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Lifestyle habits and quality of life in established rheumatoid arthritis

KARINA MALM

SECTION OF RHEUMATOLOGY | FACULTY OF MEDICINE | LUND UNIVERSITY

RA



Lifestyle habits and quality of life in established rheumatoid arthritis

Karina Malm



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DOCTORAL DISSERTATION

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To be defended at the Lecture Hall of the Rheumatology Department,

Lund University Hospital. November 17, 2017, at 09.00.

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<p>Abstract</p> <p>Rheumatoid Arthritis (RA) is a chronic, inflammatory, and systemic disease of unknown aetiology that affects 0.5–1.0% of the population in Europe, more women than men. Pain, physical disability, fatigue, and sleep disturbances are some of the most pronounced symptoms in patients with a more severe disease or with a longer disease duration, resulting in activity limitations that affect quality of life. RA is associated with an increased risk of developing comorbidities, some of which are known to be associated with a sedentary lifestyle. A healthy lifestyle can reduce the risk to develop diseases and help to improve quality of life in patients with RA. In guidelines and recommendations for management of patients with RA, health professionals are encouraged to prioritise discussions about lifestyle, especially physical activity, diet, smoking, and alcohol use.</p> <p>The overall aim of the present work was to explore factors that affect disability and quality of life in patients with established RA, especially on lifestyle habits (physical activity, diet, smoking, and alcohol use) and whether they are addressed in the clinic. The papers are based on a cohort of patients with established RA included in the Better Anti-Rheumatic Pharmacotherapy (BARFOT).</p> <p>Paper I is a longitudinal cohort study based on baseline and 5-18 years follow-up data from 1,387 patients who responded to a lifestyle questionnaire in 2010. Paper II is based on a qualitative content analysis, including interviews with 22 patients. Paper III is based a phenomenographic approach, including interviews with 22 patients. Paper IV is a cross-sectional study including 1,061 patients who responded to a lifestyle questionnaire in 2017.</p> <p>Function and pain at onset of disease in patients with RA were found to be prognostic measures of a worse physical function several years later but none of the variables studied could predict who did or did not meet WHO recommendations for physical activity in 2010. Quality of life in patients with established RA was influenced by the balance between the ideal situation and the reality with regard to the lifestyle habits physical activity, diet, smoking, and alcohol use. These lifestyle habits influenced quality of life through limitation, self-regulation, and companionship. Quality of life was conceived as independence in terms of physical functioning and financial resources, as empowerment in how to manage life, and as participation in the experience of belonging in a social context. Although being regarded as important, lifestyle habits had not regularly been discussed at health care visits, and was not always requested by the patients. This implies the importance of that health care professionals actively discuss lifestyle habits from a biopsychosocial perspective as an integral part of RA management.</p>		
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Lifestyle habits and quality of life in established rheumatoid arthritis

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Tillsammans är man mindre ensam

(Anna Gevalda)

To the BARFOT study

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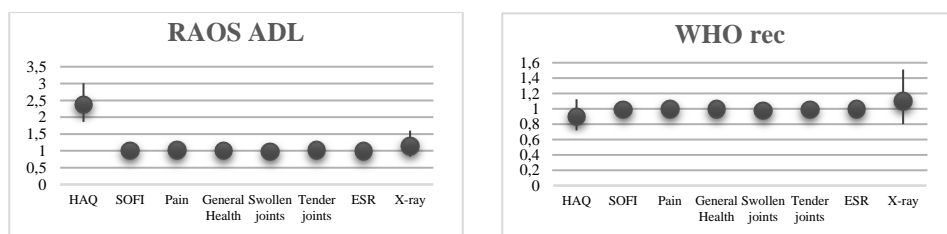
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- II. **Malm K**, Bremander A, Arvidsson B, Andersson MLE, Bergman S and Larsson I. The influence of lifestyle habits on quality of life in patients with established rheumatoid arthritis—A constant balancing between ideality and reality. *Int J Qual Stud Health Well-being.* 2016;11:30534.
- III. **Malm K**, Bergman S, Andersson MLE, Bremander A and Larsson I. Quality of life in patients with established rheumatoid arthritis: A phenomenographic study. *SAGE Open Med.* 2017 Jun 7;5:2050312117713647.
- IV. **Malm, K**, Bergman, S, Bremander, A, Larsson I, Andersson, ML. Lifestyle habits discussions as an integral part of care management in established rheumatoid arthritis. Submitted.

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Thesis at a glance

Paper I. Predictors of severe self-reported disability in rheumatoid arthritis

Aim: To identify factors predictive of severe self-reported disability in patients with established RA. *Patients and methods:* A longitudinal prospective cohort study with baseline and 5-18 years follow-up data from 1,387 patients with RA in the Better Anti-Rheumatic Pharmacotherapy (BARFOT) study who responded to a lifestyle questionnaire in 2010. Self-reported functional assessment data and disease activity data at baseline were potential predictors for severe self-reported disability. *Conclusions:* Worse physical function and worse pain at onset of disease could predict worse physical function several years later, while some parameters of inflammation could not. None of the variables studied predicted the amount of physical activity actually being performed.



Prediction of RAOS ADL and WHO recommendation for physical activity, Odds Ratios (95% CI) for outcome with regard to explanatory baseline variables

Paper II. The influence of lifestyle habits on quality of life in patients with rheumatoid arthritis

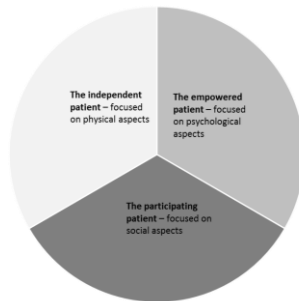
Aim: To describe and explore how patients with established RA experience the influence of lifestyle habits on quality of life. *Patients and methods:* A descriptive and explorative design, based on a qualitative content analysis was conducted and 22 patients with RA from the BARFOT study were interviewed. *Conclusions:* Quality of life for patients with established RA was influenced by the balance between the ideal and reality in the lifestyle habits: physical activity, diet, smoking, and alcohol use. These lifestyle habits influenced quality of life through limitation, self-regulation, and companionship.

The theme, categories, and subcategories reflecting the influence of lifestyle habits on the quality of life in patients with established RA.

Subcategories	Categories	Theme
Patients experienced insufficiency Patients experienced adaptation	Experiencing limitation	
Patients experienced guilt Patients experienced motivation	Experiencing self-regulation	Balancing between ideality and reality
Patients experienced belonging Patients experienced pleasure	Experiencing companionship	

Paper III. Quality of life in patients with established rheumatoid arthritis

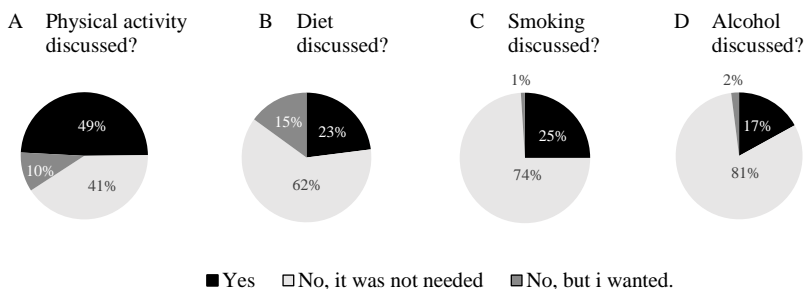
Aim: To explore variations of ways in which patients with established RA understand the concept of quality of life. *Patients and methods:* A qualitative design with a phenomenographic approach was conducted and 22 patients with RA from the BARFOT study were interviewed. *Conclusions:* Quality of life in patients with established RA was conceived as independence in terms of physical functioning and financial resources, as empowerment in how to manage life, and as participation in the experience of belonging in a social context.



The outcome space illustrating the relationship between the categories independence, empowerment and participation, and describing physical, psychological, and social considerations that influence the quality of life in patients with established RA.

