research literature: control (Albright et al., 2001; Sloan et al., 2009), engagement (Rayman & Ellison, 2004), helplessness (Omachi et al., 2010), and understanding competence (Collins, Bradley, O’Sullivan, & Perry, 2009). The perception of having less control is associated with performance of less self-management (Albright et al., 2001; Sloan et al., 2009). A number of studies have identified that self-management regimens are related to an individual’s understanding of his or her own control (Collins et al., 2009; Skodol Wilson, Hutchinson, & Holzemer, 2002; Toljamo & Hentinen, 2001; Rayman & Ellison, 2004). Those studies predominantly identified the following three self-management regimens: the first is used by participants that take on great responsibility for their self-management, the second is used by individuals who rely upon advice from healthcare providers, and the third is used by people who perform very little self-management (Collins et al., 2009; Skodol Wilson et al., 2002; Toljamo & Hentinen, 2001; Rayman & Ellison, 2004).

**Self-efficacy.** The notion of self-efficacy (e.g., the individual’s beliefs in his/her own ability to perform a task) relies on the idea that people’s expectations influence almost every human activity (Bandura, 1997). In one study, women with heart disease who had high self-efficacy at baseline performed more self-management a year later compared to women with low self-efficacy (N.M. Clark & Dodge, 1999). Self-efficacy has been found to be related to both the intended and actual performance of self-management (Gatt & Sammut, 2008). It should be acknowledged that self-efficacy is task-dependent; for instance, an individual may have higher self-efficacy for taking medications than for cooking healthy food or downhill skiing (Marks, Allegante, & Lorig, 2005). Self-efficacy should also be distinguished from the actual ability to perform an activity. Carson and Riegel
(2001) found that people with heart failure who were confident in their ability to recognize heart failure symptoms in many cases were not actually familiar with the symptoms when asked what to expect. Nonetheless, self-efficacy has been the foundation of many self-management interventions (Marks et al., 2005).

**Psychological factors and mental strategies.** Several personal factors and constructs of psychological factors have been tested and found to influence chronic illness self-management. For example, Sloan et al. (2009) showed that being cognitively able was associated with following recommendations for diabetes self-management. People with good psychological status (highly rated wellbeing, self-control and general health, and low levels of depression and anxiety) performed more self-management to control their heart failure (Schnell-Hoehn et al., 2009). In a qualitative study, individuals with multiple sclerosis found that staying positive, having a ‘fighting spirit’ and using humor had a positive effect on self-management (Malcomson et al., 2008). Additionally, Austrian et al. (2005) found that people stated that their lack of discipline and motivation impeded self-management. People’s emotions can influence their self-management in several ways. Hansen et al. (2009) found that people who thought a lot about their diabetes and were more worried also monitored their blood glucoses more often.

**Stigmatization.** The fact that having a chronic illness can lead to stigmatization and, as a result, discrimination and social injustice is well-described (Crandall & Moriarty, 1995). However, only a few studies have investigated the stigma and beliefs about normality in relation to self-management. For example, Townsend (2006) found that self-management can be impeded when the individual perceives his/her self-management as ‘abnormal’ behavior or behavior not fitting within their self-image (Townsend, Wyke, & Hunt, 2006).

**2.3.6. Problem-solving skills**

People with diabetes experience problems related to self-management regardless of whether or not they had a good glycemic control. For example, they found it problematic to adhere to a ‘boring’ diet, cook for people without diabetes, or integrate medication into schedules that work in their everyday life. However, people with good glycemic control had a positive view of self-management. They learned from their past experiences and used problem solving to overcome diabetes-related problems (Hill-Briggs, Cooper, Loman, Brancati, & Cooper, 2003). Other research has given examples of problem-solving strategies, such as writing down questions before a healthcare visit (Matthews et al., 2009) or creating routines to facilitate self-management activities (Kärner et al., 2005). Brown, Bartholomew, and Naik (2007) found that older men with hypertension wanted to
mediate their health risks, but their self-management goals were often imprecise. As a result, they lacked a plan for making a change in their behavior. An interesting find in Furler et al. (2008) study was that some people with diabetes only mentioned negative strategies when talking about diet change (e.g., not eating chocolate), whereas others could make positive diet changes (e.g., eating more healthy vegetables, substituting one dish with a better alternative).

### 2.3.7. Day-to-day self-management decision-making

People with diabetes have described that the most difficult aspect of self-management is fitting the complex self-management regimen into one’s life (Utz, Steeves, Wenzel, Jones, & Murphy, 2006). Ingadottir & Halldorsdottir (2008) concluded that the meaning of ‘mastering diabetes’ is to balance the demands of diabetes against the desires of everyday life. A feature that must be accounted for in self-management research is the fact that self-management decision-making is a complex process that occurs every day, several times a day (e.g., whether or not to eat breakfast, have a cookie with coffee, etc.) (Skodol Wilson et al., 2002; Thorne, Paterson, & Russell, 2003). The type of decisions and the number of decisions varies among individuals and diagnoses. A study by Paterson and colleagues (2003) showed that individuals with type 1 diabetes made about 20 decisions per day; meanwhile people living with multiple sclerosis and HIV made about five decisions per day (Paterson, Thorne, & Russell, 2002).

Few studies have investigated the process of everyday self-management decision-making. Paterson and Thorne (2000) identified that when a person experiences unanticipated blood glucose levels and makes decisions to control the event, the person’s experience of earlier similar situations plays an important role. The person is influenced by perception of risks, personal preferences and context. Later, the person evaluates the results of the action to know how to act in the future. People can rely on different methods of evaluating their self-management. For people with diabetes, it is rather easy to evaluate their behaviors with clinical tests (e.g., blood glucose monitoring). However, another method of evaluating self-management is to acknowledge changes in ability (e.g., the ability to walk to a nearby shop) or use body-listening (e.g., physical awareness, interpreting signs like sweating or pain) (Paterson et al., 2002; Thorne et al., 2003). Clark, Gong, and Kaciroti (2001) defined self-regulation as being observant and making judgments based upon observation. By using self-regulation, the individual increases his/her knowledge in a step-wise fashion about self-management and illness.
2.3.8. Self-management performance over time

Self-management has most commonly been investigated using single interviews or surveys, and only a few projects have used longitudinal prospective designs. Little is known about individuals' fluctuations or consistency in self-management over time. One example is provided by Criss et al. (2004), who found that the strongest predictor for heart failure self-management four months after discharge from the hospital was high self-management scores at baseline.

The processes of how self-management evolves and is carried out over time have been described using the following different terms and concepts: i) in transitional theory, development of self-management is a part of the process of adapting and changing one's life in order to live well with illness; ii) learning to self-manage includes gaining knowledge and insights about how to perform self-management; and iii) self-management integration refers to how self-management is assimilated and maintained in an individual's life. An individual goes through a transitional process to incorporate changes into his or her life, often when it is impossible to continue the old way of living, such as when one must move on with life despite an intrusive chronic illness (Kralik & van Loon, 2010). In order to go through a transitional process, people create certain life strategies, develop new values, and often challenge or change their identity and life priorities (Kralik et al., 2005). Kneck (2011) investigated how individuals go through a transitional process in order to live well with diabetes. She found that the participants' sources for gaining knowledge of their unique illness pattern included interpretation of physical signs and interacting with people in their surroundings, including healthcare providers. However, transitional processes in chronic illness concern living with illness as a whole, whereas self-management is viewed as part of the process. How individuals come to terms with self-management is not really explored.

The process of learning self-management is often described as consisting of the following chronological phases. In the first phase, the individuals adhere to a self-management regimen that is suggested by healthcare providers. In the final phase, the individuals use a complex self-management regimen that is based on their own needs (e.g., Fex, 2010; Shimizu & Paterson, 2007; Swallow, Lambert, Clarke, Campbell, & Jacoby, 2008). Fex (2010) has investigated how people learn to manage advanced medical technology at home and found that, at first, the participants rigidly followed the instructions, but they later began improvising and adapting or even developing practices to suit their life situations. The phases of the learning process often shift as a result of sudden insights, and the goal of the process is to achieve self-management expertise or a balance between self-management and
everyday life (Hernandez, 1996; Rayman & Ellison, 1998). Criticism of this kind of model is that it is culture-specific, as it is developed from a Western perspective. It is assumed that the goal of self-management is to be able to live a life that one chooses for himself or herself and that adherence to a prescribed regimen are less developed than individualized decision-making (Shimizu & Paterson, 2007).

Recent studies concerning self-management integration have shown a fluctuating or even circular process in which individuals shift back and forth between phases. People can reach points of temporary balance but, like life itself, illness and self-management may change and are ongoing (Hörnsten et al., 2011; Kralik et al., 2004; LaChapelle, Lavoie, & Boudreau, 2008; Whittemore, Chase, Mandle, & Callista Roy, 2002). Identified phases of integrating self-management into life include identifying problems and strategies to manage, exploring conflicts regarding identity and creating new ways of living (Kralik et al., 2004; LaChapelle et al., 2008; Whittemore et al., 2002). According to LaChapell (2008), the process of accepting chronic pain included both emotional and physical adaptation, and the process was more evident on ‘bad days’.

2.4. Rational

The literature review shows that self-management research is dominated by quantitative cross-sectional studies, a focus on diabetes research and studies that define self-management as adherence to treatment guidelines. Research has typically investigated self-management’s association with demographic factors, comorbidities, social support, and certain beliefs (i.e., self-efficacy and health beliefs). A few studies, predominantly qualitative ones, have explored the underlying mechanisms of those associations, but they have rarely been in-depth enough to examine the underlying structures of power or societal movements. Studies of self-management decision-making and integration are scarce, they are dominated by a focus on diabetes, and they mostly rely on retrospective accounts. In conclusion, the existing literature shows that more self-management is performed by people that are well educated, have a support network, are male, have good communication skills, and believe in their own ability and control. In contrast, people in a socially disadvantaged situation perform less self-management (e.g., people that belong to a minority, have limited financial resources, lack knowledge about the healthcare system, and have depression, chronic pain or other comorbidities). In this thesis, I intend to fill in some of those gaps by providing a model of the mechanisms underlying self-management. I intend to emphasize aspects of self-management that have rarely been explored before (e.g., attribution of responsibility, self-management integration and illness perspectives), partially by using a longitudinal approach.
Several studies have shown that self-management advice is seldom tailored to the individual’s everyday life (Balcou-Debussche & Debussche, 2009; Thorne & Paterson, 2001; Thors Adolfsson, 2008). With this thesis, I hope to achieve the following: i) provide insights to healthcare providers regarding the challenges individuals face when performing self-management, ii) explore the self-management integration process so that healthcare providers can support the implementation of self-management in their patients’ lives, iii) describe situations and beliefs that may indicate that individuals need more self-management support, and iv) give inspiration for how healthcare professionals can discuss self-management issues with their patients. Taken as a whole, this research could help individuals become more aware of their alternatives when tailoring an individually-suited self-management regimen.

3. Aim

3.1. Overarching aim

The aim of this thesis was to explain how underlying mechanisms can influence self-management from the perspective of individuals living with chronic illness.

3.2. Research questions

These research questions were synthesized from the specific aims of the included papers. The roman numerals indicate the paper from which the research question was predominantly derived.

- How is self-management influenced by the individuals’ life conditions (papers I, IV)?

- How do personal beliefs and values influence self-management, especially regarding responsibility attribution (paper II), illness perspectives (paper III) and beliefs pertaining to stigmatization and normalization (paper I)?

- How do perceived self-management needs influence the perspectives and goals of self-management (papers I, III, IV)?

- How is self-management integrated into the lives of people living with chronic illness (papers I, IV)?

