Person-centred care and preferred outcomes in early rheumatoid arthritis — the patients' perspective

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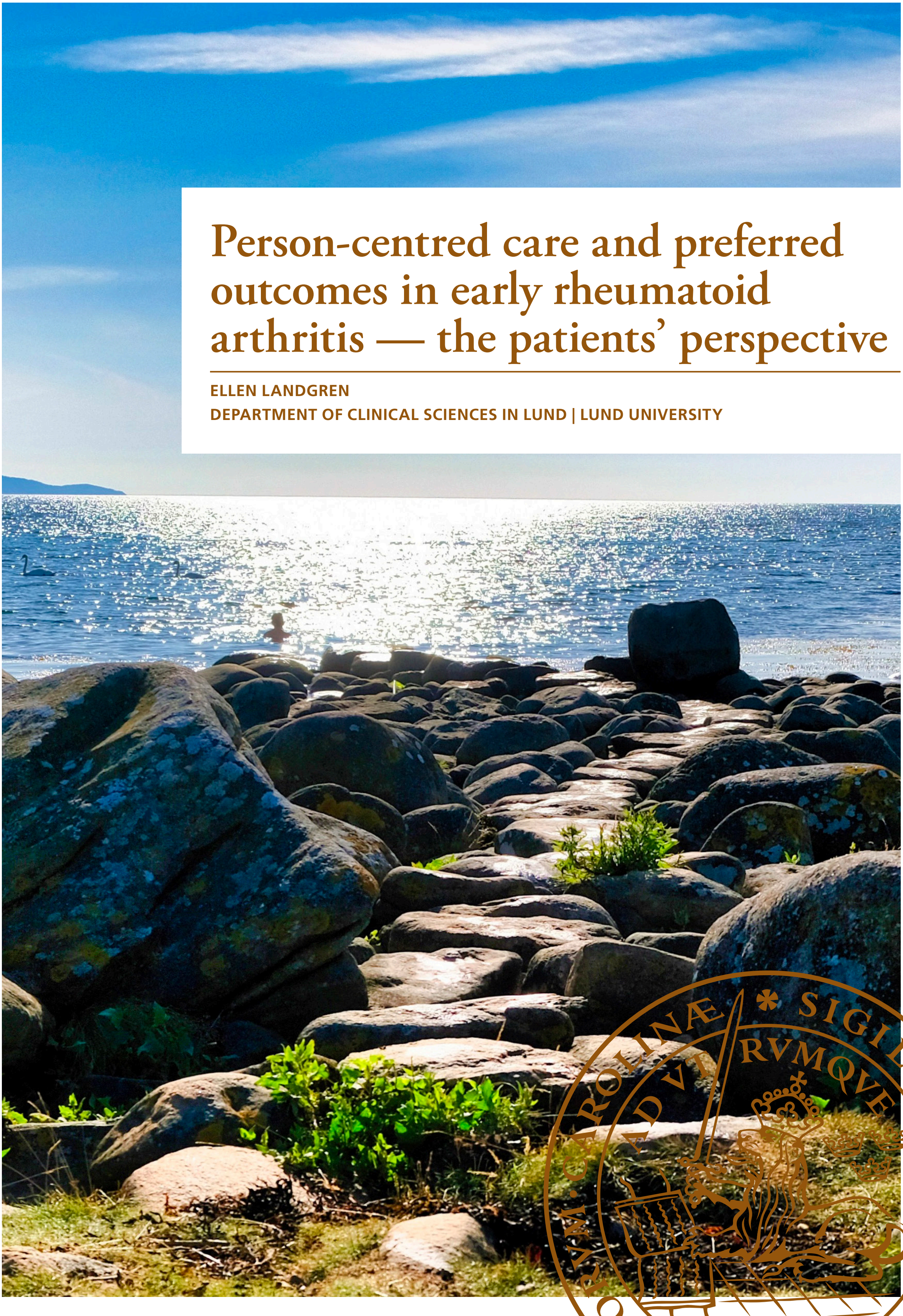

Person-centred care and preferred outcomes in early rheumatoid arthritis — the patients' perspective

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Person-centred care and preferred outcomes in early rheumatoid arthritis —the patients' perspective

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LUND
UNIVERSITY

DOCTORAL DISSERTATION

by due permission of the Faculty of Medicine, Lund University, Sweden.
To be defended at Lottasalen, Department of Rheumatology, Lund
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Faculty opponent
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Abstract: Rheumatoid arthritis (RA) is a chronic, systemic, inflammatory joint disease that affects all aspects of life. Rheumatology care strives to achieve optimal health based on person-centred care (PCC). Effective treatment is available, but patients still experience unmet needs.

Aims: The overall aim of this thesis was to explore patients' perspectives of PCC and preferred outcomes in early RA. Specific aims: to explore patients' perceptions of PCC (**I**), to describe the understanding of health among patients (**II**), to explore patients' preferred treatment outcomes during their first two years with RA, in a Swedish context (**III**), and to explore preferred treatment outcomes and how these preferences change throughout the early disease stage across three European countries (**IV**).

Methods: Individual interviews were performed and analysed using abductive qualitative content analysis (**I**) and a phenomenographic approach (**II**). In papers **III-IV**, a longitudinal, multicentre study including individual and focus group interviews was performed and analyzed using Qualitative Analysis Guide of Leuven (QUAGOL) (**III**). The meta-synthesis was inspired by meta-ethnography and QUAGOL (**IV**).

Results: PCC includes to meet professional competence, access to care, support and involvement in care, and to be satisfied and achieve optimal health (**I**). Health was understood as belonging, happiness, freedom, and empowerment (**II**). The core preferred treatment outcome were "mastering a new life situation" through disease control, autonomy, regained identity, and joy (**III**). From a European perspective, it was to "live a normal life" through disease control, physical performance, self-accomplishment, and well-being (**IV**).

Conclusions: PCC includes meeting supportive, dedicated, and professional healthcare professionals, easy access to care, and the ability to be involved in decision-making. Three key aspects were highlighted regarding preferred outcomes: independence, empowerment and well-being. Independence implies a meaningful life and a sense of freedom, empowerment reflects patient's ability to engage in self-management, and well-being encompasses the broader spectrum of physical, mental and social health; which ultimately captures the holistic benefits of a person-centred approach.

Keywords: Focus groups, health, interviews, longitudinal, meta-synthesis, patient perspective, patient-preferred outcomes, patient-centered care, person-centered care, qualitative research, rheumatoid arthritis
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Not everything that counts can be counted,
and not everything that can be counted counts.

William Bruce Cameron

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Methods: Abductive qualitative content analysis based on the theoretical framework for PCC by McCormack and McCance. Interviews with 31 patients with early RA.

Conclusion: Respectful, encouraging, professional and accessible PCC is important for patients early in the disease course, supporting the implementation of a person-centred approach through all stages of the healthcare system. The results highlight the importance of patient involvement in care, which may lead to better treatment and health outcomes.

Overview of patients' perceptions of person-centred care within the framework from McCormack and McCance (2006). Published in Landgren et al. (2021).

Categories	Prerequisites	The care environment	Person-centred processes	Person-centred outcomes
Sub-categories	Being treated with respect	Having access to a multidisciplinary team	Being listened to	Being satisfied with received healthcare
	Meeting dedicated healthcare professionals	Having access to healthcare	Being supported	Achieving optimal health
	Meeting professional competence	Encountering a supportive organisation	Being involved in decision-making	

Paper II. Belonging, happiness, freedom, and empowerment—patients' understanding of health in early rheumatoid arthritis, a qualitative study

Aim: To describe the understanding of health among patients with early RA.

Methods: Descriptive qualitative design with a phenomenographic approach. Individual semi-structured interviews with 31 patients with early RA.

Conclusion: Health was understood as belonging, happiness, freedom, and empowerment. The results showed that patients' understanding of health is both individual and diverse, and this diversity must be considered in PCC.

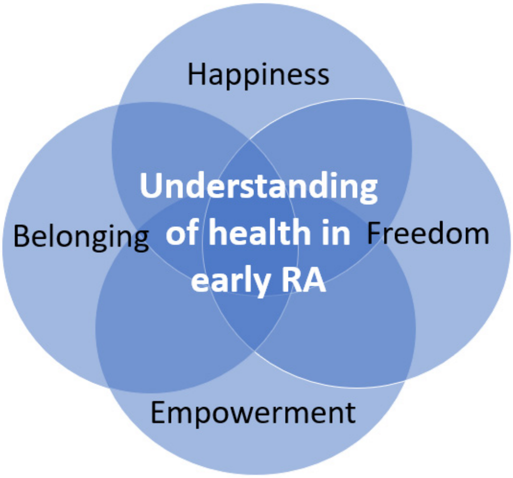


Illustration of patients' understanding of health in early RA and the relationship between the aspects.

Paper III. “Mastering a New Life Situation”—Patients’ Preferences of Treatment Outcomes in Early Rheumatoid Arthritis—A Longitudinal Qualitative Study

Aim: To explore patients’ preferred treatment outcomes during their first two years with RA.

Methods: A qualitative, longitudinal, multicentre study in Sweden. Interviews were performed at two timepoints (31 and 22 patients, respectively), either as individual or focus-group interviews, with patients with early RA. Interviews were analysed using the Qualitative Analysis Guide of Leuven (QUAGOL) and guided by Saldaña’s 16 steps for interpreting change in longitudinal data.

Conclusion: Patients wanted to master their new life situation and their preferences changed from wanting to return to a life lived prior to disease, to increased preferences of self-management and empowerment to master the new life situation and living with quality of life, despite RA. The results can help healthcare professionals to understand the dynamic process of patients’ preferred treatment outcomes early in the disease course to prevent the development of unmet needs, increase patient satisfaction, and improve quality of care.

Overview of patient-preferred outcomes in early RA. Published in Landgren et al. (2020).

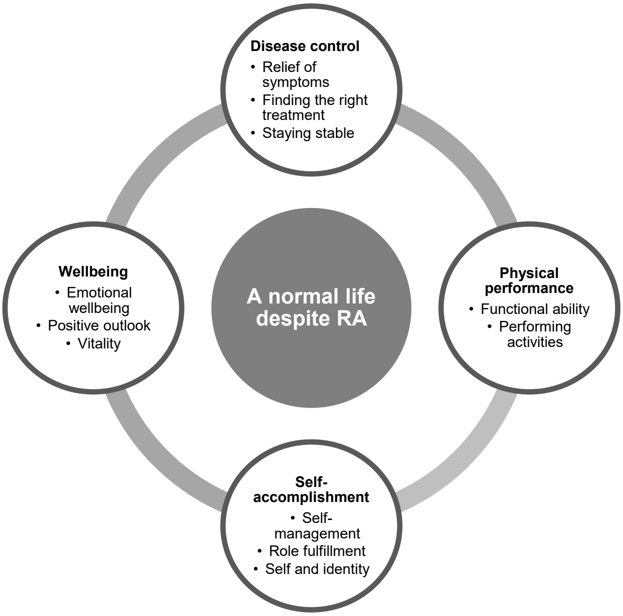
Core category	**Mastering a new life situation**			
Concepts	Experiencing control of the disease	Experiencing autonomy	Regaining identity	Experiencing joy in everyday life
Sub-concepts	Controlling the symptoms	Regaining former activity levels	Being able to participate	Experiencing vitality
	Experiencing absence of disease	Experiencing independence	Experiencing well-being	Believing in the future
		Being empowered	Regaining former self-image	

Paper IV. What do patients prefer? A multinational, longitudinal, qualitative study on patient-preferred treatment outcomes in early rheumatoid arthritis.

Aim: To explore treatment outcomes preferred by patients with early RA and how these change throughout the early disease stage across three European countries.

Methods: A longitudinal, qualitative interview study (n=80) was conducted in Sweden, Belgium, and the Netherlands. Data analysed by each country (paper III), were included in a meta-synthesis, inspired by the principles of meta-ethnography and the QUAGOL, performed by all the local research teams.

Conclusion: An overarching patient-preferred outcome across countries was to live a "normal life despite RA". Patients in Sweden, Belgium, and the Netherlands had many similarities in terms of which outcomes they preferred, while some preferences developed differently. The results can help healthcare professionals to understand what really matters to patients and implement PCC starting at treatment initiation.



A multinational perspective on patient-preferred treatment outcomes in early rheumatoid arthritis (RA), including an overarching theme, 4 main themes, and 11 subthemes. Published in Van der Elst et al. (2020).

List of papers

Paper I

Landgren, E., Bremander, A., Lindqvist, E., Nylander, M., & Larsson, I. (2021). Patients' Perceptions of Person-Centered Care in Early Rheumatoid Arthritis: A Qualitative Study. ACR Open Rheumatology, 3(11), 788–795. https://doi.org/10.1002/acr2.11326

Paper II

Landgren, E., Mogard, E., Bremander, A., Lindqvist, E., Nylander, M., & Larsson, I. Belonging, happiness, freedom and empowerment—patients' understanding of health in early rheumatoid arthritis, a qualitative study (in manuscript).

Paper III

Landgren, E., Bremander, A., Lindqvist, E., Nylander, M., Van der Elst, K., & Larsson, I. (2020). "Mastering a New Life Situation"—Patients' Preferences of Treatment Outcomes in Early Rheumatoid Arthritis—A Longitudinal Qualitative Study. Patient Preference & Adherence, 14, 1421–1433. https://doi.org/10.2147/PPA.S253507

Paper IV

Van der Elst, K., Mathijssen, E., **Landgren, E.**, Bremander, A., De Groef, A., Lindqvist, E., Nylander, M., Peters, A., Van den Hoogen, F., van Eijk-Hustings, Y., Verhoeven, G., Vriezekolk, J. E., Westhovens, R., & Larsson, I. (2020). What do patients prefer? A multinational, longitudinal, qualitative study on patient-preferred treatment outcomes in early rheumatoid arthritis. RMD open, 6(2), e001339. https://doi.org/10.1136/rmdopen-2020-001339

Abbreviations

ACPA	anti-citrullinated protein antigens
ACR	American College of Rheumatology
DMARDs	Disease Modifying Anti-Rheumatic Drugs
EULAR	European Alliance of Associations for Rheumatology (formerly the European League Against Rheumatism)
EQPERA	European Qualitative research project on Patient-preferred outcomes in Early Rheumatoid Arthritis
PCC	person-centred care
QUAGOL	Qualitative Analysis Guide of Leuven
RA	Rheumatoid Arthritis
RF	Rheumatoid Factor

Preface

My first encounter with rheumatology care was during my last year of nursing school in 2013. I did not know then about the many diagnoses and the wide spectrum of treatments within team-based rheumatology care, as I do now. I became a registered nurse in 2014, and have been working at the rheumatology clinic in Lund ever since. When I first started working at the inpatient unit, I was truly impressed by the teamwork provided by the healthcare professionals. Every day we had rounds, where each profession was able to offer their point of view regarding patients' challenges and personal needs. The clinic aims to offer person-centred team-based care—beyond the physician–nurse relationship I was accustomed to from other clinics. I was also impressed by patients' ability to handle seemingly difficult situations when the disease had led to physical disabilities. It was an eye opener to see the interaction between patients and healthcare professionals offering person-centred support intended to increase patients' ability to self-manage their disease.

Early on, I felt I wanted to educate myself and gain more knowledge, and in 2018 I earned a master's degree in social science with a major in health and lifestyle. I have been a doctoral student at the Faculty of Medicine at Lund University since 2019. During my master's and doctoral studies, I have had the opportunity to be involved in a research project within my area of interest; studies that focus on patients' experiences and preferences, with the aim of further developing rheumatology care. I hope my research will contribute to enhanced knowledge that can be useful in clinical practice to maintain and improve health and well-being among patients with rheumatic diseases.

Introduction

Being diagnosed with rheumatoid arthritis (RA) can be a life-changing experience. RA is a chronic disease with bothersome symptoms like tender and swollen joints, morning stiffness, and fatigue, and has a great impact on everyday life, such as work, family life, and leisure (Scott et al., 2010). It entails many examinations at the hospital, including blood tests and sometimes injections or infusions. Over the last few decades, avaible pharmacological treatment has drastically improved the prognosis and treatment outcomes of RA. Research has shown the importance of early treatment and a tight control regimen, as this has improved results drastically (Aletaha & Smolen, 2018). The purpose of early treatment and tight control is to suppress the disease, slow the progression of joint damage, and prevent irreversible disability. The ultimate goal is to achieve remission and improve patients' quality of life (Aletaha & Smolen, 2018). Nevertheless, pharmacological and non-pharmacological treatment alone does not enable a good and healthy life. Each person is responsible for treating themselves. Many patients are only at the clinic a couple of times a year—the rest of the time, they must self-manage their disease by taking medication, managing upcoming symptoms and flares, and learning how to live with a chronic disease such as RA.

Rheumatological care aims to provide the best care and optimal health for the patients (Smolen, 2020) and should be based on person-centred care (PCC) (Bech et al., 2020). Healthcare professionals are experts on the disease and its treatment, while patients are experts on living with the disease. Patients and healthcare professionals must work together to get the best possible results. To improve treatment and health outcomes, it is necessary to involve patients in treatment decisions and in the development of care plans by using shared decision-making (Nikiphorou et al., 2021; Smolen et al., 2023). Accordingly, it is valuable to explore patients' experiences, beliefs and values. This thesis is based on qualitative data to understand patients' perspectives in the early phase of the disease, which is important information for healthcare professionals working with these patients.

Background

Rheumatoid arthritis

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease and affects approximately 0.5–1% of adults in Europe and North America (Aletaha & Smolen, 2018). The disease predominantly affects women, 2–3 times more often than men, and can debut at any age, but the median age of diagnosis is around 60 years. The cause of RA is unknown, but genetic and environmental factors contribute to disease onset (Aletaha & Smolen, 2018). The most established risk factors for developing the disease are smoking and having a family history of RA (Di Matteo et al., 2023; Lin et al., 2020). Disease progression involves initiation and propagation of autoimmunity against modified self-proteins, which can occur years before the onset of clinical symptoms, and antibodies such as rheumatoid factor (RF) and anti-citrullinated protein antigens (ACPA) may occur. The presence of ACPA and RF is associated with a more aggressive disease course, and can be used as diagnostic and prognostic markers (Smolen et al., 2018).

Symmetric polyarticular symptoms of the joints in the hands and feet are typical in RA. Large joints such as shoulders, elbows, knees, and ankles can also be involved. Typical symptoms are morning stiffness lasting more than 30 minutes and pain and swelling of the joints (Aletaha & Smolen, 2018). The inflammation causes pain and limits movement, and with disease progression, structural damage can cause loss of joint function. Insufficiently treated RA may lead to extra-articular manifestations, such as rheumatoid nodules and vasculitis. In addition, patients with RA have an increased risk of cardiovascular disease possibly due to the consequences of chronic inflammation (Aletaha & Smolen, 2018).

Diagnostic and classification criteria of RA

Due to the variety of the symptoms, and since no single symptom is specific to RA, no diagnostic criteria exist. An RA diagnosis is based on a combination of typical symptoms, signs, and serology, and ~70% are ACPA positive (Smolen et al., 2018).

Classification criteria, developed primarily for clinical studies, may help physicians establish a diagnosis. Current classification criteria are defined by the American College of Rheumatology (ACR) and the European Alliance of Associations for Rheumatology (EULAR) (formerly the European League Against Rheumatism) (Aletaha et al., 2010). According to these criteria, a diagnosis of RA requires the presence of at least one clinically swollen joint which cannot be clearly explained by another disease, and at least six out of ten points of a scoring system regarding a patient's serology and the duration of their symptoms (Aletaha et al., 2010).

Early rheumatoid arthritis

There is no distinct criterion for early RA. Historically, early RA was defined as less than five years of disease (Scott, 2007). Due to treatment development, this timespan has decreased. In the 1980s, Lund's early RA cohort included patients with symptom duration up to 24 months after disease onset (Lindqvist et al., 2002), while studies from the 1990s used 12 months from disease onset (Andersson et al., 2015; Innala et al., 2016; Thyberg et al., 2005). Now several early-RA cohorts define early RA as six months from the onset of symptoms (Funovits et al., 2010; Singh et al., 2016), and in this thesis, early RA is defined as disease duration ≤1 year.