Paper IV. Lifestyle habits discussions as an integral part of care management in patients with established rheumatoid arthritis

Aim: To determine whether lifestyle habits (physical activity, diet, smoking, and alcohol) had been discussed during healthcare visits in patients with established RA. *Patients and methods:* A cross-sectional study including 1,061 patients with RA from the BARFOT study who responded to a lifestyle questionnaire in 2017. *Conclusion:* Physical activity had been discussed at least once with every second patient. Diet, smoking, and alcohol use had been discussed with about a quarter of them. These numbers were surprisingly low, since the patients with established RA had had opportunities to have discussions regarding lifestyle habits several times over the years.



Proportion of patients who reported that they had had a discussion regarding lifestyle habits and whether they wanted to have a discussion. **A.** Physical activity. **B.** Diet. **C.** Smoking. **D.** Alcohol use.

Authors' contributions

Paper I

Study design: Karina Malm, Stefan Bergman, Maria L.E. Andersson, Ann Bremander

Data collection: Maria L.E. Andersson and the BARFOT study group

Data analysis: Karina Malm, Stefan Bergman, Maria L. E. Andersson, Ann Bremander

Manuscript writing: Karina Malm

Manuscript revision: Stefan Bergman, Maria L. E. Andersson, Ann Bremander

Paper II

Study design: Karina Malm, Ann Bremander, Barbro Arvidsson, Maria L. E. Andersson, Stefan Bergman, Ingrid Larsson

Data collection: Karina Malm

Data analysis: Karina Malm, Barbro Arvidsson, Ingrid Larsson, Maria L. E. Andersson, Ann Bremander, Stefan Bergman

Manuscript writing: Karina Malm

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Paper III

Study design: Karina Malm, Stefan Bergman, Ann Bremander, Maria L. E. Andersson, Ingrid Larsson

Data collection: Karina Malm

Data analysis: Karina Malm, Ingrid Larsson, Ann Bremander, Maria L.E. Andersson, Stefan Bergman

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Manuscript revision: Ann Bremander, Maria L. E. Andersson, Stefan Bergman, Ingrid Larsson

Paper IV

Study design: Karina Malm, Stefan Bergman, Ann Bremander, Ingrid Larsson, Maria L. E. Andersson

Data collection: Karina Malm, Maria L.E. Andersson

Data analysis: Karina Malm, Maria L.E. Andersson, Stefan Bergman, Ann Bremander, Ingrid Larsson

Manuscript writing: Karina Malm

Manuscript revision: Stefan Bergman, Ann Bremander, Ingrid Larsson, Maria L. E. Andersson

Abbreviations

ACR	American College of Rheumatology
ACPA	Antibodies to Citrullinated Protein Antigens
BARFOT	Better Anti-Rheumatic Pharmacotherapy
CRP	C-Reactive Protein
DAS-28	28-joint count Disease Activity Score
DMARD	Disease-Modifying Anti-rheumatic Drug
EQ-5D	EuroQol-five dimensions questionnaire
ESR	Erythrocyte Sedimentation Rate
HAQ	Health Assessment Questionnaire
HEPA	Health-Enhancing Physical Activity
GH	General Health
NRS	Numerical Rating Scale
OR	Odds Ratio
RA	Rheumatoid Arthritis
RAOS	Rheumatoid and Arthritis Outcome Score
RF	Rheumatoid Factor
SOFI	Signals Of Functional Impairment
VAS	Visual Analogue Scale
WHO	World Health Organisation
WHO _{rec}	WHO recommendation for physical activity
WHO MI-PA	Moderate-Intensity Physical Activity according to WHO recommendations
WHO VI-PA	Vigorous-Intensity Physical Activity according to WHO recommendations
OMERACT	Outcome Measures in Rheumatology

Definition

In this thesis established RA are defined as having more than two years of disease duration (Conaghan et al. 1999).

Funding

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Introduction

In rheumatoid arthritis (RA), pain and fatigue are pronounced symptoms resulting in activity limitations. The course of disability in established RA is complex and may be seen as a process that runs in parallel with disease activity. This complexity may also apply to the perceived health and quality of life when living with established RA.

Changing health-related behaviour is important in reducing the burden of disease and mortality. Lifestyle habits such as physical activity, diet, smoking, and alcohol use are important factors that have impact on long-standing diseases.

Patients are seldom reminded of the importance of lifestyle habits, and some patients are even unaware of their unhealthy habits. In the clinic setting it could be difficult to have the time and opportunity to work with counselling to promote better health. This thesis explores physical function, lifestyle habits, and the concept quality of life in patients with established RA to better understand the patients and improve management in health care.

Background

Rheumatoid arthritis

RA is a chronic, inflammatory, and systemic disease of unknown aetiology that affects 0.5–1.0% of the population in Europe, more women than men (Simonsson et al. 1999, Englund et al. 2010, Scott et al. 2010).

Pain, physical disability, fatigue, and sleep disturbances are some of the most pronounced symptoms in patients with a more severe disease progression or with a longer disease duration, resulting in activity limitations that seriously affect their quality of life (Scott et al. 2010). RA not only affects the joints and its associated structures, it is also a disease with various extra-articular manifestations (scleritis, pleurisy, and vasculitis)(van Vollenhoven 2016). These are important to pay attention to, since they are associated with morbidity and an increased risk of mortality compared to patients with RA in general (Turesson et al. 2002). The original classification criteria for RA were from 1987, in which patients who fulfilled at least four of seven criteria were classified as having RA (Arnett et al. 1988) (Table 1). In 2010, in order to optimise early diagnosis, there was a new set of classification criteria consisting of a scoring system focusing on features at earlier stages of disease that are associated with persistent or erosive disease (Aletaha et al. 2008).

Table 1. The 1987 revised ACR classification criteria for RA. Four of seven criteria had to be fulfilled to be classified as having RA, and they must have been present for at least six weeks.

-
1. Morning stiffness
 2. Arthritis in at least three joints
 3. Arthritis in hand joints
 4. Symmetric arthritis
 5. Rheumatoid nodules
 6. Serum rheumatoid factor
 7. Radiographic changes
-

The prognosis in RA is predicted by non-modifiable factors including age, gender, genetic factors, and disease-specific factors, such as antibodies to citrullinated protein antigens (ACPAs) (Rantapaa-Dahlqvist et al. 2003). ACPA-positive RA is the most prominent subgroup of RA with evidence of inherited genetic factors and environmental triggers being involved in the aetiology. Smoking is the most prominent modifiable risk factor identified for the aetiology of ACPA-positive RA, but other environmental or modifiable factors that are involved in the pathogenesis of RA are not known (Klareskog et al. 2006, Radner et al. 2010, Gullick et al. 2011). RA disease is also associated with an increased risk of developing comorbidities such as cardiovascular disease, infections, cancer, gastrointestinal disease, pulmonary disease, osteoporosis, and psychiatric disorders (Dougados et al. 2014). In

clinical practice, it is common that patients who are visiting the rheumatology clinic for the first time already have one or more co-existing diseases (Tiippana-Kinnunen et al. 2013, Innala et al. 2016) and some of the RA patients tend to underestimate their cardiovascular risk (van Breukelen-van der Stoep et al. 2015). It is important to prevent cardiovascular disease, and it is the healthcare professional's responsibility to educate RA patients in this respect before they undergo treatment (Hollan et al. 2015). Comorbidities worsen disability and shorten the patient's life expectancy, and in established RA some comorbidities are related to the disease RA, and others are associated with the pharmacological treatment (Gullick et al. 2011).

Pharmacological treatment of RA

There is still no cure for RA, and despite the fact that new therapies are available, drugs do not have the capacity to induce remission in all patients with RA (Emery et al. 2014, Svensson et al. 2016). Treatments for RA are based on controlling the inflammatory process, and reducing symptoms and the destructive process to maintain the functional status of the patient (van Vollenhoven 2016). There have been major advances in the treatment and management of patients with RA, including early diagnosis and a quick, aggressive treatment. The conventional disease-modifying anti-rheumatic drug (DMARD) that is used most is methotrexate (MTX) (van Vollenhoven 2016). Over the past two decades, TNF- α blockers have been introduced and other biological agents are often used early in the treatment (Neovius et al. 2011). Many patients with RA are still affected by considerable limitations in their physical function and pain (Andersson et al. 2013b, Svensson et al. 2016). In patients with established disease, this is partly related to accrued structural damage that is irreversible (Radner et al. 2011).