- Can these influencing aspects be brought together and synthesized in a model (papers I, II, III, IV)?
4. Method

“Methods are not procedures to be followed in any standardized way, but rather are created anew in every research project by researchers who hold their work to a standard” (Sandelowski, foreword in Thorne, 2008, p11).

4.1. Design

The findings in this thesis were derived from qualitative analyses. The choice to use qualitative methods was grounded in a wish to explain how different aspects influenced self-management from the perspective of the individual. The intention was never to find causalities. Instead, the focus was to identify triggers and mechanisms that influenced self-management in a particular way in certain situations (cf. A.M Clark et al. 2008).

In this thesis, I used four different qualitative approaches (see Table 2) because the specific aims of each paper were more concordant with the use of different qualitative approaches. The practical circumstances in which these papers were created also granted different conditions for working with various approaches. For example, the use of constructive grounded theory in the beginning (paper I) allowed me to grasp how people made self-management decisions and ground myself in the topic. According to Sandelowski (1995), a researcher needs to experiment and be both imaginative and creative with methodological approaches and analyses to find a method of analysis that fits the aim and the data. Therefore, I have used the methodological approaches more as guides than rulebooks and have focused on the generation of useful knowledge rather than methodological adherence.

In this research, I used qualitative interview data from two data collection periods, which are referred to as data set A and data set B. Data set A was used in papers I, II and III. However, I investigated self-management over time in paper IV. Therefore, data set B consisted of repeated interviews that were conducted over two and a half years.
Table 2. Summary of the individual papers.

<table>
<thead>
<tr>
<th>Aim</th>
<th>Methodological approach</th>
</tr>
</thead>
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| Paper I  
   data set A 
   N=26  
To better understand the main concern of self-management processes among people with chronic illness. | Constructive grounded theory |
| Paper II  
   data set A 
   N=26  
To explore how responsibility attribution influences self-management regimens among people with chronic illness. | Qualitative content analysis |
| Paper III  
   data set A 
   N=26  
To explore people’s illness perspectives and related self-management of chronic illness. | Phenomenography |
| Paper IV  
   data set B 
   N=21  
To investigate the integration of self-management into the lives of people living with chronic illness. Thereby, we wanted to explored the actual process of self-management integration, the conditions under which self-management integration takes place, and barriers and facilitators to the process. | Interpretive description |

4.1.1. Constructive grounded theory

In paper I, I used the constructive grounded theory developed by Charmaz (2006). The differences between constructive grounded theory and the original form regard that constructive grounded theory takes up a relativist epistemology (Charmaz, 2009), allows several different analytical procedures (e.g., it is possible to use both focused coding and axial coding), and uses theory to understand a phenomenon rather than predict causality (Charmaz, 2006). I chose grounded theory for paper I because the aim of the method was in accordance with the aim of paper I, which was to describe social processes and synthesize the data to theory (Charmaz, 2006).

4.1.2. Content analysis

Paper II originated from reflections about possible individual differences or patterns in the categories that were identified in paper I. Eventually, these reflections grew into a separate paper, and the analysis of paper II was largely informed by Patton (2002) and Miles and Huberman (1994). According to Miles and Huberman (1994), an analysis can be either variable-oriented, which is more common, or case-oriented (Miles & Huberman, 1994). In a variable-oriented analysis, the researcher explores the phenomenon across the sample to find commonalities between individuals (Ayres, Kavanaugh, & Knafl, 2003; Miles & Huberman, 1994). In contrast, a case-oriented approach is more suitable for investigating how factors coexist within an individual, or how the individual’s unique context influences a phenomenon (Miles & Huberman, 1994).
4.1.3. Phenomenography

I chose phenomenography for paper III because this approach provides strategies for finding variation in conceptions. Phenomenography builds upon the notion that people understand and experience the world in qualitatively different ways, and therefore, phenomenographic researchers explore various ways of perceiving a phenomenon (Marton & Booth, 1997). My belief was that an individual’s various ways of perceiving their illness would be a strong influence on how they self-managed. Using phenomenography helped me to identify these different illness perspectives.

4.1.3. Interpretive description

Interpretive description was developed by Thorne and her colleges in order to do qualitative studies that could provide answers for clinical questions. Interpretive description is not a ‘cook-book method’ but rather consists of several suggested strategies that can be combined in a trustworthy design (Thorne, 2008). I found an interpretive description approach suitable for paper IV because this method provides strategies to manage large amounts of data and for longitudinal analysis. Interpretive description studies aim to make meaning of a phenomenon. Thereby, these studies should rise above mere description (Thorne, 2008).

4.1.4. Longitudinal qualitative research

Saldana (2003) defines qualitative longitudinal research as a study that investigates or considers temporality and change. There is no consensus for the length of time a study should include or how many follow-up points are needed for a qualitative study to be considered longitudinal. However, Saldana suggests that a longitudinal study should span months or years with consideration to the type of process that is under investigation. Longitudinal qualitative research can have one of two aims; either to investigate life experiences in depth because life is changed by the time aspect or explore the actual changes that occur over time. Using either approach, researchers must acknowledge the interaction of time with the data collection and analysis, the multiple possible changes over time, and the affect of time on human behavior. For example, societal change or participants’ life crises may affect the study in unanticipated ways. Another concern with qualitative longitudinal research is the management of large amounts of data.

Here, a longitudinal approach was chosen because I wanted to explore a process that occurred over time (paper IV) and by collecting data on several occasions, I tried to reduce some recall bias. Researchers also suggest that a longitudinal qualitative design is especially well suited for the study of the changing nature of
chronic illness (Russell & Gregory, 2000) and that multiple visits provide deeper understandings for individuals’ illness experiences (Charmaz, 2004).

4.2. Sample

In this thesis, I used two data sets, and they are described separately. However, the inclusion criteria were similar for the two data sets, including diagnosis with at least one chronic disease, aged over 18 years, and the ability to speak Swedish. The data sets inclusion criteria differed in how long the participants should have been diagnosed; data set A consisted only of people who had been diagnosed for at least one year, and the participants in data set B had been diagnosed for less than 5 months when they were first interviewed. The only exclusion criterion was an inability to speak, and no one was excluded. The individuals were diagnosed with ischemic heart disease, diabetes mellitus, multiple sclerosis, rheumatic disease, chronic kidney failure, or inflammatory bowel disease (see Table 3). There were no exclusion criteria regarding the type of chronic disease. However, the choice of recruitment location allowed for an implicit choice concerning chronic diagnoses (e.g., the possible sample was limited to diagnoses treated at the out-patient clinic). This choice was made partly to have some consistency in the material (e.g., diagnoses from medical specialists and a few participants with every diagnosis) and partly to obtain diagnoses that demanded a chronic or long-term health engagement, which necessitate substantial self-management and require continuous or periodic medication. In this thesis, I recruited individuals with various chronic diseases with variations in age and gender. This tactic was used because life experience and life-situation influence an individual’s illness experience (cf. Radley & Billing, 1999), and the intention was to have variation in illness experience and thereby a broader foundation for the understanding of chronic illness self-management.

4.2.1. Data set A (papers I, II, III)

Twenty-six adults were included in data set A (18 women and 8 men). Fourteen had comorbidities, such as chronic pain, diabetes, or a past diagnosis of breast cancer. The participants were between 19 and 83 years old (Median=58.5). The disease durations were between one and 60 years (Median=16). Five participants were employed full time, four worked part time, and one participant was unemployed. Seven participants were sick-listed or had a full disability pension, and nine participants were retired. Among the participants, 18 were married or cohabitating, and eight lived alone.
Table 3. Numbers of participants with each diagnose.

<table>
<thead>
<tr>
<th>Diagnose</th>
<th>Data set A* N=26</th>
<th>Data set B** N=21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic kidney failure</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Inflammatory bowel disease</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Rheumatism</td>
<td>9</td>
<td>5</td>
</tr>
</tbody>
</table>

*The number of diagnoses adds up to more than 26 because several participants had more than one diagnose.

**In data set 2 only the diagnosis for which the participants were recruited is accounted for.

4.2.2. Data set B (paper IV)

Data set B included 21 individuals (12 women and 9 men). Eight participants had been diagnosed previously with other chronic conditions, such as asthma, breast cancer, high blood pressure, or fibromyalgia. When the data collection started, the age of the participants ranged between 20 and 74 years (median 47 years). Fifteen participants were married or cohabitating, whereas six lived alone. At time of the first interview, ten participants working full time, one was unemployed, and four participants worked part time. One participant was sick-listed, and five participants were retired. After two and a half years, only five participants were working full time, three were unemployed, three had cut down their working hours, one had received disability pension, one had been sick-listed for a long period, and one participant had retired early.

4.2.3. Context

All participants were recruited from an outpatient clinic of a hospital in a medium-sized Swedish city with about 100,000 inhabitants. The outpatient clinic provided medical examinations, check-ups, and patient-initiated visits. The healthcare professionals included physicians, nurses, nursing assistants, physiotherapists, occupational therapists, and dieticians. The clinic is specialized in endocrinology, rheumatology, cardiology, neurology, nephrology, and gastroenterology.

Most participants had a regular income and were living in their own houses or apartments. Some participants experienced financial strain, and others worked as business managers. No participants lived in nursing homes, institutions or were homeless. Many participants lived in relationships and had children and
grandchildren. The participants that lived alone had other kinds of social networks (e.g., fellow employees) or described limited social networks. There were participants that lived in more disadvantaged positions, such as on a low disability pension, single mothers or older widows with grown children who lived far away. The participants had various degrees and experiences of illnesses, including chronic pain, periodic pain, fatigue, concentration problems, frequent hypoglycemic events, and mobility issues (e.g., experienced problems leaving their homes or using a wheelchair or other mobility aids). Some participants described that their illness demanded substantial changes in their lives. Conversely, other participants seldom thought of their illness. Some participants described that they had found some aspects or consequence of their chronic illness as positive.

4.3. Data collection

4.3.1. Data set A

Data set A was sampled using a grounded theory approach (Charmaz, 2006). Data collection and analysis were performed simultaneously and informed each other. At first, eight women with rheumatoid arthritis were interviewed. These interviews raised questions about self-management across diagnoses and in other life situations. Consequently, more males and people with other chronic diseases, including diabetes mellitus, inflammatory bowel syndrome, multiple sclerosis and ischemic heart disease, were recruited. At this stage, I wanted the material to be as broad as possible and to contain variations in illness experience and self-management practices. As the analysis evolved, there were tendencies of variations in illness experiences and self-management between participants with severe illnesses and participants that described their illness as a minor part of their life. Therefore, I recruited additional participants with a long history of chronic disease, comorbidities and/or impairments, including some with chronic kidney failure.

All participants were recruited from the outpatient clinic. To find eligible participants, I reviewed the outpatient clinic appointment schedule. Possible participants were approached and received verbal and written information at the outpatient clinic. People who were interested in participating were contacted by phone a week later. They received further information and could ask questions. If they were interested in participating, we scheduled a time for an interview. The interviews were all held in private at the convenience of the participants, either in the participants’ homes, place of work or in a seminar room at the university library. All interviews were audio taped and transcribed verbatim. The transcripts were later checked for accuracy against the tapes. The transcribed material consisted of 195 single-spaced pages.
The interviews were narrative in character and most lasted 40-50 minutes (range between 20 minutes and two hours). The interviews aimed to explore individuals’ perceptions of illness, self-management practices, and the reasons for performing or rejecting self-management. The questions were open ended probes, and additional questions were used to obtain more detail and depth (e.g., How did you feel then? Could you give me an example?). Although I used an interview guide, the interviews were adapted to the individual’s situation and the analysis process (paper I). Examples of questions were as follows. Can you describe what it is like to live with [current diagnosis]? Tell me about what you do to stay healthy/manage your disease? Can you tell me about when you find it difficult to manage your illness?

