Patients’ and healthcare providers’ experiences of the cause, management and interaction in the care of rheumatoid arthritis

Ulrika Bergsten
Romanska bågar


Del av Romanska bågar ur diktsamlingen ”För levande och döda”, Tomas Tranströmer, Liber förlag, 1989

Romanesque Arches

Inside the huge Romanesque church the tourists jostled in the half darkness. Vault gaped behind vault, no complete view. A few candle flames flickered. An angel with no face embraced me and whispered through my whole body: “Don’t be ashamed of being human, be proud! Inside you vault opens behind vault endlessly. You will never be complete, that’s how it’s meant to be.”

Abstract

**Aim:** The overall aim of this thesis was to explore and describe patients’ and healthcare providers’ experiences of the causes, management and interaction in the care of rheumatoid arthritis (RA). **Method:** The thesis is based on four studies. Studies I and II contain data from an epidemiologic project involving patients who were recently diagnosed with RA. The patients answered an open-ended question about their conception of the cause of their RA (Study I). Qualitative data from 38 patients were analysed using the phenomenographic approach in order to identify variation in conceptions. The results of Study I formed the basis for categorizing the conceptions of 785 patients in the search for patterns of background factors (Study II). Study III aimed to explore how patients experienced their management of RA in everyday life. Data were collected by interviews with 16 patients and analysed according to Grounded Theory (GT). In study IV, the aim was to explore healthcare providers’ experiences of their interaction with patients’ management of RA. Data were collected by interviews with 18 providers representing different professions and analysed using GT. **Findings:** Patients’ conceptions of the cause of their RA revealed new aspects from the patient perspective that can complement pathogenetic models. Two descriptive categories emerged: consequences beyond personal control and overloaded circumstances, which included six categories of conceptions (Study I). The most common conceptions of the cause of RA were unexpected effects of events followed by work and family-related stress (Study II). Background factors that influenced the conceptions of the cause were age, sex and educational level. Patient management of RA involved using personal resources together with grasping for support from others in their striving for a good life. When linking these aspects together, four ways of management emerged: mastering, struggling, relying and being resigned (Study III). Healthcare providers’ experiences of their interaction with patients’ management shed light upon the important issue of delivering knowledge and advice. The providers’ attitudes constituted one cornerstone and patients’ responses the other. The providers reported that the interaction led to different outcomes: completed delivery, adjusted delivery and failed delivery. **Conclusions:** The findings contribute new knowledge from both patients’ and healthcare providers’ perspectives, which could be used to develop a more person-centred approach in rheumatology care. Person-centred care involves taking patients’ beliefs and values into account in addition to creating a trusting relationship between patient and provider. A successful person-centred approach requires an organisation that supports the person-centred framework.
Original studies

This thesis is based on the following studies, which are referred to by Roman numerals in the text:

Study I
Bergsten U, Bergman B, Fridlund B, Alfredsson L, Berglund A, Petersson I, Arvidsson B.  
*Patients’ conceptions of the cause of their rheumatoid arthritis: A qualitative study.*  

Study II  
*Patterns of background factors related to early RA patients’ conceptions of the cause of their disease.*  
Clinical Rheumatology 2011 Mar;30(3):347-52

Study III  
Bergsten U, Bergman S, Fridlund B, Arvidsson B.  
"Striving for a good life" - the management of reumatoid arthritis as experienced by patients.  
Open Nursing Journal. Accepted.

Study IV  
Bergsten U, Bergman S, Fridlund B, Arvidsson B.  
"Delivering knowledge and advice" - healthcare providers’ experiences in their interaction with patients’ management of RA.  
International Journal of Qualitative Studies on Health and Well-being.  
Published online 31 October 2011.

The articles have been reprinted with kind permission of the respective journal.
Contents

Abstract ........................................................................................................................................................................ 5
Original studies .......................................................................................................................................................... 6
Abbreviations and Definitions ......................................................................................................................................... 8
Introduction .................................................................................................................................................................. 9
Background ................................................................................................................................................................. 10
  Rheumatoid arthritis .................................................................................................................................................. 10
  Rheumatology care .................................................................................................................................................... 11
The patient perspective in rheumatology care ............................................................................................................... 12
  Illness perceptions ..................................................................................................................................................... 12
  Self-management ....................................................................................................................................................... 13
  Patient-provider interaction ..................................................................................................................................... 15
From patient-centred to person-centred care ................................................................................................................ 16
Rationale of the study .................................................................................................................................................... 19
Overall and specific aims ............................................................................................................................................. 20
Materials and methods .................................................................................................................................................. 21
  Ontological and epistemological framework ............................................................................................................... 21
  Study designs ............................................................................................................................................................. 22
  Studies I and II ........................................................................................................................................................ 25
    Participants and settings ........................................................................................................................................ 25
    Data collection ......................................................................................................................................................... 25
    Data analysis .......................................................................................................................................................... 26
  Studies III and IV ..................................................................................................................................................... 28
    Participants and settings ....................................................................................................................................... 28
    Data collection ....................................................................................................................................................... 28
    Data analysis ........................................................................................................................................................ 29
Methodological considerations ...................................................................................................................................... 31
Ethical considerations .................................................................................................................................................. 37
Summary of the findings ................................................................................................................................................ 40
  Patients’ conceptions of the cause of their rheumatoid arthritis (Study I) ................................................................. 40
  Patterns of background factors related to early RA patients’ conceptions of the cause of their disease (Study II) .... 41
  “Striving for a good life” - the management of rheumatoid arthritis as experienced by patients (Study III) ............ 43
  “Delivering knowledge and advice” - healthcare providers’ experiences of their interaction with patients’management of RA (Study IV) ..................................................................................... 45
Discussion .................................................................................................................................................................. 48
Comprehensive understanding ...................................................................................................................................... 52
Conclusions ................................................................................................................................................................. 57
Clinical and research implications ............................................................................................................................... 58
Swedish summary ......................................................................................................................................................... 59
Acknowledgements ...................................................................................................................................................... 66
References .................................................................................................................................................................. 68
Abbreviations

CI  confidence interval
DMARD  disease modifying anti-rheumatic drug
EIRA  Epidemiological Investigation of Rheumatoid Arthritis, www.eirasweden.se
GT  grounded theory
OR  odds ratio
RA  rheumatoid arthritis
WHO  World Health Organisation

Definitions

Coping  the concept is generally defined as a tentative effort to mediate stressful events (1)
Patient  a person who receives professional care, irrespective of the form of care or caregiver (2)
Provider  a person who cares for a patient
RA  in this thesis the definition of RA is based on the American Rheumatism Association 1987 revised criteria for the classification of RA (3)
Introduction

Rheumatoid arthritis (RA) is a chronic disease that often implies different patterns of flares, leading to unpredictability that requires continuous adaptation to the disease both from patients and healthcare providers (4). Living with a chronic condition such as RA affects a person in many ways. Studies indicate that the experience of suffering from a chronic illness is dependent on several factors, including personal, social and cultural (5). In rheumatology care, the consequences of the disease are of great importance both for the patient and for the healthcare organisation. The WHO has developed a strategy for preparing the healthcare system to better meet the needs of persons with chronic conditions (6). One of the core competencies in the WHO document is patient-centred care, which involves taking patient preferences, values and needs into account. Healthcare providers need to encourage patients to become involved in decision-making and self-management. Healthcare providers need communication and partnering skills to succeed in managing the shift from provider-centred care to patient-centred care (6, 7). Patient-centred care is an important step in fulfilling the unmet need of patients with rheumatic diseases (8, 9). An active patient with an ability to assume responsibility and a healthcare organisation that can treat the patient as a person are necessary in the management of RA. To face these challenges, rheumatology care needs knowledge from the patients’ as well as from the healthcare providers’ perspective.
Background

Rheumatoid arthritis

RA is the most common of the inflammatory rheumatic joint diseases, affecting 0.5 -0.7% of the adult population (10, 11). RA affects joints symmetrically, mainly of the hands and feet. Major symptoms of RA are joint pain, joint swelling, stiffness and a general malaise, often with marked fatigue (12). If untreated, the inflammatory process involves the destruction of cartilage and bone as well as tendons and other soft tissue, leading to impaired function and reduced quality of life (4). RA is three times more common in women than in men. The mean age of onset is 55-60 years, but in women onset at a younger age is common (10). The aetiology of the disease is still unclear, but it is known that genetic and environmental factors interact (13). Twin studies show that environmental factors are important (14), including tobacco smoking (15) and exposure to silica (16) or mineral oils (17). Female sex hormones also play a role in the development of RA (14) as does socio-economic burden (18).

The treatment of RA consists of several components that are usually divided into pharmacological and non-pharmacological (13). The past decade has seen great progress in pharmacological treatment, which aims to deal with the symptoms of pain and stiffness by means of analgesic and anti-inflammatory drugs. In addition to symptom relief, disease-modifying drugs reduce disease activity; these are usually divided into DMARD and biological medication (19). There is a variety of DMARD drugs, but methotrexate is one of the most common for the treatment of RA. Biological medications have a more specific target in the inflammatory process and have revolutionised the treatment of inflammatory joint diseases in the past decade (4). Early initiation of disease modifying drugs is important in order to minimize the risk of joint damage (19, 20).

Non-pharmacological treatment incorporates patient education and rehabilitation, including information and advice about the disease, medication,
exercise, balancing activity level, joint-protection and non-pharmacological pain relief methods. The evidence of non-pharmacological forms of treatment is divergent; there is support for the beneficial effects of exercise and cognitive behavioural interventions (including patient education and stress management) (21) but less evidence in terms of the long-term effects of traditional patient education without any cognitive behavioural technique (22). Non-pharmacological forms of treatment are often described as self-management courses or interventions aimed at educating the patients to manage alone after the intervention or course. These forms of treatment are often provided by the rheumatology team, where several providers meet the patient (23). Although pharmacological treatment today has a great deal more to offer than previously, RA remains a chronic disease and the patient must learn to live with it. The process of learning to live with a chronic illness demands development of non-pharmacological treatment options where the patient's perspective is more in focus.

