Person-centred care in rheumatology nursing in patients undergoing biological therapy:
An explorative and interventional study

Ingrid Larsson
I have a dream

I have a dream, a song to sing
To help me cope, with anything
If you see the wonder, of a fairy tail
You can take the future, even if you fail

I believe in angels, something good in everything I see
I believe in angels, when I know the time is right for me
I’ll cross the stream. I have a dream

I have a dream, a fantasy
To help me through reality
And my destination makes it worth the while
Pushing through the darkness, still another mile

I believe in angels, something good in everything I see
I believe in angels, when I know the time is right for me
I’ll cross the stream. I have a dream

I HAVE A DREAM
Musik och text: Benny Andersson/Björn Ulvaeus
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To my beloved husband Thomas
and my wonderful kids
Johan, Martin and Jenny
Abstract

**Aim:** The overall aim was to explore and evaluate rheumatology nursing from a person-centred care perspective in patients undergoing biological therapy.

**Methods:** This thesis focuses on patients with chronic inflammatory arthritis (CIA) who were undergoing biological therapy at a rheumatology clinic in Sweden. Papers I and II had an explorative descriptive design with a phenomenographic approach. The 40 participants were interviewed about their dependence on or independence of a nurse for the administration of their infusions or injections. Paper III had a randomized controlled design involving 107 patients in the trial. The objective of the intervention was to replace every second monitoring visit at a rheumatologist-led clinic by a visit to a nurse-led rheumatology clinic, based on person-centred care. Paper IV had an explorative descriptive design with a qualitative content analysis approach. Interviews were conducted with 20 participants who attended the nurse-led rheumatology clinic.

**Findings:** Dependence on a rheumatology nurse for administration of intravenous infusions was described as invigorating due to the regular contact with the nurse, which provided security and involvement (paper I). Independence of a nurse for subcutaneous injections was understood by the patients in different ways and was achieved by struggling to cope with injecting themselves, learning about and participating in drug treatment (paper II). Patients with stable CIA receiving biological therapy were monitored by a nurse-led rheumatology clinic without any difference in outcome when compared to monitoring carried out at a rheumatologist-led clinic, as measured by the Disease Activity Score 28. Replacing one of the two annual rheumatologist outpatient follow-up visits by a visit to a nurse-led clinic for the monitoring of biological therapy was found to be safe and effective (paper III). A nurse-led rheumatology clinic, based on person-centred care, added value to the follow-up care of patients with stable CIA undergoing biological therapy by providing a sense of security, familiarity and participation (paper IV).

**Conclusions:** This thesis contributes a valuable insight into person-centred care as the core of rheumatology nursing in the area of biological therapy. The rheumatology nurse adds value to patient care when she/he gives patients an opportunity to talk about themselves as a person and allow their illness narrative to constitute a starting point for building collaboration, which encourages and empowers patients to be an active part in their biological therapy and become autonomous. A nurse who provides person-centred care and keeps the patients’ resources and needs in focus serves as an important guide during their healthcare journey.
Original papers

The thesis is based on the following papers, which are referred to in the text by Roman numerals (I-IV):

**Paper I**


**Paper II**


**Paper III**


**Paper IV**


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Hyltebruk May 2013,

Ingrid Larsson

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Abbreviations

ACR       American College of Rheumatology
anti-TNF  anti-Tumour Necrosis Factor
CIA       Chronic Inflammatory Arthritis
C.G.      Control Group
CRP       C-reactive protein
DAS28     Disease Active Score 28
DMARD     Disease-Modifying Anti-Rheumatic Drug
ESR       Erythrocyte Sedimentation Rate
EULAR     European League Against Rheumatism
HAQ       Health Assessment Questionnaire
I.G.      Intervention Group
IL        Interleukin
NRS       Numerical Rating Scale
NSAID     Non-Steroidal Anti-Inflammatory Drugs
RA        Rheumatoid arthritis
RCT       Randomized Controlled Trial
SpA       Spondyloarthritis
SRQ       Swedish Rheumatology Quality Register
TNF-α     Tumour Necrosis Factor-α
VAS       Visual Analogue Scales
WHO       World Health Organization

Definition

In this thesis persons and patients are synonymous terms and concepts (p. 17).
Introduction

Nursing care and treatment in patients with chronic conditions have developed and become more proactive, evidence-based and person-centred, which means that the role of the nurse has been extended (WHO 2010). In order to focus on patients’ needs, nurse-led clinics have been established as a complement to physician-led clinics for the management of chronic conditions such as allergies, asthma, chronic obstructive pulmonary disease, mental health problems, heart failure and diabetes (Nolte & McKee 2008). Nurse-led clinics with a holistic approach are an important element of high-quality patient care as they enable nurses to understand each patient’s life situation and confirm her/him as a unique person (Shiu et al. 2012). The objective of person-centred care is to illuminate the major importance of the patient perspective and involving her/him in care (Edvardsson et al. 2008). In order to meet the needs of each individual patient, rheumatology nursing should have a holistic approach (Oliver 2011) which means building a relationship between nurse and patient (Hill 2006b). In management of patients with chronic inflammatory arthritis (CIA) rheumatology nursing has changed from a more basic to an advanced level in line with the development of Disease-Modifying Anti-Rheumatic Drugs (DMARD) treatment and biological therapy. Nurses now have the competencies and skills to examine patients’ joints, manage disease activity and monitor drug therapies (Hill 2006b, van Eijk-Hustings et al. 2012). Although examination of patients’ joints by nurses’ is fairly new in Sweden, nurses in other countries have assessed patients’ joints for decades (Hill 1997a, Temmink et al. 2001). Since the introduction of biological therapy, disease activity and joint inflammation have declined (Simard et al. 2011). Biological therapies have transformed the rheumatology landscape and are rapidly becoming more common due to the development of new therapies for a greater number of indications (Furst et al. 2012, van Vollenhoven et al. 2012). Patients are supported by a multidisciplinary team, of which the rheumatology nurse is a vital member (Oliver 2011). Rheumatology nursing research focusing on patients undergoing biological therapy is still in its infancy and there is a need for more research on this topic (Palmer & El Miedany 2010).
Background

Patients with chronic inflammatory arthritis (CIA) undergoing biological therapy

Patients

Living with CIA affects patients physical functioning but also emotional, psychological and social aspects that have a global impact on the whole life situation (Hewlett et al. 2011, Ryan 2006). Patients with CIA often have pain, stiffness, reduced mobility, fatigue and sleep disturbances as well as dermatological, nutritional (Braun & Sieper 2007, Klareskog et al. 2009) and sexual problems (Josefsson & Gard 2010). Pain affects everyday life and may constitute a barrier to the performance of valued activities. Patients describe struggling to find balance in their lives in order to be autonomous and independent (Ahlstrand et al. 2012). Pain and stiffness, especially in the morning, are major problems, affect their mobility, quality of life (Hill 2006a) and ability to remain gainfully employed (Westhoff et al. 2008). The pain increases due to fatigue, stress and depressed mood (Ahlstrand et al. 2012). One of the most difficult symptoms is fatigue. Patients describe fatigue as significant, intrusive, overwhelming, uncontrollable and difficult to manage alone. The consequences of fatigue permeate every aspect of life, leading to a reduction in activities and self-esteem. It restricts the patients’ ability to fulfil their normal roles in the family and takes an emotional toll on relationships, causing frustration, irritability and loss of control (Hewlett et al. 2005a, Nikolaus et al. 2010). Both the physical and the total life situation also affect their sexual health, which should be viewed from a holistic perspective that includes physical, psychological and social aspects of well-being (Hill et al. 2003a, Josefsson & Gard 2010). Psychosocial aspects are important in management (Backman 2006) and partners of patients with a chronic disease such as CIA are vital in disease management, although many carry a substantial psychosocial burden (Matheson et al. 2010). Patients living with a chronic disease frequently need to include other people in their lives and are often dependent on health professionals to deal with certain aspects of their disease. Despite the fact that patients strive to achieve independence, they do not consider their dependence on health professionals as contradictory (Delmar et al. 2006). However, health care professionals should be attentive to patients’ efforts to master their life situation, which requires knowledge and understanding of their experiences in terms of dependency (Eriksson & Andershed 2008). The multidisciplinary team is important for the rheumatology care of patients with
CIA, which should be delivered with an awareness of the patients’ whole life situation. The team should enable these patients to care for themselves and retain or regain optimum independence. The various professional categories in the team have distinct roles but collaborate in order to focus on the patients’ resources and needs (FitzGerald 2006, Walker 2012). The rheumatology nurse is a key member of the team in term of guiding patients to manage their CIA and biological therapy and its impact on the many aspects of their life (Walker 2012, van Eijk-Hustings et al. 2012).

**Chronic inflammatory arthritis (CIA)**

In this thesis, the term CIA refers to rheumatoid arthritis (RA) as well as spondyloarthritis (SpA) (van Eijk-Hustings et al. 2012). The chronic joint inflammation is caused by an imbalance in the regulation of cytokines and other immune system inflammatory mediators (Braun & Sieper 2007, Klareskog et al. 2009). The overproduction of various cytokines in the joints of patients with arthritis is a part of the process that leads to joint destruction (Tracey et al. 2008). The different diagnoses within CIA are made based on established criteria including clinical findings, laboratory analyses and imaging (Aletaha et al. 2010, Rudwaleit 2010, Rudwaleit et al. 2011) and management is based on recommendations from the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) (Braun et al. 2011, Singh et al. 2012, Smolen et al. 2010). For all diagnoses within CIA, early diagnosis, quick and effective treatment, in addition to regular follow-ups with evaluation of disease activity, are important (Burmester et al. 2012, Mercieca et al. 2012, McInnes et al. 2012, Sieper et al. 2012).

RA is a chronic, systemic, inflammatory, autoimmune and complex genetic disease, meaning that several genes, environmental factors as well as other unknown factors act together to cause pathological events (Klareskog et al. 2009, Scott et al. 2010). A prevalence of about 0.7% has been reported in Swedish adults with a higher prevalence among women (Englund et al. 2010, Neovius et al. 2011). The symptoms are pain and stiffness, especially in the morning and often symmetrical mainly in the hands and feet, tender and swollen joints as well as general symptoms such as fatigue and loss of energy. RA can cause destruction of the joints leading to impaired physical function (Burmester et al. 2012). Treatment including DMARD should be started upon diagnosis in order to reduce disease activity, prevent joint damage and lessen the impact on the patients’ daily lives (McInnes et al. 2012). The disease course is usually characterized by episodes of worsening or “flares” alternating with periods of lower disease activity (Bingham et al. 2011).

SpA comprises a number of different diseases: ankylosing spondylitis, psoriatic arthritis, undifferentiated spondyloarthritis, arthritis associated with inflammatory bowel disease and reactive arthritis. The SpA subgroups include a variety of conditions that could be characterized by axial and/or peripheral arthritis, enthesitis and an
association with HLA-B27 antigen (Rudwaleit 2010). A prevalence of 0.45%-1% has been reported (Haglund et al. 2011, Reveille et al. 2012). Although the prevalence in the whole SpA group is equal among Swedish women and men, there are large differences within the subgroups (Haglund et al. 2011). The symptoms of SpA are tender and swollen joints, pain in both small and large joints, morning stiffness and fatigue resulting in impaired spinal mobility and physical function (Mercieca et al. 2012). Physiotherapy is the main non-pharmacological treatment for SpA. Non-Steroidal Anti-Inflammatory Drugs (NSAID) and sometimes DMARD are prescribed to alleviate symptoms (Ash et al. 2012, Braun et al. 2011).

**Biological therapy**

The primary goals of CIA treatment are to suppress disease activity, and achieve remission or low disease activity by controlling the symptoms and inflammation as well as prevent joint damage and early death (Braun et al. 2011, Gossec et al. 2012, Smolen et al. 2010). Rheumatology research has led to the development of biological therapies for patients with an inadequate response to conventional treatment (van Vollenhoven et al. 2012). Biological therapies block inflammatory cytokines and cells within the synovium and immune system, thus inhibiting the disease. Today, this includes therapies that target the cytokines tumour necrosis factor alpha (TNF-α), interleukin (IL) 1 and 6 as well as B- and T-cells. Biological therapies have transformed the rheumatology landscape and are rapidly becoming more common due to the development of new biological therapies for a greater number of indications e.g. RA and SpA (Buch & Emery 2011, Furst et al. 2012). Biological therapies are safe and effective in controlling the inflammatory symptoms of RA (Breedveld & Combe 2011) and SpA (Goh & Samanta 2012). Previous research has demonstrated that biological therapies lead to a reduction in disease activity, better physical function and a reduction or halt of radiological progression (Nam et al. 2010, van Vollenhoven et al. 2012), health status and quality of life (Gulfe et al. 2010). Disease activity and inflammation in patients with CIA have declined over the past decade since the introduction of biological therapy (Simard et al. 2011).