4.3.2. Data set B

The participants in data set B (paper IV) were also recruited through the outpatient clinic. During a period of seven months, the nurses at the outpatient clinic selected people in a consecutive manner. The selected people were referred to the clinic and fulfilled the inclusion criteria. The plan was to include four to seven participants from each medical discipline. Selected people received an information letter about the study and were later contacted by phone to receive additional verbal information. If the person wanted to participate, we scheduled a time for the first interview. At the time of the first interview, the participants had been diagnosed for between one and five months. The time difference mostly depended on the time delay between diagnoses and when the possible participants were referred to the outpatient clinic. The second interview was conducted six months after the first, and the third interview was conducted after about a year. The fourth interview was held approximately two and a half years after the first interview, which was nearly three years after the participants received a diagnosis (see Figure 1). One participant chose to withdraw when contacted for the second interview and was excluded. One participant chose to skip the third interview because the time was inconvenient, but he participated in the last interview. Two participants could not be reached for the fourth interview. A total of 81 interviews were included.

The participants chose the interview location. About two-thirds of the interviews were conducted at the university, and the rest of the interviews were conducted in the participants’ homes or work place. The interviews aimed to explore the experience of getting ill, the adaptation to living with a chronic disease, and the experience and beliefs of self-management practices and healthcare. The interviews were narrative, and the first interview begun with ‘What was it that made you seek care?’ I encouraged the participants to start their story from the beginning and
used probes to understand the participant’s actions, motives and emotions (e.g., What was it that lead to that decision? How did you feel about that?). The follow-up interviews all began with the question ‘How are you and how have you been doing since we last met?’ In preparation for every follow-up interview, I listened to the audio recording of the participant’s last interview and noted issues and questions to address (e.g., previously we talked about your work situation, how is it today?). The first interviews focused on identifying self-management practices and exploring the individual’s illness experience. Subsequent interviews focused on the individual’s current situation and followed up on previously identified self-management strategies. The interviews lasted between 20 minutes and 2 hours (most interviews were 40 minutes to an hour). The interviews were audio recorded and transcribed using the same procedure as described for data set A. The material consisted of a total of 726 single-spaced pages.

Figure 1. Data collection procedure, data set B.

4.4. Analysis

I performed most of the analyses, although the research team had regular meetings to discuss the evolving analyses. In these meetings, we discussed the focus of the analysis and what the next step should be, compared categorizations, and discussed categories and models. Memos have been used in all analyses. The memos were used for various reasons during different parts of the research process, including remembering aids for interview settings, reflections about interview questions, to keep track of evolving ideas, as an instrument to develop and define categories, and relationships between categories and models.
To keep track of the material, some analyses were performed in Nvivo 2.0 (I, II) and 7.0 (III).

4.4.1. Paper I – Grounded theory
This material was approached using a constant comparative analysis as described by Charmaz (2006). The analysis started with a section-by-section coding. In that phase, I identified actions and labeled them with codes. Later, the codes were developed into categories using focused coding, and the properties and variations within the categories were explored. The analysis was directed by questions such as ‘How do the participants think about and enact self-management?’ and ‘What influences the participants’ self-management actions?’ During the phase of theoretical coding, I explored the relationships between the categories, and these relationships were organized into a model. During the analysis, I went back and forth between the interview text, the evolving categories and the memos that were used for keeping track of the data and to develop ideas further.

4.4.2. Paper II - Content analysis
This analysis started with an identification of the strategies that participants used in approaching the self-management negotiation process. This analysis was performed by comparing which elements of self-management the participants described (e.g., medicine taking, managing emotions, etc.) with the parts of their self-management negotiation process (e.g., health beliefs, evaluation of self-management effectiveness). The comparisons were made in matrices. At first, each individual case (e.g., participant) was explored in a matrix of its own. In later matrices, cases were brought together to be compared with each other (cf. Miles & Huberman, 1994). This process made it possible to explore whether different individuals had various strategies that guided their self-management. I identified four strategies to approach self-management negotiation: being an active agent, faith in medical treatment, reliance on external support, and illness is perceived as challenging identity. A common base in these strategies was the different ways in which the participants understood responsibility.

During this first part of the analysis, I used 16 interviews, and in the next step, another 10 interviews were added. The choice to first use only part of the material allowed a more in-depth analysis of these 16 cases and a later testing of these preliminary strategies against the remaining 10 interviews. In this next step, I concentrated on responsibility attribution and its relation to self-management. The participants’ views on responsibility were explored by posing questions like ‘Who is considered responsible for health status and/or self-management?’ and ‘How is self-management involvement described?’ Throughout the analysis, the four
strategies were merged into internal, external and combined responsibility attribution. Later, by exploring the participants’ self-management regimens, I found that the individuals’ responsibility attribution was related to the kind of self-management the individual undertook. The participants’ self-management regimens were explored with questions like ‘What self-management behaviors are performed by participants who believe in internal, external or combined responsibility?’ and ‘What characterizes the different self-management regimens?’

**4.4.3. Paper III – Phenomenography**

I began this analysis by reading the interview transcripts and identifying all sections that illustrated the participants’ way of understanding their illness. These sections were assigned temporary codes that were later developed into temporary categories. These temporary categories aimed to describe various ways of understanding illness, and attention to their structure (i.e., the focus of the category) and the referential aspect (i.e., the meaning of the category) was taken (cf. Marton & Pong, 2005). The questions that guided this part of the analysis were ‘What is the main focus of this category?’ and ‘What distinguishes this category from the other categories?’ When I explored these temporary categories, I merged them into two illness perspectives, life-oriented and disease-oriented. After that, I chose to go beyond a strictly phenomenographic approach to further explore shifts in perspectives and their relationship to self-management. Questions directing the later part of the analysis included ‘What characterizes situations that lead to shifts from a life-oriented to a disease-oriented illness perspectives?’ and ‘What characterizes self-management in relation to a ‘life-oriented illness perspective’?’

**4.4.4. Paper IV - Interpretive description**

An interpretive description analysis starts broad with comprehending, i.e., by learning as much as possible about the material/phenomenon (Thorne, 2008). I began the fourth analysis by identifying all sections in the interviews that referred to self-management. These sections were divided into categories of self-management practices, such as symptom management, information seeking, and the management of treatment. All cases (i.e., each participant’s four interviews were treated as one case) were arranged in matrices to illuminate changes and/or consistencies in the participant’s self-management. Synthesizing is a process where the researcher looks for and describes patterns within the material (Thorne, 2008). To find patterns, I contrasted cases against each other. Cases with much self-management were contrasted to cases with less self-management, and cases with major changes in self-management performance were contrasted against cases that were largely consistent. The findings were decontextualized (e.g., a process to extract common features) (c.f. Thorne, 2008) when I searched for common
approaches in how the participants reasoned about their self-management; four phases of self-management integration were identified. In the phase of theorizing (e.g., exploring possible explanations) (c.f. Thorne, 2008), I explored the self-management integration phases further using questions like ‘What aspects impose changes or shifts between the phases?’, ‘How simultaneous or distinguished are the phases?’, and ‘How are the different phases enacted?’. The last analysis phase of interpretive description is recontextualizing, in which the findings are synthesized into a form that is applicable to other settings (Thorne, 2008). In this last phase, the model was created and the contextual factors that influenced the self-management integration were identified and explored.

4.5. Ethics

Ethical concerns are present during every phase of a research process. In this research, examples of ethical concerns were how to contact and information of eligible participants and the phrasing of the interview questions. I informed possible participants about the study and asked about participation. There was no relationship between the possible participants and myself, such as when a healthcare provider asked about participation. Their choice regarding participation was never known to their healthcare providers and did not influence their care. Information was given to each participant that the study was voluntary and that they could withdraw at any time without giving a reason. A few participants did withdraw. Five people in data set A first committed to participate but withdrew before the interviews, and one individual in data set B withdrew before the second interview. Two participants withdrew after my suggestion because I felt that they were uncomfortable with participating in the study.

Interviewing about sensitive topics without causing distress or harm was another challenge in this study. According to Charmaz (1990), each interview must be adapted to the individual’s physical and psychological status, the interviewer-interviewee relationship, and research position and topic. For example, questions about illness experience, health threats and the future can make the participants concerned or distressed. During the data collection, I tried to be adaptive regarding the wording of questions. I did not ask about ‘your chronic disease’ but used the same terms as the participants used, for example heart problems, rheumatism, or pain problems. I tried to be sensitive to the participants’ feelings regarding how much they wanted to reveal and tried not to judge acts in terms of right or wrong. I also tried to ‘lead’ the participants back to a more ‘normal communication level’ before we parted (cf. Morse et al., 2009). Researchers’ ethical obligations reach beyond the interview situation to how the material is managed and later presented. All of the names used in this thesis are pseudonyms, and details that
could be used to identify participants were changed (e.g., an interest in soccer can be described as being an active basketball fan) (cf. Kaiser, 2009).

However, it shall also be acknowledged that many participants wanted to participate and found it important to tell their story. A few even took precautions to be able to participate or stated that they were exhausted afterwards. Some participants mentioned that they looked forward to the interviews, and most participants wanted to take part in the results. All participants that wanted a short review of the findings also received a summary of the results. This study was approved by the Regional Ethical Review Board in Umeå, Sweden (No. 05-164M).
5. RESULTS

5.1. Introduction

The results are organized according to the research questions with the following sections: life conditions, beliefs and values, perceived self-management needs, self-management integration, and the Self-management Support Model. Each section is followed by a short reflection in which the findings are related to existing research.

Some of the findings are not explicitly presented in the papers. The findings were, however, included in the analyses on which the papers are based. These findings are labeled as additional analysis and are supported by extracts from data.

5.2. Life conditions

5.2.1. Life circumstances

The participants described their financial resources and living and working conditions as either motivating or impeding their self-management (I, IV). For example, participants described that living near a training center facilitated gym exercise (I), and individuals without a car described difficulties in keeping healthcare appointments or getting to a training center (see Table 4, Alison) (additional analysis I). Another example was participants with temporary jobs, unemployment or irregular working hours, who often found it hard to develop routines and structure for their regularly occurring self-management (IV). Financial hardship also influenced participants by limiting their self-management alternatives. Individuals with restrained finances stated that some self-management alternatives were closed to them, such as gym exercise, alternative therapy and/or various tools and disability aids (IV).

<table>
<thead>
<tr>
<th>Context</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alison lived with rheumatism and described that her car contributed to her quality of life. (Data set A)</td>
<td>It is difficult to have a car, it costs a lot of money. Although, it is also a freedom and for me it's an aid. It's the only way to get out and get the social part. (...) Otherwise, I think, I would be rather restricted.</td>
</tr>
</tbody>
</table>

5.2.2. Social support

The participants found support for their self-management from many sources, including family, friends, colleagues, and employers (I). They described several kinds of self-management support, such as emotional (I, IV), practical (I, IV), financial (I, IV), informational (IV), and motivational (I, IV). For example, family
and friends were a source for information about possible self-management strategies (IV). Participants that received practical help with household activities described that this support reduced stress and was emotionally comforting (See Table 5, Tom) (additional analysis IV). Several participants also described the value of having a discussion partner for the exchange of ideas and encouragement (see Table 5, Paul) (additional analysis IV).