**Rheumatology care**

In rheumatology care, there has been a long tradition of working in multi-professional teams. The most common healthcare providers in the rheumatology team are nurses, occupational therapists, physicians, physiotherapists and social workers. Historically, the care has mainly been organized by in-patient clinics, but in recent decades, there has been a shift towards out-patient clinics, where the patient is expected to assume more responsibility for the management of the chronic illness (24, 25). This shift has economic aspects as well as acknowledging patients’ requests to play a more active role in their own healthcare (24, 26, 27). The benefit of rheumatology team care is recognised (28) but there is a need to incorporate new outcome measures that are important from the patient perspective (29). Organisational aspects of rheumatology team
care must be modernized to meet the standards of patients and to be more
efficient from an economic point of view (23, 30, 31). A transition to more
patient-centred care has been highlighted by the WHO to meet the challenges of
chronic conditions (6).

The patient perspective in rheumatology care
Patient perspective focus on the inside view of having a disease - the illness
experience. Illness is described as the human experience of symptoms and
suffering and refers to how the disease is perceived, lived with and responded to
by persons - the inside view of the condition. Disease refers to the structure and
function of the condition and is often described by a pathophysiologic model -
the outside view of the condition (32).

The illness experiences of RA are affecting the patients’ life in many different
aspects. Its consequences in everyday life impact on the patient both in personal
matters as well as in social ways (33-38). Patients have described their need for
knowledge about the disease (39) and treatment options (40, 41) as well as the
need of support (41, 42), especially emotional support, to manage RA, all of
which are often lacking within the healthcare organisation (33, 43, 44).

Illness perceptions
Illness perceptions are the cognitive beliefs that a person holds about his/her
illness and a key determinant of his/her emotional response to illness
management (45). Illness perceptions are built on lay beliefs that emerge from
earlier knowledge and experiences (46) and are intertwined with the society in
which the person lives (47). Five components have been found, describing a
consisting pattern of how patients structure their perceptions of illness:
identification of the disease, its timeline, causes, consequences and
controllability (32, 48). In rheumatology care, some research has been
conducted within this area, and the illness perceptions that influence rheumatic diseases are related to; disease-modifying medication (49), causes of osteoarthritis (50) and the ability to predict disability in RA (51). Bury (52) stated that getting RA and searching for the cause of the RA implies searching for its meaning. The experience of being afflicted by RA is a biographical disruption, affecting several aspects of the patient’s life (53). The illness beliefs in RA have been investigated and the most frequently cited causes are; heredity, stress and weather (46, 54-57). On the other hand, Ailinger et al. (55) claimed that the cause of the disease is irrelevant to the patient. This position contradicts other studies, where the cause is considered very important (46, 53, 54, 56, 57). No recent study has explained patients’ illness beliefs about the cause of RA. In the case of osteoarthritis, Turner et al. (50) demonstrated that patients considered their illness to be due to heredity, wear and tear, occupation, sport, weather and that it was a natural sign of aging. Illness perceptions in RA are not associated with objective measures of disease activity or status but influence different aspects of living with RA (51). Illness perceptions are key determinants of a person’s emotional response to the illness and can influence management, such as adherence to treatment (45, 49). Illness perceptions rarely receive sufficient attention in the medical encounter (58). In rheumatology care there is a need for greater awareness of patients’ illness perceptions in order to respond to these key determinants of patients’ emotional management of RA.

Self-management

Patient management of RA is often described in the literature as coping, self-care or self-management strategies. Different coping behaviours have been described in patients with RA and studies are searching for a relationship between coping behaviour and disease outcome, but there is a lack of evidence (59, 60), which may be related to the coping concept per se. Lazarus and
Folkman (1) grounded the concept of coping in relation to dealing with stressful events, but living with and managing RA is not always stressful. The concept of self-care is sometimes used synonymously with self-management, although most researchers make a distinction between them. Self-care is mostly described as tasks performed by healthy persons to prevent the onset of an illness and self-management as tasks performed on a day-to-day basis to control or reduce the impact of an illness (61). Self-management aims to manage health and wellness despite a chronic illness. Barlow et al. (62) defined self-management in rheumatology care as the patients’ ability to handle symptoms, treatment, consequences related to physical and/or psychosocial aspects and lifestyle changes that are entailed by living with a rheumatic disease. Efficient self-management includes cognitive, emotional and behavioural responses with a constant process to maintain satisfaction in life. Kralik et al. (63) demonstrated that self-management in arthritis means an action to create order, where patients described self-management as both a structure and a process. Patient education is one part of structured self-management interventions offered by healthcare providers aimed at ensuring that patients with RA have the knowledge and ability to manage their symptoms, but there is little evidence of the long-term benefits (64). Self-management involves complex processes intended to create order from the disorder imposed by arthritis (63). Similar results were presented by Arvidsson et al. (65) when describing the meaning of self-care as a way of living and harbouring continual hope as well as a belief in one’s ability to influence health in a positive manner. The development of self-care and self-management activities has been a focus of the healthcare organisation over the past decades (66-68). Most self-management interventions in rheumatology care have been developed to teach patients what to do or not to do – a structured and sometimes more passive type of information. The importance of the self-management process, as illustrated by the literature (24, 61, 62, 67, 69, 70), has not been considered sufficiently in rheumatology care. The healthcare
organisation has changed its approach from seeing patients as passive recipients to encountering them as active partners with the right to be involved in and take responsibility for their own health. This new perspective presents a challenge to promote and develop self-management interventions as well as to gain more knowledge about patients’ perspective of managing RA.

**Patient-provider interaction**

The interaction between patients and healthcare providers has been described in different ways. A general concept is patient-provider interaction. Provider is defined as the person involved in the care of a patient (71). A central part of the patient-provider interaction is the creation of a shared meaning in the patient and provider encounter. The key to creating a shared meaning is good communication between the parties involved (71). Other factors that influence the patient-provider interaction are culture, social identity and the organisation that provides the care (71). Studies of rheumatology care reveal differences between providers and patients both in terms of what is important in the care as well as divergent goals of the medical encounter (72-75). There are also different views on the consequences of living with rheumatic diseases (76-78). Some key elements of patients’ satisfaction with healthcare is their experience of trust in the physician (9) and the providers’ communication style, where patients appreciate a more equal dialogue in the medical encounter (27, 40). The medical consultation has a positive influence on the patients’ perception of control over their disease by involving them, providing information, reassurance, empathy and access to an expert (40, 79). The shift in perspective to more patient-centred care of chronic diseases requires providers to adopt a different approach than the bio-medical model that has mostly been used. A majority of healthcare providers who have experience of working with self-management techniques among patients with chronic diseases have never
received formal training (80). Healthcare organisations are not sufficiently prepared for the transitions that are taking place in the care of chronic diseases (81). The interaction between patients and providers in rheumatology care needs to be further investigated in order to improve the quality of care.

From patient-centred to person-centred care

The WHO stated that there is a need to develop healthcare in chronic conditions and one of five core competencies is patient-centred care. The healthcare of chronic conditions needs to reorganize in order to move from a provider-centred to a patient-centred perspective (6). Chronic conditions require different approaches compared to acute conditions, both from the healthcare organisation and from the patient perspective.

The definition of the concept of patient-centred care is not established, but Mead (82) presented a five dimensions framework, which starts with the biopsychosocial perspective followed by ‘seeing the patient as a person’, sharing power and responsibility, therapeutic alliance and ‘doctor-as-person’. The focus is on the physician and the encounter with the patient, while other providers are not mentioned. Another definition of patient-centred care also focuses on the physicians’ and patients’ relationship by incorporating six interactive components; physicians’ explorations of the patients’ diseases and illness experiences, physicians’ understanding of the patient as a whole person, finding common ground regarding management, the physician’s ability to incorporate health prevention and promotion into the encounter, improvement of the patient-physician relationship and realistic patient-centred care (83). These concepts of patient-centred care have been developed from primary care settings and from the field of gerontology (84).

Person-centred care is a concept that is receiving increased attention in the literature and has similarities with patient-centred care but the former focuses on
the person (and his/her whole situation), the provider of the care and the healthcare organisation. The person-centred practice framework by McCormack et al. (85, 86) was developed from a nursing perspective (person-centred nursing framework) but the researchers used the framework in a multi-professional setting and labelled it a person-centred practice framework. The framework consists of four constructs: *prerequisites, the care environment, care processes* and *person-centred outcomes*, as illustrated in Figure 1.

![Diagram of person-centred practice framework](image)

**Figure 1.** The person-centred practice framework adapted from McCormack et al. (87).

*Prerequisites* that form the fundamental blocks for achieving person-centred practice are provider attributes such as professional competence, interpersonal skills, work commitment, clarity of beliefs and values and knowing self. Beyond professional competence there is also a need to develop personal skills and self-awareness. These qualities are of importance for the delivery of person-centred care.

*Care environment* means the context in which the care is delivered, and its characteristics have the potential to promote or hinder person-centred care. In order to enhance person-centred care it is necessary to be aware of the context of
the care environment and create a supportive organisation that facilitates active participation in the decision making process. A supportive organisation should be work with and promote team building and team development in order to create a learning culture.

Care processes include activities in which person-centred care is provided and where the interaction between patient and provider takes place. These activities focus on the patient and it is important to work with his/her beliefs and values to facilitate the shared decision-making that is central in person-centred practice. Holistic care requires increased knowledge from the patient perspective. The attributes of the provider and the characteristics of the care environment influence the care process, and all parts of the framework are dependent on each other.

The outcomes of person-centred care are satisfaction with and involvement in the care as well as a feeling of well-being. These outcomes are meant to be measured by both patients and providers in order to evaluate the person-centred care. McCormack et al. (86) suggested various questionnaires for such an evaluation, and there is a need for development in this area.