Treatment and prognosis

The development of treatment over the last three decades has considerably improved outcomes and prognosis for RA patients. Even though RA is a chronic disease with historically disabling consequences, modern pharmacological therapy offers disease control with the aim of sustained remission. Non-steroidal anti-inflammatory drugs (NSAID) and painkillers can be adjunctive treatments but are only symptomatic and do not prevent progression of structural damage and irreversible disability. Disease Modifying Anti-Rheumatic Drugs (DMARDs) are pharmacological drugs that can diminish inflammation, inhibit progression of joint damage, and improve physical function. DMARDs are grouped into conventional and targeted synthetic and biological agents. Conventional synthetic DMARDs have unspecific targets—in contrast to targeted synthetic DMARDs, which interfere with a specific molecule (Aletaha & Smolen, 2018). The overall treatment goal is to reach remission or low disease activity, based on 'tight control' and 'treat to target', to prevent joint damage, disability and increase quality of life. Since disease duration at the time of DMARDs initiation is the most important determinant of response, the recommendation is to initiate DMARD treatment before 6 months (preferably 3 months) of the onset of symptoms (Combe et al., 2017). 'Tight control' means that the treatment should be evaluated frequently (every 1–3 months in active disease), and modified until low disease activity or remission is reached (Smolen et al., 2023). With the optimal treatment strategy, low disease activity or remission is currently a realistic goal for more than 75–80% of patients with RA (Aletaha & Smolen, 2018). Patients with early RA are more likely to achieve remission than patients with established RA (Einarsson et al., 2019).

Non-pharmacological treatment and the multidisciplinary team

Non-pharmacological treatment should be considered as an adjunct to drug treatment, and healthcare professionals working in rheumatology play an important role in the care of people with rheumatic diseases. Dynamic exercises, guidance in lifestyle changes, occupational balance, patient education, and support for improved self-management skills may all benefit the prognosis positively, and are examples of recommended non-pharmacological treatments (Combe et al., 2017; Gwinnutt et al., 2022; Nagy et al., 2022). Self-management support is offered to patients to gain knowledge, confidence, and skills in managing the consequences of their disease. Supporting patients' self-management is a collaborative activity, aimed at increasing patient empowerment, health, and well-being (Bech et al., 2020; Zangi et al., 2015). Effective rehabilitation depends on a multidisciplinary team of rheumatology healthcare professionals working together with the patient toward personalised goals (Wade, 2020; Wallace et al., 2023). The purpose of rehabilitation is to enable the patient to live a meaningful life with the best possible activity, participation, coping, and quality of life (Maribo et al., 2022). Care should be person-centred, and the care plan should be tailored to the person's specific resources, perspectives, and individual goals (Wade, 2020). In the EULAR recommendations for generic core competencies of health professionals in rheumatology, Engel's biopsychosocial model (1977) is mandatory in the deployment of a holistic approach, which includes biological, social, and psychological dimensions of illness (Edelaar et al., 2020; Engel, 1977). The biopsychosocial model emphasises the importance of acknowledging the relationships between the different factors that interact with each other in health and illness. While the biological focus is on disease and bodily health, the psychological factors focus on mental and emotional well-being, and the social factors encompass the person's social environment including family, friends, culture and socioeconomic factors (Engel, 1977).

Access to a multidisciplinary team differs between countries, but in Sweden, rheumatology clinics' aim to work team-based in close collaboration with the patient. Rheumatology nurses are in frequent contact with the patient during the first year of diagnosis to support, inform, and evaluate disease activity and treatment (Bech et al., 2020). Within three months of diagnosis, preferably sooner, the patient should be invited for assessment of function and activity, support for continued exercise treatment, and follow-up from the occupational therapist and physiotherapist with special knowledge in rheumatology. The patients should also be offered contact with a counsellor upon needs (Combe et al., 2017; Nationellt kliniskt kunskapsstöd, 2023). Successful rehabilitation is inter-professional, goal-oriented, and closely established with the person in focus (Wallace et al., 2023).

Living with RA

RA is a disease with possible impacts on a person's physical, psychological, emotional, and social aspects of life (Ahlmen et al., 2005; Bergström et al., 2018; Parenti et al., 2020; Östlund et al., 2014). Persons living with RA describe painful symptoms, stiffness, and physical limitations. Symptoms can lead to inability to participate in desired activities, such as performing household chores, participating in social events, and to take care of younger children or grandchildren, resulting in decreased quality of life (Bala et al., 2017; Chen et al., 2022; Cozad et al., 2023; Sverker et al., 2015). Disturbed physical function, pain, and side effects of pharmacological treatments can also affect a persons's sex life in a negative way (Poh et al., 2017; Östlund et al., 2015). Persons living with RA describe how they manage their life by making adjustments, or via avoidance, interaction, and acceptance (Östlund et al., 2018). The disease can also affect work capacity, sick-leave, and premature retirement, with both individual and societal economic consequences (Gwinnutt et al., 2020). Sick leave has been shown to increase even in the year before diagnosis. Although disease activity and disability diminished after treatment initiation, patients' sick leave remained essentially unchanged (Björk et al., 2009); results that emphasise that problems begin prior to diagnosis.

Having paid work is important for persons with both early and established RA. Paid work increases one's self-esteem, offers financial independence, and a sense of purpose (Verstappen, 2015). Although, persons living with RA often experience challenges in career planning and work productivity (Berkovic et al., 2020; Sverker et al., 2014). For some persons, work is highly prioritised, and due to lack of energy, they choose to avoid social interactions in favour of being able to work (Sverker et al., 2014).

Physical restrictions can have a psychological impact on well-being for persons living with RA. Persons can experience hopelessness and sadness when not being able to perform regular daily tasks. Fear, anger, shame, embarrassment, and irritation can also occur in relation to physical restrictions due to RA (Östlund et al., 2014). Pain can lead to a deteriorated self-image, due to an inability to wear the same shoes and clothes as persons could prior to diagnosis (Pedraz-Marcos et al., 2018). RA can also lead to an affected body image, due to joint deformations and worry about the future (Chen et al., 2022). Previous research has shown that RA can renegotiate a person's identity. Male persons living with RA have described how they push through pain and try to accept changes and adapt their masculine identity accordingly (Flurey et al., 2017; Flurey et al., 2018). Living with RA has been described as a juggling act, where persons have to manage their disease and try to regain control and redefine their self-image (Flurey et al., 2014; Lempp et al., 2006).

RA can have a major impact on persons' social lives. Symptoms can lead to an inability to participate in desired activities, leading to difficulties in fulfilling social roles, and sometimes leading to social isolation (Cozad et al., 2023; Poh et al., 2017; Primdahl et al., 2019). RA affects not only the persons' life, but also their significant others and family members, who have to make adaptions to their activities as well (Bergström et al., 2018; Matheson et al., 2010). Partners of persons living with RA also carry a psychological burden, with frustration, and distress watching their significant other suffer. They try to protect their partner from emotional and physical distress and carry feelings of failing others and worries about the future (Bergström et al., 2018). The disease may lead to a need for increased support from family members and a change in life roles (Bala et al., 2017; Jahani et al., 2022; Poh et al., 2017).

Previous research shows that RA can affect all aspects of life and living with RA implies a need for help to manage the disease. Most research is centred on patients with established RA, leaving a knowledge gap about experiences from the patients' perspective early on in the disease course. Each patient has a unique experience, making it necessary to use PCC.

Person-centred care

Persons with RA desire a person-centred approach, and their health outcomes increase when healthcare professionals provide care, including empathy, mutual respect, good communication, continuity, and a partnership of shared decision-making (Hulen et al., 2017; Segan et al., 2018). PCC facilitates persons with RA to take greater responsibility for their treatment and provides education, thereby enhancing patients' empowerment and their ability to effectively manage their disease (Voshaar et al., 2015).

The World Health Organization (WHO) promotes a person-centred approach rooted in the universal principles of human rights and dignity, access and equity, and patient empowerment and participation (WHO, 2015). PCC is fundamental in the care of persons with rheumatic and musculoskeletal diseases (Edelaar et al., 2020), and has a holistic, respectful, and empowering approach focusing on a person's individual perspectives, needs, expectations, abilities, and capacities (Ekman et al., 2011; McCormack et al., 2015). A person-centred approach is an ethical point of view, where the person is in focus when they are receiving care. Acknowledging the person's context, resources, and limitations is important to avoid the risk of objectifying and making the patient a recipient instead of a participant in care (Ekman et al., 2011). PCC involves performing care actions primarily focused on the person, in contrast to being solely task- or disease-oriented. Treatment decisions should be based on consensus with the patient, through communication and knowledge exchange rather than on informing the patient (Combe et al., 2017). To promote true PCC, a patient's goals need to be integrated into their treatment plan systematically, which may lead to better adherence to pharmacological treatment and improved health outcomes (Hulen et al., 2017). In order to provide PCC, the care setting needs to have a person-centred culture (McCormack et al., 2015). In 2006, McCormack and McCance established a framework for person-centred nursing (McCormack & McCance, 2006), which has been developed over time to suit a multidisciplinary context (McCormack & McCance, 2017). Originally, the framework consisted of four constructs including: prerequisites, the care environment, person-centred processes, and person-centred outcomes (McCormack & McCance, 2006). The latest addition is the fifth construct, the macro context (McCormack & McCance, 2017).

1. *Macro context:* The broader strategic, political, and social context in which person-centredness is developed and operationalised. This includes healthcare policies, strategic frameworks, leadership, and workforce development.
2. *Prerequisites:* Attributes of healthcare professionals are prerequisites for PCC, and include professional competence, interpersonal interaction skills, commitment to the role, clarity of beliefs and values, self-awareness and competence.
3. *The care environment:* The context where care is delivered needs to facilitate a structure for shared decision-making and shared power. Different competencies should be valued and there should be a supportive organisation where there is potential for innovation and where risk-taking is appreciated.
4. *Person-centred processes:* The various activities healthcare professionals provide when delivering holistic care, such as demonstrating empathy, respecting patients' beliefs and values, and engaging and involving patients in shared decision-making.

5. *Person-centred outcomes:* The outcomes are the results of effective PCC and form the central component of the framework. Person-centred outcomes include satisfaction and active involvement in care, feelings of well-being, and promoting a therapeutic environment through shared decision-making.

To deliver positive person-centred outcomes for patients and healthcare professionals, prerequisites and the care environment need to be considered in providing effective care and person-centred processes (McCormack et al., 2010). To systematically implement person-centred care in healthcare, with patients as active partners in their own treatment, Ekman et al. (2011) introduced a PCC framework, including three cornerstones of the person-centred processes: the narrative, the partnership, and the documentation. These three specific practices in person-centred processes initiate the partnership by listening to and eliciting patients' narratives, implement the partnership by co-creating healthcare plans, and safeguard the partnership by documenting the mutual agreements in place in healthcare plans (Britten et al., 2020; Ekman et al., 2021; Ekman et al., 2011). Having a narrative communication between the patient and healthcare professionals about the patient's experiences creates a common understanding and gives healthcare professionals a good basis for discussing and planning treatment and care with the patient. Developing a partnership with shared goals and decision-making leads to a sense of control over the illness. Documentation of patient preferences, values, and involvement in care, gives legitimacy to patient perspective and facilitates continuity of care (Britten et al., 2020; Ekman et al., 2011).

Care that embraces the preferences and values of patients and is achieved in an partnership or alliance between the patients and healthcare professionals is often described in terms of centredness: 'person-centredness', 'patient-centredness', 'family-centredness', 'people-centredness', 'client-centredness', and 'individualised care' which appears side by side or are used interchangeably in the literature limiting the accessibility of the research (Feldthusen et al., 2022; McCormack & McCance, 2017). Centredness in healthcare is an evolving field and the lack of conceptual and terminological clarity in the field is a challenge. Håkansson Eklund et al. (2019) conclude that there are similarities between the concepts 'person-centred care' and 'patient-centred care' such as respect, engagement, empathy, individualized focus and shared decision-making; however, the goals differ. While the goal of patient-centred care is described as living a functional life, the goal of person-centred care is to live a meaningful life. Person-centred care broadens and extends the perspective of patient-centred care by considering the whole life of the patient (Håkansson Eklund et al., 2019). Person-centred care shifts the perspective from disease-orientated and often fragmented care to a holistic, relationship-focused and collaborative care model (McCormack & McCance, 2017). Respect for values is central to person-centred practice. The healthcare professional should develop a clear picture of the patients' values and goals for the future in order to cope with the disease and its consequences (McCormack & McCance, 2017).

PCC has been described to improve health outcomes (Ekman et al., 2011), but there is a lack of research regarding PCC in early RA. Previous research regarding PCC for patients with RA has focused on exercise or physiotherapy coaching with person-centred guidance (Andersson et al., 2020; Feldthusen et al., 2016; Feldthusen & Mannerkorpi, 2019; Lange et al., 2020; Lange, Kucharski, et al., 2019; Lange, Palstam, et al., 2019), and on nurse-led clinics (Bala, Forslind, Fridlund, & Hagell, 2018; Bala, Forslind, Fridlund, Samuelson, et al., 2018; Bala et al., 2012; Bergsten et al., 2019; Goodwin et al., 2016; Larsson et al., 2014; Larsson et al., 2015; Sjö & Bergsten, 2018).

Health

The World Health Organization (WHO) declares in their constitution that "*health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*" (WHO, 1948, p. 100) and that it is one of the fundamental rights of every human being to reach the highest possible level of health. Informed opinion and active co-operation are important aspects to improve health (WHO, 2020). A new perspective arose in the Ottawa Charter (WHO, 1986), emphasising health as a resource for everyday life (a process) and not as an object of living (a state) (WHO, 1986). Researchers have argued that complete well-being is a state that is nearly impossible to achieve, especially for persons with chronic diseases, and that the WHO definition proposes unattainable health goals that make almost all people unhealthy most of the time, making the definition hard to use (Huber et al., 2011). Therefore, alternative definitions of health may better suit persons with chronic diseases, such as the dynamic formulation based on resilience or capacity to cope and maintain one's integrity and well-being (Huber et al., 2011). Huber et al. (2011) suggest defining health as "the ability to adapt and to self-manage", illustrating how health can be experienced despite health challenges. A strengthened capability to adapt and manage oneself has also been described to improve subjective well-being (Huber et al., 2011). The definition by Huber et al. (2011) is based on three domains of health: physical, mental, and social; in line with the biopsychosocial model described by Engel (1977). A healthy person is capable of adapting to a stressor or a challenge to restore equilibrium in all aspects of health (Huber et al., 2011). The mental domain refer to Antonovsky's 'sense of coherence' (including comprehensibility, manageability, and meaningfulness), meaning that a strengthened capability to adapt to challenges often improves well-being

(Antonovsky, 1987). In the social domain, several dimensions of health can be identified, including the ability to manage one's life, fulfil one's potential and obligations, and be able to participate in social activities and work. People who can adapt successfully are likely to feel healthy and have the ability to participate in everyday life despite limitations or illness (Huber et al., 2011).

RA can affect persons' abilities and well-being, and Tengland's two-dimensional theory of health encompasses holistic aspects of health and integrates both dimensions of ability and well-being (Tengland, 2007b, 2020). 'Ability' refers to a person's capacity to engage in various actions and activities. It encompasses a person's skills, capabilities, motivation, and mental state, delineating what a healthy person requires to act and perform in accordance with societal norms. A person's ability is intertwined with their 'well-being', which is defined as the subjective experience of one's feelings and mood. Aspects of well-being encompass the overall state of the body and mind, including contentment, happiness, and a range of feelings, such as vitality, energy, calm, strength, and concentration, all arising from internal rather than external sources (Tengland, 2007b). The interplay between the dimensions ability and well-being is critical in understanding a person's overall health. Changes or fluctuations in well-being can impact one's abilities, and vice versa. For instance, when a person is not feeling well or lacks energy, their ability to perform certain actions may be compromised (Tengland, 2007b). This is particularly relevant for persons dealing with early RA, who often experience challenges in their daily activities (Sverker et al., 2015).

The perception of health constitutes the direction of one's own endeavour. In order for healthcare professionals to be able to support the patient, knowledge is needed about health from the patients' own perspective (Eriksson, 2018).

Ample quantitative studies exist that explore health related quality of life (HRQoL) in patients with RA. These studies are based on patient reported questionnaires and evalute HRQoL in relation to effects of pharmacological as well as non-pharmacological treament (Björk et al., 2022; Couppé et al., 2017; Galloway et al., 2021; Katchamart et al., 2019). Previous qualitative research regarding health and RA have studied patients' understanding of health and quality of life in established RA (Fagerlind et al., 2010), negative effects on physical health due to lockdown during the COVID-19 pandemic (Ramos-Petersen et al., 2022), perceptions regarding oral health (Protudjer et al., 2022), foot-health (Laitinen et al., 2022), and patients perceptions on physical activity maintenance (Swärdh et al., 2020). However, qualitative studies regarding patients with early RA are lacking.

Rationale for the thesis

Knowledge about early RA and the benefits of early and effective treatment has developed rapidly over the last few decades, which has led to increased interest in the early phase of the disease. Although, effective treatment is available, and remission or low disease activity is more frequent than before, patients still experience unmet needs. Thus, a better understanding of the experiences and preferences of treatment and care, by patients with early RA is of great importance. When this thesis project was initiated, knowledge gaps existed regarding patients’ perspectives and preferences early in the disease course. In order to understand, support, and treat patients who are going through the early phase of RA, there was a need for more research to address the patient perspective early on in the disease course.

Rheumatology care aims to be person-centred; which is a holistic, empowering, and effective approach to care. Ample studies exist on PCC; however, knowledge as to patients’ perceptions of PCC within early rheumatic care is scarce. The treatment goal of patients with RA is to reach optimal health. To fully deliver PCC, healthcare professionals need to understand how patients perceive health to create common treatment goals. Furthermore, to be able to tailor interventions to patients' needs, healthcare professionals need to gain a deeper understanding about patients’ preferred treatment outcomes, as well as whether these needs change during the first years of diagnosis. This thesis includes both national and European perspectives.

Aims

The overall aim of this thesis was to explore patients' perspectives of person-centred care and preferred outcomes in early rheumatoid arthritis.

Specific aims

Paper I: Explore patients’ perceptions of person-centred care in early RA

Paper II: Describe the understanding of health among patients with early RA

Paper III: Explore patients’ preferred treatment outcomes during their first two years with RA

Paper IV: Explore treatment outcomes preferred by patients with early RA and how these change throughout the early disease stage across three European countries

Methods

Overall study design

This thesis includes four qualitative papers. Qualitative research methodology is used when the aim is to understand the human experience. Qualitative studies capture people's stories to understand their perspectives and experiences and, through an inductive process, collect descriptive data to illuminate the phenomenon of interest (Patton, 2015). The inductive approach can be combined (to an abductive approach) or replaced by a deductive approach to relate or test the implications of existing theories or models against collected data (Graneheim et al., 2017).

Different designs were used to develop knowledge of different topics, and in order to address the aims of this thesis, the following four study designs were used:

- Paper I had an explorative design with an abductive approach. The abductive approach implies a back-and-forth (iterative) movement between inductive and deductive qualitative content analysis approaches (Graneheim et al., 2017). An abductive approach was considered appropriate for this study since the purpose was to gain a deeper understanding of patients' perspectives on PCC within a theoretical framework. The inductive part was based on the participants' experiences and descriptions of person-centred care. McCormack and McCance's (2006) framework of PCC encompasses several dimensions that guide healthcare practitioners in delivering PCC, forming the deductive part.
- Paper II had a descriptive qualitative design with an inductive phenomenographic approach. The purpose of phenomenography is to describe the various ways people understand or experience a phenomenon. Knowledge is assumed to be relational, and involves the interrelationship between thoughts, experiences, and a specific phenomenon. A conception reflects the experience of the phenomenon from the perspective of each individual person. There is only one world, which is understood and experienced in various ways by various people (Marton, 1986). Finding key aspects of these variations and mapping the relational structure between conceptions are distinguished

features of phenomenograpic analysis (Åkerlind, 2005) and it is well-suited to exploring variations in the understanding of health among patients with early RA. However, the result of a phenomenographic analysis is not always confined to categories. Internal relationships between categories, formed as the outcome space, is also part of the results (Larsson & Holmström, 2007).

- Papers III–IV had qualitative, longitudinal, multicentre study designs with an inductive approach, from a national (paper III) and international (paper IV) perspective, and data from two different timepoints. Longitudinal designs are relevant when studying the complex context of a recent diagnosis, since patients' perceptions and expectations may change during the overwhelming and rapidly evolving early disease stage (Van der Elst et al., 2019). In paper III, narratives were analysed using the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterle et al., 2012) and the longitudinal analysis was guided by Saldaña's 16 steps for interpreting change in the longitudinal qualitative data (Saldaña, 2002). The QUAGOL method is inspired by the constant comparative method of a grounded theory approach (Corbin & Strauss, 2015). The constant comparison process is a comparative procedure between the researchers' interpretations and participants' stories and is well-suited for the descriptive and inductive qualitative study designs in papers III–IV. Paper IV is a meta-synthesis analysed using inspiration from meta-ethnography and QUAGOL, integrating findings from three different countries.