<table>
<thead>
<tr>
<th>Context</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tom described how he was emotionally comforted by his girlfriend after an operation. (Data set A)</td>
<td>It’s just minor things, [someone] being home when you come home after an operation. It can be comforting to have someone who can make you a cup of tea, if you feel somewhat ill and unsure about your ability. Someone that are there for you and you can talk to, stuff like that.</td>
</tr>
<tr>
<td>Paul told about the time immediately after he was diagnosed with diabetes. (Data set B)</td>
<td>Paul: I was really low. My girlfriend has helped me a lot. It has been really thought. Alone, I had never made it. Interviewer: You talked much to her? Paul: She tried to explain to me, all the time, how things are and that it’s [diabetes] is not that extremely dangerous as you might think.</td>
</tr>
<tr>
<td>Joan described how difficult it was to suddenly need help with practical things. (Data set B)</td>
<td>I like taking care of myself. That’s the toughest part, situations like… you get embarrassed if you need help to get off the bus.</td>
</tr>
<tr>
<td>Irene took care of her children before she could take care of herself. Although, she developed strategies to manage household tasks in periods when she had energy. (Data set A)</td>
<td>If you have children you have to… all the time. (...) For example, I have to cook now when I am fine. Because I do not know [how I’m doing] in the afternoon. So it’s all about planning, much planning.</td>
</tr>
<tr>
<td>Kathleen was a widow and lived alone. She had been advised to not lift heavy object after she had a heart attack and she tried to figure out a way to shop groceries (Data set B)</td>
<td>I can walk to the grocery store and shop and then take a cab home. It’s the only way to get the food home.</td>
</tr>
</tbody>
</table>

Participants also described non-supportive relationships, such as being ignored, experiencing demands, and being belittled (I, IV). Some participants described social support as highly significant for their self-management, but others stated that they were quite knowledgeable and confident in their own ability and did not need social support (I, IV). The participants’ attitudes toward support were likely to influence what kind of support they received. Some participants made accounts such as ‘you do not want to bother others’ (I) or expressed values of wanting to position themselves as ‘strong and able’ (see Table 5, Joan) (additional analysis IV). Participants that were single often had limited social support. For example, single mothers experienced greater social responsibility; they had to tend for their children regardless of the severity of their symptoms or the state of their illness.
Additionally, widowed elderly participants described the need for practical help or emotional support, and they had difficulties getting support in everyday life when adult children lived far away. Other widowed elderly participants had a close network of friends that provided support (see Table 5, Kathleen) (additional analysis IV).

5.2.3. Healthcare support

According to the participants’ stories, healthcare providers had many opportunities to influence the participants’ self-management. For example, a few participants stated that healthcare providers had been important for guiding their self-management (I, III) and providing them with new insights (IV). Healthcare providers were described as being more or less trustworthy, and participants described that they were more prone to follow advice from trustworthy healthcare professionals (see Table 6, Irene) (additional analysis I).

The most common self-management support from healthcare providers was information about the disease and treatment (IV). According to the participants, this information was often general and concerned specific elements of self-management (e.g., medication, exercise and diet) (IV). Participants would have appreciated a more nuanced and open discussion. For example, participants wanted answers like ‘I do not know of any scientific evidence that stress is related to relapse in multiple sclerosis, but my experience is that many patients perceive that stress-management is helpful’ (see Table 6, Johanna) (additional analysis IV). Healthcare professionals could also impede self-management, such as when participants experienced that healthcare providers doubted the effectiveness of self-management (I) or when healthcare providers could not provide information about self-management practices (IV). Misunderstandings or disagreements between individuals and their healthcare providers could result in less self-management and/or leave the participants with a feeling of being misunderstood (see Table 6, Stephanie) (additional analysis I).

Participants described that they preferred different kinds of self-management guidance, either direction about self-management tasks or active participation in an on-going discussion about treatment. Participants with both preferences could be disappointed when meeting the ‘wrong’ communication style (II). The participants had different abilities to navigate the healthcare system. For example, several participants were unsure to whom they should turn with their questions, but other participants developed strategies for referrals to specialists or preferential appointments (I, IV).
### Table 6. Quotes concerning healthcare support.

<table>
<thead>
<tr>
<th>Context</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irene took prescribed medication because she trusted in her physician. (Data set A)</td>
<td>You don’t want to take pills, you don’t want to... but you do it because you simply trust in him [the physician] knowing what he’s doing.</td>
</tr>
<tr>
<td>Johanna wished for a more nuanced advice regarding how she should live with her rheumatism. (Data set B)</td>
<td>It would be so much easier if a physician said: ‘Well it’s your choice but I would not advise you to... your body is not fit for that, but it’s your choice’. You would then get a hint that you were on the right way. Or if he could say: ‘Well, it is your choice, but you should know that it will not break your body. Nothing will get damaged. You will not end up in a wheelchair, although, you will likely get pain or get exhausted.’</td>
</tr>
<tr>
<td>Stephanie described how misunderstood she felt when the physician did not understand how her illness affected her life. (Data set B)</td>
<td>He [the physician] says that this disease is not disabling. And then I think that’s not up to him to say, if it is disabling for me or not. I understand what he means when he says that it’s not disabling. No, I don’t need a wheelchair. No, I don’t need help with my daily activities. But if I compare my life[today] with [my life] five years ago... then it’s disabling for me, I cannot, at all, do the things I did then.</td>
</tr>
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</table>

### 5.2.4. Reflection

This research and previous studies (D.O. Clark et al., 2008) agree on the conditions under which an individual lives influences his or her self-management of chronic illness (I, IV). However, the underlying mechanisms are complex and divergent. All influences should be viewed as a pattern of mechanisms that create a complex web of coexisting factors. For example, a single mother might have a limited social network, many social responsibilities, and a low income. All of these factors will influence and possibly limit her ability to self-manage. Therefore, people in disadvantaged positions are likely to experience several obstacles to their self-management (cf. D.O. Clark et al., 2008). One interesting finding was that participants highlighted economical issues as important for their self-management despite the fact that Sweden has a generous healthcare subvention system (I, IV). However, it seems that the Swedish healthcare subvention system focuses on disease-directed treatment and does not provide support for improving life with a chronic illness.

### 5.3. Beliefs and values

The participants’ beliefs and values determined their preferences for both self-management and life priorities. The beliefs and values included beliefs concerning knowledge (IV), normality and stigmatization (I), illness and health (I, III, IV), ability (I), and responsibility (II). Depending on the nature of their beliefs, self-management could be impeded or facilitated, or beliefs could influence certain self-management activities but not others.
5.3.1. Knowledge

According to paper IV, the participants had various experiences of illness and knowledge concerning disease and the healthcare system. Information about the disease could be found from many sources, including the library, internet, information leaflets, healthcare providers, family and friends. However, knowledge of the healthcare system was obtained primarily through experience or by working in the healthcare sector (IV). Despite these varying experiences, knowledge of the healthcare system seemed to have substantial influence for how quickly the participants received treatment (see Table 7, Stephanie) (additional analysis IV). Participants with knowledge had advantages; they could discuss the risks and benefits of recently developed medications, demand further tests, or possibly receive earlier treatment (see Table 7, Claire) (additional analysis IV).

Table 7. Quotes concerning knowledge.

<table>
<thead>
<tr>
<th>Context</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stephanie described how she persuaded a nurse in order to get a healthcare appointment. (Data set B)</td>
<td>Well I wasn’t nice and waited, you can push [the waiting-list]. ‘I will not have any hair left if I… [have to wait any more]’… so I got [an appointment] at the clinic.</td>
</tr>
<tr>
<td>Claire told about her conclusion that the medication affected her mood. She planned to visit her physician and maybe get her medication changed. (Data set B)</td>
<td>I come to think about the beta blockers that I take, the information leaflets says that you can get low. So it could be the medication that causes me to feel bad. (…) I plan to bring this up, if I should take some other medication.</td>
</tr>
</tbody>
</table>

5.3.2. Normality and stigmatization

The participants’ image of normality relied on comparisons to their former self-image (e.g., abilities they used to perform) or healthy people (I). The participants related normality and stigmatization to either their disease or their self-management (I). When the participants experienced stigmatization from their disease, they performed self-management to control their disease to achieve a ‘normal’ life. Other participants held a notion that ‘ill people’ were special in some way, and they did not want to be part of that group. These participants strived against letting the illness take up too much space in their life. In these cases, the performance of self-management was often viewed as stigmatizing (e.g., taking insulin injections in public) because the self-management was visible evidence of their disease (I, IV). In these cases, the participants had several choices (I): they could strive against their disease (e.g., neglecting insulin injections when in a café), they could adapt their self-management to be less visible (e.g., taking insulin injections in the rest room), or they could behave ‘normally’ (e.g., just order tea and skip the injection) (I). The same individual could use different strategies in various situations (I). Another kind of belief the participants held concerned how a person
with disease ‘should’ live (e.g., being a ‘good diabetic’), and participants could either adhere or reject that kind of notion. Some participants described having a bad conscience when not living up to the picture of how they ‘should’ live and self-manage (IV).

5.3.3. Illness perspectives

Participants’ beliefs about health and illness were at different levels, including the participants’ main illness perspectives (III), beliefs about certain symptoms or disease origin (I), and beliefs about the effectiveness of medications (III, IV). Paper III revealed that the participants understood wellness in one of two ways: they could hold a life-oriented illness perspective (i.e., wellbeing was the ability to live as they desired within the constraints of the disease) or a disease-oriented illness perspective (i.e., wellness was feeling physically well and asymptomatic, with good test results).

All participants had a main illness perspective (e.g., how they predominantly described wellness), but this perspective could shift to temporarily focus on either life or disease. Participants described passive shifts that depended on external factors and active shifts when participants used strategies to shift their illness perspective (see Figure 2).

**Figure 2.** Active and passive shifts between life-oriented and disease-oriented illness perspectives (paper II).
Shifts from a life-oriented perspective to a disease-oriented perspective occurred when the participants experienced a worsening of symptoms or complications, when other people brought up the disease or when they had to control the disease to be life-focused (e.g., when a person with ulcerative colitis takes a seat nearer to the rest room at the theater). The opposite shift, from a disease-oriented to a life-oriented illness perspective, could be prompted by having no or controlled symptoms, striving against the disease, and/or using strategies to control symptoms or health threats. The two illness perspectives facilitated different kinds of self-management. Participants that held a predominantly life-oriented illness perspective described self-management that was directed toward wellbeing, such as the maintaining of activities, interests, relationships and social roles by balancing, prioritizing and/or adjusting. To keep the illness away, participants found it important to maintain a positive attitude, and at times, they were reluctant to perform self-management that could be viewed as a manifestation of their disease. However, they could also perform self-management to integrate their illness into their life (e.g., positive thinking strategies to make medication have a less negative association). Participants that held a disease-oriented illness perspective performed self-management that was directed toward disease control, such as managing symptoms and controlling disease progression. These self-management strategies mainly entailed medication and lifestyle changes (III).

5.3.4. Responsibility attribution

Some participants believed strongly in their own capacity to perform self-management (e.g., being strong, able and having will-power). They described how they could put demands on family, employers and healthcare providers (I). In contrast, other participants described themselves as lazy or lacking discipline, and these features impeded their self-management (I).

In paper II, three ways to understand self-management responsibilities were identified. Internal responsibility attribution meant that participants took responsibility then believed that sufficient self-management could prevent disease progression and restore health. Participants with an external responsibility attribution believed that treatment decisions and self-management ability were mostly dependent on external persons and factors. Finally, some participants believed in a combined responsibility attribution and wanted to share decision-making with healthcare providers or acknowledge the influence of other factors on their symptoms (See Figure 3).
The findings revealed three different ways of understanding responsibility attribution:

**Internal responsibility**
- An individual is responsible for his or her health status and disease development.
- An individual makes most decisions about his/her self-management regimens, e.g., the individual always seeks care prior to a treatment decision is made by healthcare providers.
- An individual is responsible for his day to day self-management decision-making.

**Combined responsibility**
- An individual is able to influence his/her health status, but other factors are likely to interfere.
- Decisions about self-management and treatment should be taken in collaboration between an individual and his/her healthcare provider.
- An individual is responsible for performing his or hers daily self-management.