Biological therapies are administered as subcutaneous injections or intravenous infusions (Tracey et al. 2008). In the case of subcutaneous injections the patients have control over where and when the injections are administered. The disadvantages are limited flexibility in terms of dosage due to prefilled syringes, the fact that some patients are unable or forget to inject themselves. Intravenous infusions supervised by health care professionals automatically ensure adherence, provide rapid relief as well as the possibility to adjust the dosage on each occasion in accordance with the patient’s need. The disadvantages are that the patients are dependent on a nurse and have to allocate time for the hospital visit, which also entails cost (Schwartzman & Morgan 2004).
Rheumatology nursing

Rheumatology nursing is based on a holistic approach by which the whole patient is in focus (Hill 2007) and, when optimal, is grounded in the patient perspective (Jacobi et al. 2004, Larrabee & Bolden 2001). Due to recent development, the rheumatology nurse has to be an expert with a high level of knowledge of and competence in providing evidence-based care (Arvidsson et al. 2003, Oliver 2011). The rheumatology nurse’s role is multi-faceted and challenging, as she/he has to use all of her/his knowledge and skill to the full, which benefits patients (Hill 1997a). The essence of rheumatology nursing is to identify and meet patients’ needs, understand illness and treatment from the patients’ viewpoint and encourage them to participate in the care. The rheumatology nurse has to enter into a relationship with the patient and empower, educate, support and guide her/him and her/his family. The relationship between patient and nurse is central in rheumatology nursing (Ryan 1998, van Eijk-Hustings et al. 2012) and must be based on participation. The patient’s narrative should be the point from which the partnership can commence (Ryan & Voyce 2007). The rheumatology nurse has to educate, share information and support the patients to make informed decisions and to be co-actors in the care, as well as monitor and regularly assess disease activity. The rheumatology nurse has to tailor the information and care based on the patient’s needs and facilitate management on the patient’s healthcare journey. The duties also include identifying the patient’s problems based on her/his narratives and referring the patient to other professional categories in the multidisciplinary team when necessary (Oliver 2011, van Eijk-Hustings et al. 2012, Walker 2012), including nurse-led clinics (Ryan et al. 2006b). Research has revealed that nurse-led rheumatology clinics in patients undergoing conventional DMARD therapy are effective and add value in terms of improving patients’ perceived ability to cope with arthritis (Hill 1997b, Hill et al. 1994, Hill et al. 2003b, Primdahl et al. 2012, Ryan et al. 2006b, Tijhuis et al. 2003). A nurse-led clinic can meet EULAR recommendations pertaining to the nurse’s role in the management of CIA, as it improves patients’ knowledge of CIA and its management as well as enhancing communication, continuity and satisfaction with care. The rheumatology nurse should participate in comprehensive disease management to control disease activity, as well as identify, assess and address psychosocial issues, which is a valuable complement to the medical care. In order for patients to achieve a greater sense of control, self-efficacy and empowerment, the nurse should meet their expressed needs and promote self-management skills. The encounter between nurse and patient should be at individual level, which is facilitated by a person-centred care (van Eijk-Hustings et al. 2012).
Person-centred care

Person-centred care comprising a partnership between patient and nurse is advocated by the WHO as a key component of quality health care (Nolte & McKee 2008). Morgan and Yoder (2012) defined: “Person-centred care is a holistic approach to deliver care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level that is desired by that individual who is receiving the care” (Morgan & Yoder 2012) (p.8). In this thesis the concept of person-centred care includes holistic, respectful, individualized and empowering care.

Holistic care

Holistic care means seeing the whole person and her/his physical, psychological, social and spiritual needs. To provide holistic care the nurse has to understand how an illness affects the whole person and how to respond to the real needs of the person. Holistic care that focuses on biological illness always includes psychological, social and spiritual aspects of the whole person’s condition and life situation (Morgan & Yoder 2012). A holistic view of nursing involves self-reflection, experience of meaning, values, feelings and options, all of which are parts of a humanistic view of the person, which means that she/he is regarded as unique, i.e., an autonomous, rational, social and spiritual being (Berg & Sarvimaki 2003).

Respectful care

Respectful care recognizes and respects the inherent value of each person, supports a person’s strength and abilities and promote human freedom. Each person has the right to be treated with respect and recognized as competent to make decisions about her/his care. To provide respectful care the nurse must respect the person’s decision pertaining to daily routines (Morgan & Yoder 2012). Respectful care also acknowledges the autonomy, dignity and privacy of the human being and should be based on respecting her/his rights, not merely viewing her/him as a patient who needs help (Slater 2006). These ethical assumptions constitute a framework for the nurse when creating a dialogue and relationship with patients (Berg & Sarvimaki 2003).

Individualized care

Individualized care is achieved by understanding a person’s life situation beyond her/his ability or desire to make decisions and take control of her/his care. A person’s life situation includes her/his culture, beliefs, traditions, habits, activities and preferences (Morgan & Yoder 2012). Important components of person-centred care are support for the rights, values and beliefs of the person (Edvardsson et al. 2008) and confirmation of the person’s lived experiences. From the patient perspective, fear and emotional issues can affect health outcomes, as well as the feeling of being
misunderstood in the care (Slater 2006). Person-centred care emphasizes the importance of knowing the person behind the patient as a unique person with her/his will, emotions and needs. Seeing the person with a disease means putting her/him before the disease (Ekman et al. 2011, Slater 2006).

**Empowering care**

Empowering care promotes autonomy and self-confidence, which facilitate participation in decision-making. Effective communication and negotiation are essential. A person needs to think critically, obtain information to gain knowledge and be supported to make individual choices in order to be involved in decision-making and feel genuinely empowered (Anderson & Funnell 2010, Morgan & Yoder 2012, Tengland 2008), which shifts power to her/him (Slater 2006). To provide empowering care the nurse has to involve the person in decision-making, thus sharing both power and responsibility (Edvardsson et al. 2008, Ekman et al. 2011, Tengland 2008). A partnership between the person and the nurse ensures that the person’s own decisions are valued. This therapeutic relationship must be based on mutual trust, as person-centred care implies mutuality (Slater 2006).

**Person-centred care in clinical practice**

In this thesis patients are persons with a disease. When employing a person-centred care perspective it is important to know the person behind the patient. Due to the fact that persons in need of care enter a relationship with a nurse, they will be termed patients in this thesis.

To ensure that person-centred care is systematic and consistent, routines must be established to initiate, integrate and safeguard person-centred care in clinical practice. Patients’ narratives form the basis for the partnership between the patient and nurse. The purpose is to allow the patients an opportunity to talk about themselves as a person and so that their illness narrative can constitute a starting point for building collaboration. Partnership building integrates patients in their care and empowers them to play an active role, thus making them active co-actors. Patients’ narratives create a common understanding of the illness experience, which, together with the symptoms of the disease, provide the nurse with a good foundation for discussing and planning care and treatment with the patients. Person-centred care involves creating a partnership that is characterized by shared information, deliberation and decision-making based on the patient narrative. To safeguard the partnership the nurse has to document the narratives (Ekman et al. 2011). Previous research has demonstrated that person-centred care is a way of increasing satisfaction with the care on the part of both patients (Edvardsson et al. 2010) and nurses in different contexts (Lehuluanite et al. 2012, McCormack et al. 2010). Person-centred care also leads to improved health outcomes (Chenoweth et al. 2009, Olsson et al. 2006) and reduces the length of the hospital stay with no negative impact on health-related-quality of life (Ekman et al. 2012).
Patients with CIA undergoing biological therapy often live with lifelong disease and treatment. Although patients usually have a good quality of life and feel well, they are concerned about the risk of treatment failure and relapse. In the same way as other people, their lives revolve around the family, work and social contacts but, in addition, they have to find the time for health care and medical treatment. Their lives are often characterized by regular monitoring of both the disease itself and biological therapy. There is a growing knowledge available about biological therapies in rheumatology care, as well as their effects and side effects (Furst et al. 2012, Scott 2012). However, due to the fact that biological therapy is relatively new, there is a lack of research about patients experiences of how to administer and live with biological therapy. Previous research on rheumatology nursing and nurse-led rheumatology clinics only involved patients with RA treated by means of traditional therapies who had regular contact with a nurse every or every other month (Ndosi et al. 2011, Primdahl et al. 2012). Thus, there is limited knowledge about the effect of rheumatology nursing in patients with CIA undergoing biological therapy (Firth & Critchley 2011, Oliver 2011, Palmer & El Miedany 2010). In order to understand and assist patients who are undergoing biological therapy, more research is required that focuses on rheumatology nursing from the patient perspective. Rheumatology nursing is intended to meet patients’ individual needs and improve patient care (van Eijk-Hustings et al. 2012), which can be achieved by means of person-centred care with a holistic approach that respects and empowers patients (Morgan & Yoder 2012). This thesis is based on both the naturalistic paradigm where reality is multiple and subjective and the positivistic paradigm where reality is objective and generalizable (Polit & Beck 2012). Both qualitative and quantitative approaches are used in this thesis in order to provide a more comprehensive and thorough understanding of the phenomenon of person-centred care in rheumatology nursing in patients undergoing biological therapy based on the patient perspective. It is important to obtain variations in patient experiences in order to be able to provide holistic rheumatology nursing. During illness and treatment, patients are constantly adapting to new situations, in which the rheumatology nurse plays an important role (Hill et al. 2003b, Ryan et al. 2006b). The basic approach is to see the whole person as a resourceful being who is capable of developing as a person, acting responsibly, assuming responsibility, striving for a good life as well as one who can think, feel, remember, narrate about her/his self-image, be social and create meaning in life, while at the same time being vulnerable and suffering (Kristensson-Ugglä 2011).
With person-centred care, the patients’ resources and abilities to manage their lives come into focus and the patients are seen as experts in their illness and life situation (Ekman et al. 2011). The intention is to encourage and empower patients to play an active role in their biological therapy. Rheumatology nursing has developed so that the rheumatology nurse has become an expert with in-depth nursing knowledge and competence in providing evidence-based care and supporting patients to become co-actors in the care. Today, rheumatology nursing involves comprehensive duties, but enhanced care is ultimately achieved by a more holistic approach (Palmer & El Miedany 2010) based on person-centred care that supports patients in making an informed decision to improve their well-being. In essence, the expertise of the nurse specialist is multi-faceted, involving a number of important components such as regular assessment of disease activity, support, information sharing, coordination and continuity of care (Oliver 2011). The rheumatology nurse with a person-centred care approach is important in patients with CIA undergoing biological therapy.
Overall and specific aims

The overall aim was to explore and evaluate rheumatology nursing from a person-centred care perspective in patients undergoing biological therapy.

The specific aims were:

- To describe variations in how patients with rheumatic conditions conceive their dependence on a nurse for the administration of their intravenous anti-TNF therapy (paper I).

- To describe variations in how patients with rheumatic diseases conceive their independence of a nurse for the administration of subcutaneous anti-TNF therapy (paper II).

- To compare and evaluate treatment outcomes of a nurse-led rheumatology clinic and a rheumatologist-led clinic in patients with low disease activity or in remission undergoing biological therapy (paper III).

- To describe patients’ experiences of a nurse-led rheumatology clinic for those undergoing biological therapy (paper IV).
Materials and methods

Design
The thesis had an explorative and interventional design combining both qualitative (papers I, II and IV) and quantitative (paper III) methods.

Overview
In order to address the aims of the thesis, the following four designs were used:

- An explorative descriptive design based on a phenomenographic approach including patients with CIA receiving biological intravenous infusions (paper I).
- An explorative descriptive design based on a phenomenographic approach including patients with CIA receiving biological subcutaneous injections (paper II).
- An interventional study with a randomized controlled design and 12 month follow-up including patients with stable CIA undergoing biological therapy (paper III).
- An explorative descriptive design based on an inductive qualitative content analysis approach including patients with stable CIA undergoing biological therapy from paper III (paper IV).

An overview of the papers can be found in Table 1 and the relationship between the studies is presented in Figure 1.
Table 1. Overview of the studies in the thesis, their design, the sex and age of the participants with chronic inflammatory arthritis (CIA), instruments, data collection and data analysis.