Patient-centred care focuses directly on the encounter with the patient in clinical practice and creates awareness of important factors for enabling a more equal encounter and shared decision-making. The person-centred nursing framework highlights the benefits of focusing on the attributes of the provider, the context of the care environment and discussion of the expected outcomes. Although person-centred care is becoming more common in rheumatology, research evidence is lacking and there is a need for increased knowledge. It is also necessary to develop new care models that integrate the person-centred practice framework in the entire rheumatology team – including the patient.
Rationale for the thesis

Patients with RA face a complex situation and have to deal with problems associated with different aspects of life. At the beginning, the main focus is to understand and relate to being afflicted by RA and subsequently how to manage the disease in everyday life. RA treatment goals focus on symptom relief and to controlling disease activity from the healthcare providers’ point of view, while the patients report unmet needs. Patients with RA are dependent on the relationship with healthcare providers, being the trusting party in the interaction who wish to be treated as an equal partner. Factors that influence the patients’ perspective of managing chronic illness include their own thoughts and attitudes to the illness. The cause of RA is still unknown, although there has been epidemiological and biological knowledge development in this area. However, the patients’ beliefs about the cause of RA have not been investigated recently. The thoughts about the cause, and other illness perceptions, as experienced by patients are important to consider in the medical encounter but could also give some ideas for further epidemiological research.

Earlier literature on the management of RA mainly focused on the explanation and measurement of the relationship between patients’ coping behaviour and disease outcome, but had difficulty providing sustainable evidence. There is a need for studies that explore or describe patients’ own experiences of dealing with RA, i.e. their illness experience, in order to increase knowledge of the inside view of the consequences of living with and managing a chronic illness. It is also necessary to increase knowledge of the healthcare providers’ experiences of rheumatology care as an interaction between themselves and patients, as this aspect has not been thoroughly investigated.
Overall and specific aims

The overall aim of this thesis was to explore and describe patients’ and healthcare providers’ experiences of the causes, management and interaction in the care of rheumatoid arthritis.

The specific aims of the different studies were:

- to describe the variations in how patients conceive the cause of their RA (Study I).
- to identify patterns of background factors related to the early RA patients’ conceptions of the cause of the disease (Study II).
- to generate a theoretical model of how patients experienced their management of RA in everyday life (Study III).
- to explore healthcare providers’ experiences of their interaction with patients’ management of RA (Study IV).
Materials and methods

Ontological and epistemological framework

The starting point of this thesis is the caring perspective and it has a holistic approach, as it attempts to understand the complex phenomenon of dealing with RA. The ontological standpoint is based on the naturalistic paradigm, which assumes that reality is multiple. Reality is derived from a construction of the situation and specific context, with several possibilities for interpretation (88, 89). Caring research applies to understanding issues from clinical practice and the use of different approaches to answer the research questions. This is done by exploring phenomena using an inductive approach, the pathway of discovery, but also by explaining, which implies a deductive approach, the pathway of clarification (90). To gain understanding of a phenomenon it is essential to search for knowledge from persons how have experienced it. Patients’ experiences illustrate the meaning the phenomenon has to them as unique individuals, while meaning is also formed in social interaction between persons (89). In the first study in this thesis, phenomenography was chosen to describe the phenomenon of the cause of RA as experienced by patients. Phenomenography aims to find variations in the world as it is conceived and described by persons who have lived experience of a given phenomenon. The researcher is primarily interested in how the phenomenon is perceived and not in how the world really is. The ontological and epistemological assumption is that human experiences and conceptions of the world differ, although the differences can be communicated, explained and understood by others (91). To investigate and clarify if background factors could relate to patients’ conceptions of the cause of RA a deductive pathway with statistical method was chosen (Study II). In order to search for patterns, the deductive pathway was based on the inductive one (Study I). The different approaches associated with inductive and deductive research are complementary and the research question should decide the
appropriate method. To explore phenomena in a social context such as the management of RA (Study III) and in healthcare providers’ interaction with patients (Study IV), an inductive pathway seemed appropriate and thus the GT method was chosen. GT developed from symbolic interactionism and has been a research approach in sociology for many years (92). Symbolic interactionism rests on three assumptions; human beings act towards things on the basis of the meanings the things have to them, the meaning of the things arises from social interaction with other persons and these meanings are processed in an interpretive manner by the human being (89). The main purpose of GT studies is to generate concepts, models or theories from empirical data in order to explain the phenomenon under investigation (92). The naturalistic paradigm includes the epistemological assumption that knowledge is maximized when the distance between the researcher and the person involved in the study is minimized (88). The minimized distance is necessary for understanding the person’s experiences of the phenomenon. In rheumatology care, there is a need to look at both sides of the caring interaction; the patient perspective - the main focus for nurses - and how healthcare providers (including nurses) interact with patients.

Study designs

In order to fulfil the aims of the thesis, different designs were used. An overview of the studies is presented in Table 1 and the interconnection between them in Figure 2.
Table 1. Overview of the study design, participants, data collection and analysis.

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Explorative, descriptive, qualitative approach</td>
<td>Cross-sectional, quantitative approach</td>
<td>Explorative, qualitative approach</td>
<td>Explorative, qualitative approach</td>
</tr>
<tr>
<td>Participants</td>
<td>38 patients with RA</td>
<td>738 patients with RA</td>
<td>16 patients with RA</td>
<td>18 healthcare providers from 4 rheuma teams</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Phenomenography (93)</td>
<td>Descriptive statistics and logistic regression (94)</td>
<td>Grounded theory (92)</td>
<td>Grounded theory (92)</td>
</tr>
</tbody>
</table>
Figure 2. An overview of the studies and their relationships and interconnections in the thesis.
Studies I and II

Participants and settings

Patients with RA were selected from the EIRA-project, a large population-based case-control project, including incident cases recently diagnosed of RA in Sweden (15, 16). The project began in 1996 and is still ongoing. From 1996 to 2003, a total of 1403 patients was included in the project.

Data collection

In the project, the patients were asked to answer a postal questionnaire containing a broad spectrum of questions on environmental factors, including an open-ended question regarding their own perceptions about the cause of their RA. “If you are undergoing investigation for or have a rheumatic joint disease, do you have any idea as to its cause?” Two full pages were allocated for the answer. Background factors studied were age, sex, civil status, educational level, smoking habits and the presence of anti-cyclic citrullinated peptide antibodies (Anti-CCP) in serum samples as a marker of disease phenotype.

Study I

Study I was based on the 87 patients who completed the questionnaire, including the open question, during 2003. The inclusion criterion was the answering of the open-ended question by a complete and meaningful sentence, relevant to the aim of the study. There were 78 participants who fulfilled the inclusion criterion. Of these, 38 were strategically selected to obtain variation in background variables. The length of the answers ranged between 5 and 40 lines.

Study II

Study II included the 785 patients who answered the open-ended question and the 618 patients who did not between 1996 and 2003. Categories of conceptions
regarding the patients’ own thoughts about the cause of their RA were identified from Study I: [1] unexpected effects of events, [2] work-related strain, [3] family-related strain, [4] being exposed to climate changes, [5] being genetically exposed and [6] not having a clue. These categories formed the basis for grouping the patients’ conceptions. All statements from the 785 patients were placed into the six categories of conceptions.

Data analysis

**Study I; Phenomenography**

Study I had a descriptive design based on the phenomenographic approach in order to illustrate the cognitive process of patients’ thoughts about the cause of their disease. The phenomenographic analysis was based on a procedure in line with Dahlgren and Fallsberg’s (93) seven step guidelines: the data were read several times by the researcher and the supervisors in order to become familiar with the content, *familiarization*. The second step was *compilation*, when statements that contained conceptions corresponding to the aim were identified. This step was conducted simultaneously with the next step of *condensation*, when data were reduced by only retaining the essential parts of longer answers. As the statements were of different lengths, the compilation and condensation steps were intertwined, because some of the statements did not require condensation. The next step of the analysis was *grouping* the conceptions together after they were compared for similar content. For example, statements about cold or hot weather were grouped together in the conception called ‘being exposed to climate changes’. The *comparison* step involved sorting and comparing the groups of conceptions into descriptive categories and establishing the relationship between them. The comparison step also included the identification of the exact boundaries between the descriptive categories in terms of content.
This step created two descriptive categories. When identifying the boundaries between them, *naming* was a natural step. Thus, the categories were labelled in order to highlight their essence; consequences beyond personal control (4 categories of conceptions) and overloaded circumstances (2 categories of conceptions). The final step included *contrastive comparison*, where the different categories were illustrated by quotations that demonstrated the variation in conceptions (93).

**Study II; Statistical analysis**

The data in Study II were analysed by means of descriptive statistics and logistic regression (94). The SPSS statistical package, version 16, was used in the data analyses. Multiple logistic regression analyses were performed to study associations between background factors and the different categories of conceptions. OR together with a 95 % CI were calculated. The 618 patients who did not answer the open question were used as a comparison group with regard to background factors. A total of 785 patients answered the open question. A logistic regression analysis was performed for each of the six categories of conceptions, with the background factors as independent variables. *Age* was divided into three groups based on tertiles; 17-46 years (reference), 47-57 years and 58 -70 years. In the logistic regression analysis female *sex* served as a reference. *Civil status* was divided into cohabiting (reference) and living alone. *Educational level* was divided into no university degree (reference) and university degree. *Smoking habit* was divided into never smokers (reference) and ever smokers. The *biological marker* was the anti-cyclic citrullinated peptide antibody (Anti-CCP), which was either positive or negative (reference).
Studies III and IV

Participants and settings

Study III

During autumn 2009 and spring 2010, 16 patients with RA were asked to participate in an interview and all agreed. The inclusion criteria were; diagnosed with RA and ability to speak Swedish. To obtain variation in terms of management, a purposeful sample was used with regard to: age, sex and disease duration. The mean age of women was 62 years (28-82) and of men 61 years (42-70). Civil status and education level varied, while the disease duration was between 2 and 42 years with a mean value of 14 years. They were all treated at the day-care clinic or rehabilitation department of a rheumatology hospital and contacted by a nurse in connection with their planned visit. They received written information and if willing to participate, the nurse informed the researcher who contacted them to provide more information about the study and arrange a date and location for the interview.