An overview of the papers included in the thesis can be found in Table 1.

Table 1 Overview of the papers included in this thesis, and their aim, design, sample size, and data collection and data analysis methods.

Paper	*Aim*	*Design*	*Participants*	*Data collection*	*Analysis*
I	Explore patients' perceptions of PCC in early RA	An explorative design	31 participants	Semi-structured individual interviews	Abductive qualitative content analysis
II	Describe the understanding of health among patients with early RA	A descriptive qualitative design with a phenomenographic approach	31 participants	Semi-structured individual interviews	Qualitative analysis based on a phenomenographic approach
III	Explore patients' preferred treatment outcomes during the first two years with RA	Explorative, longitudinal, and multicentre design with an inductive approach	31 participants at T_1 and 22 participants at T_2	Semi-structured individual interviews at T_1 and focus group interviews at T_2	Qualitative Analysis Guide of Leuven (QUAGOL) and Saldaña's guiding questions for analysing longitudinal data
IV	Explore treatment outcomes preferred by patients with early RA and how these change throughout the early disease stage across three European countries	A multinational, longitudinal, qualitative study design based on data from three European countries	80 participants at T_1 and 51 participants at T_2	Semi-structured individual interviews at T_1 and focus group interviews at T_2	QUAGOL and Saldaña´s guiding questions for analysing longitudinal data. After this, a meta-synthesis inspired by the principles of meta-ethnography was performed

Abbreviations: T_1 : Timepoint one T_2 : Timepoint two

Study context

The data collection (papers I–IV) was conducted in southern Sweden in four different cities representing urban and rural populations, university hospitals, and private practices with a regional care agreement.

Papers III–IV were part of the European Qualitative research project on Patient-preferred outcomes in Early Rheumatoid Arthritis (EQPERA). EQPERA involved Belgium, the Netherlands, and Sweden. These three countries all have comparable healthcare systems. However, differences exist; for example, reimbursement, referral system, and access to an interdisciplinary team. All participating countries collected their own national data, whereas paper III presents the Swedish findings, later used in the meta-synthesis (paper IV). A study protocol was published by the EQPERA group (Van der Elst et al., 2019) to enchance the quality of the research. The interdisciplinary research group was comprised of rheumatologists, nurses, physiotherapists, a psychologist, and patient research partners.

Participants

Participants in this thesis were patients with early RA who met the inclusion criteria of: 1) confirmed diagnosis according to the ACR/EULAR 2010 RA classification criteria (Aletaha et al., 2010); 2) disease duration of ≤1 year; 3) DMARDs treatment for 3–9 months; 4) age of ≥18 years; and 5) speaking, reading and writing the local language. All countries performed equal recruitment procedures. Purposive sampling (Patton, 2015) was used to ensure variation in age, gender, and that patients came from different cities. Choosing participants with various experiences increases the possibility of answering the research question from a variety of aspects (Patton, 2015). Patients were identified by rheumatologists, rheumatology nurses, or in a Rheumatology Quality Register. Patients in Sweden were invited to participate by me or by their treating healthcare professional. Thirty-one patients accepted to participate in individual interviews at timepoint one (paper I–IV), between 2017–2018. All participants were re-invited to a follow-up focus group interview at timepoint two, 12–20 months after treatment initiation (papers III & IV) and 22 accepted the invitation. A total of 17 participants took part in 7 focus groups, including 2–3 participants in each group. Five participants were interviewed individually upon request by the participant. Although the patients at the second time point had had their diagnosis up to 21 months, the term early RA will be used in this thesis. Country specific sociodemographic data of the participants are presented in Table 2.

Table 2. Participant demographic, clinical, and self-reported characteristics grouped by country and interview timepoint. Published in Van der Elst et al. (2020).

Characteristic	**Belgium**		**The Netherlands**		**Sweden**	
	t_1 (n=26)	**t_2 (n=14)**	**t_1 (n=23)**	**t_2 (n=15)**	**t_1 (n=31)**	**t_2 (n=22)**
Individual interviews	26	0	23	8	31	5
Focus groups	NA	3 (n=14)	NA	2 (n=7)	NA	7 (n=17)
Site of recruitment, n (%)						
General hospital	8 (31)	5 (36)	21 (91)	14 (93)	NA	NA
Academic hospital	9 (35)	6 (43)	2 (9)	1 (7)	28 (90)	20 (91)
Private practice	9 (35)	3 (21)	NA	NA	NA	NA
Regional rheumatology specialist outpatient clinic	NA	NA	NA	NA	3 (10)	2 (9)
Disease duration in months, median (range)	4 (3-7)	15 (12-17)	6 (3-7)	17 (12-20)	5 (3-9)	18 (12-21)
Age in years, median (range)	55 (22-68)	57 (23-66)	60 (22-83)	58 (23-83)	56 (38-80)	57 (42-81)
Women, n (%)	18 (69)	9 (64)	13 (57)	8 (53)	22 (71)	15 (68)
Level of education*, n (%)						
Low	8 (31)	5 (36)	12 (51)	8 (53)	8 (26)	5 (23)
Moderate	9 (35)	5 (36)	5 (22)	3 (20)	15 (48)	11 (50)
High	9 (35)	4 (28)	6 (26)	4 (27)	8 (26)	6 (27)
Currently employed, n (%)	15 (58)	8 (57)	11(48)	6 (40)	14 (45)	12 (55)
General health score[#], median (range)	24 (0-64)	38 (0-80)	21 (0-90)	25 (0-69)	26 (0-80)	25 (0-95)
Pain score[#], median (range)	22 (0-65)	37 (0-80)	12 (0-74)	20 (0-47)	27 (0-70)	20 (0-50)
Fatigue score[#], median (range)	29 (0-64)	37 (0-80)	39 (1-87)	28 (3-70)	30 (0-95)	40 (0-100)
Current RA treatment, n (%)						
csDMARD(s)	25 (96)	10 (71)	18 (78)	7 (47)	24 (77)	14 (64)
bDMARD(s)	NA	4 (29)	2 (9)	6 (40)	6 (19)	6 (23)
Discontinued treatment	1 (4)	NA	3 (13)	1 (7)	1 (3)	3 (14)
Unknown	NA	NA	NA	1 (7)	NA	NA

*Low: no diploma, lower secondary education; moderate: higher secondary education; high: higher education. †Position marked on a visual analogue scale (100 mm) from best (left side: 0/100) to worst (right side: 100/100).

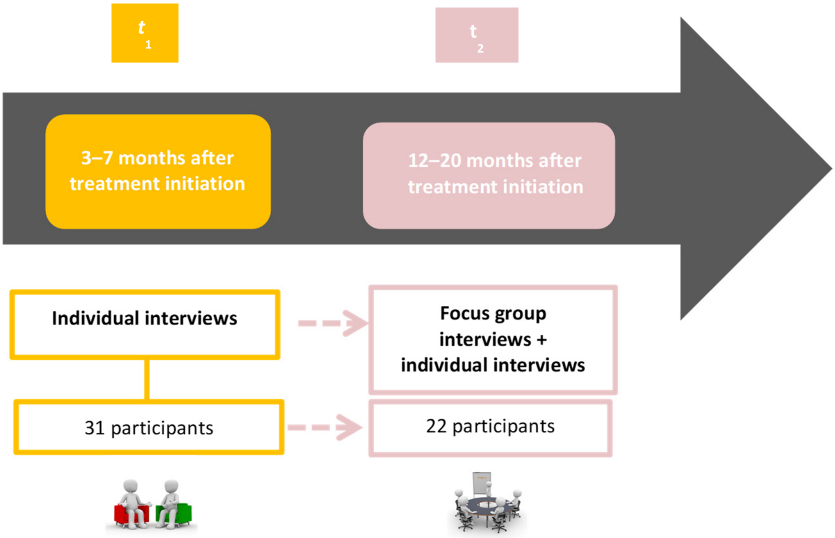
Abbreviations: bDMARD(s), biological disease-modifying antirheumatic drug(s); (cs)DMARD(s), conventional synthetic disease-modifying antirheumatic drug(s); NA, not applicable; RA, rheumatoid arthritis; t, time point.

Research partner

Aiming to improve the relevance, quality, and validity of the research process, we followed the recommendations from EULAR for inclusion of patient representatives in scientific projects (Arumugam et al., 2023; de Wit et al., 2011). As this thesis aims to capture the patient perspective, a patient research partner was involved in the study from the beginning to include patients' perspectives throughout the research process. The Swedish patient research partner has participated in the study process as an active team member in the Swedish research group during the work with the study design, giving feedback on the patient information leaflet and informed consent form. She has also reflected on the interview questions, participated in the analysis processes, and given critical input on the manuscripts, and therefore is a co-author (MN) on all the manuscripts.

Data collection

In this thesis, qualitative interviews were chosen to describe perceptions of person-centred care (paper I), the understanding of health (paper II), and patient-preferred treatment outcomes (papers III & IV). Qualitative interviews yield rich, in-depth information that can elucidate varied dimensions of a phenomenon (Patton, 2015; Polit & Beck, 2021). The data were collected during two timepoints, and with two different methods: individual interviews at timepoint one and focus group interviews at timepoint two (Figure 1).



Abbreviations: T_1 : Timepoint one T_2 : Timepoint two
Figure 1. Data collection in Sweden

Timepoint one—individual interviews

The Swedish data in papers I–IV were collected through face-to-face, semi-structured, individual interviews conducted by me and a senior qualitative researcher (my main supervisor, IL), between March 2017 and February 2018. At the first timepoint, individual interviews were chosen to create a safe environment to speak freely due to a recent diagnosis that can be seen as a personal matter and possibly an emotional time. The first timepoint, 3–7 months after DMARD initiation, was chosen to collect the participants' initial experiences after diagnosis. Conducting the interview after only a few months since diagnosis and treatment initiation helps in eliciting patients' outcome preferences early in the course of RA. Two participants chose to be interviewed at home, and 29 interviews were conducted at the clinics where they were treated or at a research and development centre. The interviews at the clinic and the research centre took place in a conference or conversation room. First, two pilot interviews were conducted to test the interview guide. Both interviews were judged to have sufficiently good quality to be included in the analysis. After invitation, the participants received oral information over the phone and written information by mail to have time to reflect upon their possible participation before the interview. At the interview, they had the chance to ask questions before the interview started. When participant had signed informed consent, the interview began. All interviews were digitally recorded and transcribed verbatim.

The interviews included the three study topics: experiences of PCC, health, and preferred treatment outcomes. A mind-map, where the participants were able to fill in words according to each topic was used as a conversational support if respondents wanted to use a more visual way of discussing the different topics. Examples of questions used to elicit different topics included “How do you perceive the early RA healthcare?” “How do you perceive the encounter with the healthcare professionals in early RA healthcare?” “What is health for you?”, “What were your expectations from your anti-rheumatic treatment at the beginning of treatment?”, “At present, is there anything you would like to change or improve regarding your disease or treatment?”. The responses were followed up with probing questions such as “Can you tell me more about that?” "Can you elaborate on that?", "What do you mean by that?", "Is there anything else you would like to add?". The interviews lasted between 16 and 127 minutes, with a median of 43 minutes and a total interview length of 26 hours and 9 minutes. After each interview, the interviewer summarised the content of the interview, and the participant was invited to correct or add meaning. The interviewers also ended the interview by asking the participant if the interview had upset him/her or created discomfort; all participants denied this was the case. The interviews were equally performed according to the study protocol in all countries (Van der Elst et al., 2019).

Timepoint two—focus group interviews and individual interviews

In papers III–IV, data were also collected at a second timepoint, intentionally through focus-group interviews, but an individual interview was also an option, to reduce potential drop-out. All participants from timepoint one were re-invited to participate. In the Swedish data collection, seven participants declined, and two did not respond. Interviews were conducted between April 2018 and November 2018. The reason for selecting different interview methods between timepoints, (individual and focus group interviews), was based on input from a patient research partner (Van der Elst et al., 2019). At the second timepoint, focus groups were chosen due to the possible positive exchange of meeting others in the same situation. After 12–20 months, it was assumed that participants had had sufficient time to develop their views regarding their preferences. The interview guide for the focus group interviews was slightly adapted compared to timepoint one in order to question participants about their views on the changes to their preferred outcomes over time. The focus group interviews took place in a conference room at the different clinics where the participants were treated, or at a research and development centre. The focus groups were moderated by me and co-moderated by IL. During the focus groups, IL took notes on a whiteboard to summarise and create consensus of what was being articulated. Before the focus groups began, information about the study was given and the participants filled in the informed consent forms and were able to ask questions. The focus groups consisted of three rounds that were designed to maximise group interactions inspired by nominal group methodology (Drennan et al., 2007; Jones & Hunter, 1995). This is a method aimed for discussing, generating, and clarifying ideas between participants (Drennan et al., 2007). The first round was a preparatory phase, round two was developing a group list of preferred outcomes and round three was exploring the evolution of their preferences over the past year. The group interviews lasted between 54 and 110 minutes, with a median of 78 minutes and a total of 9 hours and 20 minutes. The individual interviews lasted between 20 and 58 minutes with a median of 35 minutes and a total of 3 hours and 16 minutes were made with 5 participants due to personal or practical reasons. Individual interviews were conducted by me, at the treating rheumatology clinic or by phone, chosen by the participant. After every follow-up interview, the interviewer summarised the content of the interview, and asked whether the participants wanted to correct or add anything. From the 80 interviews from timepoint one in paper IV, 51 participants were interviewed again at timepoint two. Thirty-eight of them participated in a focus group and 13 in an individual interview. All interviews were digitally recorded and transcribed verbatim.

Analyses

Qualitative content analysis (paper I)

In paper I, an abductive qualitative content analysis (Graneheim et al., 2017) based on the framework of McCormack and McCance (2006) was used. This method was chosen to gain a greater understanding of the patients' perceptions of PCC by connecting the patients' perspective within the PCC framework. The four constructs in the framework constituted the categories: prerequisites, care environment, person-centred processes, and person-centred outcomes. The inductive analysis resulted in 622 meaning units. The meaning units were condensed and coded and sorted into the categories in the deductive stage. After this, the second inductive phase began. The codes, within each category were compared based on differences and similarities and grouped into a total of eleven subcategories. The analysis is presented in Table 3. The analysis process was an interactive process within the research group, where we discussed and agreed upon the meaning units, codes, and categories.

Table 3. Steps performed during the abductive qualitative content analysis

Abductive approach	Inductive approach	Step 1	The transcripts was read and listened to, to get a sense of the whole
		Step 2	The text was extracted into meaning units and condensed meaning units. These were then abstracted into codes
	Deductive approach	Step 3	The codes were sorted into the four constructs in the PCC framework (McCormack & McCance, 2006) that constituted the categories
	Inductive approach	Step 4	Codes with similar content, within each category, were grouped together into sub-categories

Phenomenographic analysis (paper II)

Phenomenography was used to analyse data in paper II, due the aim of elucidating patients' variations in their understandings of health. Data analysis was performed in seven steps, according to Larsson & Holmström (2007), see Table 4. A qualitative software programme, NVivo 1.7.1 (QSR International, London, UK) was used as an administrative tool, but the automatic analysis functions were not used.

Table 4. The seven steps of phenomenographic analysis by Larsson & Holmström (2007)

Step 1	The transcripts were read thoroughly
Step 2	The transcripts were re-read and marked where the interviewee gave answers pertaining to the main research questions; in this case 'What is health to you/What does health mean to you?'
Step 3	Focus on *what* the participants focused on and *how* he/she described it; in this case, health, and a preliminary description of each category was made
Step 4	The descriptions were grouped into categories based on similarities and differences
Step 5	Comparision of categories and attention on dominant and non-dominant ways of understanding health (Table 5)
Step 6	Attention is paid to relationships between categories, which gives structure to the outcome space
Step 7	A metaphor was assigned to each category

The analysis revealed 4 main descriptive categories. The dominant and non-dominant ways of understanding health are presented in Table 5. The assessment is based on each participants' way of describing their understanding of health. The internal relationships between categories were the next step in formulating the results; i.e., the outcome space. A logical relation between understandings; in this case, in a non-hierarchical structure, presents the intertwine of results in the outcome space. This was an interactive process within the research group, where we discussed and agreed upon the final results.

Table 5. Dominant (++) and non-dominant (+) ways of understanding health among 31 patients with early RA

Participant no.	Health as belonging	Health as happiness	Health as freedom	Health as empowerment
1	++	+	+	
2	++		+	+
3	++	+	+	+
4	++	+	+	+
5	++		+	
6	++		+	+
7	++		+	+
8	++	+	+	+
9	+	++	+	+
10	+	++	+	+
11	+	+	++	+
12		+	++	+
13	+	+	++	+
14	+		++	+
15	+	+	++	+
16	+		++	+
17	+		++	+
18	+		++	+
19	+	+	++	+
20	+	+	++	+
21	+	+	++	+
22	+	+	++	+
23	+		++	
24	+		++	+
25	+	+	++	+
26	+		++	+
27	+	+	++	+
28	+	+	++	+
29	+	+	++	+
30	+	+	+	++
31	+		+	++

Qualitative analysis guide of Leuven (paper III)

Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterle et al., 2012) was used to analyse the narratives in paper III, following the EQPERA-study protocol (Van der Elst et al., 2019). QUAGOL method is a constant comparative method and divides data analysis into two parts, each consisting of five stages (table 6). The analysis of both individual and focus group interviews was performed according to QUAGOL, but the focus group had the purpose of identifying discussions and content which evolved in the interplay between participants. The first part in QUAGOL, is a preparatory phase, while the second is where the coding begins. The analysis process started immediately after the first interview, and data collection continued until data saturation was reached. The guide is based on ten steps but is an iterative process moving between the stages (Table 6). The analysis revealed 1 core-category, 4 concepts, and 10 sub-concepts.

Table 6. Stages of the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterle et al., 2012)

Part one, preparatory phase	1. Transcripts were (re)read thoroughly to get a sense of the whole and a holistic understanding of the participants' experience. Key phrases were marked, and notes were taken.
	2. A narrative interview report was written to answer the research question, which included the essence of the participants' story.
	3. From a narrative interview report to conceptual interview scheme. The analysis went from a concrete level of experience to a conceptual, more abstract level. The most important data was filtered and clustered into concepts.
	4. A fit-test of the conceptual interview scheme was performed in order to confirm appropriateness, through moving iteratively between transcripts and concepts.
	5. A constant comparison process (within-case and across-case analyses) was undertaken, which facilitated new or common themes or concepts.
Part two, coding phase	6. The list of concepts was summarised and entered into NVivo 12 plus (QSR International, London, UK).
	7. The actual coding process started. The interviews were re-read together with the list of concepts to see to which extent the list helped to describe the essence in the transcript.
	8. Each concept with associated citations was analysed and redefined if needed.
	9. Extraction of the essential structure. Codes and concepts were organised in a table.
	10. Description of results/writing the result section.

Longitudinal data analysis (papers III & IV)

The longitudinal analysis was guided by Saldaña's 16 steps to interpreting change in longitudinal qualitative data (Saldaña, 2002), see Table 7, as presented in the EQPERA-study protocol (Van der Elst et al., 2019). It consists of *framing questions* to help the researcher focus on the context and conditions that influence changes over time; *descriptive questions* to describe what kinds of changes occur; and *analytic and interpretive questions* to reach richer levels of analysis (Saldaña, 2002). The framing questions are also inspired by a constant comparative method analysing iterative, sequential, and cyclical directions to assess what is different between datasets. The 16 guiding questions were answered during the longitudinal analysis. The framing questions helped us maintain focus and reflect on possible contextual and intervening conditions surrounding change. Noting when changes occur also assists in discerning interrelationships between events. Every person lives within a context and interacts with society, and their conditions are in constant flux. Contextual conditions or events can influence and affect change through time. The descriptive questions guided the reflection on cumulative effects of growth, development and/or change through time. The analytical questions helped us reflect on the influences and effects that may reveal links between datasets and find possible contextual or intervening conditions influencing the data. Questions 14 and 15 also note an awareness of the natural developments of time, which can affect results.