<table>
<thead>
<tr>
<th>Paper</th>
<th>I</th>
<th>II</th>
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<tr>
<td>Design</td>
<td>Explorative descriptive design</td>
<td>Explorative descriptive design</td>
<td>Randomized controlled trial</td>
<td>Explorative descriptive design</td>
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<td>20 patients with CIA receiving subcutaneous biological injections</td>
<td>107 patients with stable CIA undergoing biological therapy</td>
<td>20 patients with stable CIA undergoing biological therapy</td>
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<td>C.G. 23 (43%)</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>10 (50%)</td>
<td>10 (50%)</td>
<td>I.G. 30 (57%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>C.G. 31 (57%)</td>
<td></td>
</tr>
<tr>
<td>Mean age, years (min-max)</td>
<td>49 (21-82)</td>
<td>48.4 (17-79)</td>
<td>I.G. 54.9 (34-81)</td>
<td>55.5 (34-76)</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>C.G. 55.1 (21-77)</td>
<td></td>
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<tr>
<td>Instruments</td>
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<td></td>
<td>DAS28 HAQ VAS Pain NRS Satisfaction NRS Confidence</td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td>During the first half of 2007</td>
<td>During the first half of 2009</td>
<td>Between October 2009 and August 2011 Questionnaire at baseline and at 6 and 12 months</td>
<td>From September 2010 to April 2011 Open interview on one occasion</td>
</tr>
<tr>
<td></td>
<td>Open interview on one occasion</td>
<td>Open interview on one occasion</td>
<td></td>
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</tr>
<tr>
<td>Data analysis</td>
<td>Qualitative analysis based on a phenomenographic approach</td>
<td>Qualitative analysis based on a phenomenographic approach</td>
<td>Quantitative analysis based on parametric methods</td>
<td>Qualitative analysis based on an inductive qualitative content analysis approach</td>
</tr>
</tbody>
</table>

CIA Chronic Inflammatory Arthritis; C.G. Control Group; DAS28 Disease Active Score 28; HAQ Health Assessment Questionnaire; I.G. Intervention Group; NRS Numerical Rating Scale; VAS Visual Analogue Scale.
**Figure 1.** Overview of the four studies and their relationship in the thesis.

**Study I**
Explores and describes variations in how patients with CIA conceive their dependence on a nurse for the administration of intravenous biological therapy

**Study II**
Explores and describes variations in how patients with CIA conceive their independence of a nurse for the administration of subcutaneous biological therapy

**Study III**
Compares and evaluates treatment outcomes from a nurse-led rheumatology clinic and a rheumatologist-led clinic in patients with stable CIA undergoing biological therapy

**Study IV**
Explores and describes patients’ experiences of a nurse-led rheumatology clinic in patients with stable CIA undergoing biological therapy
Phenomenographic approach (papers I and II)

Phenomenography was developed in Sweden in the early 1970s within the domain of learning. It has since spread from the educational context to that of health science research and has been found appropriate for nursing research (Sjostrom & Dahlgren 2002). The word phenomenography means descriptions of phenomena as they appear to us. The purpose of the phenomenographic approach is to discern the variation of the world as experienced by means of identifying variation in conceptions of a specific phenomenon and to describing the qualitatively different ways in which a group of people makes sense of, experiences and understands the phenomenon in the world around them (Marton 1981, Marton & Booth 1997). The idea of variation in conceptions is important, because persons’ experiences will differ depending on their relationships to the world (Marton, 1992; Wenestam, 2000). It is essential to be aware of conceptions relating to our social reality and ourselves. Our conceptions of and knowledge about the world are not merely based on interpreted data from our senses but are dependent on our personal history. The only world that people can report about is the one they experience. These two factors help to explain our everyday lives, and the way in which we deal with them influences our opinion and directs our search for knowledge (Barnard et al. 1999). Phenomenography is grounded in a non-dualistic ontology, as the assumption is that the only world that we can communicate about is the world we experience. The experience of a phenomenon is an internal relationship between the person and the world. The epistemological assumption is that an understanding is defined as the experiential relations between a person and a phenomenon. Changes in a person’s understanding constitute the most important form of learning. Persons experience the world in different ways, but these differences can be described, communicated to and understood by others. Such descriptions of differences and similarities in how the world is conceived constitute the most essential outcomes of phenomenographic research. The researcher is primarily interested in how the phenomenon is conceived and not how the world really is. Phenomenography focuses on the analysis of the how aspect in order to identify qualitatively different conceptions that cover the major part of the variation in a population. Several ways of understanding a phenomenon can be found in a group of people. Descriptions of what and how a person conceives a phenomenon are not psychological or physical in nature but concern the relationship between her/him and the phenomenon. These descriptions form descriptive categories, which are composed of a number of aspects that the persons experience in relation to the phenomenon (Marton & Booth 1997). In this thesis an explorative, descriptive design with a phenomenographic approach (Marton 1981) was selected in order to explore the qualitative variations in how patients experienced their dependence on/independence of a nurse for the administration of intravenous/subcutaneous anti-TNF therapy. The clinical implications of such an emphasis on differences means that nurses must be prepared to take different measures to satisfy the needs of individual patients.
Randomized controlled trial (paper III)

The positive paradigm, often associated with quantitative research, has been dominant for many years in nursing research. Researchers try to understand the underlying causes of phenomena and seek objective reality and generalizations. A randomized controlled trial (RCT) is a full experimental test of an intervention, involving random assignment to treatment groups (Polit & Beck 2012), in which researchers play an active role. Polit and Beck (2012) stated that a true RCT design is characterized by three properties: manipulation, control and randomization.

Manipulation (the experimental intervention) means testing an intervention on some people and withholding it from others. Control (the control condition) implies a group (control group) of participants whose outcomes are used to compare with those of the intervention group using the same instruments. A control group does not take part in the intervention. Randomization, also known as random assignment, means that everyone who fulfils the inclusion criteria has an equal chance of being assigned to the intervention or control group. The purpose of random assignment is to have people with the same characteristics in both groups (Polit & Beck 2012). In this thesis an RCT design was chosen in order to compare and evaluate treatment outcomes of a nurse-led rheumatology clinic and a rheumatologist-led clinic in patients with low disease activity or in remission undergoing biological therapy. Accordingly, the hypothesis of this RCT was that the treatment outcomes measured by the Disease Activity Score 28 (DAS28) in patients with low disease activity or in remission, who were undergoing biological therapy at a nurse-led clinic, would not be inferior to those of patients attending a rheumatologist-led clinic at the 12-month follow-up.

Qualitative content analysis approach (paper IV)

Qualitative content analysis is a research method that provides a systematic means of making valid inferences from verbal or written data in order to describe a specific phenomenon (Krippendorff 2004). It is a widely used qualitative research technique that comprises different approaches (Hsieh & Shannon 2005). When used with an inductive approach, it aims to enhance the quality of findings by relating the categories to the context in which the data were generated. Qualitative content analysis interprets meaning from text data and hence belongs to the naturalistic paradigm. The method can be applied to analyse a person’s experiences, reflections or attitudes, making it suitable for nursing research (Downe-Wamboldt 1992). The researcher could gain a richer understanding of a phenomenon using this approach. Qualitative content analysis offers researchers a flexible, pragmatic method for developing and expanding knowledge of the human experience of health and illness (Hsieh & Shannon 2005).
Content analysis initially involved an objective, systematic and quantitative description of the manifest content of a text, but over time, it expanded to include interpretation of the latent content (Graneheim & Lundman 2004). Both manifest and latent qualitative content analysis deal with interpretation, but the interpretation varies in term of the depth and level of abstraction. Manifest qualitative content analysis is about the visible components of the text, i.e. what the text says, while latent analysis concerns the interpreted meaning, i.e., what the text is talking about (Downe-Wamboldt 1992, Graneheim & Lundman 2004). Using both latent and manifest qualitative content analyses provides more insightful and meaningful findings than either approach alone. The intention is to describe variations by identifying differences and similarities in the content, which are formulated as categories and themes at various levels, in which context plays a vital role. Qualitative content analysis was chosen in order to reveal the variation and diversity in the study (Graneheim & Lundman 2004). However, a text never contains one single meaning and interpretation involves the most probable meaning from a particular perspective (Krippendorff 2004). In this thesis an explorative descriptive design based on an inductive qualitative content analysis approach was selected in order to describe and explore patients’ experiences of a nurse-led rheumatology clinic for those undergoing biological therapy.

**Context**

The studies in this thesis were conducted at a rheumatology clinic in southern Sweden with 5,500 outpatient visits annually by 3,500 patients, of whom 600 received biological therapy either by intravenous infusions provided by a nurse or by subcutaneous injections. A nurse-led rheumatology unit managed parenteral biological therapies in patients who were prescribed subcutaneous injections or intravenous infusions. The nurse provided patients with information about both subcutaneous and intravenous therapy as well as support, monitoring and administration of the intravenous infusions every 4-8 weeks. Patients who self-administered their biological therapy by means of subcutaneous injections were allocated personal support from nurse after one or two months. Self-administration took place once a week or every other week depending on the medication prescribed. A team of rheumatologists, nurses, physiotherapists, occupational therapists and social workers worked at the clinic.
Participants (papers I-IV)

Patients with CIA undergoing biological therapy were included in the studies (Table 1). During the first half of 2007 (paper I) and the first half of 2009 (paper II), 20 patients who had received intravenous biological infusions and 20 patients undergoing self-administered subcutaneous biological injections were invited and agreed to participate in the studies. Between October 2009 and August 2010, 270 patients were assessed by a rheumatologist, of whom 125 met the inclusion criteria and were invited to participate in the trial (paper III) (Figure 2). Of these, 107 agreed to take part and were randomly assigned to the nurse-led rheumatology clinic (intervention group; n=53) or to the rheumatologist-led clinic (control group; n=54). Randomization took the form of sealed envelopes containing assignment to one of the two groups and when a patient met the inclusion criteria, an envelope was randomly picked. The power analysis was based on the primary outcome DAS28 score. A mean difference of 0.6 was considered a moderate improvement, while a difference of 1.2 was deemed clinically significant or good (van Riel et al. 1996). Based on a change of 0.6 in the DAS28 score and a standard deviation (SD) of 1.0 (Rezaei et al. 2012), the power analysis demonstrated that 95 patients would be sufficient to detect a clinically moderate difference between groups at a 5% significance level with at least 90% power. It was decided to include 107 participants to allow for the predicted 10% dropout. Between September 2010 and April 2011, 20 patients who participated in the nurse-led rheumatology clinic (paper III) were invited and agreed to take part in the final study (paper IV). Strategic sampling in terms of sex, age, civil status, education, duration of disease and duration of biological therapy was carried out in papers I, II and IV in order to achieve variation in conceptions/experiences of the phenomenon under study.
Figure 2. Flow chart of the recruitment and participants in the randomized controlled trial, with the intervention of a nurse-led rheumatology clinic, based on person-centred care (paper III).
**Intervention (paper III)**

The purpose of the intervention was to replace one of the two annual rheumatologist monitoring visits by a visit to a nurse-led rheumatology clinic in patients undergoing biological therapy who had low disease activity or were in remission.

**Rheumatologist-led clinic**

The usual care for patients with CIA undergoing biological therapy in Sweden was monitoring by a rheumatologist every 6 months in order to evaluate the effect of the medication and disease activity measured by the DAS28. Data were stored in the Swedish Rheumatology Quality Register (SRQ) (Ovretveit et al. 2013, van Vollenhoven & Askling 2005). The rheumatologist assessed disease activity by examining tender and swollen joints according to a 28-joint count in addition to evaluating the results of laboratory tests. The patients were able to contact the rheumatology clinic between the scheduled follow-up visits.

**Nurse-led rheumatology clinic**

A nurse-led rheumatology clinic based on person-centred care was designed, where five registered nurses with extensive professional experience of managing rheumatic diseases in both in- and out-patient rheumatology care assessed patients’ disease activity in the same way as a rheumatologist. The five nurses had undergone special training from a rheumatologist and RA instructors (specially trained patients who instruct healthcare staff how to examine the joints of the hands, wrists, feet and ankles as well as providing information about living with the disease) to assess swollen and tender joints based on the 28-joint count in order to make an evidence-based assessment of disease activity. The patients were monitored by a rheumatology nurse after 6 months and by a rheumatologist after 12 months. If necessary, the nurses could contact the rheumatologist for advice or to obtain a prescription.
Data collection (papers I-IV)

The interviews (papers I, II and IV) started with the researcher clarifying the aim of the studies. An open interview guide (papers I and II) with opening questions was employed as a means of ensuring that similar data were gathered from all participants (Kvale & Brinkmann 2009) in line with the phenomenographic approach (Marton & Booth 1997). In paper IV the interviews took the form of a dialogue (Kvale & Brinkmann 2009). The interviews were intended to facilitate an open conversation in order to increase the understanding of patients’ experiences of the phenomenon. The following opening questions were used in paper I: “What does it mean to you that a nurse administers your regular intravenous infusions?”, “What does the concept ‘dependence’ mean to you?” and “How do you conceive being dependent on the nurse who administers your medication?” In paper II the following opening questions were used: “What does the administration of subcutaneous anti-TNF injections involve for you?” “How do you conceive the independence provided by the fact that you yourself can administer subcutaneous anti-TNF injections?” and “How do you conceive the fact that you are not dependent on a nurse for your anti-TNF injections?” In paper IV the opening question was “What are your experiences of the encounter with a nurse in the nurse-led clinic?” In order to probe more deeply into a question, the participants were asked to “tell more”, “How do you mean?” or “What do you have in mind when you say…?”