**External responsibility**
- Health status is mainly influenced by external factors.
- Healthcare providers are responsible for treatment and deciding on self-management regimens.
- An individual is mostly responsible for self-management on a daily basis, although external factors can interfere.

**Figure 3.** The various kinds of responsibility attribution. The participants’ different responsibility attribution could be viewed as a continuum ranging from the extreme internal to an extreme external responsibility attribution. However, responsibility attribution should not be understood to be static. Some participants described that they had shifted in their responsibility attribution (paper II).

Participants with an external responsibility attribution mostly performed self-management to control disease. Participants that attributed responsibility to internal means performed a range of activities to control disease and to increase well-being. However, no responsibility attribution should be viewed as superior to the other because they all have concerns. Participants could find internal responsibility burdensome because they are always in control and have to attend to the disease. Another concern for the participants with internal attribution was that they described having a bad conscience or blaming themselves when performing self-management in a less than precise manner or when the illness progressed. Conversely, participants with external responsibility attribution could risk their health. Participants with an external responsibility attribution seemed unlikely to develop individually tailored self-management strategies, evaluate advice or seek additional help when the first advisement failed. For example, some participants lived with troublesome symptoms for years because they had been told that no treatment existed (II).
5.3.5. Reflection

Radely and Billing (1999) state that people’s accounts of health and illness are much more than descriptions of their health status. Health accounts are created in a societal context, and people use health accounts to define themselves as individuals. The participants made statements about how people with disease ‘should’ live or notions of how people with particular diagnoses ‘were’ (I, IV). They then either struggled to fulfill or reject these notions, some of which were described using both strategies (I). When participants lived up to a picture of a ‘good diabetic person’, they stated that this was a healthy way to live, and they were able to live more ‘normally’ because they controlled their disease (I). Other participants described ‘feeling bad’ about not succeeding in self-managing as one ‘should’ (II, IV). In contrast, participants that did not want to be related to ‘ill people’ often strived against their illness; they could reject their self-management because they found that self-management reminded them about their disease (I, III).

One of the interesting findings was that the participants found that medical information was widely accessible (e.g., internet, healthcare providers, information leaflets), but knowledge of the healthcare system was difficult to obtain. Knowledge about how to navigate the healthcare system had to be obtained through experience, and the participants expressed that they had more or less of this knowledge (IV). These findings are related to the on-going debate regarding whether health literacy shall be related to available resources and social structures or to the individual person’s abilities (Jordan, et al. 2010).

5.4. Perceived self-management needs

The participants perceived different needs for self-management. Perceived self-management needs were described regardless of diagnosis but were based on the participants’ life situation, illness experience and values. For example, participants that viewed their illness as not very severe found little need for managing emotions (IV). One kind of self-management need arose from perceived health threats (I). Another kind of perceived self-management need related to a wish to live a life of quality (e.g., wanting to continue with a hobby) (IV). The third kind of self-management need was aimed at facilitating social roles and other people (e.g., when participants self-managed to be able to be a ‘good mother’ or ‘good employee’) (I). Participants relied on their preferences in judging the importance of each self-management behavior (e.g., taking insulin could be viewed to be more important than always eating healthy); less important self-management behaviors could be skipped at times or totally disregarded (I). These different beliefs could
also interact or be conflicting. A woman could perceive a need to exercise to strengthen her muscular tissue, increase joint stability, and to be outdoors to feel emotionally well and reduce feelings of stress. At the same time, exercise could cause her pain, limit her mobility and prevent her from meeting friends during the weekend (I). Another example is that some participants believed that their medications were so effective that they had little need for life-style changes (II).

Table 8. Quotes concerning perceived self-management needs.

<table>
<thead>
<tr>
<th>Type of self-management need</th>
<th>Linda lived with diabetes, sight impairment and chronic kidney failure. (Data set A)</th>
<th>Lilly had rheumatoid arthritis. (Data set A)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-management in order to facilitate activity and thereby well-being.</td>
<td>“Shall we go biking?” Well what’s the time? Have I eaten? And what is the blood glucose value? It’s not just to get going. And some food, I must bring something. Then I make a sandwich or [take] a banana and something to drink or… for the blood glucose… You have your pockets full with things to manage the diabetes.</td>
<td>If you shall do special things, like you know that you will walk much, travel or if you have to manage more [than usual] I take anti-inflammatory drugs. I use to say that I prepare the body with them to be able to do the fun things.</td>
</tr>
<tr>
<td>Self-management directed to control or shield against disease in the future.</td>
<td>I want to keep my vision and my kidney. I’m very careful about the kidney. So it is… I think, I can’t afford to not try to get this working.</td>
<td>I exercise at the water exercise rehabilitation because of my muscles, because I need this exercise, because my joints shall keep flexible so I’m not getting stiff. If I wouldn’t do anything I would [get stiff]. Training can be hard at times, for you are in constant pain, but then I know that if I do things and it hurts it may get better further on.</td>
</tr>
<tr>
<td>Self-management with an immediate or short time perspective.</td>
<td>I can have between five and seven and eight [in blood glucoses level], then I feel good… but then I can’t get out walking because I will dip, boom… ten meters underground, you know. And I will feel bad… really terrible.</td>
<td>You will get problems, you will get trouble and you can get strep throat and you feel how something’s changing [in the body], something happening, now it have happened. Well you have to see the physician again.</td>
</tr>
</tbody>
</table>

The participants’ goals of self-management could be long-term, short-term or immediate but were directed toward well-being or disease control (see Table 8) (additional analysis III). Health was often viewed as a long-term goal and was seen as a strengthening of the body to shield against future illness (I). Symptom management could have both a long-term perspective (e.g., symptom prevention) and an immediate perspective (e.g., mediation of already existing symptoms) (see Table 8) (additional analysis III). The needs for self-management changed over time; needs could be met, disappear, or change, or new needs could occur. These shifts in perceived self-management needs were related to fluctuations in the participants’ illness experience and life situation. Participants who perceived
substantial self-management needs often had difficulties in integrating a suitable self-management regimen. For example, one woman experienced that work in combination with pain and fatigue drained her of energy and limited her social life. At a follow-up interview some years later, she was still working and used very few self-management strategies. She described that she wanted support for substantial changes in her life (IV).

5.4.1. Reflection

The findings in this thesis are unique because several kinds of perceived self-management needs are described across different chronic illness diagnoses (I, III, IV). In the literature, perceived self-management needs are often described as an individuals’ understanding of disease threat. This image is especially common in studies of people with diabetes (Hörnsten et al., 2011), asthma (Halm et al., 2006), and ischemic heart disease (Kärner et al., 2005). In contrast, the perceived self-management needs among people with chronic pain describe a desire to find order and balance in life (Kralik et al., 2004; Skjutar & Müllersdorf, 2010). However, in this thesis, these two perspectives are combined. The findings revealed that, for example, people with diabetes tended to limit the threats of diabetes-related complications and attempted to find daily structures that facilitated leisure activities and work. Individuals with rheumatoid arthritis took medication to limit joint destruction and used strategies to prioritize and manage household activities when having pain (III). Some participants also perceived self-management needs that were directed toward others. A mother could describe that she was taking care of herself so that she could take care of her children (I). A similar self-management goal was discussed by Townsend et al. (2006), who found that self-management performance was sometimes viewed as a moral obligation (e.g., self-manage to not burden society and healthcare).

Self-management needs could also be in conflict with each other (I, IV). This is similar to the findings of Skjutar and Müllersdorf (2010) regarding people with chronic pain who are trying to balance their need to satisfy their minds but not overexert their bodies. How the participants in this thesis managed the conflicting self-management needs and goals are described in the next section.
5.5. The process of self-management integration

The process of self-management integration was continually ongoing, but at times could reach a temporary balance. Here a temporary balance was defined as when participants described their self-management as automatic or integrated in their daily life (IV). When the participants had reached a temporary balance, they could pay less attention to their illness and self-management (II). However, these periods of temporary balance could shift to periods of an active self-management integration process. During periods of active self-management integration, the participants sought new information and incorporated it with earlier experiences (II, IV). The shifts to an active self-management integration phase were often prompted by new perceived self-management needs (IV).

![Diagram](image.png)

**Figure 4.** The process of self-management integration. The process begun with the participants’ seeking effective self-management strategies. The phases could follow in a logical order or occur simultaneous. The participants’ could also shift back to previous phases (paper IV).

The process of self-management integration involved four phases: i) seeking self-management strategies, ii) considering the costs and benefits of self-management strategies, iii) creating routines and plans of action, and iv) negotiating self-management that fits their life situations (see Figure 4). In some cases, the phases followed as a logical process, but in other cases, they occurred more simultaneously. Because the material was longitudinal, the process of self-management integration could be explored over time (for an example see Table 9). However, these phases seemed to be influenced by the individuals’ illness experience and living conditions rather than by time itself (IV).
Table 9. An example of how a self-management integration process could look. Sarah has been diagnosed with rheumatism. This table accounts for how Sarah reasoned about and enacted pain management, medication, exercise and rest. (Data set B)

<table>
<thead>
<tr>
<th>Interview</th>
<th>Seeking effective self-management strategies</th>
<th>Considering costs and benefits with self-management</th>
<th>Creating routines and action plans</th>
<th>Negotiating self-management that fits life</th>
</tr>
</thead>
<tbody>
<tr>
<td>one</td>
<td>-Sarah describes that she now listens more to her body. She tries to identify actions that increase pain. -She believes that recovery and rest are more important now than earlier.</td>
<td>-Sarah considers which kinds of exercise will be best for her; she decided to try swimming. -Sarah takes prescribed medication but wonders about side effects.</td>
<td>-Sarah plans for how she can create possibilities for her exercise.</td>
<td></td>
</tr>
<tr>
<td>two</td>
<td>-Sarah has begun to slow down when the pain increases. She is still trying to understand which activities lead to pain and how to deal with them.</td>
<td></td>
<td></td>
<td>-Sarah has continued to take prescribed medication but has decreased her use of other medications because she does not want to risk side effects.</td>
</tr>
<tr>
<td>three</td>
<td>-Sarah has ideas about what activities and situations lead to increased pain. At the same time, she wants to continue some of those activities, e.g., gardening.</td>
<td>-Sarah has established routines to rest after dinner. -It has been difficult for her to maintain exercise during the summer, and she now tries to recreate her routines.</td>
<td></td>
<td>-Sarah has experienced effects of the medication but plans to discuss her medication with her physician to decide if she really needs it. She is concerned about possible side effects.</td>
</tr>
<tr>
<td>four</td>
<td>-Sarah describes that when she get a flare, the only thing that she can do is rest. She has established routines for recovery, to sleep regular hours and to allow time for rest during weekends.</td>
<td></td>
<td></td>
<td>-Sarah manages pain depending on the situation and the source of the pain. When she experiences a flare, the only option is rest. At times, she strives against pain to do activities that are important for her, like gardening. She has disregarded other activities, like hiking. -Sarah has come to the conclusion that the medication is life-long.</td>
</tr>
</tbody>
</table>
5.5.1. Seeking effective self-management strategies

The starting point of the self-management integration process was based in the participants’ perceived self-management needs. The perceived self-management needs directed what kinds of self-management the participants sought. The strategies for seeking self-management included talking to family and friends, asking healthcare providers, searching on the internet, and using trial and error. Some participants soon found suitable self-management activities (e.g., being told to take medication) or gave up the search. Other participants took part in a long process in which they tried and evaluated different strategies, then disregarded these strategies and sought other kinds of self-management. Participants shifted back to the phase of seeking when they experienced new or different self-management needs, when they did not get the anticipated effects of self-management, or when they received new information about possible self-management. The process of seeking self-management strategies could also be prolonged if the perceived self-management needs shifted as the illness progressed (IV).