Study IV

During winter and spring 2011, 18 healthcare providers (15 women and 3 men) working in four different rheumatology clinics in southern Sweden were asked to participate in an interview. They included nurses, physicians, physiotherapists, occupational therapists and social workers. The inclusion criterion was that they had experience of working in a team with patients diagnosed with RA. The manager of each clinic was contacted for permission to carry out the study and to introduce the study to the healthcare providers. If interested in participating the researcher contacted the provider and agreed a time and place for an interview. To obtain variation in experiences of the interaction with patients in their management of RA, purposeful sampling was used with regard to age, sex and years of work experience. Their mean age was
45 years (28-64) and they had a mean rheumatology experience of 10 years (0.5-27).

Data collection

Study III
The interviews took place in a private room at the rheumatology hospital. Each interview lasted between 20 and 50 minutes, was audio-taped and transcribed verbatim. The interviews began with an opening question, “How do you manage your rheumatic disease, RA?” Follow-up questions were posed in order to deepen the answers and obtain rich meaning and experiences; “Can you tell me more about that?” and “What did you do then?”

Study IV
The interviews were conducted in a private room at the rheumatology clinic where the providers worked or in a private room that was suggested by the provider. Each interview lasted between 30 and 80 minutes and was transcribed verbatim. The interviews began with an opening question; “Tell me about your experiences of the interaction with patients in their management of RA?” Follow-up questions were posed in order to deepen the answers and obtain rich meaning and experiences; “Can you tell me more about that?” and “What did you do then?”

Data analysis
Data collection and analysis were intertwined in a process in accordance with GT methodology (92). The collection began with purposeful sampling as described in the data collection section, followed by theoretical sampling. The latter was used to collect new data and as theoretical sampling of existing data to
look for aspects to confirm or reject the emerging theory. The data analysis steps were open, axial and selective coding. The open coding began directly with the first interview, through reading the text line by line to identify words, phrases and sentences, which were then labelled with codes that captured the meaning in accordance with the aim. The data collection and analysis were intertwined by each other. By putting questions to the data, the coding process moved on to the next level of analysis where the codes were clustered into higher categories (axial coding).

**Study III**

In the axial coding process, in Study III, two different categories were defined as important parts of the management; *Making use of personal resources* and *Grasping for support from others*. In the selective coding process, the core category, *striving for a good life*, emerged as the overall theme. The theory developed when the core category was linked with the categories Making use of personal resources and Grasping for support from others. Four dimensions of RA management emerged by means of theoretical sampling in the selective coding process, constant comparison and putting theoretical questions to the data. Questions put to the data were: What is happening? Who is involved? What are the consequences? and For whom? Throughout the data collection and analysis, the researcher wrote memos in accordance with GT methodology. The memos were used in every step of the analysis and a short memo was written down after each interview to capture the first impression of the phenomenon. In the open coding process, memos were used to track to the emerging categories. The memos were subsequently important for identifying the different patterns of the four dimensions of management. After 13 interviews and analyses, no new information was obtained, indicating theoretical saturation. Three additional interviews were conducted to ensure that the information obtained was theory based.
**Study IV**

Data collection and analysis were performed simultaneously, as in Study III. After seven interviews, the interaction between the provider and the patient was discovered and focused upon in the following interviews by posing more direct questions. In the open coding process the codes were labelled and by putting questions to the data, the coding process moved on to the next level of analysis where these codes were clustered into higher categories. In the axial coding process, two categories emerged as important parts of the interaction between healthcare providers and patients; *patients’ responses* to the care given and *healthcare providers’ attitudes* with the care. The importance of healthcare providers’ need to deliver knowledge and advice emerged as the core category in the selective coding process. When linking the core category with the two categories, the theory revealed three different outcomes of healthcare providers’ experiences of how their delivery was fulfilled. The final theory emerged through theoretical sampling, the constant comparison method and by putting theoretical questions to the data. Throughout the data collection and analysis, the first researcher wrote memos in accordance with GT methodology. No new information was obtained after 15 interviews, indicating theoretical saturation. Three additional interviews were conducted to ensure that the information obtained was theory based.

**Methodological considerations**

The holistic approach and the aims of this thesis required both qualitative and quantitative methods as well as different concepts when discussing the trustworthiness of the studies (95). It is necessary to evaluate the research process and results when discussing the rigour of research (90). After consideration of the concept of trustworthiness, a more comprehensive
methodological discussion of the overall aim with reference to triangulation will be presented.

Transferability and external validity
The qualitative concept of transferability and the quantitative concept of external validity refer to the extent to which the findings can be transferred to other settings (90, 96). To judge transferability the reader needs detailed and rich facts about the data collection and analysis, in order to evaluate the applicability to other settings (96). In this thesis, a description of the context, data collection, participant characteristics and data analysis aimed to illuminate the transferability of Studies I, III and IV. Detailed facts about the data collection and participants in the epidemiological EIRA project are presented in order to judge the external validity in Study II. Threats to external validity could be the great differences in setting, persons and places (90). A threat in Studies I and II could be the time at which the patients were recruited to the study. Their answers were collected between 1996 and 2003 and the open question about their own thoughts on the cause of RA could change over time, which can influence transferability. As the EIRA project is still ongoing there are possibilities to conduct a further study in this area.

Confirmability and objectivity
The qualitative concept of conformability and the quantitative concept of objectivity refers to the use of the data, results and other facts without the influence of personal feelings and bias (90, 96). The qualitative studies in the thesis (Studies I, III and IV) were carefully considered at every step of the data analysis in order to remain unprejudiced so that the findings are derived from the participants’ text (Study I) and interview transcripts (Studies III, IV). In a qualitative interview study, the researcher becomes an integral part of both the
research process and the findings. The researcher must be aware of the risk of bias and/or the assumptions that may be present (97). Preconceptions are a possible distortion that could interfere with any research method, especially within qualitative research, which involves working with words and texts grounded in views, attitudes and conceptions. By using quotations, the reader can evaluate the confirmability of the study. Objectivity was taken into account in Study II through the discussion about and decision to use the qualitative results from Study I that formed the basis for grouping the data. Hypotheses of which variables could interact with patients’ conceptions of the cause of their RA were considered when choosing the independent variables in the logistic regression. In this thesis preconceptions were considered by the researcher and supervisors several times during the data collection and analysis. The researcher and supervisors comprises a mix of providers as well as a mix of knowledge and experiences of different research methods, all of which created a productive critical discussion, thus ensuring an unbiased research process (98).

Credibility and internal validity
The qualitative concept of credibility and the quantitative concept of internal validity refers to confidence in the truth of data (90, 96). Credibility in Studies I, III and IV was ensured by describing the data collection, analysis and use of analytical tools. Data collection, in Study I comprised text written by the participants in response to an open question in a questionnaire in the EIRA project. There were two pages in the questionnaire on which the participants could write their answers. A limitation of this method of data collection is that, unlike interviews, it allows no opportunity to ask for further information. On the other hand, the participants could answers without interference from the researcher. The phenomenographic approach (91) was employed and the data analysis followed the steps recommended by Dahlgren and Fallsberg (93) in order to ensure credibility. In Studies III and IV the GT method by Corbin and
Strauss (92) was applied and data were collected by means of interviews. The interviews in Studies III and IV contained an open as well as follow-up questions aimed at providing insight about the phenomenon under study. In GT, the data collection and analysis are intertwined and there are clear steps throughout the analysis for ensuring credibility. Internal validity in Study II partly relies on the credibility in Study I. When categorizing the statements in Study II, they all fitted into the six categories that emerged in Study I, thus underlining the credibility of the latter study. However, some statistical problems occurred due to the fact that the qualitative categories contained a wide variety of conceptions. The logistic regression demonstrated that the categories pertaining more specified causes had a greater association with the independent variables. This could be explained by the most frequent category – unexpected effects of events – in which a wide variety of events were related to the cause but had a similar meaning to the patients. Perhaps this category would benefit from the identification of more sub-categories in the logistic regression. This was not done because of the decision to base Study II on Study I. A limitation of logistic regression could be the possibility of finding associations by chance. This risk was taken into account by having a theoretical basis for the choice of independent variables and by the inclusion of at least 10 persons in the least common outcome category for each independent variable (99).

**Dependability and reliability**

The qualitative concept of dependability and the quantitative concept of reliability refers to the stability of data over time and conditions (90, 96). Dependability in Studies I, III and IV was guaranteed by the systematic and methodical approach to the data analysis and by the supervisors, who were actively involved in all steps of the analysis due to their previous experience of the methods. In Studies III and IV dependability was ensured by the fact that the researcher and the supervisors individually analysed the text, continuously
moving back and forth between the parts and the whole, while the emerging findings were discussed and reflected upon by the researcher and the supervisors in order to reach negotiated consensus. Dependability and reliability in Studies I and II have a possible limitation; the time of the data collection. The qualitative result of Study I formed the basis of Study II and the data were obtained during the EIRA project from 1996-2003. The conceptions that emerged in the phenomenographic analysis describe variations in how patients’ conceive the cause of their RA. Conceptions of a phenomenon can change over time because of developments in medical science but also within the societal discussion about health issues. As the EIRA project (15) is still ongoing it would be possible to conduct a new analysis of the responses to the open question from 2004 and further verify the earlier results.