In paper III data were collected at baseline, 6 and 12 months and entered into the SRQ. The monitoring by the rheumatology nurse (intervention group) and the rheumatologist (control group) included an assessment of swollen and tender joints based on the DAS28. The participants indicated their perceived global health the previous week (0–100, best to worst) on a 100 mm Visual Analogue Scale (VAS). The Health Assessment Questionnaire (HAQ), VAS for pain and Numerical Rating Scale (NRS) for assessment of satisfaction with and confidence in obtaining rheumatology care were used. An assessment of disease activity, medication record, employment status and any adverse events were also documented. The primary outcome was change in disease activity measured by the DAS28 over a 12-month period. All patients were monitored by the rheumatologist at baseline and after 12 months.
Measuring instruments (paper III)

Disease activity

Disease Activity Score 28 (DAS28)

The DAS28 is a validated index of RA disease activity (Prevoo et al. 1995) and a composite measurement comprising patient reported [number of tender joints based on the 28-joint count and global assessment, VAS for global health] and practitioner reported [number of swollen joints based on the 28-joint count and erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP)] scores. The outcome of the DAS28 is a number on a scale from 0 to 10, where the values >5.1, <3.2 and <2.6 indicate high disease activity, low disease activity and remission, respectively (Fransen et al. 2004). The DAS28 is also used to measure disease activity in other inflammatory joint diseases such as peripheral PsA and USpA (Fransen et al. 2006, Glintborg et al. 2011, Saber et al. 2010) as well as constituting a variable for evaluating disease activity in patients treated by means of biological therapy (Vander Cruyssen et al. 2005). In this trial the abbreviation DAS28 was used when the calculation included the ESR, while DAS28-CRP was employed when the calculation included CRP and the correlation between them was found to be good (Wells et al. 2009).

Activity limitation

Health Assessment Questionnaire (HAQ)

The HAQ is a validated questionnaire for assessing activity limitation in patients with arthritis (Bruce & Fries 2003), which is self-administered and disease-specific. It measures the ability to perform 20 items and assesses the degree of difficulty involved in performing activities of daily living during the previous week. The activities are grouped into eight categories of functioning: dressing, rising, eating, walking, hygiene, reach, grip and usual activities. The total score ranges from 0 to 3 and a higher score indicates a greater degree of disability (Ekdahl et al. 1988, Fries et al. 1980).

Pain

Visual Analogue Scale (VAS) for pain

The VAS is a validated scale for assessing pain in patients with chronic pain (Price et al. 1983) and provides a simple way to assess patients’ experienced pain. It was used in the study to estimate pain during the previous week (VAS 0–100 mm). The anchor points of the scale are 0 (no pain) and 100 (worst possible pain) (Huskisson 1974, Joos et al. 1991).
Satisfaction and confidence

Numerical Rating Scale (NRS) for satisfaction with and confidence in obtaining rheumatology care

The NRS is used in patients with arthritis to assess satisfaction with and confidence in obtaining rheumatology care (Moe et al. 2010). The questions in this study were: “How satisfied are you with the rheumatology care?” with the anchor points being 0 (not at all satisfied) and 10 (completely satisfied), and “How confident are you of obtaining help from your rheumatology clinic when you have joint problems?” with the anchor points 0 (no confidence) and 10 (complete confidence) (Eriksen et al. 2011, Moe et al. 2010).
Data analysis (papers I-IV)

**Paper I**

The analysis was performed on conceptions that dealt with the same or an interconnected area identified in each interview as well as in the data as a whole (Marton & Booth 1997). The data were processed by means of seven different steps (Dahlgren & Fallsberg 1991, Sjostrom & Dahlgren 2002).

*Familiarization*

Each interview was listened to and the transcript read several times in order to become familiar with and obtain an overall impression of the material.

*Condensation*

A search was made for statements corresponding with the aim of the study. These statements were entered into the computer in the form of a table that clearly indicated the interview from which they originated.

*Comparison*

The statements were analysed in order to identify differences and similarities. Those with the same content were grouped together.

*Grouping*

The statements were grouped on the basis of their characteristic properties in order to obtain a deeper understanding of the way in which they were connected and formed conceptions.

*Articulation*

The conceptions were compared and grouped on the basis of similarities and differences. The analysis moved back and forth between the preceding and actual step, leading to three descriptive categories.

*Labelling*

The content of the conceptions that formed each descriptive category was discussed with the co-researches, after which the categories were labelled.

*Contrasting*

The resulting descriptive categories were compared in terms of similarities and differences in order to establish that each of them had a unique character and that they were at the same level of description. Agreement about the final categories was reached by a process called negotiating consensus, which corresponds to the inter-judge reliability test often performed within the phenomenographic approach (Wahlstrom et al. 1997).
**Paper II**

The data analysis was performed in seven steps (Larsson & Holmström 2007).

1. In the first step, the transcript text was read several times, on the first few occasions while listening to the audio-recorded interviews.

2. In the second step, the whole text was reread and conceptions that corresponded with the aim of the study were identified and marked.

3. The third step involved searching for conceptions of *what* patients focus on and *how* they describe their experiences of being independent of a nurse for the administration of subcutaneous anti-TNF injections, after which a preliminary description of each patient’s dominant way of understanding the phenomenon was formulated.

4. In the fourth step, the descriptions were grouped based on similarities and differences in meaning, which resulted in descriptive categories. These categories were compared in order to establish that each of them had a unique character and the same level of description.

5. The fifth step involved searching for non-dominant ways of understanding the phenomenon, i.e. statements in which the patients described other ways of understanding it. This was undertaken to ensure that no aspect was overlooked.

6. In the sixth step, a structure was created from the resulting descriptive categories, i.e., their outcome space, which constitutes the result of a phenomenographic study.

7. In the seventh step, a metaphor was assigned to each descriptive category.

**Paper III**

Statistical analyses were performed using SPSS version 19.0 for Windows. Differences in disease activity, activity limitation, pain, satisfaction with and confidence in obtaining rheumatology care between groups were analysed by means of an independent sample t-test and within the groups by a paired t-test. The analyses form the basis of the results presented in this paper. Due to the nature of the VAS Pain, HAQ, NRS satisfaction and NRS confidence scales, non-parametric analysis was also conducted with similar results. Values of $p<0.05$ were considered statistically significant.
Paper IV

The analysis was performed in a seven-step process in accordance with Graneheim and Lundman (2004). In the analysis process the intention was to remain close to the text, preserve contextual meanings and continuously move between the whole and the parts (Graneheim & Lundman 2004).

1. The entire text (unit of analysis) was read through repeatedly to obtain a sense of the whole.

2. Meanings or phrases containing information relevant to the aim were identified and extracted, together with surrounding text in order to preserve the context (meaning units).

3. The meaning units were condensed to shorten the text while retaining the content (condensed meaning unit).

4. The condensed meaning units were abstracted and coded.

5. The codes were grouped into subcategories.

6. The subcategories were grouped into categories that reflected the central message contained in the interviews. These categories constituted the manifest content.

7. The content of the categories was brought together and abstracted. A theme reflecting the underlying meaning was formulated, constituting the latent content.
Methodological considerations

The aim of this thesis required both qualitative (papers I, II and IV) and quantitative methods (paper III). Qualitative and quantitative methods complement each other and allow the researchers to generate different kinds of assumption about key phenomena in i.g., rheumatology nursing (ontology) as well as about how to obtain and develop knowledge of these key phenomena (epistemology) (Polit & Beck 2012, Rawnsley 1998). Trustworthiness is defined differently in qualitative and quantitative research and ways of ensuring it also differ. In qualitative research, trustworthiness should be based on four criteria: credibility, dependability, confirmability and transferability (Lincoln & Guba 1985, Polit & Beck 2012), while in quantitative research it is defined as: internal validity, reliability, objectivity and external validity (Polit & Beck 2012).

Trustworthiness in the qualitative studies (papers I, II and IV)

Credibility

Credibility can be regarded as internal validity, which in qualitative research refers to confidence in the truth of the data and analysis (Polit & Beck 2012). The main author’s profession as a rheumatology nurse and extensive experience of rheumatology nursing enabled her to obtain rich data from the participants. However, the main author had no caregiver contact with the participants, allowing them greater opportunity to be open and honest in the interview. The voluntary nature of participation was emphasized, so that they did not feel obliged to participate in order to satisfy their caregivers. Credibility was strengthened by the use of open interview guides to assist the participants to reflect on the phenomenon of dependence on/independence of a nurse for the administration of biological therapy as well as their experience of the nurse-led rheumatology clinic. The main researcher asked the participants to reflect on their experience of the object of study and invited each participant to explain her/his understanding in more detail. Follow-up questions were posed to avoid misunderstanding and the participants were encouraged to talk openly. The same opening questions were posed to all participants in each study. The interviews took place in an undisturbed location chosen by the participants. The main researcher performed all the interviews, which can be considered both a strength and a weakness. The strength was that the interviews were conducted in the same way, while the weakness was that the interviewer gained new insight into the phenomenon in the course of the interviews, which might have influenced the follow-up questions.
Credibility was strengthened by the fact that two pilot interviews (papers I, II and IV) and 18 interviews (thus a total of 20 interviews) were conducted in each study. No new conceptions emerged after the seventh interview (paper I), no new descriptive categories after the sixteenth interview (paper II) and no new subcategories after the fourteenth interview (paper IV). Each conception was described by several participants (papers I and II), and by the large number of meaning units described by several participants (paper IV). The fact that the categories covered the data also increases credibility. Strategic selection was employed, as the aim of phenomenographic (Marton & Booth 1997) and qualitative content analysis (Graneheim & Lundman 2004) is to identify variations, thus all content is relevant. Credibility was enhanced by careful descriptions of the data collection and analysis. The researchers worked individually and together throughout the analysis.

**Dependability**

Dependability can be regarded as the reliability of the research and in qualitative studies refers to the stability of data over time and conditions (Polit & Beck 2012). Dependability was strengthened by the fact that all interviews began with the same opening question to ensure stability of data and facilitate comparison of the interviews. The participants were encouraged to talk openly and explain their thoughts about a concrete situation in which they had been involved. The main researcher conducted and transcribed the interviews, while attempting to remain open to all variations in experiences that were relevant to the aim. Dependability was enhanced by the fact that the data analysis sought to identify the participants’ experiences of the phenomenon while bearing in mind the aim of the study. Dependability was also strengthened due to the co-researchers’ continuous discussions and great familiarity with the methodology employed. The categories were compared and revised until the final classification emerged (Dahlgren & Fallsberg 1991, Graneheim & Lundman 2004).

**Confirmability**

Confirmability can be regarded as objectivity of the research. In qualitative studies it refers to the neutrality of the data, which ensures that the data represent the information provided by the participants and that interpretations are not subject to the researcher bias. The findings should reflect the participants’ voices (Polit & Beck 2012). Confirmability was demonstrated by the systematic and conscientious treatment of the data; repeated reading, identification of and reflection on the content. All steps of the analysis have been conscientiously reported and confirmability is enhanced by the fact that the interviews were conducted and transcribed by the main researcher. The participants’ experiences were described in as much detail as possible, while quotations enhance and illuminate the content. The results reveal that the categories are on the same contextual level but that their meanings are clearly delimited.
As a qualitative researcher, it is important to reflect on one’s own interpretations, perspectives and values. It also means being open to the research and considering it a learning process. In a successful qualitative research process, the relationship between the researcher and the phenomenon being explored as well as the researcher’s understanding of it develops (Polit & Beck 2012). Awareness of her pre-understanding helped the main researcher to bracket it, while the co-researchers did not possess such pre-understanding, thus preventing the risk of bias. Furthermore, the researchers endeavoured to be aware of their attitudes and how they might affect the interviews and analysis. A limitation could be the duration of the interviews; 30-60 minutes may be too short. However, the interview texts were deemed rich and contained great variety (Graneheim & Lundman 2004, Sjostrom & Dahlgren 2002).