Non-pharmacological treatment in RA

Non-pharmacological treatment (physical exercise, patient education, and self-management) can help the patient to cope with the consequences of the disease (Vliet Vlieland et al. 2011). It is important to encourage patients to use strategies such as self-management, pain control, and fatigue reduction in order to improve in everyday life. Self-management interventions are patient-centred and designed to be involved in health care decisions to enhance active participation of patients in order to promote well-being and to manage symptoms (Iversen et al. 2010). Healthcare professionals including nurses, physiotherapists, occupational therapists, orthopedic surgeons, dieticians, social workers, and psychologists are together with the patient all part of the rheumateam (Vliet Vlieland 2003).

Measurement of disease activity and function

In rheumatology care, the management of RA includes systematic and regular evaluation of disease activity (Smolen et al. 2017). The degree of disease activity and response to treatment in RA are evaluated with outcome measures in the RA core set. C-reactive protein (CRP), erythrocyte sedimentation rate (ESR), counts of tender and swollen joints and the patient's global assessment of health are measures in the RA core set (Felson et al. 1993). They are also included in the combined Disease Activity Score, DAS28. The core set also includes other patient-reported outcomes (PROs): physical function, pain, and global assessment (Aletaha et al. 2008). The Stanford Health Assessment Questionnaire (HAQ) and the Rheumatoid and Arthritis Outcome Score (RAOS), and observer-assessed performance measures such as Signals of Functional Impairment (SOFI) represent different measures of functioning. Previous research has identified that there are treatment outcomes related to drug intervention that are important to patients, even though they are not measured in clinical trials, such as fatigue, coping, returning to/maintaining a normal life, and enjoyment of life (Sanderson et al. 2010).

Health and quality of life

Health and quality of life are common concepts in health science, but there is still no generally accepted definition of these concepts. The importance of the concepts varies over time and in different cultures (Carr et al. 2001). Health has its origin in medicine and quality of life is a multidisciplinary concept, but despite having different origins they are often used synonymously (Svensson et al. 2011).

Health

The Constitution of the World Health Organisation (WHO) defines health as “A state of complete physical, mental, and social well-being, not only the absence of disease” in 1948 (WHO 1948). The WHO stated in the Jakarta document that health is a human right, which contributes to the fact that human beings can live socially and economically productive lives (WHO 1997). Health according to Tengland 2007, is a combination of the two dimensions, ability and well-being, which affect each other interchangeably and contribute to a collective feeling of health. Abilities describe to what degree an individual functions and performs physically, mentally, emotionally and socially (Tengland 2007). The biomedical view of health has changed into a more holistic approach, and this means that patients' experiences, thoughts, feelings, and emotions are included in the concept of health (Saylor 2004, Svensson et al. 2011). This is in line with a biopsychosocial perspective on health. This view on health is multifactorial—including the complex interaction between biological, psychological, and social aspects (Engel 1977). The biopsychosocial model describes the connection between body and mind, and changes in one domain, (biological) have implications on others (psychological and social) (Engel 1980, Borrell-Carrio et al. 2004).

Biological factors refers to medical or physical aspects; psychological to behavioural, emotional and mental aspects; and social factors referes to patients` connections with physical environments and communities, and their interaction with other people (Figure 1).

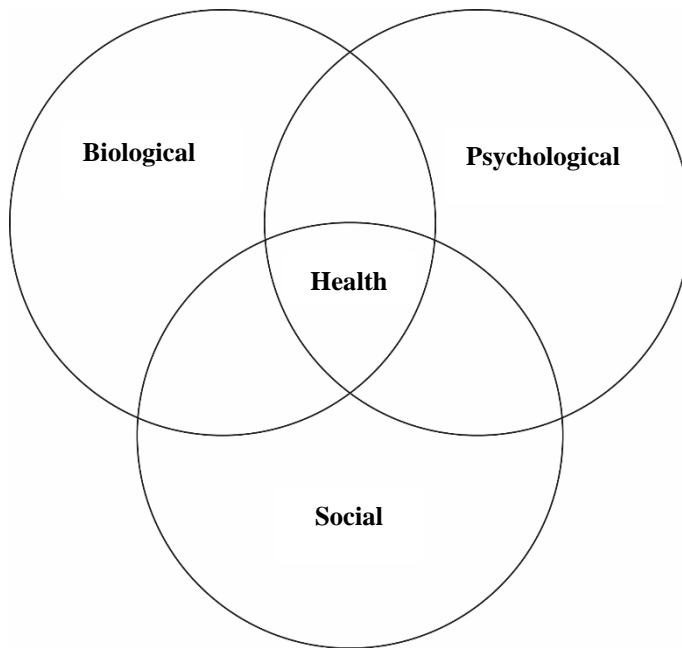


Figure 1. The biopsychosocial model of health (Engel 1977).

Quality of life

The WHO defines quality of life as “a broad-ranging concept incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, beliefs and their relationship to salient features of the environment” (WHO/FIMS 1995, WHOQOL 1995).

The concept “quality of life” can be described in many ways, in a philosophical sense by “living the good life” and in social science as a part of the welfare concept (Ventegodt et al. 2003). According to Haas et al., quality of life has four dimensions: physical, mental, social, and spiritual. These dimensions reflect a holistic vision of care (Haas 1999). The goal of raised or preserved quality of life is of the utmost importance for patients with a long-standing disease, especially when cure is no longer possible (MacMahon et al. 2002).

Quality of life is considered to be a major and important concept in healthcare, and is often used in clinical work and research to evaluate the effects of treatment. The multidimensional

nature of the concept has been seen as a problem, as the quality of life is frequently referred to but is seldom clearly defined (Barcaccia et al. 2013).

Health-related quality of life

Healthcare professionals commonly refer to health-related quality of life to define the quality of life domain, which is directly influenced by the individual's state of health and the healthcare provided (Tothova et al. 2014). Health-related quality of life is a broad concept that includes health status but also incorporates an evaluative component that assesses a person's satisfaction with their current health status (Coons et al. 2000, Kvien et al. 2005).

Quantitative assessment of health and quality of life in RA

In general, there are two categories of questionnaires: the generic instruments and disease-specific instruments that are used to assess health and health-related quality of life (Guyatt et al. 1993, Kvien et al. 2005). The most commonly used generic health-related quality of life questionnaires are the 36-item Short Form Health Survey (SF36) (Sullivan et al. 1986), the EuroQoL5D (EQ-5D) (Hurst et al. 1997), and the Nottingham Health Profile (NHP) (Houssien et al. 1997). As these are generic scales, the importance of the specific subscales for patients with RA has been studied (Kvien et al. 1998). The most frequently studied domains for quality of life are pain, functional disability, fatigue, and mental problems (Kiltz et al. 2009). It is important to measure both generic and disease specific concepts of health, as generic and disease-specific instruments are complementary. To enable comparisons with other diseases and the general population a generic instrument should often be preferable as the basic measure, and be supplemented with disease- or condition-specific measures depending on the purpose (Kvien et al. 1998). The Rheumatoid Arthritis Quality of Life instrument (RAQoL) is an RA-specific quality of life questionnaire (de Jong et al. 1997).

Qualitative assessment of health and quality of life in RA

Focusing on individuals' own views of their health and quality of life provides a different outlook regarding the consequences of the disease (Whalley et al. 1997). It is well understood that RA affects the joints and muscles, but the effect that the perception of illness has on an individual's social relationships, exercise possibility, working capacity, and financial status has received little attention (Archenholtz et al. 1999). From an earlier study we know that lifestyle habits such as physical activity and diet can be incorporated into patients' understanding of both the health concept and the quality of life concept (Fagerlind et al. 2010), while the influence of lifestyle habits on health and quality of life in patients with a long-standing disease such as RA has been less well studied.