**Triangulation**

This overall aim of this thesis was to explore and describe patients’ and healthcare providers’ experiences of the causes, management and interaction in the care of rheumatoid arthritis. A holistic approach and different research methods were required, which will now be discussed from the perspective of triangulation. In caring disciplines, triangulation is defined as an approach to promote strategies for the study of multifaceted phenomena such as human behaviour (100) and involves theory, methodology, investigator and data. Theoretical triangulation occurs when various perspectives are included (100) and in this thesis there are several theoretical perspectives. The phenomenon in this thesis - the overall aim - needs different approaches to answer the research questions, thus creating theoretical triangulation. The different perspectives are complementary and allow an opportunity to explore the phenomenon under study in a broad way. Investigator triangulation exists when several researchers are involved in the study throughout the whole process from planning to data collection, analysis and writing the manuscript (100). In this thesis the
The researcher and supervisors have different professional backgrounds and experience of quantitative as well as qualitative research. The different professional backgrounds also create interdisciplinary triangulation, which further contributes to investigator triangulation (101). Methodological triangulation includes different methods or systems of data collection (100) in order to confirm a theory with a greater degree of accuracy than similar methods (102). In this thesis different methods and forms of data collection have been used; phenomenographic (Study I), statistical (Study II) and GT (Studies III and IV). In Studies I and II, methodological triangulation was employed when using the qualitative findings from Study I as a basis for grouping the statements in Study II. The combination of different methods can provide a deeper understanding of the phenomenon under study (102). Data triangulation refers to the inclusion of multiple sources that can differ between persons, places or times (100). The present thesis contains different data sources; written text from the participants in the EIRA project (Studies I and II) as well as background and disease specific factors (Study II) and interviews (Studies III and IV). Data sources also differ in terms of participants; patients (Studies I, II and III) and healthcare providers (Study IV).

In this thesis triangulation has been used as a strategy in the research. This has been found to be a useful way to deepen the understanding of the phenomenon in the thesis.
Ethical considerations

Ethical principles in science involve ethical considerations in the performance of research and with regard to the participants (103). This thesis was guided by the Helsinki Declaration (104), and the well-being of the individuals involved was of the greatest importance. Ethical approval was obtained from The Regional Ethics Review Board in Stockholm ref. 96/174 (Studies I and II) and in Lund ref. 2009/391 (Studies III and IV). However, when the research has been granted approval, ethical responsibility must be assumed by the researcher (103).

Respect for autonomy

The principles of autonomy and self determination should be observed by the researcher in order to safeguard the rights of the participants (103). The EIRA project was thoroughly planned for the purpose of epidemiology, the data were collected in advance and informed consent obtained (Studies I and II). The participants in the interview studies were informed both in orally and in writing that participation was voluntary and that they could withdraw at any time without, in the case of the patients, consequences for their care and, in the case of the healthcare providers, for their employment. In both interview studies, written informed consent was obtained. The participants were assured that all material would be treated confidentially. None of the informants in the interview studies had been in the care of or had any professional relationship with the interviewer. When publishing studies, particularly interview studies, it is vital to protect the confidentiality of the participants. Responsibility of the integrity and anonymity of the participants in these studies were done with the respects of not disclose the person beyond. This was considered in the presentation of the participants and the selected quotations.
**Non-maleficence**

When designing the research plan the principle of non-maleficence was considered in order not to be more intrusive than necessary (104). The questionnaire that formed the basis for Studies I and II included an open-ended question that allowed the patients to answer in “a free way” or decline without any cues. An interview study involves a risk of causing emotional and psychological problems due to personal matters or problems in life being exposed, which was addressed in the studies involving patients and providers (Studies III and IV). Patients were interviewed about the management of their disease and talked openly about their experiences (Study III). This may be in line with Kvale’s (105) proposal that an interview can be regarded as a positive experience by the interviewee, as the interviewer is interested and openly listens to what (s)he has to say (105). Healthcare providers were interviewed on their experiences of the interaction with patients in their management of RA and spoke freely about their work and how they acted with regard to patients’ management (Study IV). The interviews were conducted with great respect and sensitivity towards both patients and providers. However, research participants are exposed and the researcher must have the experience to manage situations that lead to discomfort. The interviewer had several years of experience of RA care.

**Beneficence**

The reason for participating in the EIRA project aimed at finding the environmental causes of RA could be altruistic. In the interview studies, the benefits might be that patients and providers were allowed to talk about their situation. All patients who were invited to participate in the interview study (III) accepted and several described it as positive to have an opportunity to talk about their life situation. The providers’ participation in Study IV involved an
opportunity to express and reflect over their situation, which they seemed to appreciate.

*The principle of justice*

The principle of justice implies that all participants should be offered the opportunity to participate (104). All patients newly diagnosed with RA from different rheumatology units in Sweden were invited to join the EIRA project. In the interview studies (Studies III and IV), purposeful sampling was carried out, i.e. patients and providers were asked to participate because they differed from other informants, which could contribute to variation in experiences of the phenomenon under study.
Summary of findings

Patients’ conceptions of the cause of their rheumatoid arthritis (Study I)

This study focused on patients’ conception of the cause of their RA. Two descriptive categories, *Consequences beyond personal control* and *Overloaded circumstances*, comprising six conceptions emerged, see Figure 3. The conceptions revealed variations in how patients conceived the cause of their RA. The internal relationships between the descriptive categories represented different ways of thinking about the cause. Consequences beyond personal control described the patients’ conception that the disease was caused by something outside themselves. The conceptions included: not having a clue, being exposed to climatic change, being genetically exposed and unexpected effects of events. Not having a clue implied being uncertain about the cause of their RA and a lack of understanding as to why they were thus affected. Being exposed to climatic change described how different weather conditions had an effect on the cause of their RA. Being genetically exposed involved both inheritance of the disease and being born a woman. Unexpected effects of events described unforeseen and unanticipated consequences of other conditions. Overloaded circumstances included a degree of personal responsibility for contracting the disease. Work-related strain concerned how the patients’ job involved physical as well as mental strain. Patients related that they worked too hard and that their ability to influence the situation was limited. They did not have sufficient strength to manage their work and received no support from their colleagues and employers. Family-related strain concerned how the respondents had experienced their relatives’ suffering for a long time and how it influenced their risk of contracting RA. Family-related strain was also associated with grief over the death of a family member or a pet.
Consequences beyond personal control
- Not having a clue
- Being exposed to climate change
- Being genetically exposed
- Unexpected effects on events

Overloaded circumstances
- Work-related strain
- Family-related strain

Figure 3. Patients’ conceptions of the cause of their RA.

Patterns of background factors related to early RA patients’ conceptions of the cause of their disease (Study II)

This study had the starting point in Study I and the six categories of patient conceptions of the cause of their RA. Out of 1,403 patients in the EIRA project, 785 answered and 618 did not answer the open question. There were statistically significant differences between the two groups in terms of sex, with more women answering the open question. More smokers were found in the group that did not answer the open question and, in the case of educational level, significantly more patients with a university degree answered the open question. A total of 1,235 statements pertained to the cause of RA. All statements fitted into a conception category and some patients made several different statements. The number of statements per patient varied from 1 to 4 and there were differences between the number of statements and background factors (unpublished data), see Table 2.
Table 2. The number of 1,235 statements made by 785 patients related to background variables

<table>
<thead>
<tr>
<th>Number of statements</th>
<th>Number of patients</th>
<th>Sex</th>
<th>Education</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Woman</td>
<td>Men</td>
<td>University degree</td>
</tr>
<tr>
<td>n</td>
<td>n</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>440</td>
<td>56</td>
<td>71</td>
<td>29</td>
</tr>
<tr>
<td>2</td>
<td>251</td>
<td>32</td>
<td>78</td>
<td>22</td>
</tr>
<tr>
<td>3</td>
<td>83</td>
<td>11</td>
<td>81</td>
<td>19</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
<td>1</td>
<td>100</td>
<td>0</td>
</tr>
</tbody>
</table>

p-value: 0.002  p-value: <0.001  p-value: <0.001

The frequency of statements about the cause of RA in descending order were; unexpected effects of events 48%, work-related strain 32%, family-related strain 29%, being genetically exposed 11% and not having a clue with 11%.

The main findings of the multiple logistic regression were as follows: in the conception ‘family-related strain’ there was an association with being young, female and having a high educational level. Another association in the conception of ‘being genetically exposed’ was being female and having a high educational level. ‘Being exposed to climate change’ was associated with being male, having a low educational level and a positive Anti-CCP. ‘Not having a clue’ was associated with being aged 58 to 70 years.
“Striving for a good life”- the management of rheumatoid arthritis as experienced by patients (Study III)

Patients experienced the management of RA as striving for a good life, which included several aspects; making the best of the situation, striving for a good life despite the disease and achieving a sense of meaning when they tried. The management of RA was an ongoing process involving all parts of life and not only the disease. The process began with an individual reflection on making use of personal resources. Patients’ personal resources such as illness perception, self-confidence and self-efficacy were used to analyse and deal with everyday life situations. The management process also involved a grasping for support from others. Patients described the need for support from relatives and friends to do household duties or various daily chores. They also expressed a need for support from nurses and other healthcare providers including non-medical as well as medical treatment. When combining the core category and the two categories (making use of personal resources and grasping for support from others), four dimensions emerged which characterised patients’ different ways of managing RA: Mastering, Relying, Struggling and Being resigned (Figure 4).
Figure 4. Patients’ experiences of the process of managing RA when striving for a good life with four ways of management.

Mastering was described as putting life before the disease thanks to many personal resources. Patients expressed both trust and gratitude for the support they received. This way of management could involve a long process before being achieved. The struggling way of managing RA was depicted as a battle that was difficult to accept and they had to fight for respect. While they wanted to look after themselves, they were still dependent on support from others. The outcome of the struggle was of importance for a good life. Relying meant that patients striving for a good life were dependent on the support they had. They did not mention their own ability or responsibility in the management of RA and
expressed gratitude for the medical treatment and care provided. *Being resigned* described a way of management of letting the disease play a great part in life as well as ambiguity in relation to support from others. The patients expressed that RA led to various restrictions and that their strive for a good life was sometimes not fulfilled. These different ways of management often changed over time. The four dimensions were not fixed and there could be a transition between them in each patient. When crises occurred in everyday life, the need to seek support as well as personal resources could change.