**Transferability**

Transferability can be regarded as external validity and in qualitative research it refers to the potential for extrapolation. Transferability in qualitative research means that the study actually identifies and investigates the phenomenon that it set out to study and that the context is described, thus allowing the results to be transferred to similar contexts (Polit & Beck 2012). The participants were strategically selected to obtain maximum variation in line with the phenomenographic (papers I and II) (Marton & Booth 1997) and the qualitative content analysis approach (paper IV) (Graneheim & Lundman 2004). Transferability can be deemed to be ensured due to the fact that the selection took account of several variables; sex, age, civil status, education, diagnosis, disease duration, administration methods, duration of biological therapy and distance to the clinic. A limitation may be that all data were collected in the same clinic. Providing that the strategic selection ensured variation within the group of patients undergoing biological therapy, the results could be transferable to a wider population. Morse (1999) claimed that in qualitative studies each participant is purposefully selected to contribute increased knowledge to the research field. The goal of qualitative research is to modify theory and transfer the knowledge gained, thus generalizing it. It is essential that qualitative findings are generalizable, useful, powerful and considerable (Morse 1999).
Trustworthiness in the quantitative study (paper III)

In view of the growing demand for evidence-based practice, RCTs are considered the best design for testing the effect of nursing interventions, as they contribute strong evidence about effects. Randomization and the use of a comparison group make the trial as similar as possible to clinical practice. Thus in the present trial, replacing every second visit to a rheumatologist with one to a rheumatology nurse and simulating normal biological therapy follow-up care increased the possibility to implementing such a clinic in everyday care. Although RCTs are sometimes criticized for their artificiality (Polit & Beck 2012), the present intervention can be directly integrated into the clinical routine. A difficulty with RCTs conducted in clinical settings is that those in the intervention group take part in the intervention while those in the control group do not. However, this problem did not arise, as the intervention was performed by nurses who do not normally monitor biological therapy while the control group received the usual rheumatologists care.

Internal validity

Internal validity concerns the degree to which it can be inferred that the experimental intervention, rather than something else, is responsible for the outcome. Threats to internal validity include selection, history and maturation, comprising possible events or other changes that can influence the results (Polit & Beck 2012). Selection did not pose a major problem, as there were no significant differences in demographic and clinical characteristics between the participants in the two groups. A history and maturation affected both randomized groups, it was not a typical threat in this trial. A threat to internal validity is loss of data due to dropouts. In this trial 107 patients were enrolled from 125 potential participants (86%). The retention rate was high, with 90% completing the 12-month follow-up for whom we obtained a full set of data. The dropout rate was acceptable and understandable; 11% in the intervention group and 7% in the control group. Dropout was due to moving to another location, death and medical reasons. The trial was not blinded, which constitutes a limitation. Blinding of participants and nurses/rheumatologists was practically impossible, but we were able to ensure that the nurses could not influence recruitment, randomization or data analysis (Lindsay 2004) and did not take part in any aspect of the research process other than the intervention itself. The rheumatologists invited patients who met the inclusion criteria to participate in the trial and those who accepted were randomized to the intervention or control group. The researchers were not involved in the intervention or assessment of the patients. Internal validity can be enhanced through judicious design and analytical decisions. The structure of the nurse-led clinic was designed for the trial, and both the nurses and the rheumatologists adhered to national and international guidelines for management and treatment of biological therapy in
patients with CIA. The main outcome, disease activity, was measured by means of the DAS28 which is the gold standard in Sweden (van Vollenhoven & Askling 2005), Europe (Furst et al. 2012) and North America (Singh et al. 2012). A limitation was the short time perspective (12-month) as a two-year follow-up is ideally to reveal the long-term outcome. Furthermore, data were registered in the SRQ and most of the questionnaires had been previously used for evaluation of biological therapy, thus internal validity was ensured by using standardized and validated instruments.

Reliability

Reliability concerns the accuracy and dependability of information obtained in a trial, i.e. instruments must be stable and consistent over time and the result possible to reproduce using a similar methodology. The stability of an instrument is assessed by a test-retest procedure and internal consistency by whether the sub-sections measure the same information. Equivalence, which is an assessment of the degree to which two or more independent investigators agree about the scoring of the instrument, is also important when studying the reliability of a trial (Polit & Beck 2012). To prevent a threat, the instruments must have good or acceptable reliability and validity. The main outcome, disease activity, was measured by means of the DAS28, a validated instrument (Prevoo et al. 1995), that together with the other used validated instruments HAQ (Bruce & Fries 2003) and VAS pain (Price et al. 1983) are common in daily clinical monitoring of biological therapy in Sweden, Europe and North America. The present trial can be reproduced with similar methodology. All rheumatologists are familiar with the instruments, as are all patients, due to using them at every clinical visit. The main advantage of using a composite measurement is the wider applicability to various patient groups and the smaller sample needed in clinical trials to obtain the same power to detect a difference between groups (van der Heijde & Boyesen 2012).

Objectivity

Objectivity concerns confirmability, which means that the findings from a trial must be derived from the participants and context as opposed to the researchers’ biases, thus making it possible for other researchers to arrive at similar conclusions (Polit & Beck 2012). Objectivity is promoted by the use of standardized instruments that prevent the researcher from influencing the interpretation of results. All participants in both the intervention and the control group answered the questionnaires at the clinic before the monitoring visit at the rheumatologist or the rheumatology nurse as they were accustomed to doing. Data were registered in the SRQ with the exception of level of satisfaction with and confidence in the rheumatology care, thus the trial simulated normal follow-up care of biological therapy, which increases the possibility for an independent researcher to arrive at similar conclusions.
**External validity**

External validity concerns the extent to which evidence from RCT settings can be generalized to real-world clinical practice setting (Polit & Beck 2012). Previous research focusing on conventional therapies indicated that consultation with an expert rheumatology nurse in a drug monitoring clinic may add value in terms of improving patients’ perceived ability to cope with arthritis (Ryan *et al.* 2006b). Implementation of nursing consultations as part of follow-up care in patients with stable RA is recommended (Primdahl *et al.* 2012). This trial included patients with CIA and low disease activity or in remission, which is a broader population than that in previous research, where the majority of participants had been diagnosed with RA. Our trial included patients who exhibited an insufficient response to conventional therapies, thus making biological therapy necessary. If rheumatology nurses receive specialized training to undertake an extended role, we believe that this trial is applicable to monitoring more therapies other than biological and also in a wider population.
Ethical considerations

This research conforms to the ethical principles for medical research on human beings set out in the declaration of Helsinki (WMA 2008) and the national guidelines on ethical principles (Swedish Research Council 2011). The operations manager at the hospital approved the studies. The Local Ethics Committee at Halmstad University, Sweden, issued a guiding statement: (No. 90-2006-2508) (paper I). Permission was obtained from the regional Ethics Committee at Lund University, Sweden for papers II (No. 594/2008), III (No. 2009/245) and IV (No. 2010/283). Paper III was registered at http://clinicaltrials.gov with the identification number NCT01071447. According to the Northern Nurses’ Federation (2003), this thesis fulfils the four requirements on research: information, consent, confidentially and safety of the participants and is guided by the following four ethical principles: autonomy, beneficence, non-maleficence and justice (Northern Nurses’ Federation 2003).

Autonomy

The principle of autonomy is safeguarded by respecting voluntariness, informed consent and the right to withdraw from the research at any time. Autonomy also involves confidentiality. The participants (papers I, II, III and IV) received verbal and written information about the aim of the research, including the fact that participation was voluntary and that they could withdraw from the study at any time without any explanation and with no consequences for their continued care. All participants who agreed to take part provided written informed consent and confidentiality was guaranteed. For reasons of confidentiality, the interviews (papers I, II and IV) were tape-recorded, transcribed verbatim and coded to protect the participants’ identity and the questionnaires (paper III) were coded so as to protect the confidentiality of the participants.

Beneficence

The principle of beneficence or doing good implies that the research should be of potential benefit to the participants or similar groups. All patients invited to participate in the interviews (papers I, II and IV) agreed and several expressed that it was positive to have had the opportunity to talk about the impact of biological therapy on their life situation. When setting up an interventional trial, the hypothesis must be to benefit participants. The hypothesis (paper III) was that the treatment outcomes for the
patients at a nurse-led rheumatology clinic would not be inferior to those obtained by a rheumatologist-led clinic at the 12-month follow-up. The utility of the research lies in improving the quality of care in patients with CIA undergoing biological therapy.

**Non-maleficence**

The principle of non-maleficence or not causing harm implies that the research must not have harmful effects on the participants. Interviews can give rise to emotional or psychological distress. Immediately after the interviews (papers I, II and IV), the participants were given the opportunity to discuss any emotions or thoughts that had emerged with staff who possessed the necessary knowledge to deal with their concerns. The nurses who participated in the trial (paper III) had extensive experience of rheumatic diseases and had on several occasions received education from both a rheumatologist and RA instructors (specially trained patients who instruct healthcare staff about how to examine the joints). In addition, the patients had low disease activity or were in remission, meaning that they had few or no swollen or tender joints.

**Justice**

The principle of justice means that it is the duty of the researcher to protect vulnerable groups, ensure that they are not exploited and that all participants are treated equally, i.e., a control group should not be denied effective treatment. The goal of nursing research is to increase knowledge of the potential for helping all patients. Before the interviews (papers I, II and IV), strategic sampling was carried out to ensure variation, i.e., participants who differed from each other in term of sex, age, civil status, education, duration of disease and duration of biological therapy were asked to participate, in order to contribute variations in experiences of the phenomenon under study. All participants in the RCT (paper III) had the same opportunity to attend the nurse-led rheumatology clinic intervention. The nurses who participated in the trial received education and the participants had stable CIA, low disease activity or were in remission, meaning that they had few or no swollen and tender joints. If necessary, the nurse could contact the rheumatologist for consultation or the participants could be referred to the rheumatologist clinic. The control group received standard care.
Summary of the findings

This thesis explored, described and evaluated rheumatology nursing in patients undergoing biological therapy from a person-centred care perspective with focus on: how patients experienced their dependence on or independence of a rheumatology nurse for the administration of biological intravenous infusions and subcutaneous injections, how a nurse-led rheumatology clinic based on person-centred care could replace a visit to a rheumatologist-led clinic for the monitoring of biological therapy and how patients experienced the nurse-led rheumatology clinic.

Patients’ dependence on a nurse for the administration of their intravenous anti-TNF therapy (paper I)

Three descriptive categories and seven conceptions emerged. Patients experienced that their dependence on a rheumatology nurse for the administration of intravenous anti-TNF therapy afforded security, created involvement and was invigorating. The patients conceived security due to continuity and a competent nurse who provided information that enabled them to manage daily life. The realization that the rheumatology nurse provided care for them, knew and treated them as persons influenced the patients on a personal level and afforded them security. Furthermore, increased well-being was present when the nurse provided individual care. The encounter with a competent and committed rheumatology nurse also created confidence and trust. The sharing of information and experiences with the nurse and fellow patients afforded security. The patients’ experienced that their dependence created involvement. The opportunity to influence the anti-TNF therapy and thus gain the freedom to live without too many restrictions meant that the patients conceived that they were involved in the treatment. The patients described the nurse’s accessibility and flexibility and ability to deal with administration, care and coordination with other health care professionals. This provided a sense of freedom, as the patients did not need to think about their treatment between infusions nor perform the treatment themselves. Dependence on a rheumatology nurse for the administration of intravenous biological therapy invigorates. Relaxation and being encountered in a peaceful environment were necessary prerequisites for gaining new energy in everyday life. The patients experienced the administration of infusion as relaxation and appreciated the opportunity to have some time to themselves, which they considered essential. They emphasized that a peaceful and beautiful environment had a beneficial influence (Table 2).
Table 2. Patients’ dependence on a rheumatology nurse for the administration of intravenous anti-TNF therapy illuminated by means of conceptions and descriptive categories.