Lifestyle habits

Healthy lifestyle recommendations for patients with RA are similar to those for the general population (WHO 2002, Swedish State Institute of Public Health 2010, Socialstyrelsen 2012). WHO present the global health situation in terms of epidemics of diseases, such as cardiovascular diseases associated with unhealthy lifestyle-related habits (WHO 2002). Most of these cardiovascular diseases are associated with the four lifestyle habits: insufficient physical activity, unhealthy diet, smoking, and use of substances (including alcohol). According to the Swedish National board of Health, half of all women living in Sweden and 65% of the men have at least one unhealthy lifestyle habit, and around 20% of the disease burden in Sweden are related to unhealthy lifestyle habits (Socialstyrelsen 2012). Lifestyle habits such as physical activity, diet, non-smoking and moderate alcohol use seem to influence the risk and the prognosis in several diseases as well as mortality especially when the habits are combined (King et al. 2009, Pronk et al. 2011).

RA is associated with an increased risk of developing comorbidities, some of which are known to be associated with a sedentary lifestyle (Hollan et al. 2015). In 2010, the European League Against Rheumatism (EULAR) published general guidelines on risk management in patients with RA, in which health professionals are encouraged to prioritise discussions with patients regarding their lifestyle (Beaglehole et al. 2011).

Lifestyle can be understood as a series of daily habits and behavioural patterns. People make choices every day—about what to wear, what to eat, and how to behave. Individual choices are affected by many different things: for example, self-esteem, family and friends, and work (Svensson et al. 2011).

Physical activity

Physical activity has been defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen et al. 1985). Physical activity can be categorised as activities concerning household activity, leisure activity, or any other kind of activity. This broad term means that physical activity includes almost everything a person does, and that inactivity or sedentary behaviour is spending time doing things that do not markedly increase energy expenditure (time spent sitting or lying).

Physical exercise is defined as being a subset of physical activity—“planned, structured, and repetitive bodily movement done to improve or maintain one or more components of physical fitness”. Physical fitness is defined as “a subset of attribute that a person has or achieve that relates to ability to perform physical activity” (Caspersen et al. 1985).

Physical activity and physical exercise give health benefits to the general population and to people with chronic conditions such as RA. The concept of health-enhancing physical

activity (HEPA) was developed by the American College of Sport Medicine (ACSM) and the American Heart Association (AHA) and it applies to healthy adults aged 18–65 years (Haskell et al. 2007). The recommendations for HEPA have also been adopted by the Swedish Board of Health and Welfare (Socialstyrelsen 2012). The recommendations include that moderate-intensity aerobic physical activity should be performed regularly for a minimum of 30 minutes at least five days a week, or be substituted by 20-30 minutes of vigorous activity three days a week. The 30 minutes of moderate-intensity aerobic physical activity can be accumulated in several bouts performed for at least 10 minutes. Muscular strength exercise should be performed twice a week, including ten exercises and 8–12 repetitions of each exercise. There are separate recommendations for adults who are 65 or older, and for those aged 50–64 years with chronic conditions and/or functional limitations. This includes balance training for those 65 or older, and that those with chronic diseases or functional limitations should be as active as the condition permits (Nelson et al. 2007).

Physical activity in patients with RA

Physical activity is an important factor in RA self-management (Smolen 2013) and there is substantial evidence that moderate or vigorous physical activity and exercise is beneficial and safe for patients with RA if adjusted according to their aerobic fitness (Haskell et al. 2007). Many patients with RA do not reach recommended levels of physical activity (Tierney et al. 2012). According to international studies 14% to 29% were reported to be physically active at a recommended level (Sokka et al. 2008, Iversen et al. 2017). Physical activity and exercise are important components of RA treatment and they can reduce symptoms such as pain, fatigue, and morning stiffness and improve quality of life (Hurkmans et al. 2009, Cooney et al. 2011). In healthy individuals, physical activity leads to reduced levels of pro-inflammatory cytokines, and those who are physically active before onset of the disease appear to present with milder RA. This adds to the evidence that physical activity has beneficial effects also on inflammatory diseases (Sandberg et al. 2014, Benatti et al. 2015).

Psychosocial factors such as self-efficacy, social support, and outcome expectations are associated with current and maintained self-reported physical activity. Identification of predictors of unwarranted responses and how to prevent them will provide the foundation for personalized exercise prescription (Demmelmaier et al. 2013). Focus groups and qualitative studies of people with arthritis have identified different types of barriers to physical activity: physical (pain, mobility, and fatigue), psychological (lack of confidence, lack of enjoyment, or lack of motivation), social (competing responsibilities, and lack of advice and support), and environmental (lack of equipment and exercise facilities (Veldhuijzen van Zanten et al. 2015). It is also important to address and include the patient's own attitudes to physical activity. Findings from a previous qualitative study reported two different attitudes; motivation to do physical activity, described as the patient's own needs and satisfaction with actual level of physical activity, and four different combinations of them, motivated and satisfied, unmotivated and dissatisfied (Eurenius 2003).

Diet

Diet recommendations are individual and depend on how active a person is. It is important not just to look at particular kinds of foods or nutrients, as it is the overall dietary habit that matters. The national guidelines regarding good dietary habits are aimed at adults, adolescents, and children, and can be adjusted for different food cultures. People with certain diseases and food allergies may need individually tailored nutritional advice or dietary treatments from their healthcare professionals. The recommendations regarding healthy eating are based on the Nordic nutritional recommendations (NNR 2012).

Diet in patients with RA

Patients with RA have used different diets to try to alleviate their symptoms, and dietary regimes are widely used (Hagen et al. 2009). There is some evidence that fasting followed by a vegetarian diet and a Cretan Mediterranean diet can alleviate pain, but it cannot improve stiffness and physical function, when compared to an ordinary diet (Hafstrom et al. 2001, Skoldstam et al. 2003). The effects of vegan and elimination diets in RA are uncertain and conflicting results have been published. The complex relationship between diet and RA disease activity need further research before recommendation can be done (Tedeschi et al. 2016) or if there are a dietary patterns that could increase the risk of RA (Sundstrom et al. 2015). Previous studies are often small and single trials, with a high risk of bias (Hagen et al. 2009).

Diet habits and obesity are closely linked to disease activity in RA, where almost 50% of the patients have been reported to be overweight or obese at disease onset (Ajeganova et al. 2013). Patients also have higher frequency of comorbidities which lowers the chances of achieving good clinical outcomes, highlighting the importance of lifestyle modifications (Levitsky et al. 2017).

In patients with RA, the risk of cachexia needs to be addressed in relation to dietary recommendations (Elkan et al. 2009). Patients with RA may have a higher percentage of fat mass than healthy controls, and an increase in fat mass can be undetected because it often occurs with a decrease in muscle mass and normal BMI (Stavropoulos-Kalinoglou et al. 2007).

Smoking

Smoking is the largest cause of preventable deaths in the world (Danaei et al. 2009) and should be avoided. Cigarette smoking is not always discussed in the clinical setting; health professionals need to consider its impact on health (Abate et al. 2013).

Smoking in RA

Smoking is the best-studied modifiable risk factor for RA (Abate et al. 2013) and there is strong evidence that smoking increases the risk to develop RA, aggravate its progression and increases the risk of developing extra articular RA (Klareskog et al. 2006, Nyhall-Wahlin et al. 2009, Soderlin et al. 2011, Lahiri et al. 2012). Smoking contributes up to 25% of the burden of RA (Lahiri et al. 2012). Both past and current cigarette smoking has been found to be a risk factor for development of seropositive RA, with an increased risk up to 20 years after cessation (Costenbader et al. 2006). Current smokers are also less likely to respond to medical treatment of RA (Saevarsdottir et al. 2011, Soderlin et al. 2012). This also implies that it is important to refrain from smoking for those having a genetic risk for RA.