“Delivering knowledge and advice” - healthcare providers’ experiences of their interaction with patients’ management of RA (Study IV)

Healthcare providers experienced the interaction with patient management of RA as *Delivering knowledge and advice*. This was their most important task and involved providing the patient with information about the disease and appropriate treatment. The healthcare providers’ attitudes to delivering knowledge and advice formed one cornerstone of the theory and patients’ responses the other. Their attitudes were dependent on factors such as adjustments, attitudes, expectations, intentions, responsibilities and roles, while patients’ responses depended on factors such as needs, reactions and responsibilities. The outcome of delivering knowledge and advice led to three dimensions; *Completed delivery, Adjusted delivery* and *Failed delivery* (Figure 5).
Figure 5. Healthcare providers’ experiences of the process of delivering knowledge and advice through the interaction between their own attitudes and patients’ responses and with three dimensions of the outcome.

**Completed delivery:** described when the delivering of knowledge and advice was successful. Healthcare providers expressed that their intentions in terms of the care was completed and that the patient understood their advice. They were fairly sure that the patient was able to follow the prescribed medicine or treatment. Delivery was easier when the patient was compliant, active and responsibility taking of the advice and prescriptions the healthcare providers delivered. A situation of completed delivery occurred when patients responded in an anticipated manner and their needs seemed to be fulfilled. **Adjusted delivery:** healthcare providers experienced the delivery of knowledge and advice as something ongoing and in progress. They described their experience as a process of reaching out and stated that they needed time to create a good relationship with the patient. Responsibility in the interaction was described as being on an equal level with a clear goal and the outcome expected by the
patient. Adjusted delivery included a shifting interplay, sometimes due to adjustment on the part of the providers or bargaining about the different desires of the patient and provider. They displayed an empathetic attitude towards the patient and used tailored delivery. Failed delivery included situations in which the delivery of knowledge and advice was unsatisfactory. This was described as a failure, both with regard to the interaction between the provider and patient and as a failure in a professional sense; the delivery of knowledge and advice did not take place. Although the reason for this failure was related to the patients’ response to the message delivered, there was also a level of awareness of the importance of the interaction between the actors involved. Circumstances of the healthcare organisation became visible; legislation, economic aspects, accessibility, time and rheuma-team organisation influenced the whole care situation.
Discussion

This thesis aimed to explore and describe the phenomenon of dealing with RA as experienced by patients and providers from a caring perspective, using a holistic approach.

The conceptions of the cause of RA as described by patients (Study I) reveal variation in beliefs and provide new knowledge that complements current pathogenetic models. The findings of overloaded circumstances include self awareness, where the patients expressed that they contributed to causing the disease. This could lead to a sense of guilt, weakness and insufficiency that must be addressed and highlighted by healthcare providers (49, 57). Illness perceptions can be very important for the patient, depending on the meaning they ascribe to what is happening and why (106). Their emotional response to their illness perceptions could affect in which they manage the condition (48, 58). With regard to the frequency of the conceptions of the cause of RA (Study II) differences in background factors were revealed; women reported more causes than men, patients with a higher educational level mentioned more causes and patients in the oldest group had fewer conceptions of the cause than those in the younger groups. The socioeconomic factors relationship to lay beliefs of health is controversial and studies have produced diverse results, both supporting (107, 108) and contradicting the differences found in this thesis (39, 109). The results of Study II provide knowledge of the complexity of patients’ conceptions of the cause of RA, in terms of the patterns as well as differences in background factors. Studies I and II led to further questions, especially how patients manage RA in everyday life, which were therefore addressed in Study III.
Patients’ management of RA (Study III) is described as an ongoing process aimed at striving for a good life. The process of managing RA involves making use of personal resources and grasping for support from others. Patients reported different ways of management: mastering, relying, struggling and being resigned, in order to control or reduce the impact of the disease. In the mastering, patients made an active decision to be a partner in the medical encounter and had faith and hope in the future. These results are confirmed by Kralik et al. (63), who stated that self-management is an action aimed at creating order, and by Ishikawa et al. (110), who illustrated that patients who participated more actively in the medical consultation felt better understood. Patients who used mastering expressed that they were in charge of their life, including the management of their illness. This was also highlighted by Lempp et al. (27), who confirmed that patients no longer see themselves as passive recipients of care and welcome a dialogue with healthcare providers on equal terms. A greater sense of purpose in life was associated with a better mental health status and an optimistic life style (106).

In the relying way of managing RA the patients did not mention their level of control, but reported their dependency on others in a positive way. Patients expressed both trust and gratitude for the support of relatives and healthcare providers. The treatment of RA has mainly been pharmacological, which meant that patients previously relied more on external opposed to their own resources (111). If the medical consultation includes interaction and partnership, patients can feel that they are in control (79, 112). The patients that used the struggling way were searching for respect, expressed ambivalence about the need for support from others and experienced a battle for independence. Similar results were presented by Ward et al. (40), who reported that patients gained a sense of control by refusing interventions and/or medication when feeling not listened to in the meeting with healthcare providers. If their illness perception is
incongruent with the healthcare providers’ view of the disease, it could lead to a struggle for respect (72). Other studies have highlighted the difficulties in the medical encounter and the necessity of ensuring a dialogue on more equal terms between patients and healthcare providers (34, 72, 79). The being resigned way is defined by having fewer personal resources and less positive experiences of support from others. Patients described adjusting to the disease. They did not think that they could change their situation and had no faith in the healthcare system. Similar results were presented by Stamm et al. (113), where patients described RA as “something to get used to”. Being resigned can involve helplessness, a concept which has been found to correlate with depression, lower physical and functional status as well as higher levels of pain (114, 115). The healthcare providers in the rheumatology care need to identify which patients are most in need and would gain the most benefit from their efforts (4). Patients’ need of support (Study III) raised further questions about the healthcare providers’ interaction with patients’ management of RA (Study IV).

The main focus of healthcare providers’ experiences of their interaction with patients was delivering knowledge and advice. Healthcare providers described themselves as a source of information and that their goal was to deliver knowledge and information to the patients. However, the delivery of knowledge and advice was also related to the circumstances of the healthcare organisation. Both economic and organizational issues are highlighted as the main barriers to the development of chronic care from the healthcare providers’ point of view (116). The delivery of knowledge and advice is characterized by diverse ways of conducting the delivery as well as different levels of awareness of the process. Furthermore, there were differences in the attitudes of providers in terms of how they experienced the interaction with patients. There was information transfer in the completed delivery dimension, and the interaction between provider and patient was described as completed from the providers’ point of view. The
providers’ attitude and intentions were focused on providing information and they did not describe the need for emotional support experienced by patients with rheumatic diseases, as reported by Zangi et al. (117). On the other hand, Lim et al. (118) claimed that patients were satisfied when their information need was fulfilled. These discrepancies show the differences in patients’ need of information and support.

The adjusted delivery dimension showed a provider with the purpose of reaching out to patients through dialogue and by tailoring the delivery. This dimension highlights the important issue of a dialogue on equal terms in the encounter, as presented by Lempp et al. (27) and by Ishikawa et al. (110). Patients’ involvement in their own care implies a sense of control over the disease, and feelings of being understood are associated with patients’ preferences in decision-making (79, 110). The failed delivery dimension described providers who tried to reach out to patients but their attempts failed and they expressed feelings of frustration when the dialogue did not work. Providers were dissatisfied when patients did not assume responsibility for the advice given or failed to change their lifestyle as recommended. Difficulties in the interaction may occur if healthcare providers do not take patients’ expectations and preferences into account when giving advice (119, 120). Studies have highlighted the importance of incorporating patients’ preferences into the medical encounter in order to increase the quality of care (40, 73, 110). Failed delivery was a result of how patients responded and some exhibited a “bad” response. However, providers did not report reflecting on their own behaviour. This is supported by Gorter et al. (121), who concluded that patients were critical of the providers’ behaviour and communication style and that the providers were unaware of this problem.
Comprehensive understanding

The findings in this thesis, seen in the caring and holistic perspective, calls for a development of rheumatology care, where it is necessary to be more person-centred. The main findings can be linked to the person-centred practice framework that is built on four parts, care processes, person-centred outcome, care environment and prerequisites (86).

Care processes includes activities in which person-centred care is provided by taking interest in patients’ perspective and within the interaction between patient and provider takes place. Patients’ conceptions of the cause of their RA (Study I) are examples of their beliefs and values and differ from the current medical and pathogenetic models. These differences illustrate the acknowledged discrepancies between the lived experiences of a disease - the illness perspective and the pathophysiologic model of a disease – the disease perspective. Aspects that influence patient conceptions of the cause of RA are related to age, educational level and sex (Study II). Illness perceptions are emerged by previous experiences, the patients’ situation and social identity (47, 122). The findings pertaining to patients’ conceptions illustrate different ways of experiencing the cause of RA as something that “happened” due to overloading or factors outside their control. These variations in explaining the cause of RA could be important with regard to the connection between illness perception and patients’ emotional response to illness management as demonstrated by Petrie et al. (45). Taking patients’ beliefs and values into account in the care situation is crucial when aiming to encourage them to become involved in their own care (85, 123). Involvement in care also implies recognising the patients’ own management – i.e. self-management. Patients used their personal resources to manage RA and experienced that they had either many or few (Study III). The need for support from others highlights the complexity of managing a chronic condition such as RA, which was also reported by Ryan et al. (79). The necessity of support from
relatives and friends to manage everyday life was expressed, as was their grasping for support from healthcare providers. Variations in experiences of the support from others, including patient-provider interaction, revealed both good and bad experiences (Study III). The medical consultation is an important occasion for the patient to gain control over the situation and when satisfactory he/she experiences reassurance and empathy (79). The main issue of patient management of RA in everyday life is their striving for a good life, which they describe as an ongoing process (Study III). Another aspect of the care process is shared decision-making, which involves the patient and provider playing an active role when a decision about treatment must be taken. There were both positive and negative experiences of shared decision-making; a patient who used the mastering to manage RA reported a good and trusting relationship, while patients who managed RA by means of resignation expressed the opposite. Shared decision-making demands good communication between the parties involved and the creation of shared meaning is essential (71). The providers within the adjusted delivery dimension expressed awareness of the importance of having the patient with them and setting a shared goal for the treatment period. They also highlighted the necessity of creating an equal dialogue with the patient. In contrast, some providers in the failed delivery dimension did not mention interaction or the shared decision-making process (Study IV). Shared decision-making is influenced by ideology and basic principles of health care and there is a need of balancing the different values in regard to fulfil the shared decision-making process. This could be done by taking patient best interest in focus together with patients’ perspective and the creation of the trusting relationship in consideration (124).