<table>
<thead>
<tr>
<th>Conceptions</th>
<th>Descriptive categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encountering continuity</td>
<td>Dependence that affords security</td>
</tr>
<tr>
<td>Encountering competence</td>
<td></td>
</tr>
<tr>
<td>Obtaining information</td>
<td></td>
</tr>
<tr>
<td>Being allowed influence</td>
<td>Dependence that creates involvement</td>
</tr>
<tr>
<td>Being given freedom</td>
<td></td>
</tr>
<tr>
<td>Obtaining relaxation</td>
<td>Dependence that invigorates</td>
</tr>
<tr>
<td>Encountering the environment</td>
<td></td>
</tr>
</tbody>
</table>
Patients’ independence of a nurse for the administration of subcutaneous anti-TNF therapy (paper II)

Four metaphors that facilitated understanding of how patients experienced their independence of a nurse for the administration of subcutaneous anti-TNF therapy emerged: the struggling patient, the learning patient, the participating patient and the independent patient. The struggling patient described being restricted by the injections, preferring the relationship with a rheumatology nurse. In this descriptive category, the conceptions focused on striving for independence. However, injecting medication into their own body and the pain involved gave rise to worry and influenced their motivation. They were willing to administer the subcutaneous injections themselves, as the medication was good, but the discomfort it caused made every injection a struggle between reason and emotion. They worried that they would not inject themselves properly and missed regular contact with a rheumatology nurse. The learning patient experienced that self-administration of subcutaneous injections was a learning process the increased her/his knowledge and competence. In this descriptive category, the conceptions focused on learning as a means of achieving independence. The patients experienced security with this form of treatment, and their independence of others made them grow as human beings. When they needed information, they contacted a nurse and self-administration became a habit and routine. The participating patient experienced control over her/his life by administering the subcutaneous injections themselves. The focus of this descriptive category was patient participation in the form of treatment that provided independence. Participation was interpreted as the opportunity to influence one’s life by taking control of the administration of the injections as well as by complying with instructions. Involvement provided them with security and flexibility both in terms of the treatment and decisions. The independent patients experienced that they could manage their lives and live independently by administering the subcutaneous injections themselves. The conceptions in this descriptive category focused on the freedom provided by self-administration. They stressed that managing the treatment gave them a feeling of freedom, which included independence of other people and not having to plan their lives according to appointments with a nurse. Thus, the patients experienced self-administration as liberating as it led to independence, which is a matter of course for those who do not need regular medication (Figure 3).
Figure 3. Metaphors of how patients experienced their independence of a nurse for the administration of subcutaneous anti-TNF therapy.
A nurse-led rheumatology clinic for monitoring biological therapy (paper III)

In accordance with our hypothesis, treatment outcomes measured by DAS28 in patients with low disease activity or in remission whose biological therapy was monitored at a nurse-led clinic were not inferior to those obtained at a rheumatologist-led clinic at the 12-month follow-up.

Disease activity was assessed by the DAS28 and DAS28-CRP total score. There were no statistically significant differences in changes in the DAS28 (p=0.66) or DAS28-CRP (p=0.70) between the intervention and control group. Within both groups there were small but not clinically relevant deteriorations in the DAS28 score (intervention group 0.14; p=0.19; control group 0.20; p=0.048) between baseline and the 12-month follow-up.

Limitations in performing the activities of daily living were measured by the HAQ. There were no statistically significant (p=0.79) differences in mean change after 12 months in the HAQ or in pain assessed by VAS (p=0.95) between the groups. Nor were there any statistically significant differences between them after 12 months in terms of satisfaction with (p=0.43) and confidence (p=0.42) in obtaining rheumatology care. Within the intervention group and the control group there were no statistically significant mean changes in HAQ, VAS pain, satisfaction with or confidence in obtaining rheumatology care (Table 3).
Table 3. Comparison of mean change after 12 months between and within the intervention group (I.G. = Nurse-led rheumatology clinic) (n=47) and control group (C.G. = Rheumatologist-led clinic) (n=50).

<table>
<thead>
<tr>
<th></th>
<th>I.G. vs. C.G.</th>
<th>I.G. (95% CI)</th>
<th>C.G. (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean difference of change</td>
<td>Mean change</td>
<td>Mean change</td>
</tr>
<tr>
<td>DAS28</td>
<td>-0.06; -0.34; 0.22</td>
<td>0.14; -0.07; 0.34</td>
<td>0.20; 0.00; 0.39</td>
</tr>
<tr>
<td>DAS28-CRP</td>
<td>0.05; -0.28; 0.19</td>
<td>0.14; -0.03; 0.31</td>
<td>0.10; -0.07; 0.26</td>
</tr>
<tr>
<td>ESR (mm/h)</td>
<td>-1.05; -3.97; 1.86</td>
<td>1.09; -0.40; 2.57</td>
<td>2.14; -0.36; 4.64</td>
</tr>
<tr>
<td>CRP (mg/L)</td>
<td>-1.07; -2.02; -0.12</td>
<td>0.13; -0.10; 0.35</td>
<td>1.20; 0.29; 2.10</td>
</tr>
<tr>
<td>Swollen joints</td>
<td>0.13; -2.18; 0.61</td>
<td>0.13; -0.27; 0.53</td>
<td>0.00; -0.29; 0.29</td>
</tr>
<tr>
<td>Tender joints</td>
<td>0.33; -0.47; 1.13</td>
<td>0.47; -0.05; 0.99</td>
<td>0.14; -0.47; 0.75</td>
</tr>
<tr>
<td>VAS GH (mm)</td>
<td>4.29; -2.58; 11.16</td>
<td>2.49; -2.59; 7.56</td>
<td>1.22; -4.02; 6.47</td>
</tr>
<tr>
<td>VAS Pain (mm)</td>
<td>-0.24; -7.89; 7.40</td>
<td>0.98; -4.74; 6.69</td>
<td>1.22; -4.02; 6.47</td>
</tr>
<tr>
<td>HAQ</td>
<td>0.02; -0.10; 0.13</td>
<td>0.04; -0.04; 0.12</td>
<td>0.02; -0.05; 0.10</td>
</tr>
<tr>
<td>NRS Satisfaction</td>
<td>0.25; -0.37; 0.88</td>
<td>-0.19; -0.57; 0.18</td>
<td>-0.44; -0.94; 0.06</td>
</tr>
<tr>
<td>NRS Confidence</td>
<td>0.20; -0.29; 0.69</td>
<td>0.00; -0.22; 0.22</td>
<td>-0.20; -0.63; 0.23</td>
</tr>
</tbody>
</table>

DAS Diseases Activity Score (scale 0-10), ESR Erythrocyte Sedimentation Rate, CRP C-reactive protein, Swollen and Tender joint (28 count), VAS Visual Analogue Scales, VAS GH Global health (scale 0-100 worse to best), VAS Pain (scale 0-100 best to worse), HAQ Health Assessment Questionnaire (0-3 best to worse), NRS Numerical Rating Scale Satisfaction and Confidence (0-10 worse to best).

Independent sample t-test for comparison between and Paired t-test for comparison within the groups.
Patients’ experiences of a nurse-led rheumatology clinic (paper IV)

One theme, three categories and six subcategories emerged. The nurse-led rheumatology clinic, based on person-centred care provided added value due to the patients experiencing security, familiarity and participation. The rheumatology nurse’s competence in assessing disease activity and knowledge of the disease and treatment created a sense of security. The patients perceived that the rheumatology nurse’s care complemented that of the rheumatologist and added a new dimension. The rheumatology nurse did not see the patients as someone with a diagnosis but as a whole human being. For their part, the patients experienced a sense of security by having their life situation highlighted from various perspectives in addition to encountering different professional categories. The patients also described accessibility and flexibility on the part of the rheumatology nurse who was there when they needed help. Familiarity was present when the patients received confirmation. Caring about and taking an interest in the patients’ life situation and seeing them as persons were important for experience of trust. The rheumatology nurse was perceived as being more on the same level and closer to them than the rheumatologist, which contributed to the development of a valuable relationship. Moreover, the rheumatology nurse respected the patients’ integrity and exhibited consideration, which was emphasized as an important piece of the jigsaw puzzle that made the rheumatology care complete. The patients experienced sensitivity in the conversation with the rheumatology nurse and dared open up when the latter listened attentively to details of their illness experience and life situation. The patients experienced participation due to sharing information and experiences with the rheumatology nurse. The nurse–patient encounter represented a learning opportunity for both parties and contributed to patients’ sense of participation. The rheumatology nurse involved them in a dialogue about planning and examination, which led to awareness of the disease and treatment. This dialogue allowed an opportunity for reflection, whereby the patients could analyse and play a more active role in the management of their disease, making them co-actors in the care, which was important for the experience of participation (Table 4).
**Table 4.** An overview of the subcategories, categories and theme that emerged from the qualitative content analysis of patients who attended a nurse-led rheumatology clinic.

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Categories</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients experienced competence</td>
<td>Experiencing security</td>
<td>The nurse-led rheumatology clinic, based on person-centred care provided added value to patient care</td>
</tr>
<tr>
<td>Patients experienced accessibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients experienced confirmation</td>
<td>Experiencing familiarity</td>
<td></td>
</tr>
<tr>
<td>Patients experienced sensitivity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients experienced exchange of information</td>
<td>Experiencing participation</td>
<td></td>
</tr>
<tr>
<td>Patients experienced involvement</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Discussion

This thesis demonstrates the importance of person-centred care in the rheumatology nursing of patients undergoing biological therapy. During illness and treatment, patients constantly have to adapt themselves to new situations and strive to achieve a good life (Bergsten et al. 2011), which lead to balancing and adapting in the whole life situation (Gronning et al. 2011, Ohman et al. 2003). The encounter with the rheumatology nurse who has a person-centred care approach creates a sense of security and familiarity that enables patients to narrate their experience of the illness and how it influences daily life. When patients are seen as capable persons who can narrate about and assume responsibility for their actions, there is participation in care and the patients experience independence. However, in most cases a person is only a patient for a short period of her/his life during which the nurse can play an important role by creating a safe and familiar relationship, as well as opportunities for participation and independence. Person-centred care in rheumatology nursing in patients undergoing biological therapy can be based on the findings of this thesis, namely the concepts of security, familiarity, participation and independence (papers I, II and IV).

Person-centred care creates security

Person-centred care concerns seeing the person behind the illness and requires knowledge of her/his life and needs (Ekman et al. 2011). The participants in the studies in this thesis described how the rheumatology nurse treated them as persons (papers I and IV), confirmed their experiences of illness and was sensitive to their needs. They perceived that the rheumatology nurse’s care complemented that of the rheumatologist and added a new dimension. The rheumatology nurse did not see the patients as someone with a diagnosis but as a whole human being (paper IV). Accessibility and continuity are important tools for enhancing healthcare (Arthur & Clifford 2004b, Bala et al. 2012, Ek et al. 2011). Patients considered the relationship with the rheumatology nurse important, while continuity provides the opportunity to establish a confidential and long-standing relationship (papers I and IV). The rheumatology nurse tends to be more accessible to patients than the rheumatologist and can facilitate access to other team members. On the basis of the nurse accessibility, patients find it easier to discuss professional, sexual or other personal issues with the rheumatology nurse, who can then gain a more complete picture of the patient’s problems. The participants expressed the importance of knowing where to turn when they wanted a heart-to-heart conversation and recognized that the rheumatology nurse saw the entire person.
(papers I and IV). Patients value a holistic assessment (Arvidsson et al. 2006) with quality and continuity in their care (Arvidsson et al. 2006, Temmink et al. 2000). A nurse-led rheumatology clinic that administers and monitors patients’ biological therapy (paper I) and assesses disease activity (paper III) constitutes advanced nursing. The rheumatology nurse’s competence is a vital component in patients’ experience of security. The participants underlined the rheumatology nurse’s medical and technical competence as important factors that contributed an extra dimension in the comprehensive care. Person-centred care and the rheumatology nurse’s holistic view were also valued (papers I, III and IV). Patients who encounter a competent rheumatology nurse are more satisfied than those who receive traditional care (Arthur & Clifford 2004a). The findings of this thesis (paper III) are in accordance with the WHO’s recommendation for the introduction of advanced practice roles for nurses (WHO 2010).