Table 7. Saldañas 16 steps to interpret change in longitudinal data (Saldaña, 2002)

Framing questions	1. What was different from one pond of data through the next?
	2. When did change(s) occur through time?
	3. What contextual and intervening conditions appeared to influence and affect participant change(s) through time?
	4. What were the dynamics of participant change(s) through time?
	5. What preliminary assertions about participant change(s) could be made as data analysis progresses?
Descriptive questions	6. What increased or emerged through time?
	7. What was cumulative through time?
	8. What kinds of 'growth spurts' or epiphanies occured through time?
	9. What decreased or ceased through time?
	10. What remained constant or consistent through time?
	11. What was idiosyncratic through time?
	12. What was missing through time?
Analytic and interpretive questions	13. Which changes were interrelated through time?
	14. Which changes through time opposed or harmonised with natural human development or constructed social processes?
	15. What were participant or conceptual rhythms (phases, stages, cycles, etc.) through time?
	16. What was the through-line of the study?

Meta-synthesis (paper IV)

The meta-synthesis was based on three independently performed qualitative studies from Sweden (Landgren et al., 2020), the Netherlands (Mathijssen et al., 2019), and Belgium (van der Elst et al., 2016). The method used is presented in the EQPERA-study protocol (Van der Elst et al., 2019) and was inspired by the principles of meta-ethnography, as practiced by Britten et al., (Britten et al., 2002), and by the QUAGOL coding process (preparatory phase). The four steps of meta-synthesis are presented in Table 8.

Table 8. Four steps the meta-synthesis were performed according to the study protocol by Van der Elst et al. (2019)

Step 1	Each country's results (case) were described
Step 2	Differences, similarities, and patterns across cases were recognised
Step 3	Differences and similarities across cases were disentangled
Step 4	A fit-test of the meta-interpretations was undertaken

The analysis was done by face-to-face interaction between the local teams in a consensus meeting moderated by a senior researcher of the EQPERA team who was not linked to a local team result. In step one, every participating country presented their study context (country-specific information about population, healthcare system, treatment guidelines for RA), sociodemographic and clinical characteristics about the participants, results (core-category, concepts, and sub-concepts), and changes through time in the local longitudinal analysis. In step two, every participant reflected on 'What do I hear in every case?', 'What do I only hear in our case?', 'What do I not hear in our case?' to stimulate across-case analysis. Then, the researchers wrote patient-preferred outcomes (codes and concepts) on colour-coded sticky notes to visually compare local findings (picture 1).

Picture 1. From left: Elke G E Mathijssen (The Netherlands), Kristien Van der Elst (Belgium) and Ellen Landgren (Sweden) doing a visual, color-coded comparison between local findings, during the analysis of the meta-synthesis (Published with permission from Elke G E Mathijssen and Kristien Van der Elst).

In step two, an across-cases analysis started with recognition of differences, similarities, and patterns across cases. We also determined how the studies were related (i.e., what emerges across cases) and recognised what was typical for each case. After reaching a consensus on similarities and differences, the grouped outcomes (concepts and sub-concepts) were renamed. In step three, we recognised, discussed, and explained differences and similarities across-cases, why (or why not) certain outcomes emerged in a particular country or across countries. The analysis/group discussion was digitally recorded and transcribed verbatim. In step four, each local team drafted a written summary of the discussion with similarities and differences to the other cases. After this, the fit-test of the meta-interpretations began. Each local team performed a fit-test of common and novel meta-interpretations within local data. During the conference call meetings, the meta-interpretations were adapted, and then completed based on the fit-test of each country.

Pre-understanding

Since the researcher is the instrument of qualitative inquiry, the background, experience, training, and skills undergird the credibility of the findings (Patton, 2015). Therefore, it is important for a researcher to be reflective about one's pre-understanding. During this work, all co-authors reflected on our influence on the process. I've been a nurse at the rheumatology clinic for ten years, and all co-authors have been working in different healthcare professions (nurses, physiotherapists, rheumatologist) in the rheumatology field for 25-32 years. Working in an interdisciplinary team with a patient research partner has been fruitful. The pre-understanding of the team was discussed, reflected upon, and bracketed throughout the analysis in order to refrain from judging or influencing the interpretation in a biased way.

Ethical considerations

The studies were carried out in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2022). Ethical considerations were also taken into account according to the Swedish Research Council (Swedish Research Council, 2017), All European Academies (ALLEA)'s 'the European code of conduct for research integrity' (All European Academies, 2023), and the Swedish legislation on good research practice (Lag om ansvar för god forskningssed och prövning av oredlighet i forskning [Swedish legislation on good research practice] SFS 2019:504) and was discussed throughout the research processes of the four papers. Ethical approval was obtained from the Regional Ethical Review Board in Lund, Sweden (2016/618, 2017/205).

Informed consent and confidentiality

Informed consent means that a person has evaluated the potential risks and benefits of participating in a study (Swedish Research Council, 2017; World Medical Association, 2022). The participants received repeated oral and written information (by mail and offered again at the interview), including the voluntary nature of their participation and that participation or non-participation would not influence their treatment in any way, and their right to discontinue their participation at any time without offering an explanation. The participants in this thesis signed a consent form including information about the study's purpose, specific expectations, risks, and benefits. All participants were guaranteed confidentiality. It is important to protect the person's privacy and personal information and all data have been handled confidentially (World Medical Association, 2022). The participants' names were protected in a code list and these codes were used in the transcripts. The code list was kept separate from the data, and all data were stored securely.

Researcher–participant relationship

There is always a risk that the participants may find themselves in a relationship of dependency with the researcher. To avoid this, the interviewers had no treatment relationship with the participants, and the interviewers were aware and made an effort to minimise cases in which participants felt obligated to participate. The interviewers did not wear any working uniforms, and the interviews were performed in a conference room, conversation room, or at participants homes and not in a treatment or examination room. Interviewers made every effort to show respect and be non-judgemental, and clarification to eliminate misunderstandings was sought in as neutral manner as possible. An interview is a reflective process and can evoke both positive and negative feelings and thoughts (Patton, 2015). Therefore, the interviewers were attentive to negative feelings, and, if needed, were prepared to offer them guidance for further support. Patton (2015) highlights that the participants usually report a very good experience of being interviewed. Several of the participants in this thesis spontaneously expressed positive feelings after the interview. The interviewers also reflected upon the power imbalance (Kvale & Brinkmann, 2014; Marton & Booth, 1997) in interview situations and tried to diminish it. The interviewers tried to communicate that there were no right or wrong answers, and that the participant was the expert in this context and about this subject, in an attempt to equalise any possible power imbalance. In an attempt to make the participants comfortable during the interviews, they were asked to choose a day and time that suited them. The interviewers also strived to make the interview a friendly and relaxed conversation where participants could speak freely and feel they could do so without risk of judgement.

Results

This thesis explored patients' perspectives of PCC and preferred outcomes in early RA. Paper I explored patients' perspectives of PCC proceeding to achieve optimal health and satisfaction with care. To gain a deeper understanding of the person-centred outcomes of health and treatment outcomes, paper II described patients' understanding of health, and papers III–IV, explored patients' preferred treatment outcomes. Last, a comprehensive understanding of the results is presented.

Paper I; patients' perceptions of PCC in early RA

Patients' perceptions of PCC in the early course of RA were described within the PCC framework by McCormack and McCance (2006). The four constructs in the framework: prerequisites, the care environment, person-centred processes, and person-centred outcomes, were used as categories in the abductive analysis of the perceptions of PCC among patients with early RA. The analysis resulted in 11 subcategories (Table 9). The prerequisite for PCC was described as meeting a respectful, dedicated, and competent healthcare professional with good communication skills. The care environment in PCC included access to a multidisciplinary team and healthcare professionals who worked in structured collaboration with colleagues and with patients. The person-centred processes were described as meeting supportive, good listening, encouraging healthcare professionals involving patients in treatment decisions. To be able to make informed decisions, patients needed individualised support. Person-centred outcomes demonstrated that PCC was important to the participants and was aimed at optimal health and well-being. Another person-centred outcome was satisfaction with care in terms of effective treatment and the inclusion of next of kin (Table 9).

Table 9. Results from paper I. Overview of the categories and subcategories showing patients' perceptions of PCC within the PCC framework established by McCormack and McCance (2006). Published in Landgren et al. (2021).

Categories	Prerequisites	The care environment	Person-centered processes	Person-centred outcomes
Sub-categories	Being treated with respect	Having access to a multidisciplinary team	Being listened to	Being satisfied with received health-care
	Meeting dedicated healthcare professionals	Having access to healthcare	Being supported	Achieving optimal health
	Meeting professional competence	Encountering a supportive organization	Being involved in decision-making	

Paper II; patients' understanding of health in early RA

The understanding of health was explored to gain a deeper understanding of patients' perspectives of optimal health as a person-centred outcome. The results showed that patients with early RA understood health as a sense of belonging, happiness, freedom, and empowerment. Figure 2 shows the internal relationships between the four categories, described as the outcome space, and represents variation in the patients' collective understanding of health. The categories have no hierarchical relationship but are linked to one another in different ways. Health as a sense of belonging was described as the importance of having a meaningful day and of being needed. This was expressed as participating in family life and leisure and being able to maintain work capacity and contributing to a sense of belonging. Maintaining a sense of coherence despite the challenges of disease, was perceived as a manifestation of good health. Poor health was linked to discomfort. Health was also described as a foundation for enjoyment and a lust for life. Health as freedom was described as experiencing physical, mental, and financial independence. Despite the occasional need for assistance, participants described health as the ability to make autonomous, independent decisions and the ability to fulfil life goals with no restrictions due to the disease. Health as empowerment was described as the ability to self-manage and experience capability. When it came to taking charge of their life and of disease management, patients also appreciated support from healthcare professionals.

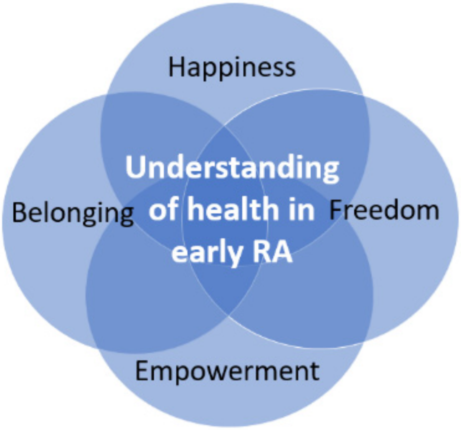


Figure 2. Results from paper II. The understanding of health among patients with early RA (In manuscript)

Paper III; patients' preferred treatment outcomes in early RA—from a Swedish perspective

Patient-preferred treatment outcomes over a longitudinal perspective contribute to a deeper understanding of the person-centred outcome: 'being satisfied with received healthcare' from paper I (Table 10). Patients progressed from a preferred treatment outcome of returning to life prior to disease to a preferred outcome of living with quality of life despite RA. The main outcome was that the patients wanted to master their new life situation, described in the four concepts: experiencing control of the disease, experiencing autonomy, regaining identity, and experiencing joy in everyday life. Experiencing control of the disease was described as patients wanting to cope with the disease and not being restricted by the disease in any way. Preferences developed over time, and changed from an acute need for help to a resilient standpoint of mastering their life by themselves. Non-pharmacological treatment was added to the preferred treatment spectrum over time, from a narrow focus solely on pharmacological treatment. Patients experienced positive effects and highlighted these non-pharmacological treatment modalities. There was also a different focus on symptoms over time; when joint-related symptoms were suppressed by effective treatment, fatigue was more distressing at follow-up appointments. Patients wanted to experience the absence of disease and independence through effective treatment. Autonomy was expressed as a strong will to maintain both physical and financial independence and an ability to self-manage the disease through empowerment. The preferred treatment outcome of 'being empowered' became more important over time in coping with symptoms. Empowerment was a preferred outcome when it came to experiencing autonomy. Knowledge gave patients the power and confidence they needed to master and cope with their new life situation, which was another preferred outcome within the sub-concept of being empowered. Patients preferred to regain their former identity and be able to participate in social activities, their workplace, and their enjoyment in everyday life. RA affected the patients' relationships and their own and their spouses' social lives. Their profession was closely related to their identity, and furthermore, identity and self-image were important treatment outcomes. The patients also described a sense of dissatisfaction with medical side effects affecting their work life, self-image, and overall sense of identity. Experiencing joy in everyday life was a preferred treatment outcome and included experiencing vitality and believing in the future. Experiencing joy and having a positive outlook became more important over time.

Table 10. Results from paper III. Overview of patient-preferred outcomes in early RA. Published in Landgren et al. (2020).

Core category	**Mastering a new life situation**			
Concepts	Experiencing control of the disease	Experiencing autonomy	Regaining identity	Experiencing joy in everyday life
Sub-concepts	Controlling the symptoms	Regaining former activity levels	Being able to participate	Experiencing vitality
	Experiencing absence of disease	Experiencing independence	Experiencing well-being	Believing in the future
		Being empowered	Regaining former self-image	

Paper IV; patients' preferred treatment outcomes in early RA—a meta-synthesis from a European perspective

In three European countries, the preferred treatment outcome among patients with early RA was 'to experience a normal life despite RA'. The preferred treatment outcomes among the included countries were disease control, physical performance, self-accomplishment, and well-being (Figure 3), with existing similarities and differences. The results showed shared preferences across countries and preferences unique to specific countries, suggesting that variations in healthcare systems and cultures may influence preferred outcomes. Disease control was expressed as relief of symptoms, finding the right treatment, and remaining stable. Most notably, only the Swedish patients considered non-pharmacological treatment to be an important outcome, while patients in Belgium and the Netherlands focused on pharmacological treatment. Patients in Belgium also preferred visual proof of disease control, such as blood test results. Regarding physical performance, patients in all countries wanted to maintain their independence by retaining function and the ability to perform activities. Self-accomplishment included self-management, role-fulfilment, and notions of the self and identity. Patients in the three countries wanted to play an active role in treatment decisions. Self-management became increasingly important over time, as patients were clinically stable and felt more confident in taking control. Swedish patients more frequently discussed self-management and were more focused on adopting healthy lifestyle changes compared to participants from Belgium and the Netherlands. Patients from the three countries wanted to maintain their identity unaffected by RA over time, while Swedish patients also expressed that maintaining physical appearance was an important preference. Well-being included emotional well-being, a positive outlook on the future, and vitality. Swedish patients tended to express a greater negative impact of RA on their emotional well-being and expressed more threats to their normal life caused by RA over time, than Belgian and Dutch patients did. To be treated and identified as a patient had a negative impact on their sense of self and was an unwanted experience. All patients preferred to live a normal life; at the first timepoint it was described as ‘their life prior to RA’ and at the second timepoint, it was described as ‘living a normal life despite RA’.

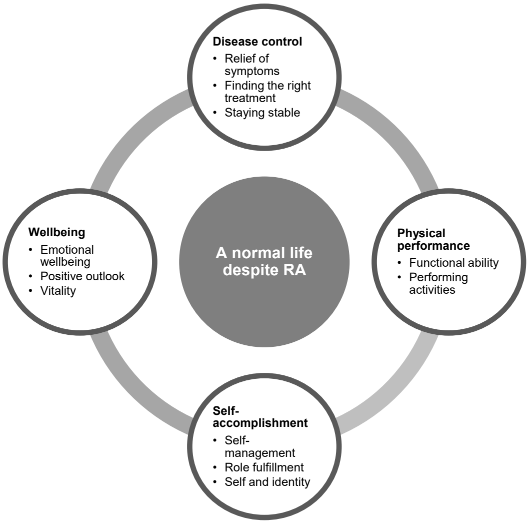


Figure 3. Results from paper IV. A multinational perspective on patient-preferred treatment outcomes in early RA, published in Van der Elst et al. (2020).

Comprehensive understanding

A comprehensive understanding of the patients' perspectives of PCC and preferred outcomes in early RA, is illuminated in this thesis. PCC is characterised by the presence of supportive, professional, and dedicated healthcare professionals (paper I–II), and for patients to have easy access to care (paper I) and be involved in decision-making (papers I–IV). Preferred outcomes are intertwined with person-centred outcomes, as outlined within the theoretical framework for PCC by McCormack and McCance (2006). Three essential aspects were identified as preferred outcomes: independence, empowerment, and well-being; all of which can be found in papers I–IV. The three aspects are representing crucial outcomes of PCC and treatment, and describe patients' perspectives in early RA.

Independence is important to patients in the early disease course and is both a preferred treatment outcome (paper III) and constitutes an essential aspect of health (paper II). Independence is considered as the capacity to maintain engagement in meaningful activities (papers I–IV) and sustain financial and physical independence (papers II-III), but independence also involves the freedom to preserve one's identity, physical appearance (papers III–IV), and as the capability to achieve life goals (papers II–IV). PCC foster independence through shared decision-making (paper I).

Empowerment is a fundamental element of PCC and encompasses the agency needed to master one's life situation regarding both participation in treatment, self-management, and social life (paper III, IV). Empowerment is also considered as an aspect of health (paper II) and a preferred treatment outcome, and part of self-management (paper III). Over time, the significance of a supportive environment and self-management increased (paper III). Acquiring knowledge empowers patients to master the new life situation (paper III). Empowerment is facilitated through PCC, especially in the tailored information offered by supportive healthcare professionals, who play a crucial role in enabling patients to achieve independence (paper I).

Well-being represents a significant outcome of PCC and treatment outcomes. The aspect encompasses diverse dimensions such as joy in everyday life (paper III), happiness (paper II), and general well-being (paper IV). Access to healthcare is also an important part of 'well-being' by fostering feelings of safety and trust in provided care (paper I). Patients' well-being is intrinsically linked to disease control—both physically and emotionally—given the unpredictable nature of early RA (papers II–IV). At the onset of RA, patients were primarily concerned with physical well-being and related limitations. Nevertheless, after a year, emotional burdens increased due to doubts about the future (paper III).

Discussion

Four papers in this thesis have explored patient perspectives on PCC and preferred outcomes in early RA. The results from paper I showed that PCC is important for patients with early RA. The prerequisite for PCC is respectful treatment from dedicated and professional healthcare professionals. For patients with early RA, having access to multidisciplinary care, being supported and listened to, and involved in shared decision-making are all crucial for PCC. Person-centred outcomes were identified as satisfaction with the healthcare one received and achieving optimal health. In paper II, health among patients with early RA was understood as belonging— including the feeling of being needed and having a meaningful day; happiness and enjoyment; freedom through independence; and empowerment through self-management and capability. In paper III, the results showed that the Swedish perspective on patient-preferred treatment outcomes in early RA was mastering one's life situation through disease control, autonomy, identity, and joy, despite RA. The fourth paper is based on a European perspective, where the patient-preferred treatment outcome was to live a normal life despite RA through well-being, disease control, physical performance, and self-accomplishment. In this thesis, the comprehensive understanding of PCC was described as meeting dedicated, supportive, and professional healthcare professionals (paper I, II), being involved in decision-making (papers I–IV) and having easy access to care (paper I). Three key aspects were highlighted as the comprehensive understanding of preferred outcomes in early RA; independence, empowerment, and well-being (papers I–IV) and will be discussed as insights from the thesis.

Person-centred care

This thesis emphasises that PCC enables a patient to be seen as an equal and to be treated with respect by dedicated healthcare professionals. A perception of the opposite—namely, a lack of respect and disorganised healthcare professionals—led to feelings of disappointment and despair (paper I). Patients in remission or with a low disease activity can usually continue their normal participation in work and social life (Aletaha & Smolen, 2018), which is in line with the preferred outcomes of participation and continuation of work and social life presented in this thesis (papers III–IV). Despite consistent treatment goals between healthcare professionals and the patient-preferred treatment outcomes presented in this thesis (papers III–IV), patients still experience unmet needs (Bala et al., 2017; Kvrgic et al., 2018; Taylor et al., 2016; Winthrop et al., 2019). Developing therapeutic relationships within the PCC framework undergirded by mutual trust and understanding may diminish unmet patient needs. PCC is characterised by respect for each person's subjectivity, capability, and personhood, and is a desired approach that leads to better patient health outcomes (Hulen et al., 2017; McCormack & McCance, 2006; Segan et al., 2018).