Several ethical considerations must be discussed within rheumatology care, as well as in other settings, in order to find a balance between providers’ attitude and patients’ responses that leads to the creation of shared decision-making and thus the development of person-centred care (125).
Person-centred outcomes entail satisfaction with and involvement in the care as well as a feeling of well-being. Patient management of RA (Study III) includes varied experiences, and those in the mastering dimension were clearly satisfied with and reported a high level of involvement in the care. In the dimension of relying, the patients expressed satisfaction with the care but did not refer to involvement. Struggling is a dimension in which the patients were dissatisfied with the care provided. Although reporting a high level of involvement, they described difficulty creating a therapeutic relationship. In the dimension of being resigned, patients expressed no positive care experiences. However, striving for a good life and a desire to increase their well-being were common to all four dimensions of management (Study III). Evaluation of the care from the healthcare providers’ perspective (Study IV) revealed differences between the three dimensions of the delivery of knowledge and advice. Delivery has the starting-point from the providers’ professional attitude and not clearly described as based on the patient as a person. In the completed delivery dimension, the providers were satisfied with their work and expressed a feeling of well-being when successful. The adjusted delivery dimension is a more complex situation, where the provider endeavoured to listen and reach out to the patient with the aim of involving him/her in the care. Providers in the failed delivery dimension reported none of these positive outcomes (Study IV). Person-centred care and several outcome measures have been developed in the gerontology area, but they are fairly specific to dementia and/or long-term aged care (126). Rheumatology care mostly concerns out-patient treatment, but as the condition is chronic, continuity of care must be taken into account when designing measurements for person-centred care outcomes.

Care environment means the context in which the care is delivered. The care environment is not focused upon in this thesis, although aspects of the rheumatology team care settings (Study IV) illustrate the importance of rheumatology team organisation, economic aspects, time, accessibility and the legislation that
governs healthcare. The providers described the care environment as controlling the care with regard to accessibility of physicians and limited time with patients (study IV) i.e. lack of support in the healthcare organisation. The care environment needs to be developed if the person-centred practice framework is to function (87). The context of the care is also important to develop in order to increase the new way of deliver care, however, the healthcare organisations are neither prepared nor equipped to meet the changing needs of care (26). Examples of interventions developed to intensify the management of RA are provided, but they are not suitable for all patient and providers express disappointment when patients fail to fit in (Study IV). New strategies pertaining to the person-centred framework need to be developed in rheumatology care in order to meet the transitions in the care of this chronic condition (6, 26).

Prerequisites involve the providers attribute and beyond professional competence there is also a need to develop personal skills and self-awareness. There are some examples in which the prerequisites are of importance or non-existent. In the dimensions of struggling and being resigned, the patients reported that the interaction with the providers did not work. They described the importance of being taken seriously and respected by providers. On the other hand, the dimensions of mastering and relying reveal gratitude for the support from providers and patients expressed trust in the encounter. These descriptions from the patient perspective highlight this issue as very important (Study III). The providers also exhibited different levels of awareness of their prerequisites. In the dimensions of completed delivery and failed delivery, the providers did not reflect on their own role in the caring situation. According to the providers, patients’ responses to the care provided could be related to compliance or non-compliance. This is highlighted by Sandman et al. (2011), who described the need to move from compliance to adherence in order to develop provider-patient interaction (127). The dimension of adjusted delivery indicates awareness of the providers’ own part in the encounter. Providers described their previous
experiences as a resource and stated that they had learned what worked or did not work (Study IV). The clarity of beliefs and values should be discussed in rheumatology care and particularly within the organisation of rheuma teams, because the tradition of delivering provider-centred care and the challenge of the transition to person-centred care highlight providers’ beliefs and values (87). A lack of awareness among providers was found within their own caregiver role, when they stated that their delivery of the message had failed (Study IV). A discussion and reflection on providers’ beliefs and values could benefit both providers and patients when trying to develop rheumatology care.

The person-centred practice framework provides a way of implementing person-centred care and discussing the whole healthcare situation including organisational aspects, professional circumstances, evaluating the outcomes and the care process. In order to implement this in clinical practice there is a need to establish routines that initiate, incorporate and maintain person-centred care in daily practice, this could be done by documenting patient narratives and the shared decision-making process (128).
Conclusions

- Patients’ conceptions of the cause of their RA revealed new aspects from the patient perspective that can be complementary to pathogenetic models. The most common conception was unexpected effects of events, followed by work and family-related strain. The conceptions were associated with background factors such as sex, age and educational level.

- Patients with RA used their own resources and grasped for support from others in their striving for a good life. Four different dimensions of managing RA emerged; Mastering, Relying, Struggling and Being resigned. These dimensions of self-management were not fixed and patients could move from one to another, depending on their life situation.

- Delivering knowledge and advice was the main issue for healthcare providers in their interaction with patients’ management of RA. The delivery of knowledge and advice was dependent on the providers’ attitudes and the patients’ responses, leading to three outcomes; Completed delivery, Adjusted delivery and Failed delivery.

- Conceptions of the cause and management of RA contributed new knowledge from a patient perspective and together with the providers’ experiences of their interaction with patients’ management of RA led to a new platform of knowledge that can be used to develop person-centred care in rheumatology. Person-centred care involves taking patients’ beliefs and values into account in addition to creating a trusting relationship between the patient and provider.

- A successful person-centred approach requires an organisation that enhances the person-centred framework.
Clinical and research implications

In rheumatology care it is important to take the patient perspective into consideration in order to better understand him/her and achieve a trusting relationship. The patient perspective is made up of different parts. One of the parts is illness perception, and it is important for the patient to discuss it in the encounter with healthcare providers. The conceptions of the cause of RA contribute new knowledge of illness perceptions and the potential to increase awareness and understand patients’ views as well as indicating new research areas related to the medical models.

Patients’ need of support from others to manage their RA is knowledge that should be considered by providers when meeting patients in rheumatology care. Interventions to improve self-management of RA must incorporate this knowledge when trying to enhance patient self-management and their experience of support from others. The different views of the illness and disease perspectives complement each other, and cooperation and partnership between patients and providers are vital and under development in many countries.

The interaction and relationship between patients and healthcare providers must be further investigated in rheumatology care in order to ensure a good encounter and build the foundation for shared decision-making. This requires more research to increase understanding of the interaction from both a patient and a provider perspective. There is also a need to develop methods to evaluate rheumatology care.

To meet the high goals of modernising rheumatology care and enabling patients to be more active partners, the healthcare organisation must put the patients first. The providers need education and training to develop their communication skills and the new demands must be discussed in the entire healthcare organisation. Further studies are required to evaluate the progress of rheumatology care from both the patient and the provider perspective and in terms of the person-centred framework.
Swedish summary

Bakgrund

patientperspektiv. Genom ett person-centrerat förhållningssätt kan vården utvecklas till att bli mer anpassat till patientens behov samt möjliggöra patientens önskemål att bli mer delaktig i vården.

Syfte och resultat

Det övergripande syfte var att utforska och beskriva orsakerna till och hanteringen av RA och interaktionen i vården såsom det erfars av patienter och vårdare. Avhandlingen innehåller fyra studier där kvantitativa eller kvalitativa analyser valdes för att studera avhandlingens syfte.


Den andra studien, som är en fortsättning på den första hade som syfte att identifiera mönster av bakgrunds faktorer i relation till de olika uppfattningarna. Studien byggde på ett material med 785 patienter som svarat på den öppna frågan i frågeformuläret och dessa svar sorterades in i de sex grupper av uppfattningar som framkom i studie I. Resultatet visade att den vanligaste
orsaken som patienterna angav var oförutsedda effekter av andra händelser följt av arbets- och familjerelaterad stress. Det fanns skillnader mellan uppfattningarna främst vad gällde ålder, kön och utbildning.

Syftet med den tredje studien var att generera en teori om patienters hantering av RA i sitt vardagliga liv. Sexton patienter intervjuades och datamaterialet analyserades med grundad teori. Kärnkategorin i studien var; strävan efter ett gott liv, vilket var patienternas huvudsakliga fokus i hanteringen av sin sjukdom. Vägen till ett gott liv innebar att patienten använde sina personliga resurser samtidigt som de sökte stöd hos andra för att hantera sin sjukdom. Fyra olika sätt att hantera RA framkom; bemästrande, kämpande, att förlita sig på och att resignera. Dessa dimensioner var beroende av patientens egna resurser tillsammans med det stöd som han/hon fick från andra. De olika hanteringssätten kunde skilja sig åt beroende på patientens aktuella situation.

Syftet med fjärde studien var att utforska vårdpersonalens erfarenheter i interaktionen med patienter och deras hantering av RA. Intervjuer genomfördes med 18 vårdpersonal med olika professioner och från olika kliniska verksamheter och analyserades med grundad teori. Vårdpersonalens huvudfokus i samspelet med patienter med RA var att överlämna kunskap och råd, informera om sjukdomen och behandlingen. Att leverera kunskap och råd var beroende dels på vårdpersonalens attityder men också på hur patienterna respondegrade. Utfallet av detta utmynnade i tre dimensioner; fullgjort överlämnande, anpassat överlämnande och misslyckat överlämnande.