5.5.2. Considering the costs and benefits of self-management strategies

The participants weighed the benefits of self-management against the costs (e.g., exercise could lead to increased pain but was beneficial for joint stability) (IV). The participants had to perceive or believe in some of the effects of self-management to proceed with activities (I, IV). Participants evaluated effects by listening to their bodies (e.g., did the pain decrease) (I, IV) or by medical tests (e.g., did lipid levels decrease) (IV). However, it was difficult for participants to evaluate long-term effects. At times, participants also found it hard to evaluate which strategy had which consequence; for example, which effects were the result of medication, stress reduction or alternative therapy. Self-management directed to an increase in well-being and health was often more complicated to evaluate than self-management directed toward disease control (I).

5.5.3. Creating routines and plans of action

Having routines supported the remembrance of self-management, eased the everyday decision-making process (IV) and helped the participants put their illness in the background (II). A plan of action encouraged the participants to act when they found themselves in a specific situation (e.g., experiencing hypoglycemia or chest pain). The participants described that routines had to be created; they did not appear by themselves. When the participants experienced disruptions of habits (e.g., getting a cold or going on a holiday), these routines were challenged, and the participants had to put effort into the reestablishment of their routines (IV).
5.5.4. Negotiating self-management that fits into life

The process of negotiating self-management can be viewed as an ongoing inner dialogue that weighed contrary perspectives and goals. In this process, the goals and needs of self-management were weighed against the individuals' life goals. The goal of the negotiation process was to find self-management strategies that could fit well and be integrated into the participants' life so that the participants could reach a temporary balance in their self-management integration. The negotiation could concern which of the several self-management strategies fits best (e.g., taking pain killers or a hot bath), if life goals were more important than self-management (e.g., skipping insulin to train for basketball without getting hypoglycemia) or if self-management could be adapted to fit life better (e.g., exercising in a private gym instead of attending a rehabilitation program) (I, IV). In the negotiation process, the participants evaluated the effects of self-management on health and life. Self-management could have both positive and negative effects on health and life. For example, seeking information could be time consuming and put the illness in focus, but at the same time, it could increase general and specific knowledge and lead to new possibilities for self-management of the illness. When the positive effects of self-management dominated the participants' experiences, the negotiation process was unproblematic, and they were prone to continue with self-management. In contrast, the longitudinal data shows that participants who negotiated substantial changes in their life could have a lengthy negotiation process, because they found it difficult to compromise between self-management and life priorities. For example, participants could consider giving up work long before they actually did. During that time, they often tried to modify their work and looked for other means to mediate their symptoms (IV).

5.5.5. Reflection

The individuals' perceived self-management needs were identified as driving the process of self-management integration. The complexity of the regimen that the participants developed was a negotiated balance between the perceived demands of the illness and what their life situation allowed. Self-management integration was temporarily balanced when the participants' self-management practices and life goals matched. Important findings included situations in which the participants shifted back to previous phases (IV). These findings can be used to help individuals identify situations that can trigger a shift back in the process of self-management integration. If individuals are more aware of the phases in the self-management integration process, they may prevent some backward shifts and maintain a phase of temporary balance. Individuals that have already shifted to a previous phase might be comforted by receiving information that they could again reach a period of temporary balance.
The process of self-management integration showed that individuals weighed the pros and cons of their self-management, although the inner dialogue could be rather unreflective. In the phase of considering the costs and benefits of self-management, the effects and side effects of self-management were in focus (IV). During the negotiating phase of self-management, the weighing concerned the goals of self-management and life goals (I, IV). This negotiation could concern i) which self-management strategies fit best, ii) which life goals or self-management goals should be prioritized, or iii) if self-management could be modified to fit the individuals’ life (III). Previously identified strategies for the solving of self-management conflicts are action planning (Lorig & Holman, 2003), the creation of routines (Kärner et al., 2005), and finding the positive aspects of self-management (Furler et al., 2008). This research showed that those strategies were actually related to each other and part of the same process (IV).

5.6. The Self-management Support Model

The Self-management Support Model showed that different parts of individuals’ life, beliefs, and abilities were integrated in supporting or impeding their self-management (I, IV) (see Figure 5) (for examples see Table 10). At first, the participants’ life conditions set the conditions for which self-management they could perform (I, IV). Second, the participants’ beliefs and values determined their priorities for and understandings of self-management (I, II, III, IV). A part of the individuals’ beliefs and values was the individuals’ perceived needs for self-management (III). Depending on the individuals’ perceived needs for self-management, the individuals started the self-management integration process by trying to find strategies for self-management that matched their perceived needs (IV). How the participants succeeded in integrating self-management was crucial for whether they were able to continue with intended self-management strategies. The self-management integration process was ongoing and fluent and was influenced by the participants’ ever-changing life and illness. However, at times, the participants reached periods of temporary balance (IV).

The individuals’ creativity and resourcefulness were important for his or her abilities and possibilities of self-management (IV). The participants’ could be resourceful in many ways, including financially, socially, informational, and having a problem-solving mind (IV). Participants used creativity to mobilize resources or mediate when they lacked resources, to find self-management strategies, to create routines for self-management and to negotiate innovative solutions for self-management-related problems. For example, a creative person could modify various self-management strategies to suit different situations (I, IV). This thesis identified several underlying mechanisms for self-management. For
example, unemployment can make it more difficult to create routines for self-management. However, by being creative and resourceful, participants could neutralize these underlying mechanisms. Participants who were unemployed created other life routines that they could relate to their self-management (IV).

Figure 5. The Self-management Support Model. The individual’s life conditions and beliefs and values sets the possibilities for which self-management the individual can develop and will prioritize. The process of self-management integration is driven by the individual’s perceived self-management needs. The heart of the model consists of the individual’s possibility to integrate self-management into daily life.
Table 10. Three examples of the Self-management Support Model. All three participants described themselves as satisfied with their self-management although they lived under different conditions, had various beliefs and values, and found different self-management solutions.

<table>
<thead>
<tr>
<th>Example One</th>
<th>Example Two</th>
<th>Example Three</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Niel</strong> is a married middle-aged man with teenaged children. He is a manager for a small company and has ischemic heart disease. (Data set A)</td>
<td><strong>Irene</strong> has been sick-listed for about two years because of her multiple sclerosis. She is a single mother with two children. (Data set A)</td>
<td><strong>George</strong> is married with adult children. He retired a few years ago. He has inflammatory bowel disease and diabetes. (Data set A)</td>
</tr>
</tbody>
</table>

**Life conditions**

- Since Niel had his heart attack, he has modified some working tasks and has started to delegate more work to his colleagues.
  - He and his family have an ongoing dialogue concerning this new situation. Niel has a friend with ischemic heart disease and finds his friend to be an encouraging positive example of how one can live with illness. Niel does not want to be pitied; this makes him feel low.
  - Niel has had mixed experiences in receiving healthcare. For example, he has experienced the communication as brief with little focus on his resources and abilities.

- Irene’s low income is an obstacle for some self-management. She cannot afford to have a car, and the public transportation in her residential area is limited. With her mobility problems, Irene has found it difficult to get to healthcare appointments.
  - Irene tries to pace and prioritize activities according to her current functional status. However, she always has to prioritize her children, and therefore, she cannot rest as much as she needs.
  - She has no relatives in town and expresses that she wants to be able to take care of herself and her children.
  - Irene experiences that the management of all of the health-care and social insurance contacts is demanding and distressing. Irene has confidence in her physician, and she continues to take medication because she trusts him.

- George has played golf for many years and that gives him regular exercise.
  - George has good contact with his health-care providers. He finds their advice very helpful.
<table>
<thead>
<tr>
<th>Beliefs and values</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Niel has taken on much responsibility for his self-management (internal responsibility attribution). When he experiences angina, he interprets it as a sign that he could and should manage better.</td>
</tr>
<tr>
<td>- Niel has a positive life attitude; he focuses on how he can live a good life with his illness (life-oriented illness perspective). At times, he has shifted to a disease-oriented illness perspective when friends asked him how he feels. He gets low when faced with such non-constructive social support.</td>
</tr>
<tr>
<td>- Niel believes strongly in the effects of his medication and states that he is lucky that his disease in not of a more severe nature. However, having a heart attack was an eye-opener as to how he was living.</td>
</tr>
<tr>
<td>- Irene describes herself as a fighter. She has taken on much responsibility, both for her self-management and for her treatment.</td>
</tr>
<tr>
<td>- She holds a dominant life-oriented illness perspective. She focuses on her abilities and resources and tries to modify activities that are difficult for her. At times, she strives against her illness; for example, she takes a long walk although she is exhausted for the rest of the day. Irene really enjoys doing things that make her feel ‘normal’, predominantly things she appreciated earlier.</td>
</tr>
<tr>
<td>- Irene describes that she can feel stigmatized with mobility aids, so at times, she uses walking poles or disregards mobility aids altogether.</td>
</tr>
<tr>
<td>- Irene is doubtful of the effects of her medication, and she relates taking medication with older people and drug abuse.</td>
</tr>
<tr>
<td>- George states that external factors mostly control his illness; his own actions have limited influence (external responsibility attribution).</td>
</tr>
<tr>
<td>- He holds a dominant disease-oriented illness perspective; namely, that health and wellness are equal to being asymptomatic. George has had long asymptomatic periods, so he has found his illnesses to be rather unproblematic.</td>
</tr>
<tr>
<td>- George believes that his medication is the main reason to that he feels so well.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived self-management needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Niel wants to limit the risk of future heart symptoms. He focuses on disease-oriented self-management during stressful periods or when he gets angina.</td>
</tr>
<tr>
<td>- Niel prefers a life-oriented illness perspective in which he prioritizes to do things that put him at ease, seize the moment, and ‘does fun things’ to increase his mental well-being and decrease his stress.</td>
</tr>
<tr>
<td>- Niel believes that living healthy is important for his ability to live a good life in the future. Living healthy includes caring both for the body and mind.</td>
</tr>
<tr>
<td>- Irene mediates pain and fatigue. Most of the time, she cannot limit her symptoms, but she uses thinking strategies to accept them and rests.</td>
</tr>
<tr>
<td>- Irene gets mental comfort doing things she appreciates, such as exercise. At times, she strives against her illness to feel independent and healthy.</td>
</tr>
<tr>
<td>- She tries to create a new way of living that is more in accordance with her ability. She prioritizes her health, describing her life as ‘slower’ and somewhat more ‘boring’. She uses strategies of pacing and prioritizing and manages emotions to accept her limitations.</td>
</tr>
<tr>
<td>- Irene states that she must take care of herself to be able to take care of her children.</td>
</tr>
<tr>
<td>- George self-manages to control his disease in a long-term perspective. He takes medication and has performed some dietary changes.</td>
</tr>
</tbody>
</table>
**Self-management integration**

- Niel uses trial and error to evaluate the effectiveness of self-management. He listens more to his body and has set up goals for the self-management of his health.
- Niel describes that the heart attack has had some positive consequences in his life; for example, it changed his life attitude.
- He has developed routines for taking medication and action plans for stress management.
- Niel seems to have reached a temporary balance in his self-management integration. He describes himself as satisfied with his self-management and his life.

- Irene uses body-listening to modify activities. She considers the pros and cons of her self-management.
- Irene cares for the household during periods of the day when she has energy. She takes several short rests during the day and between activities. Irene has ongoing negotiating about her self-identity; she can no longer be a person with a perfectly clean home. She uses thinking strategies to accept untidiness.
- Irene has negotiated whether to try working again. She has gotten worse when she has worked, but working would generate more money. She would also meet colleagues, and working is important for her self-identity.
- Some of Irene’s self-management is well integrated into her life; she hardly notices that she often walks close to walls to get balance support.
- Irene says that her disease is worsening, but her management is improving.