In this thesis, PCC was described as meeting dedicated, supportive, and professional healthcare professionals (papers I and II) and being involved in decision-making (papers I–IV). To adopt PCC in all levels of the healthcare organisation, it requires a systematic approach with regulations to motivate PCC in clinical practice (Rosengren et al., 2021). The physical environment, the organisational philosophy of care, and healthcare professionals' actions are essential features of a person-centred climate (McCormack & McCance, 2017). For the management of RA, EULAR recommends shared decision-making—which is an important aspect of PCC—to achieve effective treatment outcomes (Combe et al., 2017; Smolen et al., 2023). However, not all patients desire or have the capacity to participate actively, and healthcare professionals cannot abandon patients who do not have the resources or expertise to enable self-management (Batalden et al., 2016). In addition, the number of patients who can not but want to participate in shared decision-making is higher than the number of patients who do not want to participate. Research has shown that most patients want to be more actively involved in decisions regarding their healthcare, but there is a lack of knowledge and empowerment required for participation. Addressing and resolving this issue should be a priority for healthcare professionals (Joseph-Williams et al., 2014). Patients in this thesis had had positive experiences with PCC and preferred to be involved in decisions regarding their care, which align with published results showing that participation is important and that the ability to influence ones' situation facilitates a positive feeling of being included and a sense that you matter as a person, which in turn provides a sense of belonging (Sverker et al., 2019).

In this thesis, the patients valued easy access and support from a multidisciplinary team, which was appreciated by patients and instilled in them feelings of safety (paper I). This is supported by previous research that emphasises the importance of easy access to dedicated and competent healthcare professionals to patient satisfaction (Primdahl et al., 2011; Sjö & Bergsten, 2018). On the other hand, this thesis showed that an unsupportive healthcare system left patients feeling lonely while trying to master the healthcare system (paper I). Kristensson Uggla (2020) described a three-fold disadvantage of being a patient in a hospital setting. First, there is the institutional disadvantage of being at the very bottom of the hierarchical ladder in the healthcare organisation. Secondly, there is the existential disadvantage of being vulnerable due to poor health or complicated illness, and third, the cognitive disadvantage of lacking knowledge and previous experience of one's current illness or health situation (Kristensson Uggla, 2020). Healthcare professionals must acknowledge the initially unequal relationship and understand that PCC is implemented to reduce the patient's multiple disadvantages, involve and respect patients' needs and perspectives, and enter into mutual agreements (Forsberg & Rantala, 2020). PCC has been critiqued as time-consuming and costly. However, previous research has shown that patients were less uncertain about their illness after PCC (which may help equip and empower patients in managing their illness) (Dudas et al., 2013) and that PCC improved the experience of health (Feldthusen et al., 2016; Lange, Kucharski, et al., 2019; Wallström et al., 2020), reduced hospital stays (Ekman et al., 2012; Olsson et al., 2016; Ulin et al., 2016), and demonstrated that PCC was both cost-effective and improved patients' quality of life (Hansson et al., 2016; Larsson et al., 2015; Sahlen et al., 2016).

Preferred outcomes

The comprehensive understanding of preferred outcomes in early RA revealed three key aspects: independence, empowerment, and well-being—all of which were found in papers I–IV.

Independence

This thesis highlights how patient independence is essential in PCC and is an outcome characterised by the capacity to live a meaningful life without RA-based restraints (paper III). 'Independence' includes maintaining engagement in meaningful activities, such as work and social involvement (papers III and IV)—but independence also constitutes an essential aspect of health (paper II). Participating in paid work is important for individual's self-esteem and gives their days purpose, offers financial independence, and contributes to a positive feeling of belonging and the sense that you matter as a person (Sverker et al., 2019; Verstappen, 2015); all aspects in line with the results of this thesis. Independence is entailed by the freedom to preserve one's identity; an identity which is connected to work, leisure, and physical appearance (papers III–IV). Previous research shows the negative effects RA can have on social roles, interpersonal and intimate relationships, and dilemmas regarding an inability to fulfil social roles (Sverker et al., 2015), all of which frame the present results pertaining to a patient's ability to participate as a preferred outcome. Independence was also characterised as the capability to achieve life goals (papers II–IV) and to sustain physical and financial independence (papers II–III) while engaging in desired activities (papers I–IV). A recently published scoping review defines independence in RA literature as the possibility to perform work, social activities, and to maintain physical function to experience freedom in activities (Khoo et al., 2023), which matches our results. PCC encourages patients to engage in treatment decisions and foster independence when requested (paper I). It is known from previous research that an RA diagnosis challenge the experience of freedom and independence. Patients preferred to foster self-sufficiency, engage in care, live their lives to the fullest, and be independent without relying on assistance from others (Cornelissen et al., 2021; Cozad et al., 2023; Khoo et al., 2023).

Empowerment

This thesis emphasises empowerment as a fundamental outcome of treatment and PCC. Empowerment encompasses the power to master one's life situation (paper III), the ability to take charge of one's life and disease management, and the capability to participate in both treatment and social life (paper IV). Empowerment is a process that increases a person's assets to build capacities to gain control. This aligns with previous research showing that person-centred support and advice given in dialogue create conditions necessary to become empowered. Experiences of being empowered and recognised as a person also contribute to feeling prepared and in control (Nivestam et al., 2021). Knowledge serves as a source of power and confidence to master one's new life situation (paper III). Empowerment is facilitated through PCC—particularly in the tailored information provided by healthcare professionals (paper I). Supportive and motivated healthcare professionals play a vital role in empowering patients to achieve independence (paper I). Previous research shows that empowered patients manage their disease better (Voshaar et al., 2015) and experience a strengthened capability to adapt and self-manage, which often improves subjective well-being (Huber et al., 2011).

The results of this thesis demonstrated that PCC empowers patients to maintain their independence and involvement in decision-making regarding their treatment and care (papers I and III). This is congruent with international policies that emphasise patient participation as essential in fostering a sustainable and empowering healthcare environment that promotes health and self-management (Smolen et al., 2023; United Nations, 2015; WHO, 2015). WHO recommends PCC based on the positive benefits of improved health literacy and empowered and engaged patients who participate in their care and in shared decision-making. PCC has also been associated with increased satisfaction with care (WHO, 2015). Furthermore, the results from this thesis regarding patient empowerment are supported by a systematic review of qualitative studies where patients experienced positive outcomes from holistic and empathic PCC. These outcomes include a sense of empowerment, security, and increased confidence (Sweeney et al., 2021).

In addition, empowerment and capability are both aspects related to the concept of overall health (paper II). Huber et al., (2011) suggest a definition of health as "the ability to adapt and to self-manage", and that a healthy person is capable of restoring an equilibrium regarding health and disease. This is in line with the preferred treatment outcomes in paper III regarding the role of empowerment in managing life and disease. When patients understand the factors affecting their health, they can feel empowered and experience an enhanced quality of life. Having autonomy, knowledge, and the control to make shared decisions may lead to stronger self-esteem and improve patient well-being (Tengland, 2007a).

In this thesis, empowerment was a desired treatment outcome and a component of self-management (paper III). Over time, the significance of self-management and of experiencing a supportive care environment increased (paper III). Patient support by healthcare professionals increased patients' skills to manage the disease and to make preferred lifestyle changes (paper II). This is in line with previous research showing that personalised support and PCC increases motivation for lifestyle changes, self-management, adherence to pharmacological treatment, and enhanced vitality (Barenfeld et al., 2020; Mayo et al., 2022; Trento et al., 2020). Self-management interventions empower patients and facilitate behavioural changes and the ability to cope with disease symptoms in order to improve well-being and independence (Bech et al., 2020). Having an understanding relationship with healthcare providers also increases confidence, self-knowledge, and self-efficacy (Oshotse et al., 2018). Self-efficacy is related to peoples' self-management skills and is essential for patients to remain in charge of their lives (Lorig et al., 1989). A persons' self-efficacy has been found to be strengthened in patients receiving PCC (Ali et al., 2021; Fors et al., 2015; Fors et al., 2017; Fors et al., 2020; Pirhonen et al., 2017).

Well-being

In this thesis, well-being emerged as a preferred outcome of PCC and treatment, and comprises various dimensions, including happiness (paper II), joy in everyday life (paper III), general well-being (paper IV), and access to healthcare (paper I). Health and well-being serve as the ultimate person-centred outcomes (paper I). Access to healthcare fosters feelings of safety, security, and trust (paper I). Previous research shows that PCC delivered through good communication, a personal relationship, and a holistic and empathic approach increases patients' overall well-being (Oshotse et al., 2018; Ragouzeos et al., 2019; Sjö & Bergsten, 2018; Sweeney et al., 2021; van Eijk-Hustings et al., 2013; Zuidema et al., 2015), which aligns with the results of this thesis regarding the prerequisites that healthcare providers treat patients with respect, listen carefully, support patients, and share decision-making (paper I). Knowledge about disease and treatment affected patients' abilities to master their new life situation (paper III). Previous research showed that increased knowledge regarding one's health, increased patient understanding, autonomy, and improved well-being (Eriksson, 2022; Tengland, 2007a). Also, a strengthened capability to adapt and self-manage often improved subjective well-being (Huber et al., 2011). Given the unpredictable nature of RA in its early stages, patients' well-being is a result of disease control, both physically and emotionally (papers II–IV). At RA onset, patients were primarily concerned with physical well-being and physical limitations. Previous research on patient-preferred outcomes shows that patients prefer improved physical function, reduced pain, decreased joint swelling and stiffness, and increased energy levels to increase their overall well-being. Patients also preferred to prevent further progression of RA, and they experienced concerns about sexuality and reproduction (Hulen et al., 2017). However, after a year, when the disease became more manageable, patients in this thesis expressed that emotional burdens intensified due to uncertainties and anxieties about the future, which had a negative impact on their emotional well-being (paper III). Patients described a transition from hope to despair over time, with increased feelings of anxiety and frustration occurring later in the disease course, affecting their ability to regain their identity and manage their life situation (paper III). Psychological distress as a complication of early RA is well-known (Östlund et al., 2014). Sadness, hopelessness, fear, anger, and shame can occur in relation to restrictions on patient participation in their preferred activities (Östlund et al., 2014), and pain can lead to a deteriorated self-image (Pedraz-Marcos et al., 2018).

The results show that well-being is dependent on treatment effectiveness. Despite greater control of physical symptoms, the Swedish participants in this thesis tended to express a greater negative impact of RA on their emotional well-being compared to their European counterparts. They expressed more threats to their normal life caused by RA after 1–2 years with the condition (paper IV). These differences may be explained by the local context and specific cultural characteristics that influence how patients understand, evaluate, and make decisions related to their health and care (Agency for Healthcare Research and Quality, 2020). Previous research shows that despite advancements in pharmacological treatment of RA, patients still have a significantly lower quality of life than the general population (Poh et al., 2015). In terms of well-being and independence, patients in this thesis expressed a preference to be able to make long-term plans and commitments (paper IV). Previous research showed that a good mood, the ability to live a socially active life, to be self-sufficient, and to maintain one's identity and life roles all led to increased well-being (Hulen et al., 2017), which underscores the results from this thesis.

Methodological considerations

This thesis used qualitative methods to explore patients' perspectives of PCC and preferred outcomes in early RA. One of the most difficult challenges in healthcare is that humans vary in their experiences, reactions to diseases and treatment, and thoughts about the surrounding world. Thus, it is important that patient care is tailored and based in a consideration of the vast differences among people (Sjöström & Dahlgren, 2002). Qualitative methods are well-suited to describing or elucidating the central meaning of a lived experience. The purpose of interviewing is to enter into the other person's perspective (Patton, 2015). Qualitative methods were chosen in this thesis in order to gain a deeper understanding of the experience and preferences of living with early RA. The purpose of the research guided the selection of designs. By employing various designs across different papers, a comprehensive understanding of the patients' experiences and preferred outcomes was developed. In qualitative research, interviews are a commonly used method of data collection. In this thesis, individual and focus group interviews with patients with early RA were the data sources.

Trustworthiness

Trustworthiness in this thesis has been discussed in the light of the four criteria suggested by Lincoln and Guba (1985): credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985). To ensure trustworthiness, the studies are reported following the Consolidated Criteria for Reporting Qualitative Research 32-item checklist (Tong et al., 2007).

Credibility

Credibility refers to the truthfulness of the results and conclusions. The quality of qualitative data depends on the methodological training and skills of the researcher. Skilful interviewing and credible analysis demands more than just straightforward reading to generate meaningful data collection, and therefore requires knowledge, training, and discipline (Patton, 2015). In this thesis, credibility was strengthened through preparation and training. I was trained in interviewing, and pilot interviews were performed to strengthen the credibility of the studies. Data collection was performed together in a close relationship with the main supervisor (IL) an experienced senior qualitative researcher. The interview guide was revised by the research group and discussed with the patient research partner to intrecrease its relevance. To strengthen the credibility of the results, the analysis was verified by all co-authors as well as by the research partner. This triangulation made it possible for co-authors to confirm or disagree with the interpretations and assured them that it was not influenced by interest or pre-understanding, strengthening the credibility. An additional method to assure credible results is to use member checks, which is a method of validating data through debriefings or discussions with study participants (Lincoln & Guba, 1985; Polit & Beck, 2021). Since interpretation immediately begins in order to decide upon probing questions during interviews, any misunderstandings may jeopardise the quality of the data (Sjöström & Dahlgren, 2002). In this thesis, the interviewer summarised what was said during the interview and confirmed with the participant whether it had been understood correctly before the interview ended. Collaboration with the patient research partner further strengthened credibility (Lincoln & Guba, 1985).

A limitation regarding credibility in interviewing could be the participants' motivation to be interviewed. In this thesis, one of the interviews was considered short (16 minutes) but was concise and rich in content. A person's motivation to talk could depend on their personality, but of course could also be affected by the interviewer's skills and experience in interviewing. All participants participated voluntarily and their responses after the interviews were positive. The interviewers' experiences as rheumatology nurses strengthened the credibility of the research. Being familiar with the context and culture of the research area instils trust to the participants and increases the researcher's credibility (Lincoln & Guba, 1985).

Dependability

Dependability relates to the reliability of the data (Polit & Beck, 2021). The research process needs to be logical, traceable, and clearly documented in order to judge dependability (Lincoln & Guba, 1985). Therefore, the research process in this thesis is described as clearly as possible so others can follow along with data collection and analysis. In paper I, the abductive approach—or alternating between inductive and deductive analyses—contributed to a more comprehensive understanding (Graneheim et al., 2017; Patton, 2015) of the perceptions of PCC within the PCC framework as outlined by McCormack and McCance (2006). Paper II used a phenomenographic approach, which was considered the most appropriate method since the aim was to describe different ways of understanding health. The aim of phenomenography is to describe variation in people's experiences and understanding of a phenomenon, not the phenomenon itself (Marton, 1981). In papers III and IV, the aim was to explore patients' preferred treatment outcomes during the first years of RA treatment and QUAGOL (Dierckx de Casterle et al., 2012), and Saldaña's guiding questions for analysing longitudinal data (Saldaña, 2002) were chosen as the most appropriate method. They are described in the published study protocol for the EQPERA project (Van der Elst et al., 2019). The meta-synthesis developed for EQPERA was inspired by the principles of meta-ethnography, as practiced by Britten et al. (2002). This can be considered a limitation, but since it is uncommon to perform meta-synthesis based on empirical data, it was feasible.

Dependability was further strengthened by the fact that all interviews began with the same questions to ensure the stability of the data. However, there is a possible influence on the results in the meta-synthesis due to plural interviewers being part of this study in different countries, with a possible impact on the probing questions. It is a strength to have native interviewers who understand the local guidelines and potential cultural context, but it can also affect probing questions. However, actions were taken in the planning of the study to reduce the risk of bias, and the same interview guide with the same questions translated into native languages was used, and a study protocol was published (Van der Elst et al., 2019). The interviewer's experiences can affect the interviews and cultural differences between countries and healthcare systems can affect the conversations. The Swedish participants were the only ones who discussed non-pharmacological treatment (paper IV), which may be due to the fact that they were the only patients being offered non-pharmacological care as a part of standard care. The Swedish patients also experienced increased negative emotional well-being, which can depend on the cultural context, the interviewers' interest, or the probing questions asked as follow-ups to the interview questions. The international research group tried to counter these potential biases by discussing, planning, translating, and reviewing the interview questions with research partners.

To strengthen dependability, purposive sampling was used to maximise the possibilities of capturing variations in participants' experiences. We invited the same participants for a second interview in order to explore the development over time.

Dependability was strengthened since the interviews were conducted close to treatment initiation in order to collect the experiences as closely as possible but still allow the amount of time needed for the patient to feel safe and ready to share their experiences and preferences. For the second interview, focus groups were chosen to understand how people who have something in common feel or think about an issue (Krueger, 1988). In addition, focus group interviews take advantage of group dynamics to access rich information. By participating in discussions and listening to others, experiences can lead to personal reflections and new perspectives. After one year, participants were probably more comfortable sharing thoughts in a group environment due to a growing disease perspective. Group interviews aim to let participants consider their own views in the context of others and should be a safe environment that encourages participants to share ideas and perceptions (Patton, 2015).

Confirmability

Confirmability refers to the neutrality and objectivity of the data. Data should, ideally represent participants' voices (Polit & Beck, 2021). Confirmability was demonstrated through systematic handling of the data: repeated readings, reflections during interpretations, and descriptions of all steps in the different analyses. Quotations were used from the interviews to verify findings and to help readers assess the confirmability of the data.

In qualitative research, the authors' pre-understanding is part of the interpretative process and needs to be reflected upon to ensure that it doesn't affect the results (Dahlberg et al., 2008). Having a pre-understanding of the topic could be seen as both a strength and a limitation. During the research process, the authors' preunderstandings were discussed and critically reflected upon in order to broaden their awareness of the risk of biased interpretation. To elaborate pre-understanding, is vital in evaluating the trustworthiness of the research (Dahlberg & Dahlberg, 2019).

Transferability

Transferability refers to the applicability of the findings to other settings or groups. The reader should be able to evaluate the relevance of the data to other contexts (Polit & Beck, 2021). In terms of transferability, data was collected from several cities as well as from university hospitals and private practices. Regarding sample size in qualitative inquiry, an appropriate sample size depends on the purpose of the study and the method being used, and is driven by purposeful strategies instead of methodological rules (Patton, 2015). One guiding principle that has been used in this thesis is data saturation. Data collection continued until no new information was obtained, and enough in-depth data was available to illuminate patterns of the phenomenon (Polit & Beck, 2021). Experiences from a large number of phenomenographic studies have shown that data from 20 informants is usually enough to discover different ways of understanding (Larsson & Holmström, 2007). In this thesis, 31 participants were included to ensure variations in experiences and backgrounds. The sample sizes in this thesis can be regarded as sufficient for ensuring variation. However, the optimal size for focus groups is 6–12 participants (Polit & Beck, 2021). In this thesis, the groups were smaller than intended (2–3 participants per group), which could limit rich discussion. It could, however, also make participants feel more secure in speaking out loud and being equally involved in discussions (Polit & Beck, 2021). However, we found no negative impact on the interactions of the small groups. Not all participants at the second interview were able to participate in focus groups. To decrease the risk of drop-out, we also offered individual interviews to increase the likelihood of reaching persons who, depending on personal reasons, had not agreed to participate in a group interview. The absence of interaction with other participants may have limited some aspects of discussion, but it could also have encouraged participants to share more openly than they might have in a focus group setting.

Longitudinal designs are preferable when studying development or changes over time (Polit & Beck, 2021) and are well-suited due to the focus in this thesis on the evolving early stage of the disease (papers III and IV). The findings can be considered transferable to similar contexts involving patients with early RA or other chronic diseases in the early stages of their illness and to the development of the disease over time.

Conclusion

This thesis has developed knowledge regarding patients' perspectives of PCC and preferred outcomes in early RA. The results emphasise PCC as meeting supportive, dedicated, and professional healthcare professionals, easy access to care, and the ability to be involved in decision-making. Three key aspects were highlighted when exploring the comprehensive understanding of preferred outcomes of treatment and PCC: independence, empowerment, and well-being. Independence implies a meaningful life and a sense of freedom; empowerment reflects patient's ability to engage in self-management; and well-being encompasses the broader spectrum of physical, mental, and social health, ultimately capturing the holistic benefits of a person-centred approach. Furthermore, the results describe patients' experiences and preferences in managing their life situation and their ability to make independent decisions and use improved self-management skills and increased empowerment to manage their new life situation, which facilitates well-being. Thus, this thesis highlights the importance of working with a person-centred approach in clinical practice, from the patients' perspectives.