Person-centred care creates familiarity

Person-centred care is a way of seeing patients as a whole person and confirming their experiences of the illness (Edvardsson et al. 2008). In accordance with Ryan et al. (1996), the participants valued the nurse’s holistic approach comprising physical, social, mental and spiritual aspects. They also expressed positive feelings relating to their encounter with the rheumatology nurse and her/his skill that enabled them to feel important and cared for (papers I and IV). Patients experienced being seen and confirmed in the holistic approach of the rheumatology nurse’s care (Ryan et al. 2006a), something that patients who did not meet the rheumatology nurse lacked (paper II). The participants experienced familiarity due to being confirmed by the rheumatology nurse. Nurses, who cared about, took an interest in the patients’ life situation and saw them as persons were important for experiencing trust. In person-centred care, the rheumatology nurse respected the patients’ integrity and exhibited consideration (papers I and IV). Optimal care should focus on the person’s needs and perspectives both in terms of the role and skills of the rheumatology nurse and the way care is organized (Bala et al. 2012). Person-centred care means that the encounter between nurse and patient takes place at an individual level, thus promoting the patients’ self-image and identity (Ternstedt et al. 2012). The nurse’s knowledge of each individual patient contributes to the feeling of familiarity (Larsson et al. 2011). It is also acknowledged that the relationship between the nurse and patient is essential for the experience of familiarity and a way to provide care that is tailored to the person (Ryan et al. 2003). When the care is provided in a calm and secure environment with a person-centred care approach, the opportunity for a good dialogue between the rheumatology nurse and the patient is strengthened (paper I), which finding is supported by Ek et al. (2011). The participants experienced sensitivity in the conversation with the rheumatology nurse and dared open up to her/him, as she/he
listened attentively to their illness experience and life situation. They narrated that it was easier to open up to the rheumatology nurse than to the rheumatologist, especially when they wished to discuss sensitive matters and everyday issues (papers I and IV), which is in accordance with Arvidsson et al. (2006).

**Person-centred care creates participation**

Person-centred care emphasizes the importance of knowing the person behind the patient as a unique person with her/his own will, emotions and needs. Seeing the person means to putting the person before the disease and engaging with the patient as a co-actor in the care by sharing both power and responsibility (Ekman et al. 2011). Important components of person-centred care are supporting the rights, values and beliefs of the person and involving patients in shared decision-making (Edvardsson et al. 2008). Person-centred care is the initiation of a partnership by means of the patients’ narratives, as well as integrating it by sharing information, deliberation and decision-making (Ekman et al. 2011). The participants experienced participation in the administration and monitoring of their biological therapy (papers I, II and IV). The rheumatology nurse has to understand the patients’ situation and see the world from their perspective. Having influence and taking part in decision-making regarding the disease and treatment are important for the experience of participation and making the patients co-actors in the care (papers I, II and IV). A prerequisite for participation is active involvement on the part of both patient and nurse. Partnership and collaboration between patient and nurse is essential for good care (Sahlsten et al. 2007, Sahlsten et al. 2008) in which patients are regarded as co-actors (Larsson et al. 2011). The participants experienced participation despite being dependent on a nurse for the administration of their intravenous biological infusions. The rheumatology nurse’s flexibility led to a sense of being a co-actor. Participation was interpreted as the opportunity to influence one’s life by allowing influencing in planning of the next intravenous infusions and the arrangements for the treatment (paper I), by taking control over the administration of the injections and complying with instructions (paper II). When monitoring biological therapy in the nurse-led rheumatology clinic based on person-centred care (paper III), the rheumatology nurse involved patients in the planning and examination by means of dialogue. This led to awareness of the disease and treatment as well as encouraging them to reflect, whereby the patients had an opportunity to analyse and take a more active role. They became co-actors in the care, which is important for the experience of participation (paper IV). The rheumatology nurse must ensure that patients are co-actors in the care process, whereby they dare to make their own decisions in relation to their disease, treatment and the activities of daily living (Arvidsson et al. 2006). In person-centred care it is important to promote patients’ self-determination (Ternstedt et al. 2012). This thesis
reveals that in person-centred care the role of the nurse has developed from that of an expert advisor to a co-actor, where the patients are necessary and equal participants (Edwards 2002).

**Person-centred care creates independence**

Person-centred care means promoting a good life, which includes making the patient feel valued and respected, thus promoting a sense of power and control (Edvardsson et al. 2008, Ternstedt et al. 2012). The participants in the present thesis experienced that a nurse-led rheumatology clinic added value to patient care due to the rheumatology nurse’s ability to provide confirmation, be sensitive and involve them in the care (paper IV). A central component of person-centred care is the patient and nurse developing a care and treatment plan together, based on each patient’s narrative (Ekman et al. 2011). Despite the fact that the participants were dependent on a nurse for the administration of their intravenous biological infusions, they experienced freedom because they did not have to think about their treatment between nor perform the treatment themselves (paper I). Participants who experienced a positive effect from their subcutaneous biological injections obtained double freedom, due to being able to care for themselves and be independent of a rheumatology nurse (paper II). As in the study by Delmar et al. (2006), the participants did not express any contradiction between independence and dependence. They received person-centred care, and their narratives constituted a vital part of the encounter with the rheumatology nurse. The nurse-led rheumatology clinic based on person-centred care focusing on the whole person proved effective, safe and fruitful (papers III and IV). Person-centred care formed the core of patients’ desire to be independent despite a chronic disease (papers I, II and IV). Independence provides a sense of freedom. The striving for independence is closely linked to the need for support and respect from other people, but also to responsibility and the ability to control treatment and thus everyday life. This need differs between persons (Ingadottir & Halldorsdottir 2008) and therefore person-centred care provides a means of allowing them to experience independence.
Comprehensive understanding

Rheumatology care is based on the individual patient and both pharmacological and non-pharmacological treatment is tailored to her/his need to control the inflammation process and minimize joint damage with the intention of improving physical function. Treatment is guided by guidelines based on mainly objective data such as clinical findings, laboratory analyses and imaging (Furst et al. 2012, Smolen et al. 2010, Vliet Vlieland & Li 2009, Vliet Vlieland & Pattison 2009), which entails a skewed position of power in which patients are told what to do and which form of treatment is appropriate. This approach is changing to a more patient-initiated care (Hewlett et al. 2005b) and the role of the rheumatology nurse has developed and become more holistic (Roussou et al. 2012). The EULAR recommendations for the role of the nurse in the management of CIA states that the rheumatology nurse should promote self-management skills to enable the patients to have a greater sense of control, self-efficacy and empowerment (van Eijk-Hustings et al. 2012). Empowerment is a process that involves the patients in decision-making and action, thus creating a balance of power (Tengland 2008), which in turn requires a person-centred care approach that encourages patients to become co-actors that recognizes their abilities (Morgan & Yoder 2012, Sahlsten et al. 2008). A paradigm shift is taking place in rheumatology nursing and a person-centred care approach is gradually being integrated into daily care routines (Bala et al. 2012).

This thesis describes the importance of person-centred care in rheumatology nursing. When monitoring biological therapy, a nurse-led rheumatology clinic, based on a person-centred care, with a competent and available rheumatology nurse is a secure and familiar base that increases patient participation and independence. A person-centred care approach is based on interdependence between patient and rheumatology nurse. The patients are dependent on the nurse’s professional knowledge about disease and treatment and in some case for administration of intravenous infusions. In order to provide a good and safe care, the rheumatology nurse is, in turn, dependent on the willingness of the patients to share their illness narrative with her/him. Thus, interdependence and an equal relationship between patient and rheumatology nurse are essential for the development of an optimal partnership, which is the goal of person-centred care (Ekman et al. 2011).

Person-centred care is characterized by four underlying concepts; holistic care, individualized care, respectful care and empowering care (Morgan & Yoder 2012). Rheumatology nursing will be further developed by a person-centred care approach.
Figure 4. Person-centred care is the core of rheumatology nursing that creates and strengthens security, familiarity, participation and independence in patients undergoing biological therapy in an ongoing interactive process.

When providing holistic care, the rheumatology nurse sees the patient as a whole person with skills and resources who lives in a personal context. Being seen as a whole person who has expertise creates an encounter between two persons who are experts: the patient on her/his illness and life situation and the rheumatology nurse in her/his profession (Sahlsten et al. 2007). This encounter between two experts leads to a sense of security and familiarity for the patient that enables participation and independence. Respectful care is also a prerequisite for an equal relationship based on mutual respect between patient and rheumatology nurse. When the rheumatology nurse listens sensitively to the patients’ narratives that form the basis of care, it creates a sense of security and familiarity that leads to patient participation and independence. In individualized care based on the person’s resources and needs, the rheumatology nurse works and plans through mutual negotiation with the patient. This mutual negotiation leads to a sense of security and familiarity and promotes patient participation and independence (Sahlsten et al. 2007). Empowering care is intended to increase the patients’ capacity to think critically and make independent and well considered care decisions. The rheumatology nurse should facilitate and assist patients to use their own
innate ability to gain control over their life situation (Anderson & Funnell 2010, Hill & Hale 2004). Furthermore, empowering care means creating a partnership between patient and rheumatology nurse due to the rheumatology nurse's involvement, invitation to dialogue and exchange of information and experience with the patient. For their part, patients become co-actors and experience a sense of security and familiarity, leading to participation and independence.

Patients’ experience of security is closely related to that of familiarity. Security and familiarity interact and increase in person-centred care. When patients experience security and familiarity in their care, they become empowered to participate in it, which in turn enhances their sense of independence. Furthermore, participation and independence interact and are strengthened, leading to security and familiarity. This is an ongoing process in which person-centred care is the core that generates positive interaction. This thesis demonstrates that person-centred care is essential in rheumatology nursing, as it creates and strengthens security, familiarity, participation and independence in patients undergoing biological therapy (Figure 4).
Conclusions

The conclusions of this thesis are:

- Patients undergoing intravenous biological therapy conceived regular contact with a rheumatology nurse as invigorating, as well as providing security and involvement (paper I).

- Patients undergoing biological therapy valued being seen as a person by the rheumatology nurse (papers I and IV).

- Patients undergoing subcutaneous biological therapy struggled to participate and achieve independence in their life (paper II).

- Rheumatology nurses can support patients undergoing biological therapy in their struggle for participation and independence (papers I, II and IV).

- Rheumatology nurses can monitor biological therapy in patients with stable CIA with comparable safety and effectiveness as a rheumatologist (paper III).

- Rheumatology follow-up care of patients undergoing biological therapy could be improved by a nurse-led rheumatology clinic based on person-centred care as a complement to a rheumatologist-led clinic (papers III and IV).

- Patients undergoing biological therapy experienced that a nurse-led rheumatology clinic based on person-centred care provided added value and led to a sense of security, familiarity and participation (paper IV).

- Person-centred care is the core of rheumatology nursing and creates security, familiarity, participation and independence in patients undergoing biological therapy.

- Person-centred care leads to an equal relationship between patient and rheumatology nurse that strengthens security, familiarity, participation and independence in patients undergoing biological therapy in an ongoing interactive process.

- Rheumatology nursing will be further developed with a person-centred care approach. This thesis supports the implementation of person-centred care in rheumatology nursing in patients undergoing biological therapy.
Clinical and research implications

When caring for patients with CIA undergoing biological therapy in clinical practice, it is important to see every patient as a unique person. This means giving patients the opportunity to talk about themselves as a person and allowing their illness narrative to constitute a starting point for collaboration. Person-centred care is essential as a nursing philosophy as well as an approach to providing rheumatology nursing care. Person-centred care emphasizes the importance of knowing the person behind the patient and treating her/him as a unique person with her/his own will, emotions, needs and resources, who is an expert on her/his illness and life situation. In clinical care it is important to enhance the quality of the dialogue in the mutual negotiation between the two persons who are experts. Future research should evaluate person-centred care from the perspectives of both health care professionals and patients using validated instruments.