Alcohol use

Alcohol use is a modifiable factor with an important impact on public health. Excessive alcohol use can lead to the development of chronic diseases such as systemic hypertension, alcoholic cardiomyopathy, arterial arrhythmias (Klatsky 2015), stroke (Larsson et al. 2016), and cancer of the breast and gastrointestinal tract (Bagnardi et al. 2015). Moderate drinking is associated with a lower risk of initial presentation with several, but not all, cardiovascular diseases. In public health work and in clinical research, when counselling patients, suggesting a more nuanced approach to the role of alcohol in prevention of cardiovascular disease is necessary (Bell et al. 2017).

Alcohol use in RA

Studies on RA and alcohol use have found divergent results. Alcohol use may protect against development of RA (Maxwell et al. 2010), especially in ACPA-positive RA (Scott et al. 2013), and is also associated with less radiographic progression of RA in men (Nissen et al. 2010). In women with RA moderate alcohol has been found to be associated with reduced disease activity and a higher quality of life (Bergman et al. 2013).

Alcohol use has many negative effects on health (Klatsky 2015), and there is a hepatotoxic risk associated with alcohol use if methotrexate is being used for treatment (Kremer et al. 2017).

Rationale of this thesis

The course of disability in established RA is complex and may be seen as a process running in parallel with disease activity (even with well-controlled disease) and physical limitations affecting health status and quality of life. There is a need for a deeper understanding of the patient's perspective on lifestyle habits and quality of life in order to improve management of RA from a biopsychosocial perspective. Findings based on qualitative studies can complement quantitative research to give this deeper understanding.

It is well known that a healthy lifestyle can reduce the risk to develop a number of diseases and improve quality of life, findings that are also applicable to patients with RA. In guidelines and recommendations for management of patients with RA, health professionals are encouraged to prioritise discussions about lifestyle, while concentrating on the following considerations: physical activity, diet, smoking, and alcohol use.

Few studies have explored patients' perception of lifestyle habits and very little information has been available on whether lifestyle habits are addressed in the clinic.

Aims

Overall aim

The overall aim was to explore factors that affect disability and quality of life in patients with established RA, concentrating especially on lifestyle habits (physical activity, diet, smoking, and alcohol use) and whether they are addressed in the clinic.

Specific aims

The specific aims of this thesis were:

- to identify factors predictive for severe self-reported disability in patients with established RA (Paper I).
- to describe and explore how patients with established RA experience the influence of lifestyle habits on quality of life (Paper II).
- to explore the variation of ways in which patients with established RA understand the concept of quality of life (Paper III).
- to explore if lifestyle habits physical activity, diet, smoking, and alcohol use were discussed with patients with established RA when visiting healthcare units (Paper IV).

Methods

Study design

This thesis is based on four studies of both quantitative and qualitative design (Table 2). Paper I was a longitudinal prospective cohort study, Paper II and III were qualitative studies with two different explorative approaches, and Paper IV was a cross-sectional study based on a postal survey.

Table 2. Overview of papers I–IV in this thesis: their design, the sex and age of the participants, instruments used, data collection, and data analysis

Study	I	II	III	IV
Design	Longitudinal cohort study	Descriptive, explorative design	Descriptive, explorative design	Cross-sectional study
Data collection	Register Questionnaire	Interviews	Interviews	Questionnaire
Participants, n	1,387	22	22	1,061
Women	967	12	12	769
Men	420	8	8	292
Age, years	65 (mean)	30–84 (range)	30–84 (range)	67 (mean)
Women	64			66
Men	68			70
Duration of disease, years	9 (mean)	8-23 (range)	8-23 (range)	15 (mean)
Variables	HAQ SOFI RAOS ADL RAOS sport/rec WHO rec WHO MI-PA WHO VI-PA Swollen joints Tender joints Pain General health			HAQ EQ-5D Lifestyle habits Physical activity Diet Smoking Alcohol Pain General health
Data analysis	Logistic regression	Qualitative content analysis	Phenomenographic analysis	Inferential statistics

HAQ = Health Assessment Questionnaire; SOFI = Signals Of Functional Impairment; RAOS = The Rheumatoid and Arthritis Outcome Score; EQ-5D = EuroQol5D; WHO = World Health Organization recommendation; MI-PA = Moderate intensity physical activity, VI-PA = Vigorous intensity physical activity.

Study population

The BARFOT cohort

The Better Anti-Rheumatic Pharmacotherapy (BARFOT) study is a multicentre study in southern Sweden that included adult patients (age ≥ 18 years) with early RA according to the American College of Rheumatology (ACR) criteria (Arnett et al. 1988) during the years 1992 to 2006. The six participating rheumatology clinics are located at the general hospitals in Helsingborg, Kalmar, Kristianstad, and Mölndal; at Spenshult Hospital for Rheumatic Diseases (from 2014, Capho Movement); and at the Department of Rheumatology, Karolinska University Hospital, Huddinge, Stockholm. These centres cover a population of approximately 1.5 million inhabitants. The patients have been followed in a structured way, including follow-ups at 3 and 6 months and thereafter at 1, 2, 5, 8, and 15 years (the BARFOT study register). Details of the study have been published elsewhere (Svensson et al. 2000, Forslind et al. 2007). All papers in the thesis are based on data from the BARFOT cohort (Figure 2).

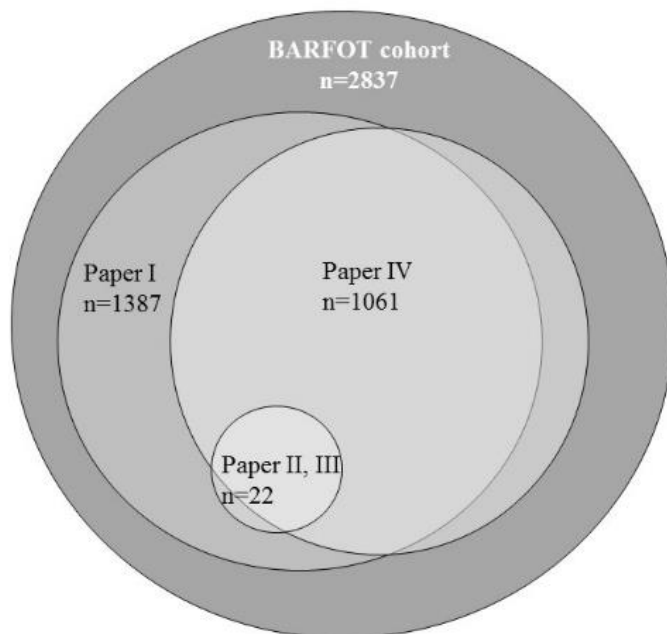


Figure 2. Overview of the four papers, where 61% of the patients in Paper I were included in Paper IV. All participants in Paper II and III were sampled from participants in Paper I, and 82% (n=18) of them also participated in Paper IV.

Sources of data

BARFOT study register

Baseline data for Paper I were retrieved from the BARFOT study register. In addition to data from the BARFOT study register, two lifestyle questionnaires were sent out, the first one in 2010 and a second one in 2017 (Figure 3).

In 2010 and 2017 a questionnaire was sent out to all the surviving patients in the BARFOT study. This included questions concerning the lifestyle habits: physical activity, diet, smoking, and alcohol use. Paper I included data from the 2010 questionnaire, and Paper IV was based on the 2017 questionnaire. The variables used are presented below. Data from the 2010 questionnaire were also used for the strategic sampling for studies II and III.