Clinical implications

Since PCC is acknowledged as a key dimension of high-quality care, a patient perspective is advocated to achieve optimal person-centred outcomes in the treatment of RA. PCC is an approach that is intended to encourage and empower patients to play an active role in treatment and to support them in making informed decisions and treatment goals to improve their well-being. Patients' experiences can change during different stages of the disease and greater knowledge about patients' experiences and preferences is important for facilitating the development of care. Results from this thesis increase the understanding of patients' experiences in early RA and it emphasize that patients' experiences are individual and diverse, which must be considered in PCC. Healthcare professionals can use the results from this thesis to improve PCC and deepen patient's participation in treatment goals, which may lead to better treatment and health outcomes in early RA care. The results from this thesis can also contribute to a deeper understanding of the dynamic process of patients' preferred treatment outcomes in early RA to prevent the development of unmet needs, increase patient satisfaction, and improve the quality of care through PCC.

Future perspectives

Results from this thesis can be used to develop clinical practice and address the importance to standardise, assess, and improve PCC for a successful systematic implementation and evaluation. Targeted interventions are needed to reach patient's treatment goals, and further research is needed to optimise the way healthcare addresses and handles patients' needs through PCC. Further research is needed to:

- Evaluate PCC in early RA clinics with a 'treat to target' and 'tight control' approach to provide a deeper understanding of how patients experience this type of clinic. This should include both patient-reported outcomes and interviews of patients and health care professionals.
- Develop and evaluate interventions that support patient empowerment and independence.

Summary in Swedish

Patienters perspektiv på personcentrerad vård och deras förväntningar på behandlingsresultat vid tidig reumatoid artrit

Reumatoid artrit (RA), även kallat ledgångsreumatism, är en kronisk, systemisk, inflammatorisk ledsjukdom som kan påverka alla aspekter av livet och kan vara en livsomvälvande upplevelse. RA för med sig besvärande symtom som ömma och svullna leder, morgonstelhet och trötthet som kan påverka vardagen såsom arbete, fritid och familjeliv (Scott et al., 2010).

Reumatologisk vård och behandling syftar till att uppnå optimal hälsa för patienterna genom personcentrerad vård (PCC) (Bech et al., 2020). I Sverige har personcentrerade och sammanhållna vårdförlopp för både tidig och etablerad RA tagits fram via Nationellt system för kunskapsstyrning inom hälso- och sjukvård (Nationellt kliniskt kunskapsstöd, 2023). Målet med dessa är en bättre samordning, gott bemötande och delaktighet i den reumatologiska vården. De senaste tre decennierna har läkemedelsbehandlingen förbättrats avsevärt beträffande resultat och prognos för patienter med RA. Forskning har visat vikten av tidigt insatt behandling och täta kontakter och besök på den reumatologiska kliniken samt att detta förbättrat resultaten drastiskt (Aletaha & Smolen, 2018). Syftet med tidigt insatt behandling och tät kontakt med utvärdering av behandlingen är att bromsa utveckling av ledskador och nedsatt funktion. Det övergripande behandlingsmålet är att nå symtomfrihet eller låg sjukdomsaktivitet (Aletaha & Smolen, 2018) och att erbjuda bästa möjliga vård och behandling i samråd med patienten (Smolen et al., 2023). Trots att det numera finns effektiv behandling tillgänglig som förbättrat prognosen för flertalet patienter, har forskningen visat att patienter fortfarande upplever otillfredsställda behov (Bala et al., 2017; Kvrgic et al., 2018; Taylor et al., 2016; Winthrop et al., 2019). Patienter och vårdpersonal har olika perspektiv och expertis och måste samarbeta för att få bästa möjliga resultat. Tidigare forskning har visat att delat beslutsfattande och involvering av patienter i behandlingsbeslut och utveckling av vårdplaner behövs för att förbättra och utveckla vården och dess resultat för den enskilda personen (Nikiphorou et al., 2021; Smolen et al., 2023). Det är därför viktigt att utforska patienters uppfattningar, erfarenheter och förväntningar. Denna avhandling är baserad på upprepade intervjuer för att förstå patienters perspektiv under den tidiga fasen av sjukdomen, vilket är viktig information för vårdpersonal som arbetar med dessa patienter, i det tidiga sjukdomsförloppet. Patienter som nyligen diagnostiserats med RA bjöds in till en individuell intervju beträffande deras erfarenheter och uppfattningar av personcentrerad vård, hälsa och behandlingsresultat. Efter ca 1 år, bjöds samma patienter in till en uppföljande fokusgruppsintervju, för att i grupp utbyta erfarenheter och förväntningar på behandlingsresultat.

Det övergripande syftet med denna avhandling var att utforska patienters perspektiv på personcentrerad vård och förväntningar på behandlingsresultat vid tidig RA. Studie 1 utforskade patienters uppfattningar av personcentrerad vård tidigt i sjukdomsförloppet, studie 2 beskrev vad hälsa innebar för patienter med tidig RA, studie 3 utforskade patienters förväntade behandlingsresultat under de första åren med RA och studie 4 utforskade patienters förväntade behandlingsresultat och hur dessa förändrades under det tidiga sjukdomsskedet i tre europeiska länder.

Resultatet från delstudie 1 visade att bland patienter med tidig RA beskrevs personcentrerad vård i termerna av 1) förutsättningar som innebär att bli behandlad med respekt, möta engagerad och kompetent personal, 2) vårdmiljö som innebär tillgänglighet till vården och ett tvärprofessionellt team (reumatolog, sjuksköterska, fysioterapeut, arbetsterapeut, kurator) som arbetar i en stödjande organisation, 3) personcentrerade processer som innebär att bli lyssnad till, få stöd och bli involverad i beslutsfattande, 4) personcentrerade resultat innebär att vara nöjd med den givna vården och uppnå optimal hälsa.

Delstudie 2 visar att patienter med tidig RA beskriver hälsa som att ha en 1) tillhörighet genom att känna ett sammanhang och att ha en meningsfull vardag, 2) livsglädje genom att känna glädje i vardagen, 3) frihet genom att känna sig oberoende och klara sig själv samt 4) empowerment genom att känna sig kapabel till att hantera livet.

Delstudie 3 visar att ett övergripande förväntat behandlingsresultat för patienter med tidig RA är att hantera den nya livssituationen med en kronisk sjukdom. Deras förväntningar på behandlingsresultatet är att uppleva att 1) ha sjukdomen under kontroll genom symtomkontroll och känslan av frånvaro av sjukdom, 2) ha autonomi i livet genom självständighet och att återfå tidigare aktivitetsförmåga, 3) återfå sin identitet genom att kunna delta i önskade aktiviteter och uppleva välbefinnande och återfå sin självbild och 4) känna framtidstro genom vitalitet och framtidstro.

Delstudie 4 är en internationell metasyntes av resultatet från två studier i Belgien och Nederländerna och delstudie 3 utifrån ett gemensamt studieupplägg (Van der Elst et al., 2019). Resultatet visar att förväntat resultat med behandlingen för patienter med tidig RA är att leva ett så normalt liv som möjligt trots en kronisk sjukdom. Behandlingsresultat som värdesätts är 1) sjukdomskontroll som innebär symtomlindring, hitta rätt behandling och att ha en stabil sjukdom, 2) fysisk förmåga genom att ha funktionsförmåga och att kunna utföra aktiviteter och upprätthålla sin självständighet, 3) självförverkligande genom förmåga att hantera sjukdom och behandling, arbete, vardag och familj samt återfå identiteten som sjukdomen påverkat, 4) välbefinnande genom att känna emotionellt välbefinnande, ha en positiv inställning och känna vitalitet. Resultatet visar på flera likheter men även skillnader mellan länderna, vilket kan bero kulturella variationer eller variationer i sjukvårdsystem trots att samtliga länder erbjuder likande behandling. Skillnader som uppmärksammades vara att svenska patienter till skillnad från övriga tog upp icke-farmakologisk behandling som viktig behandling, medan patienterna i Belgien och Nederländerna fokuserade på den medicinska behandlingen vilken även värdesattes av de svenska patienterna. Patienter från alla tre länderna ville dock vara delaktiga i sin behandling och dess beslut. Detta önskemål ökade med tiden och de svenska patienterna fokuserade även på hur de själva kan hantera sin sjukdom och behandling och vilka livsstilsval de kan göra för att påverka behandlingsresultaten. Patienter från alla tre länderna ville uppleva självständighet och leva ett ’normalt’ liv, och vid den första intervjun beskrevs det som att återgå till hur livet var innan och vid den andra intervjun beskrevs det som att leva ett normalt liv trots RA.

Sammantaget visar avhandlingens resultat att personcentrerad vård innebär att möta lättillgänglig vård med stödjande, professionell och engagerad vårdpersonal och att få möjlighet att vara delaktig i sin vård och behandling. Beträffande förväntade behandlingsresultat så uppdagades tre nyckelaspekter: självständighet, empowerment och välbefinnande. Självständighet är både ett önskat behandlingsresultat men beskrivs även som en hälsoaspekt. ’Självständighet’ innebär att upprätthålla förmågan att kunna uppleva frihet genom att delta i önskade aktiviteter och förmågan att uppnå livsmål. Personcentrerad vård främjar självständighet genom delat beslutsfattande och delaktighet i vården.

Empowerment är en grundläggande del av personcentrerad vård och innebär att få det stöd som behövs för att bemästra sin livssituation. Empowerment beskrivs som en hälsoaspekt och som ett önskat resultat av den personcentrerade vården. Med tiden ökade betydelsen av en stödjande miljö, och patientens vilja att delta i sin vård och behandling. Personcentrerad vård skapar förutsättningar för patienter att utveckla empowerment – exempelvis genom skräddarsydd information och stödjande vårdpersonal, som spelar en viktig roll för att göra det möjligt för patienter att uppnå självständighet.

Välbefinnande är en hälsoaspekt likväl som ett förväntat resultat av den personcentrerade vården och behandlingen. Det omfattar olika dimensioner som glädje och allmänt välbefinnande. Ökad tillgänglighet till hälso- och sjukvård kan öka välbefinnandet hos patienter genom att främja känslan av trygghet och tillit till den vård som erbjuds. Patienters välbefinnande är naturligt kopplat till sjukdomskontroll – både fysiskt och känslomässigt – med tanke på de oförutsägbara symtom som kan uppstå vid tidig RA. Under den första sjukdomstiden var patienter främst oroade över fysiskt välbefinnande och begränsningar men efter ett år, ökade känslomässiga utmaningar på grund av tvivel och oro inför framtiden.

Genom att i denna avhandling lyfta patientperspektivet på personcentrerad vård, beskriva hälsobegreppet, samt undersöka förväntningar på behandlingsresultat vid tidig RA har ny kunskap erhållits kring vad patienter värdesätter och vad vården behöver fokusera på inom ramen för personcentrerade och sammanhållna vårdförlopp. Resultaten understryker vikten av att arbeta med ett personcentrerat förhållningssätt i den kliniska vården som uppmuntrar till delat beslutsfattande och gemensamt uppsatta behandlingsmål, tillsammans med patienterna.

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References

Agency for Healthcare Research and Quality, R., MD. (2020, September 2020). *Consider Culture, Customs, and Beliefs: Tool #10.* . Agency for Healthcare Research and Quality, Rockville, MD. Retrieved 27 September 2023 from https://www.ahrq.gov/health-literacy/improve/precautions/tool10.html

Ahlmén, M., Nordenskiöld, U., Archenholtz, B., Thyberg, I., Rönnqvist, R., Lindén, L., Andersson, A. K., & Mannerkorpi, K. (2005). Rheumatology outcomes: the patient's perspective. A multicentre focus group interview study of Swedish rheumatoid arthritis patients. Rheumatology (Oxford, England), 44(1), 105–110. https://doi.org/10.1093/rheumatology/keh412

Aletaha, D., Neogi, T., Silman, A. J., Funovits, J., Felson, D. T., Bingham, C. O., 3rd, . . . Hawker, G. (2010). 2010 Rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Arthritis Rheum*, *62*(9), 2569–2581. https://doi.org/10.1002/art.27584

Aletaha, D., & Smolen, J. S. (2018). Diagnosis and Management of Rheumatoid Arthritis: A Review. *Jama*, *320*(13), 1360-1372. https://doi.org/10.1001/jama.2018.13103

Ali, L., Wallström, S., Ekman, I., Swedberg, K., & Fors, A. (2021). Effects of person-centred care via telephone on self-efficacy in patients with chronic obstructive pulmonary disease: Subgroup analysis of a randomized controlled trial. *Nurs Open*, *8*(2), 927-935. https://doi.org/10.1002/nop2.701

All European Academies, A. (2023). *The European Code of Conduct for Research Integrity—Revised Edition 2023*. http://www.doi.org/10.26356/ECOC

Andersson, M. L., Forslind, K., & Hafström, I. (2015). Comparing Five Year Out-Come in Two Cohorts of Patients with Early Rheumatoid Arthritis—A BARFOT Study. *Open Rheumatol J*, *9*, 8–15. https://doi.org/10.2174/1874312901409010008

Andersson, S. E. M., Lange, E., Kucharski, D., Svedlund, S., Önnheim, K., Bergquist, M., Josefsson, E., Lord, J. M., Mårtensson, I. L., Mannerkorpi, K., & Gjertsson, I. (2020). Moderate- to high intensity aerobic and resistance exercise reduces peripheral blood regulatory cell populations in older adults with rheumatoid arthritis. Immunity & ageing : I & A, 17, 12. https://doi.org/10.1186/s12979-020-00184-y

Antonovsky, A. (1987). *Unraveling the mystery of health : how people manage stress and stay well.* Jossey-Bass.

Arumugam, A., Phillips, L. R., Moore, A., Kumaran, S. D., Sampath, K. K., Migliorini, F., Maffulli, N., Ranganadhababu, B. N., Hegazy, F., & Botto-van Bemden, A. (2023). Patient and public involvement in research: a review of practical resources for young investigators. BMC rheumatology, 7(1), 2. https://doi.org/10.1186/s41927-023-00327-w

Bala, S. V., Forslind, K., Fridlund, B., & Hagell, P. (2018). Measuring person-centred care in nurse-led outpatient rheumatology clinics. *Musculoskeletal Care*, *16*(2), 296–304. https://doi.org/10.1002/msc.1234

Bala, S. V., Forslind, K., Fridlund, B., Samuelson, K., Svensson, B., & Hagell, P. (2018). Person-centred care in nurse-led outpatient rheumatology clinics: Conceptualization and initial development of a measurement instrument. *Musculoskeletal Care*, *16*(2), 287–295. https://doi.org/10.1002/msc.1233

Bala, S. V., Samuelson, K., Hagell, P., Fridlund, B., Forslind, K., Svensson, B., & Thome, B. (2017). Living with persistent rheumatoid arthritis: a BARFOT study. *J Clin Nurs*, *26*(17-18), 2646-2656. https://doi.org/10.1111/jocn.13691

Bala, S. V., Samuelson, K., Hagell, P., Svensson, B., Fridlund, B., & Hesselgard, K. (2012). The experience of care at nurse-led rheumatology clinics. *Musculoskeletal Care*, *10*(4), 202-211. https://doi.org/10.1002/msc.1021

Barenfeld, E., Ali, L., Wallström, S., Fors, A., & Ekman, I. (2020). Becoming more of an insider: A grounded theory study on patients' experience of a person-centred e-health intervention. *PLoS One*, *15*(11), e0241801. https://doi.org/10.1371/journal.pone.0241801

Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L., & Hartung, H. (2016). Coproduction of healthcare service. *BMJ Qual Saf*, *25*(7), 509-517. https://doi.org/10.1136/bmjqs-2015-004315

Bech, B., Primdahl, J., van Tubergen, A., Voshaar, M., Zangi, H. A., Barbosa, L., Boström, C., Boteva, B., Carubbi, F., Fayet, F., Ferreira, R. J. O., Hoeper, K., Kocher, A., Kukkurainen, M. L., Lion, V., Minnock, P., Moretti, A., Ndosi, M., Pavic Nikolic, M., Schirmer, M., … van Eijk-Hustings, Y. (2020). 2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Annals of the rheumatic diseases,* 79(1), 61–68. https://doi.org/10.1136/annrheumdis-2019-215458

Bergsten, U., Almehed, K., Baigi, A., & Jacobsson, L. T. H. (2019). A randomized study comparing regular care with a nurse-led clinic based on tight disease activity control and person-centred care in patients with rheumatoid arthritis with moderate/high disease activity: A 6-month evaluation. *Musculoskeletal Care*, *17*(3), 215-225. https://doi.org/10.1002/msc.1403

Bergström, M., Sverker, A., Larsson Ranada, Å., Valtersson, E., Thyberg, I., Östlund, G., & Björk, M. (2018). Significant others' influence on participation in everyday life - the perspectives of persons with early diagnosed rheumatoid arthritis. *Disabil Rehabil*, 1-9. https://doi.org/10.1080/09638288.2018.1499825

Berkovic, D., Ayton, D., Briggs, A. M., & Ackerman, I. N. (2020). "I Would be More of a Liability than an Asset": Navigating the Workplace as a Younger Person with Arthritis. *J Occup Rehabil*, *30*(1), 125-134. https://doi.org/10.1007/s10926-019-09853-2

Björk, M., Dragioti, E., Alexandersson, H., Esbensen, B. A., Boström, C., Friden, C., Hjalmarsson, S., Hörnberg, K., Kjeken, I., Regardt, M., Sundelin, G., Sverker, A., Welin, E., & Brodin, N. (2022). Inflammatory Arthritis and the Effect of Physical Activity on Quality of Life and Self-Reported Function: A Systematic Review and Meta-Analysis. *Arthritis care & research,* 74(1), 31–43. https://doi.org/10.1002/acr.24805

Björk, M., Thyberg, I., Rikner, K., Balogh, I., & Gerdle, B. (2009). Sick leave before and after diagnosis of rheumatoid arthritis--a report from the Swedish TIRA project. *J Rheumatol*, *36*(6), 1170-1179. https://doi.org/10.3899/jrheum.080523

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *J Health Serv Res Policy*, *7*(4), 209-215. https://doi.org/10.1258/135581902320432732

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H., & Wolf, A. (2020). Learning from Gothenburg model of person centred healthcare. *Bmj*, *370*, m2738. https://doi.org/10.1136/bmj.m2738

Chen, S.-H., Yu Dr, K.H., Kao, Y.C., & Shao, J.H. (2022). It Is Like a Puppet Show-Experiences of Rheumatoid Arthritis Among Adult Chinese: A Qualitative Study. *Clin Nurs Res*, *31*(5), 795-802. https://doi.org/10.1177/10547738211037467

Combe, B., Landewe, R., Daien, C. I., Hua, C., Aletaha, D., Álvaro-Gracia, J. M., Bakkers, M., Brodin, N., Burmester, G. R., Codreanu, C., Conway, R., Dougados, M., Emery, P., Ferraccioli, G., Fonseca, J., Raza, K., Silva-Fernández, L., Smolen, J. S., Skingle, D., Szekanecz, Z., … van Vollenhoven, R. (2017). 2016 update of the EULAR recommendations for the management of early arthritis. *Annals of the rheumatic diseases,* 76(6), 948–959. https://doi.org/10.1136/annrheumdis-2016-210602

Corbin, J. M., & Strauss, A. L. (2015). *Basics of qualitative research : techniques and procedures for developing grounded theory*. SAGE.