Övergripande förståelse

Resultaten i denna avhandling, sett från ett omvårdnads- och helhetsperspektiv, påvisar ett behov av att utveckla den reumatologiska vården till att bli mer person-centrerad. Person-centrerad vård har beskrivits i ett ramverk som lyfter fram olika delar vilka tillsammans påverkar möjigheterna till att bedriva en
person-centrerad vård. De olika delarna av ramverket är; vårdprocesser (mötet mellan patient och vårdare), utvärdering, vårdarens förutsättningar och vårdens organisation och kultur. Avhandlingens resultat diskuteras utifrån ramverket av person-centrerad vård.

Vård processer i person-centrerad vård innebär att lyssna in patienters tankar och värderingar för att möjliggöra ett gemensamt beslutsfattande. Patienterna beskrev uppfattningar av vad som orsakat deras RA (studie I) och deras uppfattningar skiljde sig till viss del åt från de medicinska förklaringsmodeller som existerar. Synen på sjukdom skiljer sig ofta mellan patienter och vårdare eftersom patienterna utgår från sina egna erfarenheter och vårdarens syn grundar sig på hur sjukdomen i allmänhet ter sig. Detta påverkar samspelet mellan parterna. Patienternas bakgrundsfaktorer såsom ålder, kön och utbildningsnivå påverkade vilken uppfattning de hade om orsaken till deras RA (studie II), vilket visar att tankar och värderingar är knutna till patienten som person och inte specifikt till sjukdomen. För att möjliggöra ett gemensamt beslutsfattande i vården behöver vårdarna uppmuntra patienten till ett aktivt deltagande i sin egen vård och behandling. Patienternas hantering av RA i sitt vardagliga liv (studie III) visade på olika sätt att klara av vardagen och också att vården brister i att stödja patienternas i deras strävan efter ett gott liv. Vårdpersonal som anpassade informationen och råden till patienten (studie IV) visade en medvetenhet om Vikten att ”ha med sig” patienten för att nå det mål som de satt upp gemensamt. De lyfte fram vikten av att skapa en dialog med patienten. När vårdpersonal misslyckades i överlämnandet av kunskap och råd nämndes inte samspelet eller några gemensamma målsättningar alls av personalen.

Det är viktigt att utvärdera vården för att förbättra och påvisa på nyttan av person-centrerad vård. Avhandlingens studier synliggör olika sätt hur patienterna är nöjda eller missnöjda med sin vård och hur vårdpersonalen är nöjd eller missnöjda med sin insats för patienten.

Vårdarens förutsättningar innebär de egenskaper som vårdaren behöver för att kunna bedriva person-centrerad vård. När patienterna beskrev sina erfarenheter av att hantera sin sjukdom (studie III) så framkom också deras erfarenheter av vårdarnas bemötande. Exempel gavs när det fungerade eller inte. I studien med vårdpersonal (studie IV) så framkom vikten av att använda och utveckla sina personliga egenskaper för att ”nå fram till” patienten.

Det person-centrerade ramverket visar på betydelsen av att diskutera hela situationen kring patienten och vården, och inte bara det enskilda mötet mellan patient och vårdare. Det är påtagligt att den reumatologiska vården behöver utvecklas för att möta framtidens krav både från patienter och samhället i övrigt vilket denna avhandling ger kunskap och implikationer om.

Patienter med RA använde sina egna resurser och sökte stöd hos andra för att klara av att sträva efter ”det goda livet”. Fyra dimensioner av att hantera RA framkom: bemästrande, kämpande, att förlita sig på och att resignera. Dessa sätt att hantera sin sjukdom kunde variera och patienterna kunde förflytta sig emellan de olika hanteringssätten beroende på deras livssituation.

Att överlämna kunskap och råd till patienter med RA var viktigt för vårdpersonalen i deras möte med patienten. Överlämnandet av kunskap och råd var beroende på vårdpersonalens attityder och hur patienten responderade. Detta frambringade tre dimensioner av överlämnandet: fullgjort överlämnande, anpassat överlämnande och misslyckat överlämnande.

Patienters uppfattning av orsaken till deras RA och hantering av sin sjukdom ger ny kunskap från patientperspektivet som tillsammans med vårdpersonalens erfarenheter av samspelet med patienter med RA skapar en kunskapsplattform som kan användas för att utveckla person-centrerad vård inom reumatologi. Person-centrerad vård innebär att ta hänsyn till patientens tankar och värderingar för att skapa en förtroendefull relation mellan patienten och vårdaren.

En framgångsrik person-centrerad vård kräver en organisation som möjliggör genomförandet av ett person-centrerat synsätt.
Kliniska och forsknings implikationer

I vården av reumatiska sjukdomar är det viktigt att lyssna och ta till vara patientens perspektiv för att bättre förstå honom/henne och för att möjliggöra en förtroendefull relation. Patientperspektivet består av olika delar där sjukdomsuppfattning är en del som är viktig att diskutera i mötet mellan patient och vårdare. Genom att intressera sig för patienters uppfattningar ökar medvetenheten och förståelsen för deras synsätt samtidigt som de kan ge nya ledtrådar till den medicinska forskningen.

Patienternas behov av stöd från andra för att klara av sin sjukdom är viktig kunskap att ta till sig som vårdpersonal inom reumatologisk vård. Interventioner som syftar till att stärka patientens egenförmåga att hantera sin sjukdom behöver också använda kunskapen om patientens stödbehov från andra, för att ytterligare förbättra patientens möjlighet att hantera sin sjukdom. Interaktionen mellan patienter och vårdare behöver studeras mer för att utveckla och förbättra mötet mellan parterna och för att förbättra möjligheterna till ett gemensamt beslutsfattande. Det behövs också en utveckling av metoder för att utvärdera reumatologisk vård.

För att kunna möta de höga målen inom den moderna reumatologiska vården och möjliggöra för patienten att bli en aktiv partner, krävs det en hälso- och sjukvårdsorganisation som sätter patienten i centrum. Vårdpersonal behöver utbildning och träning för att utveckla sina såväl teoretiska som kliniska kunskaper, och inte minst vad gäller kommunikation. Fler studier behövs för att utvärdera vården från patientens och vårdarens perspektiv samt utifrån det person-centrerade synsättet.
Acknowledgements

I would like to thank many people without whose help and support it would not have been possible to complete this thesis. A research education and writing a thesis is like a journey on uncertain roads with ups and downs as well as unexpected experiences. The person who challenged and in some way “tricked” me into the field of research was Ingemar Petersson, co-author and my former boss at the R&D centre at Spenshult. You gave me the opportunity to grow. Thank you for believing in me and introducing me to the pathway of research!

Thank you to all the persons who participated in the studies for willingly sharing your thoughts, feelings and experiences as patients and providers. There would be no thesis without your participation!

I had a great need of supervision to manage the research education and conduct the studies. I therefore wish to express my appreciation to my group of supervisors: Bengt Fridlund, my supervisor, thank you for sharing your scientific knowledge and for your commitment. You have taught me to think and think again and to face difficulties in new ways. I especially want to thank you for your first words to me, when you advised me to take care of my relationships at home, because writing a thesis is demanding work. Wise words from a wise man!

Barbro Arvidsson, co-supervisor, thank you for your never ending interest in my work and in me as a person! Thank you also for sharing your great knowledge of science and life. You made me aware of and socialised me into the academic world. A special thanks for your company during our visits to various conferences.

Stefan Bergman, co-supervisor and my boss at the R&D centre, thank you for being so open minded and encouraging. When I have felt down, you have always lifted me up in some way. Special thanks for sharing your knowledge of statistics and for your efforts to teach me the English language!

My co-authors from the EIRA project; Anita Berglund and Lars Alfredsson, you gave me the opportunity to learn about the EIRA project and opened my eyes to the field of epidemiology. Thank you for your collaboration!

My colleagues and friends at the Research and Development Centre at Spenshult, Ann, Carina, Emma, Henrik, Karina, Maria A, Maria S, Monica, Pernilla, Susann and Åsa for support and friendship during our “table-talks” at breakfast and lunch. Pia, our secretary, Thanks for everything you do for me,
transcriptions of interviews, “pep-talks” and many more things! Ingrid, my room-mate, colleague and friend, without your support, I would never have managed this thesis. Thank you and good luck with your own book!

My colleagues and friends at Spenshult Hospital, Thank you all for supporting me in different ways, helping me to recruit participants for the studies or just showing an interest in my work!

Sincere thank Gullvi Nilsson and Monique Federsel for the professional language editing both of the articles and thesis.

My dear colleagues and friends, Sonia, Susanne and Maria, thank you all for inspiration, discussions and pleasant company, during our work with the description of competence within rheumatology nurses. Our meetings really contributed to my thesis!

My dear friends and “sisters”; Åse, and her family, Brittmarie and Eva, and her family, thank you for your support and friendship and for reminding me to “take one day at a time”.

My aunt, Birgitta and Bo, thank you for introducing me to the world of books! I think that this journey would not have been possible without the passion for reading that you inspired in me, which helped me to find a way to satisfy my curiosity.

My mother Désirée, for never ending support for whatever I do in life! You are an inspiration and a role model of encouraging parenting.

My brothers and their families, Magnus and Anna-Lena, Anders and Anette, Thank you for your support and for “lending” your children to their aunt! They have helped me to focus on what is important in life!

My three children, Sofie with your family - Lars and little Sixten, Johan and Viktor, you are the sunshine of my life! Hopefully I will now have more time to be a present mother and grandmother! I look forward to that!

My beloved husband Jan, thank you for being you and for standing by me on this journey! When I was ready to give up, you encouraged me to go on, and I think you have learned a great deal about research too! I hope we will have a long life together!

This thesis was made possible by financial support from; the Swedish Rheumatism Association, Halland County Council, the South Regional Health Care Committee, the Association of Rheumatology Nurses in Sweden and Spenshult Hospital.
References


117. Zangi HA, Hauge MI, Steen E, Finset A, Hagen KB. "I am not only a disease, I am so much more". Patients with rheumatic diseases' experiences of an emotion-focused group intervention. Patient Education and Counseling. 2011/02/09 Feb 5.