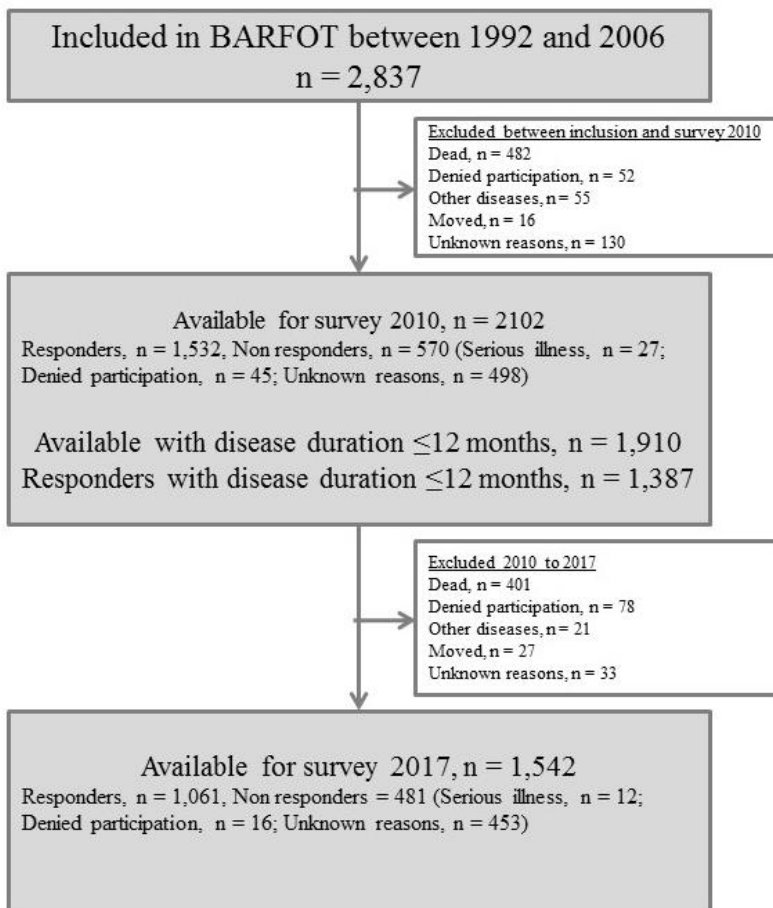


Figure 3. Flowchart over the two postal surveys.

Interviews

Papers II and III were based on interviews with 22 patients with established RA from the BARFOT cohort.

Procedures

Paper I

Paper I had a prospective cohort design where baseline data were collected in the BARFOT study during the period 1996–2006. The follow-up data were retrieved from the lifestyle questionnaire that was sent out in 2010, 5–18 years after inclusion in the BARFOT study. The questionnaire was sent out to all BARFOT patients who were still alive (disease duration \leq 12 months at inclusion, $n = 1,910$). After receiving two reminders, 1,387 had responded (73%) and were included in the study. The questionnaire included several well-used and validated questionnaires on physical functioning: the Stanford Health Assessment Questionnaire (HAQ), the Rheumatoid and Arthritis Outcome Score (RAOS), and questions on physical activity, which all served as our outcome variables.

Paper II

Paper II had a descriptive and explorative design, based on qualitative content analysis, in order to determine how lifestyle habits influenced the quality of life. The study was based on interviews with 22 patients with established RA (defined as having a disease duration of more than two years). All of these patients were enrolled in the BARFOT study. The participants were selected by using a strategic sampling procedure in order to achieve variations in terms of gender (14 females, eight males), age (range 30–84 years), marital status (15 married or co-habiting, seven single), education (eight compulsory comprehensive school, nine upper secondary school, five undergraduate studies), disease duration (range 8–23 years), employment (eight employed, 14 on sick leave or retired), physical function (HAQ 0–1.38), health-related quality of life (EQ5D 0.52–1.0), and sampling from all six BARFOT centres (with 2–7 participants per centre) covering both urban and rural patient referral areas.

Data were collected through individual interviews focusing on each of four lifestyle habits (physical activity, diet, smoking, and alcohol use), and all the interviews began with an open-ended question: “How do your lifestyle habits influence your quality of life?” The interviews were carried out as a dialogue with follow-up questions, in order to obtain in-depth data. Each interview lasted 30–70 minutes, was audio-recorded and then transcribed verbatim.

Paper III

Paper III had a descriptive and explorative design based on a phenomenographic approach, in order to explore variations in how the patients experienced their quality of life. The study was based on interviews with the same 22 patients with established RA from the BARFOT study who are described above (Paper II).

Data were collected in the individual interviews, focusing on the concept quality of life, using three open-ended questions: “What does quality of life mean to you?”, “How do you conceive your quality of life?”, and “How has your RA affected your quality of life?” To capture the patients’ fundamental and genuine conceptions, the interviewer returned to the main questions, and by asking probing questions and appropriate comments, encouraged the patients to openly express their own life experience. Each interview lasted 30–70 minutes, and it was audio-recorded and then transcribed verbatim.

Paper IV

Paper IV was a cross-sectional study based on the 2017 lifestyle questionnaire, and involved all 1,542 surviving patients from the BARFOT study. Two reminders were sent to those who did not respond to the first mailing, and 1,061 patients (response rate 68%) were included in the study. The questionnaire had questions concerning lifestyle habits: physical activity, diet, smoking, and alcohol use. There were also questions regarding physical function, and health status.

Variables studied and outcome measures used for evaluation

Several outcome variables were considered in this thesis.

Clinical measurements

Disease activity score (DAS28) (paper I)

The DAS28 is a validated index of RA disease activity (Prevo et al. 1995). DAS28 is a commonly used index that includes components from the point of view of the patient and from the point of view of the doctor. DAS28 includes the number of swollen and tender joints, erythrocyte sedimentation rate (ESR), and the patients’ global assessment of general health measured with a visual analogue rating scale (VAS) ranging from 0–100, meaning best to worst) (van Gestel et al. 1998). In paper I, we have chosen not to calculate the DAS28 score at baseline, in order to be able to study the separate variables in the regression analysis.

Medical treatment (paper IV)

Treatment with different disease-modifying anti-rheumatic drugs (DMARDs), glucocorticoids, and biologics was derived from the lifestyle questionnaire, 2017.

Radiography (paper I)

Radiographic joint damage (yes/no) was assessed at baseline by ACR criteria from 1987 (Arnett et al. 1988).

Pain assessment (papers I and IV)

Pain intensity was assessed with numerical rating scales (NRS) in the 2010 and 2017 questionnaires (0–10, best to worst), and at baseline pain was assessed with VAS (0–100, best to worst) (Joos et al. 1991).

Fatigue assessment (papers I and IV)

Fatigue was assessed with NRS (0–10, best to worst) in the 2010 and 2017 questionnaires (Gossec et al. 2015).

The patients' global assessment of general health (papers I and IV)

Global assessment of general health at inclusion was measured with VAS (0–100, meaning best to worst) (Joos et al. 1991). In the 2010 and 2017 questionnaires, it was measured with NRS (0–10, best to worst).

Health status measured by EQ-5D-3L (paper IV)

EQ-5D is a generic measure of health status including the following five dimensions: mobility, self-care, pain, usual activities, and psychological status. Each dimension is divided into three levels: no problems/some problems, moderate problems, and extreme problems, with a total value of between 0 and 1 defining health status (0 = death, 1 = full health) (Hurst et al. 1997). EQ-5D was previously described as a health-related quality of life instrument but is now referred to as a measure of health status (<https://euroqol.org/eq-5d-instruments/>).

The Stanford Health Assessment Questionnaire (HAQ) (paper I)

The HAQ is a validated questionnaire for assessment of activity limitations in patients with arthritis. The HAQ is self-administered and consists of 20 questions distributed in eight categories of functioning: dressing, rising, eating, walking, hygiene, reach, grip, and usual activities, with a sum score varying between 0 and 3 (best to worst). A higher score indicates a worse degree of disability (Fries et al. 1980, Ekdahl et al. 1988).

Signals of Functional Impairment (SOFI) (paper I)

The SOFI index measures range of motion in the hand, arm, and lower extremities, and it involves 12 functional tests (eight on the upper extremities and four on the lower extremities, yielding a total score in the range 0–44 (meaning best to worst)). SOFI has been found to have acceptable validity and reliability in patients with RA (Eberhardt et al. 1988).

The Rheumatoid and Arthritis Outcome Score (RAOS) (paper I)

The RAOS is a patient-reported outcome measure and consists of 42 items assessing five separate dimensions: pain (nine items); other symptoms like stiffness, swelling, and range of motion (seven items); activities of daily living (ADL) (17 items); sport and recreational activities (sport/rec) (five items); and lower limb-related quality of life (four items). Two of the subscales were used in paper I: activities of daily living (ADL) and the subscale sport and recreational activities (sport/rec) with the score ranging from 0 to 100 (meaning worst to best). The RAOS subscales can be used independently (Bremander et al. 2003).