- One problem that George experiences is the interactions of the medications. He has decided to cut down on the cortisone to get better control of his blood glucose levels.
- Exercise is well integrated in George’s life because of his interest in golf.
- George keeps away from sweets but does not experience this decision as difficult. He says it is a habit and that the desire for sweets has declined after some time.
6. DISCUSSION AND CONCLUSION

6.1. Discussion

6.1.1 The main findings

This thesis aims to explain how underlying mechanisms work to facilitate or impede the self-management of chronic illness. The findings reveal that individuals’ life conditions set the conditions for their self-management. Living conditions and financial resources were important in limiting or allowing participants to try several alternative ways of self-managing. The participants’ social and healthcare support provided information, motivation and instrumental support. The participants’ beliefs and values accounted for the individuals’ self-management understanding and priorities. For example, participants who held a dominant disease-oriented illness perspective were unlikely to seek self-management factors that facilitated mental well-being. Participants who succeeded in integrating their self-management into their lives could maintain their self-management regimen and put less emphasis on their illness.

The main contribution of this thesis is the Self-management Support Model describing how life circumstances, individual beliefs and the ability to integrate self-management work together to support or impede chronic illness self-management (see Figure 5). Previous models of self-management tend to focus on the decision-making process and the influence of individual factors (Hill-Briggs, 2003; Skodol Wilson et al., 2002). In contrast, the Self-management Support Model focuses upon different kinds of influencers and accounts for living conditions, beliefs and values, and how the self-management is integrated into a participant’s life. Further, the model views the individual as part of a larger societal system that influences living conditions, beliefs and values and the individual’s ability to integrate self-management. All individuals are complex open systems that are influenced by innumerable interrelated factors (A.M. Clark et al., 2008). The aspects of the Self-management Support Model interact with and thereby either reinforce or undermine other effects. For example, individuals who receive little information and support from relatives and healthcare workers and at the same time held an external responsibility attribution were likely to be more disposed to not finding self-management strategies, because the nature of holding an external responsibility attribution was to rely on the advice and directions of other people. Similarly, individuals that already have considerable disease knowledge and confidence are likely to receive more information and support from healthcare providers because they are interested and pose interesting questions. Daniel O Clark and colleges (2008) found that disadvantaged people had limited resources
but also had health beliefs that prevented them from seeking care and enacting self-management. There is little previous research on a comprehensive overview about how different aspects interact when creating possibilities for peoples' self-management.

6.1.2. Who needs self-management support?

Many people in my research integrated their self-management without many difficulties, and they seemed to have limited need for the support of healthcare providers. Most of the participants seemed to be creative enough to tailor a suitable self-management regimen and have sufficient resources to support their self-management (IV). In order to use the healthcare sector resources effectively, healthcare providers should identify the individuals that are in most need for self-management support, and the Self-management Support Model can be used to identify certain situations or beliefs that can impede self-management. However, all individuals in such situations or that hold such beliefs should not be regarded as having problems with their self-management. Instead, certain situations should be considered as mechanisms that can impede self-management, but without any causal relationships. However, further quantitative studies should be conducted upon identifying individuals who may need more self-management support.

According to the model, individuals in disadvantaged positions, such as people with strained finances (IV), single mothers (I), and/or those that are unemployed (IV), need self-management support. These individuals are more in need of self-management support for a number of reasons: single mothers have great social responsibilities and may not be able to prioritize self-management (I); and individuals with financial hardship have fewer possibilities to attempt expensive self-management strategies (IV). Previous research supports those findings, showing that people in disadvantaged positions perform less self-management because of the lack of resources and other life priorities (Carbone et al., 2007; D.O. Clark et al., 2008). In this research, people that lived in unstructured life situations (e.g., periods of employment and unemployment, or irregular working hours) often had difficulties when they tried to create routines for their self-management (IV).

The Self-management Support Model shows that individuals’ beliefs and perspectives are important for how they understand and later prioritize self-management. According to these findings, individuals that regarded self-management as ‘not normal’ or held notions such as ‘ill people are special’ were at risk of striving against their illness. These participants were often reluctant to perform self-management in public and may need support in reflecting on their
illness and self-identity (I, III, IV). Participants with a dominant disease-oriented illness perspective risked being controlled and absorbed by their illness because they were unlikely to see the possibility to actively choose a life-oriented illness perspective (III). People that had an external responsibility attribution seldom sought additional healthcare if they had been advised once (II), and some participants sought no self-management strategies when they were told that they could not influence their illness (II, IV). This can result in that people not taking up self-management and/or getting treatment for their illness. Participants with less knowledge about the healthcare organization described difficulties in accessing care and treatment (IV).

According to Hill-Briggs et al. (2003) some people with diabetes view their self-management in a positive way, whereas others only described the negative effects of their diabetes management. Similarly, some participants found that the negative impact on life goals out-weighted the positive health aspects of self-management when they tried to integrate their self-management. Participants with mostly negative experiences in self-management were likely to give up their self-management intentions (IV); individuals with such concerns could be supported by discussing and identifying life goals and reflecting on ways to modify self-management practices.

Participants that perceived extensive and/or ever-changing self-management needs (e.g., adapting their life to living with pain and fatigue or structuring their life after a strict diabetes regimen) tended to continue their search for self-management strategies over a long time period because they did not find suitable self-management strategies. When they did, they had difficulties negotiating substantial changes in their life (IV). Previous research has identified individuals with co-morbidities as at-risk for performing less self-management (Egede et al., 2009; Schnell-Hoehn et al., 2009), and one explanation may depend on extensive and contradicting self-management needs (Bayliss et al., 2003).

6.1.3. Individual and society - a combined perspective

The notion of self-management has been greatly influenced by diabetes research, which is one reason to why researchers and healthcare providers have assumed that the main goal with self-management has been to avoid disease-related complications (cf. Kralik et al., 2010). Researchers and healthcare providers have taken for granted that individuals want to take on responsibility and perform self-management. In contrast, the data in this thesis suggests that people that take on significant responsibility (e.g., internal responsibility attribution) found their self-management to be double-edged: crucial for their health but arduous for their
well-being (II). Further, some participants found that self-management challenged their self-identity and/or was stigmatizing (I). Hansen et al. (2009) investigated aspects related to diabetes blood glucose monitoring and found that individuals who performed more blood glucose monitoring also exhibited more worry. Similarly, a woman in my research claimed that she stopped monitoring her blood glucose because it was too distressing to be constantly considering her blood glucose levels (II).

It is quite natural that people will strive against their illness, hide their illness and/or disregard self-management (I, III). Many people have lay notions that being healthy is equal to being normal and without diseases and that an individual’s health is closely connection to his or hers self-realization (Goldstein, 1999). Research has found that ill individuals who want to live healthy reformulate their inner values and shift their identities (Kralik et al., 2005). In this thesis, individuals with a dominant life-oriented illness perspective seemed to have undertaken this shift and defined wellness in terms of emotional well-being, while the participants who held a dominant disease-oriented illness perspective defined wellness in terms of symptoms or other disease indications. The participants that held a dominant life-oriented illness perspective could embrace self-management that facilitated activities and well-being while either performing or rejecting disease-focused self-management (III). More research is needed to understand how illness perspectives evolve.

Participants with an internal responsibility attribution described a tendency to blame themselves when they ‘cheated’ with self-management or when they experienced illness-related problems that they ‘ought to have prevented’ (e.g., pain from gardening, high blood lipids) (II). In our post-modern society, there is a tendency to place more and more choices and responsibility upon the individual (Kjellström, 2005), which raises two major concerns. First, when individuals are given the responsibility to self-manage, they cannot later be blamed for self-managing the ‘wrong’ way. By handing over responsibility, the person’s own method of self-managing must be accepted (Anderson & Funnell, 2009). Second, illness development and self-management are influenced by many more variables than the individual’s behavior (e.g., societal factors, pollution and genetic inheritance). Therefore, the individual should never be accountable for his or her illness progression (Mechanic, 1999). By focusing too much upon the individual’s responsibility and behavior, we may reach a point where individuals who smoke, are obese or have a chronic illness are blamed both for their condition and their way of managing treatment (cf. Goldstein, 1999).
In my research, participants with an external responsibility attribution relied on others for strategies to manage their disease. Consequently, they did not identify patterns of response by actively listening to their bodies or noting how various activities affected their symptoms or disease (II). They were also unlikely to experiment with self-management strategies or to be actively involved in tailoring their self-management to suit their needs and contexts (IV). However, passivity can be beneficial, particularly in the face of well-controlled chronic disease or when one’s energies are diverted by other life priorities. Future research should examine how such passivity affects the progression and experience of the illness.

Stakeholders and policy-makers have argued for increased self-management among people with chronic illness, among many reasons, to save healthcare resources (Rogers et al., 2009). When more responsibility is laid upon the individual, the individual’s different possibilities to self-manage must be acknowledged (II). What can happen to individuals who have fewer possibilities and abilities? Do they receive less care, cheaper and less effective medication or less self-management support? Individuals with an internal responsibility attribution can seek information and pose demands about new and effective treatments (II). Inequalities in care and treatment could surface between individuals with knowledge and demands and those that simply follow the instructions of healthcare officials. However, it is also possible that people with internal responsibility attribution try to self-manage instead of seeking care. Townsend, Adam, Cox, and Li (2010) found that some people who were unaware that they might have undiagnosed rheumatism delayed seeking care and instead used different self-management strategies, therefore limiting their chances to receive medication that prevented future joint destruction. Taking on the responsibility for self-management can result in people not seeking help when they actually need it and who therefore might demand additional care in the future.

In Sweden, there are no large projects aiming to increase chronic illness self-management, which is in contrast to many other western countries (Rogers et al., 2009). According to my research, most individuals create their self-management by themselves (IV). This is partly positive because individual receive an individually tailored self-management plan. However, for some individuals, it took a long time to reach a temporary balance for their self-management, and some of the participants had not reached temporary balanced self-management three year post-diagnosis (IV). Charmaz (1997) stated that the daily management of chronic illness is invented by every individual, and the consequences are that individuals do not see choices or reflect over the strategies they use. In Sweden, a discussion is needed to clarify who should support self-management. Should self-management
support be provided collectively by the healthcare sector, voluntarily by patient associations or commercially by fitness centers, drugstores or advertisers for alternative therapies? According to this research, the participants' life conditions, beliefs and values were crucial for their self-management. Perhaps self-management is best supported by working with values, attitudes and inequalities in society.

6.2 Methodological considerations

6.2.1. Methodological approaches and design issues

The choice of using different qualitative approaches for the different papers was useful, because the various approaches provided different analytic tools for the analyses. However, some methodological concerns could also be raised. I have analyzed data set A three times with different aims, methods and outcomes, which placed certain demands on the interviews to contain enough material for three analyses and because different qualitative methods are related to various kinds of interviews. In constructive grounded theory, interviews are modified when new analytical questions occur (Charmaz, 2006), which is contrary to phenomenographic research that favors standardized semi-structured interviews (Bowden & Green, 2005). However, insightful probing is important in both constructive grounded theory (Charmaz, 2006) and phenomenography (Bowden & Green, 2005). When I collected data set A, I knew that it would be used for both constructive grounded theory and phenomenography. Therefore, I added topics to and adjusted the part of the interview that was influenced by the ongoing grounded theory analysis and kept the questions concerning illness perspective more consistent.