Cornelissen, L. E., van der Mark, E. J., Pennings, P., Maat, B., Foekens, T., Willemsen-de Mey, G., & Voogdt-Pruis, H. R. (2021). What Matters to Patients with Rheumatoid Arthritis When Facing Medical or Non-Medical Treatment Decisions? *Patient Prefer Adherence*, *15*, 1827-1841. https://doi.org/10.2147/ppa.S322257

Couppé, C., Comins, J., Beyer, N., Hansen, S. E., Stodolsky, D. S., & Siersma, V. (2017). Health-related quality of life in patients with chronic rheumatic disease after a multidisciplinary rehabilitation regimen. *Qual Life Res*, *26*(2), 381-391. https://doi.org/10.1007/s11136-016-1402-7

Cozad, M. J., Lindley, L. C., Crosby, K., Alshareef, N., Kennedy, A. B., Merchant, G., Evans, P., & Horner, R. D. (2023). Patient Goals for Living with Rheumatoid Arthritis: A Qualitative Study. *Clinical nursing research*, 32(1), 40–48. https://doi.org/10.1177/10547738221075784

Dahlberg, H., & Dahlberg, K. (2019). The question of meaning—a momentous issue for qualitative research. *International Journal of Qualitative Studies on Health & Well-Being, 14*(1), 1-12. https://doi.org/10.1080/17482631.2019.1598723

Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research*. Studentlitteratur.

de Wit, M. P., Berlo, S. E., Aanerud, G. J., Aletaha, D., Bijlsma, J. W., Croucher, L., Da Silva, J. A., Glüsing, B., Gossec, L., Hewlett, S., Jongkees, M., Magnusson, D., Scholte-Voshaar, M., Richards, P., Ziegler, C., & Abma, T. A. (2011). European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Annals of the rheumatic diseases,* 70(5), 722–726. https://doi.org/10.1136/ard.2010.135129

Di Matteo, A., Bathon, J. M., & Emery, P. (2023). Rheumatoid arthritis. *The Lancet*. https://doi.org/10.1016/S0140-6736(23)01525-8

Dierckx de Casterle, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud*, *49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

Drennan, V., Walters, K., Lenihan, P., Cohen, S., Myerson, S., & Iliffe, S. (2007). Priorities in identifying unmet need in older people attending general practice: a nominal group technique study. *Fam Pract*, *24*(5), 454-460. https://doi.org/10.1093/fampra/cmm034

Dudas, K., Olsson, L. E., Wolf, A., Swedberg, K., Taft, C., Schaufelberger, M., & Ekman, I. (2013). Uncertainty in illness among patients with chronic heart failure is less in person-centred care than in usual care. *Eur J Cardiovasc Nurs*, *12*(6), 521-528. https://doi.org/10.1177/1474515112472270

Edelaar, L., Nikiphorou, E., Fragoulis, G. E., Iagnocco, A., Haines, C., Bakkers, M., Barbosa, L., Cikes, N., Ndosi, M., Primdahl, J., Prior, Y., Pchelnikova, P., Ritschl, V., Schäfer, V. S., Smucrova, H., Storrønning, I., Testa, M., Wiek, D., & Vliet Vlieland, T. P. M. (2020). 2019 EULAR recommendations for the generic core competences of health professionals in rheumatology. *Annals of the rheumatic diseases,* 79(1), 53–60. https://doi.org/10.1136/annrheumdis-2019-215803

Einarsson, J. T., Willim, M., Ernestam, S., Saxne, T., Geborek, P., & Kapetanovic, M. C. (2019). Prevalence of sustained remission in rheumatoid arthritis: impact of criteria sets and disease duration, a Nationwide Study in Sweden. *Rheumatology*, *58*(2), 227-236. https://doi.org/10.1093/rheumatology/key054

Ekman, I., Ebrahimi, Z., & Olaya Contreras, P. (2021). Person-centred care: looking back, looking forward. *Eur J Cardiovasc Nurs*, *20*(2), 93-95. https://doi.org/10.1093/eurjcn/zvaa025

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L. E., Rosén, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. *European journal of cardiovascular nursing,* 10(4), 248–251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

Ekman, I., Wolf, A., Olsson, L. E., Taft, C., Dudas, K., Schaufelberger, M., & Swedberg, K. (2012). Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *Eur Heart J*, *33*(9), 1112-1119. https://doi.org/10.1093/eurheartj/ehr306

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129-136. https://doi.org/10.1126/science.847460

Eriksson, K. (2018). *Vårdvetenskap: vetenskapen om vårdandet : om det tidlösa i tiden*. Liber.

Eriksson, M. (2022). The Sense of Coherence: The Concept and Its Relationship to Health. In M. B. Mittelmark, G. F. Bauer, L. Vaandrager, J. M. Pelikan, S. Sagy, M. Eriksson, B. Lindström, & C. Meier Magistretti (Eds.), *The Handbook of Salutogenesis* (pp. 61-68). Springer Copyright 2022, The Author(s). https://doi.org/10.1007/978-3-030-79515-3_9

Fagerlind, H., Ring, L., Brülde, B., Feltelius, N., & Lindblad, A. K. (2010). Patients' understanding of the concepts of health and quality of life. *Patient Educ Couns*, *78*(1), 104-110. https://doi.org/10.1016/j.pec.2009.05.016

Feldthusen, C., Dean, E., Forsblad-d'Elia, H., & Mannerkorpi, K. (2016). Effects of Person-Centered Physical Therapy on Fatigue-Related Variables in Persons With Rheumatoid Arthritis: A Randomized Controlled Trial. *Archives of Physical Medicine & Rehabilitation*, *97*(1), 26-36. https://doi.org/10.1016/j.apmr.2015.09.022

Feldthusen, C., Forsgren, E., Wallström, S., Andersson, V., Löfqvist, N., Sawatzky, R., Öhlén, J., & J Ung, E. (2022). Centredness in health care: A systematic overview of reviews. *Health expectations : an international journal of public participation in health care and health policy*, 25(3), 885–901. https://doi.org/10.1111/hex.13461

Feldthusen, C., & Mannerkorpi, K. (2019). Factors of importance for reducing fatigue in persons with rheumatoid arthritis: a qualitative interview study. *BMJ Open*, *9*(5), e028719. https://doi.org/10.1136/bmjopen-2018-028719

Flurey, C., Hewlett, S., Rodham, K., White, A., Noddings, R., & Kirwan, J. R. (2017). "You Obviously Just Have to Put on a Brave Face": A Qualitative Study of the Experiences and Coping Styles of Men With Rheumatoid Arthritis [Article]. *Arthritis Care and Research*, *69*(3), 330-337. https://doi.org/10.1002/acr.22951

Flurey, C., Morris, M., Richards, P., Hughes, R., & Hewlett, S. (2014). It's like a juggling act: rheumatoid arthritis patient perspectives on daily life and flare while on current treatment regimes. *Rheumatology (Oxford)*, *53*(4), 696-703. https://doi.org/10.1093/rheumatology/ket416

Flurey, C., White, A., Rodham, K., Kirwan, J., Noddings, R., & Hewlett, S. (2018). 'Everyone assumes a man to be quite strong': Men, masculinity and rheumatoid arthritis: A case-study approach. *Sociol Health Illn*, *40*(1), 115-129. https://doi.org/10.1111/1467-9566.12628

Fors, A., Ekman, I., Taft, C., Björkelund, C., Frid, K., Larsson, M. E., Thorn, J., Ulin, K., Wolf, A., & Swedberg, K. (2015). Person-centred care after acute coronary syndrome, from hospital to primary care - A randomised controlled trial. *International journal of cardiology*, 187, 693–699. https://doi.org/10.1016/j.ijcard.2015.03.336

Fors, A., Swedberg, K., Ulin, K., Wolf, A., & Ekman, I. (2017). Effects of person-centred care after an event of acute coronary syndrome: Two-year follow-up of a randomised controlled trial. *Int J Cardiol*, *249*, 42-47. https://doi.org/10.1016/j.ijcard.2017.08.069

Fors, A., Wallbing, U., Alfvén, G., Kemani, M. K., Lundberg, M., Wigert, H., & Nilsson, S. (2020). Effects of a person-centred approach in a school setting for adolescents with chronic pain-The HOPE randomized controlled trial. *Eur J Pain*, *24*(8), 1598-1608. https://doi.org/10.1002/ejp.1614

Forsberg, A., & Rantala, A. (2020). The Being Taken Seriously Questionnaire-Development and Psychometric Evaluation of a PREM Measure for Person-Centeredness in a High-Tech Hospital Environment. *Int J Environ Res Public Health*, *17*(8). https://doi.org/10.3390/ijerph17082660

Funovits, J., Aletaha, D., Bykerk, V., Combe, B., Dougados, M., Emery, P., Felson, D., Hawker, G., Hazes, J. M., Huizinga, T., Kay, J., Kvien, T. K., Smolen, J. S., Symmons, D., Tak, P. P., & Silman, A. (2010). The 2010 American College of Rheumatology/European League Against Rheumatism classification criteria for rheumatoid arthritis: methodological report phase I. *Annals of the rheumatic diseases*, 69(9), 1589–1595. https://doi.org/10.1136/ard.2010.130310

Galloway, J., Edwards, J., Bhagat, S., Parker, B., Tan, A. L., Maxwell, J., Wallington, M., Blanthorn-Hazell, S., Bellamy, C., & Cole, Z. (2021). Direct healthcare resource utilisation, health-related quality of life, and work productivity in patients with moderate rheumatoid arthritis: an observational study. *BMC musculoskeletal disorders*, 22(1), 277. https://doi.org/10.1186/s12891-021-04110-1

Goodwin, V. A., Paudyal, P., Perry, M. G., Day, N., Hawton, A., Gericke, C., Ukoumunne, O. C., & Byng, R. (2016). Implementing a patient-initiated review system for people with rheumatoid arthritis: a prospective, comparative service evaluation. *Journal of evaluation in clinical practice*, 22(3), 439–445. https://doi.org/10.1111/jep.12505

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper [Article]. *Nurse Education Today*, *56*, 29-34. https://doi.org/10.1016/j.nedt.2017.06.002

Gwinnutt, J. M., Leggett, S., Lunt, M., Barton, A., Hyrich, K. L., Walker-Bone, K., & Verstappen, S. M. M. (2020). Predictors of presenteeism, absenteeism and job loss in patients commencing methotrexate or biologic therapy for rheumatoid arthritis. *Rheumatology (Oxford)*, *59*(10), 2908-2919. https://doi.org/10.1093/rheumatology/keaa027

Gwinnutt, J. M., Wieczorek, M., Balanescu, A., Bischoff-Ferrari, H. A., Boonen, A., Cavalli, G., de Souza, S., de Thurah, A., Dorner, T. E., Moe, R. H., Putrik, P., Rodríguez-Carrio, J., Silva-Fernández, L., Stamm, T., Walker-Bone, K., Welling, J., Zlatković-Švenda, M. I., Guillemin, F., & Verstappen, S. M. M. (2022). 2021 EULAR recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases. *Annals of the rheumatic diseases*, 82(1), 48–56. https://doi.org/10.1136/annrheumdis-2021-222020

Hansson, E., Ekman, I., Swedberg, K., Wolf, A., Dudas, K., Ehlers, L., & Olsson, L. E. (2016). Person-centred care for patients with chronic heart failure - a cost-utility analysis. *Eur J Cardiovasc Nurs*, *15*(4), 276-284. https://doi.org/10.1177/1474515114567035

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., van der Meer, J. W., Schnabel, P., Smith, R., van Weel, C., & Smid, H. (2011). How should we define health?. *BMJ (Clinical research ed.),* 343, d4163. https://doi.org/10.1136/bmj.d4163

Hulen, E., Ervin, A., Schue, A., Evans-Young, G., Saha, S., Yelin, E. H., & Barton, J. L. (2017). Patient goals in rheumatoid arthritis care: A systematic review and qualitative synthesis. *Musculoskeletal Care*, *15*(4), 295-303. https://doi.org/10.1002/msc.1173

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Summer Meranius, M. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient education and counseling*, 102(1), 3–11. https://doi.org/10.1016/j.pec.2018.08.029

Innala, L., Sjöberg, C., Möller, B., Ljung, L., Smedby, T., Södergren, A., Magnusson, S., Rantapää-Dahlqvist, S., & Wållberg-Jonsson, S. (2016). Co-morbidity in patients with early rheumatoid arthritis - inflammation matters. *Arthritis research & therapy*, 18, 33. https://doi.org/10.1186/s13075-016-0928-y

Jahani, S., Haghighi, S., Ansari, S., Rajaei, E., & Sayadi, N. (2022). The Lived Experiences of Iranian Patients with Rheumatoid Arthritis: A Qualitative Research. *Iran J Nurs Midwifery Res*, *27*(3), 204-210. https://doi.org/10.4103/ijnmr.ijnmr_84_21

Jones, J., & Hunter, D. (1995). Consensus methods for medical and health services research. *Bmj*, *311*(7001), 376-380. https://doi.org/10.1136/bmj.311.7001.376

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*, *94*(3), 291-309. https://doi.org/10.1016/j.pec.2013.10.031

Katchamart, W., Narongroeknawin, P., Chanapai, W., & Thaweeratthakul, P. (2019). Health-related quality of life in patients with rheumatoid arthritis. *BMC Rheumatol*, *3*, 34. https://doi.org/10.1186/s41927-019-0080-9

Khoo, T., Jones, B., Chin, A., Terrett, A., Voshaar, M., Hoogland, W., March, L., Beaton, D., Gazel, U., Shea, B., Tugwell, P., Flurey, C. A., & Proudman, S. (2023). Defining independence: A scoping review by the OMERACT patient perspective of remission in rheumatoid arthritis group. *Seminars in arthritis and rheumatism*, 58, 152152. https://doi.org/10.1016/j.semarthrit.2022.152152

Kristensson Uggla, B. (2020). Personfilosofi – filosofiska utgångspunkter för personcentrering inom hälso- och sjukvård [Personal Philosophy-Filosophical Starting Points for Person-Centeredness in Health Care]. . In I. Ekman (Ed.), *Personcentrering inom hälso- och sjukvård: Från filosofi till praktik [Person-Centeredness in Health Care. From Philosophy to Practice]* (pp. 25-72). Liber. (Personcentrering inom hälso- och sjukvård: Från filosofi till praktik)

Krueger, R. A. (1988). *Focus groups: A practical guide for applied research*. Sage Publications, Inc.

Kvale, S., & Brinkmann, S. (2014). *Den kvalitativa forskningsintervjun [The qualitative research interview]*. Studentlitteratur.

Kvrgic, Z., Asiedu, G. B., Crowson, C. S., Ridgeway, J. L., & Davis, J. M., 3rd. (2018). "Like No One Is Listening to Me": A Qualitative Study of Patient-Provider Discordance Between Global Assessments of Disease Activity in Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)*, *70*(10), 1439-1447. https://doi.org/10.1002/acr.23501

Lag om ansvar för god forskningssed och prövning av oredlighet i forskning [Swedish legislation on good research practice] (SFS 2019:504). Pub. L. No. SFS 2019:504, https://svenskforfattningssamling.se/sites/default/files/sfs/2019-06/SFS2019-504.pdf

Laitinen, A. M., Boström, C., Hyytiä, S., & Stolt, M. (2022). Experiences of foot health in patients with rheumatoid arthritis: a qualitative study. *Disabil Rehabil*, *44*(1), 88-95. https://doi.org/10.1080/09638288.2020.1758966

Landgren, E., Bremander, A., Lindqvist, E., Nylander, M., & Larsson, I. (2021). Patients' Perceptions of Person-Centered Care in Early Rheumatoid Arthritis: A Qualitative Study. *ACR Open Rheumatol*, *3*(11), 788-795. https://doi.org/10.1002/acr2.11326

Landgren, E., Bremander, A., Lindqvist, E., Nylander, M., Van der Elst, K., & Larsson, I. (2020). “Mastering a New Life Situation” – Patients’ Preferences of Treatment Outcomes in Early Rheumatoid Arthritis – A Longitudinal Qualitative Study [article]. *Patient Prefer Adherence*, *ume 14*, 1421-1433. https://doi.org/10.2147/ppa.S253507

Lange, E., Gjertsson, I., & Mannerkorpi, K. (2020). Long-time follow up of physical activity level among older adults with rheumatoid arthritis. *Eur Rev Aging Phys Act*, *17*, 10. https://doi.org/10.1186/s11556-020-00242-w

Lange, E., Kucharski, D., Svedlund, S., Svensson, K., Bertholds, G., Gjertsson, I., & Mannerkorpi, K. (2019). Effects of Aerobic and Resistance Exercise in Older Adults With Rheumatoid Arthritis: A Randomized Controlled Trial. *Arthritis Care Res (Hoboken)*, *71*(1), 61-70. https://doi.org/10.1002/acr.23589

Lange, E., Palstam, A., Gjertsson, I., & Mannerkorpi, K. (2019). Aspects of exercise with person-centred guidance influencing the transition to independent exercise: a qualitative interview study among older adults with rheumatoid arthritis. *Eur Rev Aging Phys Act*, *16*, 4. https://doi.org/10.1186/s11556-019-0211-8

Larsson, I., Fridlund, B., Arvidsson, B., Teleman, A., & Bergman, S. (2014). Randomized controlled trial of a nurse-led rheumatology clinic for monitoring biological therapy. *J Adv Nurs*, *70*(1), 164-175. https://doi.org/10.1111/jan.12183

Larsson, I., Fridlund, B., Arvidsson, B., Teleman, A., Svedberg, P., & Bergman, S. (2015). A nurse-led rheumatology clinic versus rheumatologist-led clinic in monitoring of patients with chronic inflammatory arthritis undergoing biological therapy: a cost comparison study in a randomised controlled trial. *BMC Musculoskelet Disord*, *16*, 354. https://doi.org/10.1186/s12891-015-0817-6

Larsson, J., & Holmström, I. (2007). Phenomenographic or phenomenological analysis: does it matter? Examples from a study on anaesthesiologists' work. *Int J Qual Stud Health Well-being*, *2*(1), 55-64. https://doi.org/10.1080/17482620601068105

Lempp, H., Scott, D., & Kingsley, G. (2006). The personal impact of rheumatoid arthritis on patients' identity: A qualitative study. *Chronic Illn*, *2*(2), 109-120. https://doi.org/10.1179/174592006X110987

Lin, Y. J., Anzaghe, M., & Schülke, S. (2020). Update on the Pathomechanism, Diagnosis, and Treatment Options for Rheumatoid Arthritis. *Cells*, *9*(4). https://doi.org/10.3390/cells9040880

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.

Lindqvist, E., Saxne, T., Geborek, P., & Eberhardt, K. (2002). Ten year outcome in a cohort of patients with early rheumatoid arthritis: health status, disease process, and damage. *Ann Rheum Dis*, *61*(12), 1055. https://doi.org/10.1136/ard.61.12.1055

Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis Rheum*, *32*(1), 37-44. https://doi.org/10.1002/anr.1780320107

Maribo, T., Ibsen, C., Thuesen, J., Nielsen, C., Johansen, J., & Vind, A. R. (2022). *Hvidbog om rehabilitering [White book on rehabilitation]* (Vol. 1). Rehabiliteringsforum.

Marton, F. (1986). Phenomenography—A Research Approach to Investigating Different Understandings of Reality. *Journal of Thought*, *21*(3), 28-49. http://www.jstor.org/stable/42589189

Marton, F. & Booth, S. (1997). Learning and awareness. Mahwah, N.J.: Erlbaum.

Matheson, L., Harcourt, D., & Hewlett, S. (2010). 'Your whole life, your whole world, it changes': partners' experiences of living with rheumatoid arthritis [Article]. *Musculoskeletal Care*, *8*(1), 46-54. https://doi.org/10.1002/msc.165

Mathijssen, E., Peters, A., Verhoeven, G., Van der Elst, K., Van den Hoogen, F., & Vriezekolk, J. (2019). Welke behandeluitkomsten zijn voor patiënten met vroege reumatoïde artritis belangrijk? What treatment outcomes are important for patients with early rheumatoid arthritis?. . *TVZ*, *2019;1:36–9.*

Mayo, N. L., Russell, H. A., Holt, K., & Williams, G. C. (2022). Implementation of a self-determination based clinical program to reduce cardiovascular disease risk. *J Health Psychol*, *27*(13), 2898-2908. https://doi.org/10.1177/13591053211068124

McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Janes, N., Karlsson, B., McCance, T., Mekki TE., Porock, D., Van Lieshout, F., & Wilson, V. (2015). Person-centredness – the 'state' of the art. *International Practice Development Journal*, *5, 1-15.* /https://doi.org/10.19043/ipdj.5SP.003

McCormack, B., Karlsson, B., Dewing, J., & Lerdal, A. (2010). Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scand J Caring Sci*, *24*(3), 620-634. https://doi.org/10.1111/j.1471-6712.2010.00814.x

McCormack, B., & McCance, T. (2017). *Person-centred practice in nursing and health care : theory and practice*. Wiley Blackwell.

McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *J Adv Nurs*, *56*(5), 472-479. https://doi.org/10.1111/j.1365-2648.2006.04042.x

Nagy, G., Roodenrijs, N. M. T., Welsing, P. M. J., Kedves, M., Hamar, A., van der Goes, M. C., Kent, A., Bakkers, M., Pchelnikova, P., Blaas, E., Senolt, L., Szekanecz, Z., Choy, E. H., Dougados, M., Jacobs, J. W., Geenen, R., Bijlsma, J. W., Zink, A., Aletaha, D., Schoneveld, L., … van Laar, J. M. (2022). EULAR points to consider for the management of difficult-to-treat rheumatoid arthritis. *Annals of the rheumatic diseases*, 81(1), 20–33. https://doi.org/10.1136/annrheumdis-2021-220973

Nationellt kliniskt kunskapsstöd [National Clinical Knowledge Support]. (2023). *Vårdförlopp Reumatoid Artrit [Care pathways – Rheumatoid Arthritis].* https://www.nationelltkliniskt kunskapsstod.se/Skane/kunskapsstod/vardforlopp/?uuid=3b83a61a-e32b-4f9a-99a4-f9cf32eb6378

Nikiphorou, E., Santos, E. J. F., Marques, A., Böhm, P., Bijlsma, J. W., Daien, C. I., Esbensen, B. A., Ferreira, R. J. O., Fragoulis, G. E., Holmes, P., McBain, H., Metsios, G. S., Moe, R. H., Stamm, T. A., de Thurah, A., Zabalan, C., Carmona, L., & Bosworth, A. (2021). 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis. *Annals of the rheumatic diseases*, 80(10), 1278–1285. https://doi.org/10.1136/annrheumdis-2021-220249

Nivestam, A., Petersson, P., Westergren, A., & Haak, M. (2021). Older person's experiences of benefits gained from the support and advice given during preventive home visits. *Scandinavian Journal of Caring Sciences*, *35*(4), 1096-1103. https://doi.org/10.1111/scs.12923

Olsson, L. E., Hansson, E., & Ekman, I. (2016). Evaluation of person-centred care after hip replacement-a controlled before and after study on the effects of fear of movement and self-efficacy compared to standard care. *BMC Nurs*, *15*(1), 53. https://doi.org/10.1186/s12912-016-0173-3

Oshotse, C., Zullig, L. L., Bosworth, H. B., Tu, P., & Lin, C. (2018). Self-Efficacy and Adherence Behaviors in Rheumatoid Arthritis Patients. *Prev Chronic Dis*, *15*, E127. https://doi.org/10.5888/pcd15.180218

Parenti, G., Tomaino, S. C. M., & Cipolletta, S. (2020). The experience of living with rheumatoid arthritis: A qualitative metasynthesis. *J Clin Nurs*, *29*(21-22), 3922-3936. https://doi.org/10.1111/jocn.15428

Patton, M. Q. (2015). *Qualitative research & evaluation methods : integrating theory and practice*. SAGE Publications, Inc.

Pedraz-Marcos, A., Palmar-Santos, A. M., Hale, C. A., Zarco-Colón, J., Ramasco-Gutiérrez, M., García-Perea, E., Velasco-Ripoll, T., Martín-Alarcón, J., & Sapena-Fortea, N. (2020). Living With Rheumatoid Arthritis in Spain: A Qualitative Study of Patient Experience and the Role of Health Professionals. *Clinical nursing research*, 29(8), 551–560. https://doi.org/10.1177/1054773818791096

Pirhonen, L., Olofsson, E. H., Fors, A., Ekman, I., & Bolin, K. (2017). Effects of person-centred care on health outcomes-A randomized controlled trial in patients with acute coronary syndrome. *Health Policy*, *121*(2), 169-179. https://doi.org/10.1016/j.healthpol.2016.12.003

Poh, L. W., He, H. G., Chan, W. C. S., Lee, C. S. C., Lahiri, M., Mak, A., & Cheung, P. P. (2017). Experiences of Patients With Rheumatoid Arthritis: A Qualitative Study. *Clin Nurs Res*, *26*(3), 373-393. https://doi.org/10.1177/1054773816629897

Poh, L. W., He, H. G., Lee, C. S. C., Cheung, P. P., & Chan, W. C. S. (2015). An integrative review of experiences of patients with rheumatoid arthritis. *International Nursing Review*, *62*(2), 231-247. https://doi.org/10.1111/inr.12166

Polit, D. F., & Beck, C. T. (2021). *Nursing Research: generating and assessing evidence for nursing practice*. Wolters Kluwer.

Primdahl, J., Hegelund, A., Lorenzen, A. G., Loeppenthin, K., Dures, E., & Appel Esbensen, B. (2019). The Experience of people with rheumatoid arthritis living with fatigue: a qualitative metasynthesis. *BMJ Open*, *9*(3), e024338. https://doi.org/10.1136/bmjopen-2018-024338

Primdahl, J., Wagner, L., & Hørslev-Petersen, K. (2011). Being an outpatient with rheumatoid arthritis - a focus group study on patients' self-efficacy and experiences from participation in a short course and one of three different outpatient settings. *Scandinavian Journal of Caring Sciences*, *25*(2), 394-403. https://doi.org/10.1111/j.1471-6712.2010.00854.x

Protudjer, J. L. P., Billedeau, C., Hurst, K., Schroth, R., Stavropoulou, C., Kelekis-Cholakis, A., & Hitchon, C. A. (2022). Oral Health in Rheumatoid Arthritis: Listening to Patients. *JDR Clin Trans Res*, *7*(2), 127-134. https://doi.org/10.1177/23800844211012678

Ragouzeos, D., Gandrup, J., Berrean, B., Li, J., Murphy, M., Trupin, L., Yazdany, J., & Schmajuk, G. (2019). "Am I OK?" using human centered design to empower rheumatoid arthritis patients through patient reported outcomes. *Patient education and counseling*, 102(3), 503-510. Advance online publication. https://doi.org/10.1016/j.pec.2018.10.016

Ramos-Petersen, L., García-Campos, J., Banwell, G., Ortega-Ávila, A. B., Gijon-Nogueron, G., & Reinoso-Cobo, A. (2022). Experiences of patients with rheumatoid arthritis during and after COVID-19-induced quarantine in terms of physical activity and health status: A qualitative study. *J Nurs Manag*, *30*(7), 2568-2576. https://doi.org/10.1111/jonm.13784

Rosengren, K., Brannefors, P., & Carlstrom, E. (2021). Adoption of the concept of person-centred care into discourse in Europe: a systematic literature review. *Journal of Health Organization and Management*, *35*(9), 265-280. https://doi.org/10.1108/JHOM-01-2021-0008

Sahlen, K. G., Boman, K., & Brännström, M. (2016). A cost-effectiveness study of person-centered integrated heart failure and palliative home care: Based on a randomized controlled trial. *Palliat Med*, *30*(3), 296-302. https://doi.org/10.1177/0269216315618544

Saldaña, J. (2002). Analyzing change in longitudinal qualitative data [Article]. *Youth Theatre Journal*, *16*(1), 1-17. https://doi.org/10.1080/08929092.2002.10012536

Scott, D. L. (2007). Early rheumatoid arthritis. *British Medical Bulletin*, *81-82*(1), 97-114. https://doi.org/10.1093/bmb/ldm011

Scott, D. L., Wolfe, F., & Huizinga, T. W. (2010). Rheumatoid arthritis. *Lancet*, *376*(9746), 1094-1108. https://doi.org/10.1016/s0140-6736(10)60826-4

Segan, J. D., Briggs, A. M., Chou, L., Connelly, K. L., Seneviwickrama, M., Sullivan, K., Cicuttini, F. M., & Wluka, A. E. (2018). Patient-perceived health service needs in inflammatory arthritis: A systematic scoping review. *Seminars in arthritis and rheumatism*, 47(6), 765–777. https://doi.org/10.1016/j.semarthrit.2017.10.019

Singh, J. A., Saag, K. G., Bridges, S. L., Jr, Akl, E. A., Bannuru, R. R., Sullivan, M. C., Vaysbrot, E., McNaughton, C., Osani, M., Shmerling, R. H., Curtis, J. R., Furst, D. E., Parks, D., Kavanaugh, A., O'Dell, J., King, C., Leong, A., Matteson, E. L., Schousboe, J. T., Drevlow, B., … McAlindon, T. (2016). 2015 American College of Rheumatology Guideline for the Treatment of Rheumatoid Arthritis. *Arthritis & rheumatology (Hoboken, N.J.)*, 68(1), 1–26. https://doi.org/10.1002/art.39480

Sjö, A. S., & Bergsten, U. (2018). Patients' experiences of frequent encounters with a rheumatology nurse-A tight control study including patients with rheumatoid arthritis. *Musculoskeletal Care*, *16*(2), 305-312. https://doi.org/10.1002/msc.1348

Sjöström, B., & Dahlgren, L. O. (2002). Applying phenomenography in nursing research [Article]. *J Adv Nurs*, *40*(3), 339-345. https://doi.org/10.1046/j.1365-2648.2002.02375.x

Smolen, J. S. (2020). Insights into the treatment of rheumatoid arthritis: A paradigm in medicine. *J Autoimmun*, *110*, 102425. https://doi.org/10.1016/j.jaut.2020.102425

Smolen, J. S., Aletaha, D., Barton, A., Burmester, G. R., Emery, P., Firestein, G. S., Kavanaugh, A., McInnes, I. B., Solomon, D. H., Strand, V., & Yamamoto, K. (2018). Rheumatoid arthritis. *Nature reviews. Disease primers, 4,* 18001. https://doi.org/10.1038/nrdp.2018.1

Smolen, J. S., Landewé, R. B. M., Bergstra, S. A., Kerschbaumer, A., Sepriano, A., Aletaha, D., Caporali, R., Edwards, C. J., Hyrich, K. L., Pope, J. E., de Souza, S., Stamm, T. A., Takeuchi, T., Verschueren, P., Winthrop, K. L., Balsa, A., Bathon, J. M., Buch, M. H., Burmester, G. R., Buttgereit, F., … van der Heijde, D. (2023). EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2022 update. *Annals of the rheumatic diseases*, 82(1), 3–18. https://doi.org/10.1136/ard-2022-223356

Sverker, A., Ostlund, G., Thyberg, M., Thyberg, I., Valtersson, E., & Bjork, M. (2015). Dilemmas of participation in everyday life in early rheumatoid arthritis: a qualitative interview study (The Swedish TIRA Project). *Disabil Rehabil*, *37*(14), 1251-1259. https://doi.org/10.3109/09638288.2014.961658

Sverker, A., Thyberg, I., Ostlund, G., Waltersson, E., & Thyberg, M. (2014). Participation in work in early rheumatoid arthritis: a qualitative interview study interpreted in terms of the ICF. *Disabil Rehabil*, *36*(3), 242-249. https://doi.org/10.3109/09638288.2013.789086

Sverker, A., Thyberg, I., Valtersson, E., Bjork, M., Hjalmarsson, S., & Ostlund, G. (2019). Time to update the ICF by including socioemotional qualities of participation? The development of a "patient ladder of participation" based on interview data of people with early rheumatoid arthritis (the Swedish TIRA study). *Disabil Rehabil*, 1-8. https://doi.org/10.1080/09638288.2018.1518494

Swedish Research Council, V. (2017). *God forskningssed/Good Research Practice*. Vetenskapsrådet. https://www.vr.se/analys/rapporter/vara-rapporter/2017-08-29-god-forskningssed.html

Sweeney, A. M. T., McCabe, C., Flurey, C. A., Robson, J. C., Berry, A., Richards, P., & Ndosi, M. (2021). The patient perspective of nurse-led care in early rheumatoid arthritis: A systematic review of qualitative studies with thematic analysis. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *30*(1/2), 145-160. https://doi.org/10.1111/jocn.15531

Swärdh, E., Nordgren, B., Opava, C. H., & Demmelmaier, I. (2020). "A Necessary Investment in Future Health": Perceptions of Physical Activity Maintenance Among People With Rheumatoid Arthritis. *Phys Ther*, *100*(12), 2144-2153. https://doi.org/10.1093/ptj/pzaa176

Taylor, P. C., Moore, A., Vasilescu, R., Alvir, J., & Tarallo, M. (2016). A structured literature review of the burden of illness and unmet needs in patients with rheumatoid arthritis: a current perspective. *Rheumatol Int*, *36*(5), 685-695. https://doi.org/10.1007/s00296-015-3415-x

Tengland, P. A. (2007a). Empowerment: a goal or a means for health promotion? *Med Health Care Philos*, *10*(2), 197-207. https://doi.org/10.1007/s11019-006-9027-1

Tengland, P. A. (2007b). A two-dimensional theory of health. *Theor Med Bioeth*, *28*(4), 257-284. https://doi.org/10.1007/s11017-007-9043-z

Tengland, P. A. (2020). Health and capabilities: a conceptual clarification. *Med Health Care Philos*, *23*(1), 25-33. https://doi.org/10.1007/s11019-019-09902-w

Thyberg, I., Hass, U. A., Nordenskiöld, U., Gerdle, B., & Skogh, T. (2005). Activity limitation in rheumatoid arthritis correlates with reduced grip force regardless of sex: the Swedish TIRA project. *Arthritis Rheum*, *53*(6), 886-896. https://doi.org/10.1002/art.21595

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*, *19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

Trento, M., Fornengo, P., Amione, C., Salassa, M., Barutta, F., Gruden, G., Mazzeo, A., Merlo, S., Chiesa, M., Cavallo, F., Charrier, L., & Porta, M. (2020). Self-management education may improve blood pressure in people with type 2 diabetes. A randomized controlled clinical trial. *Nutrition, metabolism, and cardiovascular diseases : NMCD*, 30(11), 1973–1979. https://doi.org/10.1016/j.numecd.2020.06.023

Ulin, K., Olsson, L. E., Wolf, A., & Ekman, I. (2016). Person-centred care - An approach that improves the discharge process. *Eur J Cardiovasc Nurs*, *15*(3), e19-26. https://doi.org/10.1177/1474515115569945

United Nations. (2015). Resolution A/RES/70/1 Transforming our world: the 2030 Agenda for Sustainable Development. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N15/291/89/PDF/N1529189.pdf?OpenElement

Van der Elst, K., Bremander, A., De Groef, A., Larsson, I., Mathijssen, E. G. E., Vriezekolk, J. E., Westhovens, R., & van Eijk-Hustings, Y. J. L. (2019). European Qualitative research project on Patient-preferred outcomes in Early Rheumatoid Arthritis (EQPERA): rationale, design and methods of a multinational, multicentre, multilingual, longitudinal qualitative study. *BMJ open*, 9(3), e023606. https://doi.org/10.1136/bmjopen-2018-023606

Van der Elst, K., Mathijssen, E. G. E., Landgren, E., Bremander, A., De Groef, A., Lindqvist, E., Nylander, M., Peters, A., Van den Hoogen, F., van Eijk-Hustings, Y., Verhoeven, G., Vriezekolk, J. E., Westhovens, R., & Larsson, I. (2020). What do patients prefer? A multinational, longitudinal, qualitative study on patient-preferred treatment outcomes in early rheumatoid arthritis. *RMD open, 6(2),* e001339. https://doi.org/10.1136/rmdopen-2020-001339

van der Elst, K., Meyfroidt, S., De Cock, D., De Groef, A., Binnard, E., Moons, P., Verschueren, P., & Westhovens, R. (2016). Unraveling Patient-Preferred Health and Treatment Outcomes in Early Rheumatoid Arthritis: A Longitudinal Qualitative Study. *Arthritis care & research,* 68(9), 1278–1287. https://doi.org/10.1002/acr.22824

van Eijk-Hustings, Y., Ammerlaan, J., Voorneveld-Nieuwenhuis, H., Maat, B., Veldhuizen, C., & Repping-Wuts, H. (2013). Patients' needs and expectations with regard to rheumatology nursing care: results of multicentre focus group interviews. *Ann Rheum Dis*, *72*(6), 831-835. https://doi.org/10.1136/annrheumdis-2012-202810

Verstappen, S. M. (2015). Rheumatoid arthritis and work: The impact of rheumatoid arthritis on absenteeism and presenteeism. *Best Pract Res Clin Rheumatol*, *29*(3), 495-511. https://doi.org/10.1016/j.berh.2015.06.001

Voshaar, M. J., Nota, I., van de Laar, M. A., & van den Bemt, B. J. (2015). Patient-centred care in established rheumatoid arthritis. *Best Pract Res Clin Rheumatol*, *29*(4-5), 643-663. https://doi.org/10.1016/j.berh.2015.09.007

Wade, D. T. (2020). What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clin Rehabil*, *34*(5), 571-583. https://doi.org/10.1177/0269215520905112

Wallace, S. J., Barnett, A., Cheng, B. B., Lowe, J., Campbell, K. L., & Young, A. M. (2023). What is 'successful rehabilitation'? A multi-stakeholder nominal group technique study to inform rehabilitation outcome measurement. *Clin Rehabil*, *37*(9), 1248-1259. https://doi.org/10.1177/02692155231157181

Wallström, S., Ali, L., Ekman, I., Swedberg, K., & Fors, A. (2020). Effects of a person-centred telephone support on fatigue in people with chronic heart failure: Subgroup analysis of a randomised controlled trial. *Eur J Cardiovasc Nurs*, *19*(5), 393-400. https://doi.org/10.1177/1474515119891599

WHO. (1948). *Summary report on proceedings, minutes and final acts of the International Health Conference held in New York from 19 June to 22 July 1946.* World Health Organization. Retrieved 16 October 2023 from https://iris.who.int/bitstream/handle/10665/85573/official_record2_eng.pdf?sequence=1

WHO. (1986). *The Ottawa charter for health promotion, 1986.* World Health Organization.

Retrieved 15 October 2023 from https://www.who.int/publications/i/item/WH-1987

WHO. (2015). *WHO global strategy on people-centred and integrated health services: interim report.* Retrieved 16 October 2023 https://www.who.int/servicedeliverysafety/areas/people-centred-care/global-strategy/en/

WHO. (2020). *Basic documents: forty-ninth edition (including amendments adopted up to 31 May 2019).* Retrieved 16 October 2023 https://www.who.int/about/governance/constitution

Winthrop, K. L., Weinblatt, M. E., Crow, M. K., Burmester, G. R., Mease, P. J., So, A. K., Bykerk, V., Van Vollenhoven, R. F., Dougados, M., Kay, J., Mariette, X., Sieper, J., Melchers, F., Cronstein, B. N., Shevach, E., Breedfeld, F. C., Kalden, J., Smolen, J. S., & Furst, D. E. (2019). Unmet need in rheumatology: reports from the Targeted Therapies meeting 2018. *Ann Rheum Dis*, *78*(7), 872-878. https://doi.org/10.1136/annrheumdis-2018-214280

World Medical Association. (2022). WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects. *Jama*, *310*(20), 2191-2194. https://doi.org/10.1001/jama.2013.281053

Zangi, H. A., Ndosi, M., Adams, J., Andersen, L., Bode, C., Boström, C., van Eijk-Hustings, Y., Gossec, L., Korandová, J., Mendes, G., Niedermann, K., Primdahl, J., Stoffer, M., Voshaar, M., van Tubergen, A., & European League Against Rheumatism (EULAR) (2015). EULAR recommendations for patient education for people with inflammatory arthritis. *Annals of the rheumatic diseases*, 74(6), 954–962. https://doi.org/10.1136/annrheumdis-2014-206807

Zuidema, R. M., Repping-Wuts, H., Evers, A. W. M., Van Gaal, B. G. I., & Van Achterberg, T. (2015). What do we know about rheumatoid arthritis patients' support needs for self-management? A scoping review [Review Article]. *Int J Nurs Stud*, *52*(10), 1617-1624. https://doi.org/10.1016/j.ijnurstu.2015.05.008

Åkerlind, G. S. (2005). Variation and commonality in phenomenographic research methods. *Higher Education Research & Development*, *24*(4), 321-334. https://doi.org/10.1080/07294360500284672

Östlund, G., Bjork, M., Thyberg, I., Thyberg, M., Valtersson, E., Stenstrom, B., & Sverker, A. (2014). Emotions related to participation restrictions as experienced by patients with early rheumatoid arthritis: a qualitative interview study (the Swedish TIRA project). *Clin Rheumatol*, *33*(10), 1403-1413. https://doi.org/10.1007/s10067-014-2667-2

Östlund, G., Björk, M., Thyberg, I., Valtersson, E., & Sverker, A. (2018). Women's situation-specific strategies in managing participation restrictions due to early rheumatoid arthritis: A gender comparison. *Musculoskeletal Care*, *16*(2), 251-259. https://doi.org/10.1002/msc.1225

Östlund, G., Björk, M., Valtersson, E., & Sverker, A. (2015). Lived Experiences of Sex Life Difficulties in Men and Women with Early RA - The Swedish TIRA Project. *Musculoskeletal Care*, *13*(4), 248-257. https://doi.org/10.1002/msc.1105

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About the author

Ellen Landgren is working as a nurse at the rheumathology department at Skåne University Hospital in Lund. The focus of her research interest is the patient's perspective of care. The overall aim of her thesis is to explore patients' perspectives of person-centred care and preferred outcomes in early rheumatoid arthritis.

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