Lifestyle habits

Physical activity (papers I and IV)

Data on physical activity were collected by using questions in accordance with the World Health Organisation (WHO) recommendation concerning frequency and duration during the previous 7 days (min/week): (1) vigorous-intensity (jogging or intense exercise), and (2) moderate-intensity (walking, gardening, and/or bicycling) (Olsson et al. 2016).

Diet (paper IV)

The present diet was assessed using eight options in the questionnaire from 2017: traditional mixed, Mediterranean, low-glycaemic (GI), vegetarian, vegetarian with seafood, vegan, gluten-free, and other (free text).

Smoking (paper IV)

Smoking habits were assessed in the questionnaire from 2017 and the responses were coded into “never-smoker”, “previous smoker”, and “current smoker” (Soderlin et al. 2011). When smoking habits were dichotomized, the previous smokers and current smokers were called “ever-smokers” and compared to never-smokers.

Alcohol use (paper IV)

Alcohol use was assessed in the questionnaire from 2017 with the AUDIT-C, a validated subset of items from the full alcohol AUDIT (Fleming et al. 1991) consisting of three questions concerning (1) frequency per month, (2) volume per occasion, and (3) number of times with six or more drinks on one occasion. All questions were scored 0–4 (meaning best to worst), with a total score of 0–12 points. The limit for hazardous drinking according to the Swedish National Institute of Public Health is AUDIT-C > 4 points for women and > 5 points for men, cut-offs that were also used in this study (www.fhi.se).

Data management and analysis

Quantitative methods (papers I and IV)

In paper I, in order to study those most affected by the disease at the time of the questionnaire in 2010, the outcome variables HAQ and RAOS (adl and sport/rec) were split into tertiles. In multiple logistic regression analyses, the tertiles with the worst scores were compared with the two better tertiles with regard to potential predictive factors. The outcome variable physical activity was split into two groups: those who reached recommended levels of physical activity (WHO MI-PA, WHO VI-PA, and WHOrec) compared to those who did not. Proposed predictive factors were HAQ, SOFI, pain, presence of radiographic changes or not, the number of swollen and tender joints, ESR, and the patient's global assessment at baseline. Each of these predictors were studied in separate analyses, controlled for age, gender, and disease duration (time between baseline and questionnaire survey), included as possible confounding factors.

In paper IV, independent t-tests were used to study differences in mean values between groups, and the chi-square test was used for comparisons of proportions. All significance tests were two-tailed and conducted at the 5% significance level. Continuous data are shown as mean and SD and categorical data are shown as frequency (with percentage). All analyses in Paper I and IV were performed using SPSS versions 19.0–22.0 for Windows.

Qualitative methods

Qualitative content analysis (paper II)

In paper II, a qualitative content analysis was used in order to provide a systematic way of making valid inferences from the transcribed verbal data, to determine how the patients experienced how lifestyle habits influenced their quality of life. The method is useful to provide knowledge and understanding of a phenomenon and to analyse a person's experiences, attitudes, and reflections (Krippendorff 2013). This research technique is aimed at describing variations by identifying differences and similarities in the content, both the manifest content (what the text says) and the latent content (the interpreted meaning). The method is often used in healthcare research, and in this study both the manifest content and the latent content were analysed in seven steps according to Graneheim and Lundman (2004)(Graneheim et al. 2004).

1. The entire text (units of analysis) was read in combination with listening to the audio-recorded interviews to obtain a sense of the whole.
2. Meanings or phrases containing information relevant to the aim were identified and extracted, together with surrounding text in order to preserve the context (meaning units).
3. The 526 meaning units were condensed to shorten the text while retaining the content (condensed meaning units).
4. The condensed meaning units were abstracted and coded.

5. The codes were compared based on similarities and differences after they were grouped into six subcategories.
6. The subcategories were grouped into three categories that reflected the central message contained in the interviews. These categories constituted the manifest content.
7. The content of categories was brought together and abstracted. A theme reflecting the underlying meaning was formulated, which expressed the latent content.

Phenomenography (paper III)

Paper III had a qualitative design with a phenomenographic approach in order to describe the different ways the phenomenon under study (quality of life) could be understood. Phenomenography proposes that a phenomenon is understood by individuals in qualitatively different ways and that a group of individuals creates an understanding of the phenomenon on a collective level. The conceptions are based on the life experience of the individuals and the ways of understanding have both “what” and “how” aspects (Marton 1981, Marton F et al. 1997). The conceptions are related both to our social reality and to ourselves. These two factors help to explain our everyday lives, and the ways in which we deal with them guide our opinion and direct our search for knowledge (Barnard et al. 1999).

The analysis was performed in seven steps according to Larsson and Holmström (2007)(Larsson et al. 2007).

1. The entire text was read several times in combination with listening to the audio-recorded interviews.
2. When re-reading the whole text, marks were made where participants gave information corresponding to the aim of the study.
3. The marks were then compared and discussed to identify the participant’s predominant way of understanding quality of life and how this was described, formulating a preliminary description of each patient’s predominant way of understanding his or her quality of life.
4. Based on similarities and differences, descriptions were categorised into three descriptive categories. These were reported in the form of text and illustrated by quotations.
5. The participant’s non-dominant ways of understanding the phenomenon were identified. This was done to ensure that no aspect was overlooked.
6. A structure of descriptive categories was created in order to find the internal relationship between the three categories, which created the outcome space, constituting the result of the phenomenographic study.
7. A metaphor was assigned to each of the three descriptive categories.

Ethical considerations

Permission was obtained from the regional ethics committee in Sweden, for the BARFOT cohort (Gbg Ö 282-01; LU 398-01; LI 01-263; KI 02-075, Stockholm EPN 2016/297-31/1), and for papers I (LU. 2009/670), papers II and III (LU 2014/146), and paper IV (LU 2016/896). The participants received a letter stating the aim of the study, its design, and the voluntary nature of participation; and they gave their informed consent. All participants were guaranteed confidentially and were informed that they could withdraw at any time without having to explain their decision, and without there being any consequences for future care. The studies were carried out in accordance with the ethical principles of the Declaration of Helsinki (as amended in 2013) (WMA 2013).

Results

Predictors of severe self-reported disability in RA in a long-term follow-up study (Paper I)

Function and pain at onset of disease in patients with RA were found to be prognostic measures of a worse physical function outcome several years later. Worse scores in function at baseline, both patient-reported outcome (HAQ) and observed (SOFI), predicted a worse patient-reported outcome in HAQ and RAOS five to 18 years later (Table 3). Questions concerning physical activity were answered by 1,076 patients and 65% met the WHO recommendations (WHOrec), women more often than men ($p = 0.006$). There was also a sex difference in meeting the recommendations for WHO VI-PA; this was more common in women ($p = 0.023$). None of the variables studied could predict who did or did not meet WHO recommendations for health-enhancing physical activity in 2010 (Table 3). Physical activity was not predicted by disease activity or function at baseline and these are different entities. This may indicate that factors other than functional disability may be of greater importance in prediction of physical activity.

Table 3. Results from the multiple regression analysis showing Odds Ratios (OR) for RAOS adl, sport/rec and WHOrec, with regard to explanatory baseline variables.