6.2.2. The sample

Both data set A and B contain variations in gender, age and diagnosis. I strived for variation, because I wanted to collect various illness narratives, although other variations that influence self-management are not well represented in my material. For example, a majority of the participants were of Swedish ethnicity, and the individuals that were born in other countries (N=3) had all lived in Sweden for several years. Using a variable sample was positive because the participants told various illness experiences and views of self-management. However, I have not performed comparative analyses between diagnoses, age and gender because the material is quite small, and, therefore, specific age groups and genders dominated some diagnoses. I believe that to enhance self-management research, several kinds of perspectives are needed, including both qualitative and quantitative studies conducted upon specific diagnoses, multiple diagnoses and studies that compare the self-management of two or three diagnoses.
6.2.3. The interviews

When researchers chose interviews as a data collection method they hope that people will tell them their concerns. According to Charmaz (2004), this is not always possible because participants’ main concern can be hidden even to themselves. Many of my participants had never talked about or reflected on self-management prior to the interview because for some of them, self-management was a more or less automatic behavior. People with diabetes, though, tended to be more familiar with the notion of self-management.

The concept of self-management is grounded in the notion that individuals are free to make their own choices. However, when investigating self-management performance, it becomes evident that individuals’ choices are influenced by many factors, including family, available healthcare, society, values and social structures. Many individuals might not be aware of how society or family influence their actions and may therefore not acknowledge those perspectives in private interviews. For example, a man whom I interviewed did not mention that his family influenced his self-management, but later over coffee, his wife described how she was cooking and caring for him. Complimentary interviews with family and/or healthcare providers would have granted other complimentary perspectives about the ‘relational’ part of self-management.

The limitations of language added some difficulty to my data-gathering, because the Swedish language lacks a good word for self-management (‘egenvård’). Therefore, I did not use the term self-management in the interviews and instead probed with questions like: ‘Tell me about what you do to stay healthy?’, ‘What do you do to manage your disease?’, and ‘What makes you feel well?’. Another concern during the interviews was of an ethical nature. Some participants did not view themselves as having a chronic disease or of having a disease at all. Instead, they talked about having diabetes, having had a heart attack or having problems with long-lasting pain. In the interviews, I usually used the same term as the participants.

A limitation of this study is that it only relied upon interviews. I have investigated peoples’ narrative descriptions of their self-management but not their actual self-management performance. People may not recall or be able to describe their self-management, or participants may (more or less consciously) pose themselves in a ‘favorable light’ and describe more self-management than they actually perform on a regular basis. Future research could complement interviews with other data
sources, such as ‘modified think aloud’ (e.g., Paterson, Thorne, Crawford, & Tarko, 1999) or diaries (e.g., Nicholl, 2010).

6.2.4. Trustworthiness

I have tried to reflect on my own part in the research, explore negative cases in the analyses, work close to data, and move back and forth between the interview text and the interpretations (cf. Morse, Barrett, Mayan, Olson, & Spiers, 2002; Whittemore, Chase, & Mandle, 2001). Memos have been used both to reflect on the research process, the material and my own part in the research. We have had ongoing discussions within the research team, but I have also reached out to discuss preliminary findings and models with other researchers. Throughout the research analysis, I have tried to be transparent in how the research has been conducted by exemplifying analytical decisions and provide quotes and narrative examples.

The material of data sample B was collected during several meetings with each participant. Longitudinal material often generates more trustworthy results than one-time data collection methods (Thorne, 2008). In data sample B, I brought up issues from the earlier interviews, and the participants could discuss and reflect on their earlier statements.

All research is contextual. Some results are applicable to the general field and other findings are unique to a Swedish (or even a Västernorrlands) population (cf. Thorne, 2008). I believe that the main findings can be transferred to other similar contexts, e.g., aspects that influence self-management, and the process of self-management integration. It is likely that individuals with chronic illness in other parts of the world also seek self-management strategies and negotiate their self-management against other life goals. It is also likely that many underlying mechanisms work in similar ways in other countries; for example, how financial strain limits the choices of self-management, or how individuals’ responsibility attribution influences their self-management. However, I think that particular findings are more bound by context, such as access and beliefs regarding medical treatment, the limited use of alternative therapy, the nature of healthcare providers’ self-management support or the fact that religious beliefs are not described in relation to self-management.
6.3. Conclusions

In this thesis, several underlying mechanisms of chronic illness self-management are identified. The main contribution is a model describing how life circumstances, individual beliefs and the ability to integrate self-management work together to support or impede chronic illness self-management.

Social inequalities limit people’s possibilities to develop self-management regimens, although individuals can balance some impeding aspects by being creative in their self-management performance.

6.4. Implications for practice

According to this thesis, some individuals do not seek much self-management by themselves. Instead, they are quite convinced that no management strategies exist and start looking for and practicing self-management first after being advised to do so (II, IV). The results of this approach are that a few participants lived with difficult symptoms for several years without attempting much self-management (IV). It is possible that if those participants had received more information about self-management strategies, they could have found ways to deal with their illness and change their life situation. This thesis provides important implications for clinical practice, namely:

- If healthcare providers are aware of self-management mechanisms, they might better understand what difficulties their patients face, what resources their patients hold, and why some patients reject self-management, and striving against their illness.
- To integrate self-management into everyday life can be a lengthy and challenging process. Patients in different parts of that process are likely to need different kinds of self-management support. Healthcare providers can use the findings in this study to discuss self-management integration with their patients.
- In this thesis, I describe certain situations and beliefs that can determine which individuals need more self-management support. Healthcare providers can reflect on these suggestions and discuss self-management with individuals that might need self-management support.
- In order to support healthcare provider self-management communication, I intend to develop a communication tool based on my findings (for a preliminary version see Appendix 1.). The communication tool provides a number of questions that aim to explore motives and barriers for self-management but also identify needs and self-management integration. The overall aim with the communication tool is to support a reflexive dialogue
between healthcare providers and their patients about self-management and help to find a self-management regimen that fits individuals’ life situation. The intention is that the communication tool can be used as inspiration, in parts, or during a series of consultations.

In conclusion, healthcare providers have great possibility to influence and support individual self-management, and this thesis provides suggestions about how this can be done. At the same time, healthcare providers should acknowledge that they are but one influence in their patients’ lives.
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APPENDIX. 1. COMMUNICATION TOOL FOR SELF-MANAGEMENT DISCUSSIONS

A preliminary version of a communication tool developed from the Self-management Support Model. This tool is intended to provide health-care providers with questions they can use or be inspired by when they discuss self-management with their patients. The tool contains questions and some statements that aim to direct an open discussion about the individuals’ possibilities and abilities for self-management and to identify problems, barriers and facilitators that will hopefully create a dialogue about how such issues can be overcome. The health-care provider can complement this tool with information drawn from his or her clinical knowledge and experience.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Examples of questions and discussions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>-There are no rights or wrongs about how people manage chronic illness. However, many people are unaware about how they manage illness, and upon reflection, they can get insights about other ways of self-managing. Many people also experience problems and barriers to their intended self-management. This discussion is intended to relieve problems and then we may find ways to deal with them.</td>
</tr>
<tr>
<td><strong>The individuals' current self-management</strong></td>
<td>-What kind of activities or strategies do you use to control your illness? (e.g., medication, diet, stress-management, life structure, management of fatigue, pain, or other symptoms) -Do you use additional activities or strategies to increase or maintain your health and well-being? (e.g., exercise, rest, positive thinking, stress-management, or alternative therapy) -Many people adapt their life somewhat when they live with many symptoms or manage a complex treatment. How is it for you? -Strategies to adapt to daily life can include prioritizing, pacing or reducing activities. Do you use these strategies?</td>
</tr>
<tr>
<td><strong>The individuals' social network and perceived need for support</strong></td>
<td>-What does your family look like? Do you have close friends or family that has supported you regarding your illness? In what ways? There are several kinds of support (i.e., emotional, practical, financial, informational or motivational). Are there additional activities you would like to get supported? -Some individuals experience non-constructive support (e.g., being told what to do, lectured, or not listened to). Have you had these experiences? What have these experiences meant to you? -Being single can result in less support because people may lack someone close to provide on-going support in daily life. What is your experience?</td>
</tr>
</tbody>
</table>
| The individuals’ responsibility attribution | -What would you say is the most important influence of your health status? (e.g., the illness itself, your behavior, the treatment)  
-What is most important for your self-management performance?  
-What role of responsibility do you want me as a healthcare provider to take?  
-What is your confidence in your ability to self-manage? |
|---|---|
| The individuals’ experiences of stigma and normalization | -Some people have described how they perceive self-management performance as challenging their sense of living a “normal life” (e.g., it is weird to take medication when you have never done that before). Have you had similar thoughts?  
-Do other people’s opinions prevent you from doing self-management (e.g., taking insulin injections in a restaurant or using mobility aid)?  
-Do you have a specific notion of how individuals with your illness ‘should be’ or behave? |
| The individuals’ health-care expectations | -Do you have knowledge of how the health-care organizations work?  
-What are your expectations of health-care and of me as a health-care provider?  
-People want to take more or less part in discussing and deciding their treatment and treatment decisions? How would you like our communication to proceed?  
-Do you know where to turn if you have questions later? |
| The individuals’ illness perspective | -How would you describe a good life/living well?  
-People’s description of wellness often influences how they describe self-management. A person who describes wellness as being asymptomatic often performs self-management to control illness. A person that describes wellness as being able to do what one wants and maybe live a good life with symptoms uses self-management to facilitate activity and relationships. People can hold both perspectives and often shift between the two. How would you describe yourself? |
| The individuals’ perceived self-management needs | -What would you define as problematic in your situation regarding illness/regarding life?  
-Self-management can have different goals (e.g., control symptoms, mediate health threats, find a new way to do things or live).  
-Do some of your self-management practices have goals that lie in the future? Please describe.  
-Which of your self-management goals are of a more immediate character?  
-Do you regard some self-management as more important than others? (Each behavior must be evaluated on its own). |
### Seeking self-management strategies:

The provider and the patient can talk about possible self-management based on the individuals’ needs

- Have you looked for information of possible self-management strategies?
  - What have you found? What sources of information have you used (e.g., family, friends, health-care advice, leaflets, internet, library, risks and benefits with different sources)?
  - Some people experience that financial issues restrain their self-management (e.g., expensive to visit a physiotherapist or exercise at a gym). Have you had such concerns?
  - External factors, like how you live and work, can be a barrier or support to your self-management. What is your experience?

### Considering costs and Benefits:

The healthcare provider can inform about likely effects and side effects of various self-management strategies

- What benefits do you experience from your self-management? What experienced effects had you anticipated? Have you experienced any negative effects? Do you have other concerns?
- How do you evaluate your self-management practices?
- Each self-management practice has to be evaluated on its own. For example, how effective do you regard your medication (e.g., exercise, cutting down work)? What risks do you identify regarding your medication? Have you experienced any sensations that could be side effects?

### Creating routines and plans of action:

The healthcare provider can suggest routines or discuss what routines the patient already has in his/her life.

Action plans can be developed in collaboration with the healthcare provider and patient.

- Have you found routines for any of your self-management practices? Are there additional self-management practices that you need routines for?
- Do you have life routines that you can relate to your self-management?
- How should routines look to be naturally incorporated in your life?
- An unstructured life situation (like unemployment, irregular work) can impede routines. How would you describe your life situation?
- Changes, like holidays or bad weather can break routines. Can you identify situations that would challenge your routines? How could you meet these challenges?
- Which events would benefit from an action plan (e.g., risk events; chest pain, low blood glucose levels, a rheumatic flare)? How could you manage these situations? What are the risks and benefits of different actions? In what situations would you seek care?

### Negotiating self-management that fits life

- What problems do you experience in relation to your self-management? In what situations do you perform or reject self-management? What health goals are at stake if self-management is rejected? What life goals and perspectives are concerned (e.g., practical goals: convenience, life schedule, time, and work; emotional goals: normality, self-identity, and emotions)? More substantial self-management regimens are often more difficult to negotiate.
- What possibilities do you see for prioritizing or compromising between these goals? Can goals change? Can self-management strategies be performed in another way?