Due to the lack of time and money in clinical practice it is important to involve patients in their care and use their resources in the best possible way. A nurse-led rheumatology clinic based on person-centred care is one way of achieving this objective. Person-centred care is designed to encourage and empower patients to play an active role in their care and treatment as co-actors. A rheumatology nurse, who employs a person-centred care approach can be a key to reducing costs without affecting quality of care. A nurse-led rheumatology clinic can save money and will enable rheumatologist to prioritize and allocate more time to patients in the early stages of the disease or who have high disease activity and require more frequent monitoring or changes in medication. The cost-effectiveness of replacing rheumatologists with rheumatology nurses for the monitoring of biological therapy in patients with low disease activity or in remission should be evaluated. Such an evaluation should mainly focus on health related quality of life and the cost-effectiveness of a nurse-led rheumatology clinic for monitoring biological therapy in patients with stable CIA. Future research needs to evaluate the long-term effect and cost-effectiveness of nurse-led rheumatology clinics in monitoring therapies in patients with CIA.
For patients with CIA and biological therapy, life is often characterized by a constant routine of assessment, administration, management and monitoring of both the disease and the biological therapy. It is important to have a competent and available rheumatology nurse to guide the patients during their healthcare journey. Patients have confidence in the rheumatology nurse’s competencies and skills in management of biological therapy and appreciate being treated and monitored by a rheumatology nurse. The rheumatology nurse’s role is to tailor the information and care based on the patients’ resources and needs. In a person-centred care approach, the rheumatology nurse respects and supports the patients’ skills and resources. To achieve this, the rheumatology nurse’s role is being constantly developed. It would be desirable to implement person-centred care in which two equal experts meet in mutual negotiation. Rheumatology nurses should be encouraged to expand their roles after their specialized education and training in order to complement rheumatologists and other professionals in the multidisciplinary team. Further research is necessary to develop and evaluate a core curriculum comprising educational nursing programmes at basic and advanced level for rheumatology nurses.
Summary in Swedish/
Svensk sammanfattning

Personcentrerad vård i reumatologisk omvårdnad för patienter med biologisk läkemedelsbehandling:
En utforskande och interventionell studie

Bakgrund

Patienter med kronisk inflammatorisk artrit (CIA) behandlande med biologiska läkemedel


blockerar specifika inflammatoriska cytokiner och celler i ledvätska och immunsystem och därmed hämmar sjukdomen. Biologisk läkemedelsbehandling har förändrat behandlingsmöjligheterna och blir allt vanligare för patienter med CIA (Buch & Emery 2011, Furst et al. 2012), vilket resulterat i minskad sjukdomsaktivitet och inflammation under det senaste decenniet hos denna patientgrupp (Simard et al. 2011). De biologiska läkemedlen administreras antingen genom subkutana injektioner av patienterna själva eller genom intravenösa infusioner givna av en sjuksköterska (Tracey et al. 2008).

Reumatologisk omvårdnad
Personcentrerad vård


Holistisk vård


Respektfull vård

En respektfull vård erkänner och respekterar varje persons egenvärde och lyfter personens styrkor och förmågor samt uppmuntrar mänsklig frihet. Varje person har rätt att behandlas med respekt och ses som kompetent att fatta egna beslut angående sin vård. För att ge respektfull vård behöver sjuksköterskan respektera personens val i olika sammanhang (Morgan & Yoder 2012). Respektfull vård respekterar också personens autonomi, värdighet och integritet och bör baseras på respekt för hela personens rättigheter, inte bara som en patient i behov av vård (Slater 2006). Detta etiska förhållningssätt utgör ett ramverk inom vilket sjuksköterskan skapar en dialog och en relation med personer som behöver vård (Berg & Sarvimaki 2003).

Individanpassad vård

Personstärkande vård


Personcentrerad vård i klinisk verksamhet

I denna avhandling ses patienter som personer med en sjukdom och med en personcentrerad vård är det viktigt att lära känna personen bakom patienten. Eftersom personerna enbart har en relation till sjuksköterskan när de är i behov av vård kommer de att kallas patienter i denna avhandling.


Syfte

Det övergripande syftet med denna avhandling var att utforska och utvärdera den reumatologiska omvårdnaden utifrån ett personcentrerat perspektiv för patienter med biologisk läkemedelsbehandling.
**Metod**

Studierna i denna avhandling genomfördes vid en reumatolog klinik i södra Sverige med 5 500 öppenvårdsbesök årligen och 3 500 patienter, varav 600 patienter med biologisk läkemedelsbehandling. De biologiska läkemedelsbehandlingarna administreras antingen genom intravenösa infusioner eller genom subkutana injektioner. De intravenösa infusionerna administreras av sjuksköterskor på en behandlingsenhet. Patienter med CIA och biologisk läkemedelsbehandling ingick i studierna och datainsamlingen skedde mellan år 2007-2011. I denna avhandling som har en utforskande och interventionell design kombineras både kvalitativa (artikel I, II och IV) och kvantitativa (artikel III) metoder.

**Resultat**

Avhandlingen utforskar, beskriver och utvärderar reumatologisk omvårdnad för patienter med biologisk läkemedelsbehandling från ett personcentrerat perspektiv med fokus på hur patienter uppfattade sitt beroende eller oberoende av sjuksköterskan vid administration av biologiska intravenösa infusioner och subkutana injektioner, hur en sjuksköterskeledd reumatologimottagning baserad på personcentrerad vård kan ersätta besök på en reumatologmottagning vid monitorering av biologisk läkemedelsbehandling och hur patienter erfor den sjuksköterskeledda reumatologimottagningen.

**Patienters beroende av en sjuksköterska för administration av intravenöös anti-TNF behandling (artikel I)**


Resultatet visade att patienterna uppfattade att beroendet av en sjuksköterska vid administrering av intravenös anti-TNF behandling gav trygghet, skapade delaktighet och var energigivande. Patienterna erfor en trygghet genom kontinuitet med en kompetent sjuksköterska som försag patienterna med information, vilket underlättade det dagliga livet. Insikten att sjuksköterskan behandlade dem som personer och hade ett genuint intresse av den enskilde påverkade patienterna på ett personligt plan. De beskrev att den individuellt utformade vården ökade deras välbefinnande och gav en trygghet. Mötet med en kompetent och engagerad sjuksköterska skapade förtroende och tillit. Informations- och erfarenhetsutbytet med sjuksköterskan och andra patienter gav även

**Patienters oberoende av en sjuksköterska för administration av subkutan anti-TNF behandling (artikel II)**

Syftet med studien var att beskriva variationer i hur patienter med reumatiska sjukdomar uppfattar sitt oberoende av en sjuksköterska för administrering av subkutan anti-TNF behandling. Deltagarna bestod av 20 patienter med CIA behandlade med biologiska subcutana injektioner. Datainsamlingen skedde med öppna intervjuer och frågor angående patienternas uppfattningar av oberoendet av en sjuksköterska för administrering av läkemedel. Intervjuerna skrevs ut ordagrant och analyserades i olika steg med en fenomenografisk ansats (Larsson & Holmström 2007).

En sjuksköterskeledd reumatologimottagning för monitorering av biologisk läkemedelsbehandling (artikel III)


Resultatet visade i enlighet med vår hypotes att efter 12 månader var det ingen skillnad i förändring i sjukdomsaktivitet, DAS28 eller i de andra utfallsmåtten mellan patienter som monitorerades via en sjuksköterskeledd mottagning eller via en reumatologmottagning. Patienter med biologisk läkemedelsbehandling som är lågaktiva eller i remission kan monitoreras säkert och effektivt av en sjuksköterska.

Patienters erfarenheter av en sjuksköterskeledd reumatologimottagning (artikel IV)

Övergripande förståelse


I en individanpassad vård där personens resurser och behov utgör grunden för sjuksköterskans arbete och vårdplanering sker en ömsesidig förhandling. Den ömsesidiga förhandlingen mellan sjuksköterska och patient leder till en känsla av trygghet och förtrogenhet samt främjar delaktighet och oberoende (Sahlsten et al. 2007). En personstärkande vård syftar till att öka patientens kapacitet och kritiska tänkande för att kunna ta självständiga och genomtänkta beslut i vården. Sjuksköterskan kan genom att vara engagerad och inbjudna till dialog samt informations- och erfarenhetsutbyte bidra till att patienten blir en medaktör. Som medaktör erfar patienter en känsla av trygghet och förtrogenhet som även leder till delaktighet och oberoende i vården.

Patienters trygghet och känsla av förtrogenhet samverkar och ökar med en personcentrerad vård. När patienter erfar trygghet och förtrogenhet stärks patienter till delaktighet i vården, vilket i sin tur ökar oberoendet. Delaktighet och oberoende samverkar och ökar med en personcentrerad vård. När patienter erfar delaktighet och oberoende i vården blir de trygga och känner en förtrogenhet. Detta är en pågående process där personcentrerad vård är kärnan som bidrar till en positiv samverkan (Figur 5). Denna avhandling visar att personcentrerad vård är kärnan i reumatologisk omvårdnad som skapar trygghet, förtrogenhet, delaktighet och oberoende för patienter med biologisk läkemedelsbehandling.
Slutsatser

Slutsatserna från denna avhandling är:

- Patienter med intravenös biologisk läkemedelsbehandling uppfattar en regelbunden kontakt med sjuksköterskan som trygg, delaktig och energigivande (artikel I).
- Patienter med biologisk läkemedelsbehandling värdesätter att bli sedda som en unik person av sjuksköterskan (artikel I och IV).
- Patienter med subkutan biologisk läkemedelsbehandling kämpar för att bli delaktiga och uppnå oberoende i livet (artikel II).
- Sjuksköterskor kan underlätta för patienter med biologisk läkemedelsbehandling i deras strävan efter delaktighet och oberoende (artikel I, II och IV).
- Patienter med biologisk läkemedelsbehandling som är lågaktiva eller i remission kan monitoreras säkert och effektivt av en sjuksköterska (artikel III).
- Uppföljning av patienter med biologisk läkemedelsbehandling kan utvecklas genom en sjuksköterskeledd mottagning baserad på personcentrerad vård och vara ett komplement till en reumatologmottagning (artikel III och IV).
- Patienter med biologisk läkemedelsbehandling erfar att en sjuksköterskeledd mottagning baserad på personcentrerad vård tillför ett mervärde i vården och skapar trygghet, förtrogenhet och delaktighet (artikel IV).
- Personcentrerad vård är kärnan i reumatologisk omvårdnad och skapar trygghet, förtrogenhet, delaktighet och oberoende för patienter med biologisk läkemedelsbehandling.
- Personcentrerad vård leder till en jämbördig relation mellan patient och sjuksköterska som stärker trygghet, förtrogenhet, delaktighet och oberoende för patienter med biologisk läkemedelsbehandling i en pågående interaktiv process.
- Reumatologisk omvårdnad kan utvecklas med personcentrerad vård. Denna avhandling stöder införandet av personcentrerad vård i reumatologisk omvårdnad för patienter med biologisk läkemedelsbehandling.
**Kliniska implikationer och forskningsimplikationer**

I den kliniska vården av patienter med CIA och biologisk läkemedelsbehandling är det viktigt att se varje patient som en individuell person. Detta betyder att patienter får möjlighet att berätta om sig själva som personer och att låta deras sjukdomsberättelse utgöra grunden för vården. I reumatologisk omvårdnad är det viktigt att ha en personcentrerad vård som en omvårdnadsfilosofi och ett arbetssätt. Personcentrerad vård betonar vikten av att lära känna personen bakom patienten, en unik person med egen vilja, känslor, behov och resurser, en expert på sin sjukdom och livsituation. I klinisk vård är det viktigt att det blir en dialog och en ömsesidig förhandling mellan två experter: patient och vårdpersonal. Ytterligare forskning behövs för att utvärdera personcentrerad vård med validerade instrument från både patienters och vårdpersonals perspektiv.

När tid och pengar tenderar att bli en bristvara i vården är det viktigt att göra patienter delaktiga i sin vård och använda resurserna på bästa sätt. Ett sätt att minska kostnaderna utan att påverka kvaliteten i vården kan vara att inrätta sjuksköterskeledda mottagningar baserade på personcentrerad vård, vilka syftar till att främja och stärka patienter att ta aktiv del i vård och behandling. En sjuksköterskeledd mottagning kan spara pengar och ge ökade resurser för reumatologer att prioritera och avsätta tid till patienter med nydebuterad sjukdom eller hög sjukdomsaktivitet, vilka kräver tätare kontroller eller medicinjusteringar. Kostnadseffektiviteten med att ersätta reumatologer med sjuksköterskor vid monitorering av biologisk läkemedelsbehandling för patienter med låg sjukdomsaktivitet eller i remission bör utvärderas. Ytterligare forskning behövs för att utvärdera de långsiktiga effekterna och kostnadseffektiviteten av en sjuksköterskeledd mottagning i monitorering av olika behandlingar för patienter med CIA.

För patienter med CIA och biologisk läkemedelsbehandling är livet ofta kantat av bedömningar, administration, behandling och monitorering av både sjukdom och biologiskt läkemedel. Det är viktigt med en kompetent och tillgänglig sjuksköterska för att vägleda patienter i vården. Vid biologisk läkemedelsbehandling har patienter stort förtroende för sjuksköterskans kompetens och färdigheter samt uppskattar att bli behandlad och monitorerad av en sjuksköterska. Sjuksköterskans roll är att individuanta information och vård utifrån patienternas egna resurser och behov. Inom reumatologin är sjuksköterskans roll under ständig förändring och utveckling. Sjuksköterskor bör uppmuntras till vidareutbildning samt att utvidga sin roll i att vara ett komplement till reumatologer och övriga professioner i teamet. Ytterligare forskning behövs för att utveckla och utvärdera utbildningsprogram för att öka sjuksköterskans kompetens.
References