	RAOS adl		RAOS sport/rec		WHOrec	
	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p
HAQ [0–3] n = 973–1,301	2.37 (1.864–3.013)	0.000	2.33 (1.826–2.961)	0.000	0.90 (0.718–1.125)	0.35
SOFI [0–44] n = 765–1,025	1.09 (1.057–1.118)	0.000	1.08 (1.053–1.114)	0.000	0.99 (0.966–1.020)	0.6
Pain ¹ [0–100] n = 1,003–1,337	1.02 (1.013–1.026)	0.000	1.01 (1.008–1.020)	0.000	1.00 (0.992–1.002)	0.27
GH ¹ [0–100] n = 1,009–1,345	1.01 (1.009–1.020)	0.000	1.01 (1.005–1.01)	0.000	1.00 (0.994–1.004)	0.73
Swollen ² [0–28] n = 919–1,231	0.98 (0.955–1.005)	0.11	1.00 (0.973–1.023)	0.84	0.98 (0.955–1.002)	0.07
Tender ² [0–28] n = 917–1,229	1.03 (1.009–1.056)	0.006	1.03 (1.009–1.057)	0.01	0.99 (0.972–1.015)	0.52
ESR n = 1,014–1,355	1.00 (0.996–1.006)	0.74	1.01 (1.002–1.013)	0.01	1.00 (0.995–1.006)	0.95
X-ray [0/1] n = 914–1,224	1.15 (0.825–1.606)	0.41	1.32 (0.938–1.854)	0.11	1.10 (0.800–1.512)	0.56

HAQ = Health Assessment Questionnaire; SOFI = Signals of Functional Impairment; GH = general health; ESR = erythrocyte sedimentation rate; X-ray = radiographic joint damage

¹ Measured with visual analog scale (VAS).

² Number of swollen and tender joints (of 28).

The results from Paper I led to an interest in the relationship between function and quality of life. Previously unpublished results from the 2010 questionnaire showed that patients with high or low function (dichotomized on median score) as measured by HAQ, could have high or low quality of life (dichotomized on median score) as measured by EQ-5D (Figure 4).

It was especially notable that about half of those with low function expressed that they had a high quality of life, and the question was raised as to whether this could be due to different ways of handling lifestyle habits or different ways of understanding quality of life. This led to the two qualitative studies (Paper II and Paper III).

	High EQ5D	Low EQ5D
Low HAQ	n = 591	n = 59
High HAQ	n = 309	n = 344

Figure 4. Shows the relationship between function assessed by HAQ and quality of life assessed by EQ5D.

The influence of lifestyle habits on quality of life in patients with established RA—A constant balancing between ideality and reality (Paper II)

The analysis of the influence of lifestyle habits on quality of life in patients with established RA resulted in one theme, three categories, and six subcategories (Table 4). Quality of life was influenced by the balance between ideality and reality in the lifestyle habits physical activity, diet, smoking, and alcohol use. These could be described in terms of limitation, self-regulation, and companionship, which influenced the patients' experiences of their quality of life.

The participants described a limitation in physical activity in everyday situations that they were not able to walk in some environments and to perform some activities, which led to a sense of insufficiency. Another limitation was a fear of falling and not being able to manage the situation. On the other hand, they described how they used different strategies and adaptations to overcome their limitations. The participants talked and used different types of adapted training equipment to facilitate walking, which influenced their quality of life. Regarding diet, the participants expressed a limitation and a feeling of insufficiency by having little knowledge of how diet could affect their health. They expressed a fear of having an unhealthy diet and of gaining weight. Participants who smoked felt a limitation. They knew about the harmful effects on smoking and expressed a feeling of insufficiency, and a fear of not being able to stop smoking. There was an insufficiency in using alcohol and the participants expressed a concern about using alcohol because of the harmful effects; some participants had adapted their use of alcohol after disease onset and drug treatment, even though it resulted in a restriction in their life. Self-regulation in physical activity was affected by a feeling of guilt about being physically inactive. The participants expressed a desire and a motivation to be physically active in spite of not being physically able to. They saw an opportunity to improve their quality of life if they were physically active. Their motivation to perform physical activity was based on individual experiences. Self-regulation was affected by guilt if their diet was unbalanced, or if family and friends had opinions concerning different diet recommendations, but there was also a motivation to change to a healthy diet. Smoking induced a sense of guilt, since smoking affected their health and their treatment. On the other hand there was a motivation to influence their health by stopping smoking. Self-regulation in relation to alcohol was described with varied emotions; those who used alcohol knowing that it was dangerous for their health and in combination with their medication, felt guilty. Others expressed that they were motivated to abstain from alcohol in order to achieve a better quality of life, but they also experienced an opportunity to improve their quality of life by drinking small amounts of alcohol.

Physical activity was based on a sense of belonging, a feeling of experiencing companionship, or the opposite—a sense of loneliness—if they were limited in carrying out physical activity. To be able to participate in activities was seen as a source of pleasure.

Quality of life was also influenced by companionship in relation to diet and alcohol: there was a sense of pleasure when eating and drinking in a social situation. A sense of belonging even emerged among those participants who did not smoke, and pleasure from not being exposed to smoking.

Table 4. An overview of the subcategories, categories, and theme that reflected the influence of lifestyle habits on the quality of life of patients with established RA

Subcategories	Categories	Theme
Patients experienced insufficiency Patients experienced adaptation	Experiencing limitation	
Patients experienced guilt Patients experienced motivation	Experiencing self-regulation	Balancing between ideality and reality
Patients experienced belonging Patients experienced pleasure	Experiencing companionship	

Note that there is an errata in paper II on page 4 line 24, where seven subcategories should be six subcategories.

Quality of Life in established RA (Paper III)

Quality of life in established RA was understood in three different ways: the independent patient, the empowered patient, and the participating patient (Figure 5).

Independence was one way of understanding quality of life, and focused on various physical aspects such as being independent in terms of physical functioning and personal finances. The independent patient experienced quality of life as being free and independent in the ability to choose and manage daily activities of living at home, at work, and during leisure time. Quality of life also entailed having financial security and the possibility to choose where and how to live, in an apartment or in a house, and what to eat; and to be able to afford to continue with a self-chosen hobby, such as travelling or going to the theatre.

Empowerment was another way of understanding quality of life, and focused on different psychological aspects of how to manage life. The empowered patient felt that quality of life meant taking charge of and using different resources, such as positive thinking in order to manage fatigue, pain, and physical functioning. The patients' conception of being empowered was to believe in their own capacity to self-manage their everyday life, to be flexible, and to influence their own situation. There were also conceptions about the empowered patient, that quality of life entailed being able to see opportunities and to be able to continue with planned activities by using ordinary routines, and to accept the need for help in certain situations. The empowered patient talked about having a sense of security in mind and body in order to cope with a situation in an individual way.

Quality of life was also understood as participation and focusing on different social considerations, such as having the experience of belonging and participating. The participating patient experienced quality of life in terms of being part of a social community, participating in different projects at home, at work, or in the community. Quality of life also entailed having the ability to meet old and new friends, and to have meaningful things to do. The participating patient took part in different contexts with other people of different ages and gender.

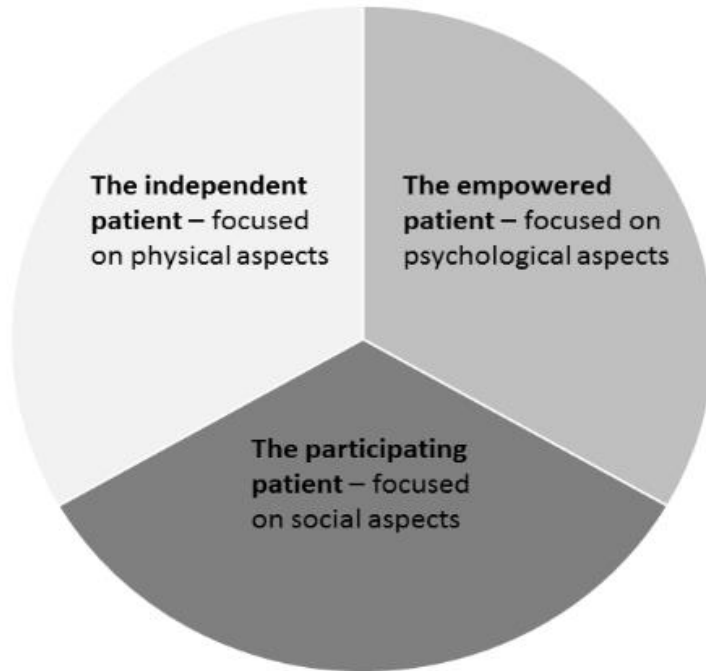


Figure 5. The outcome space illustrating the relationship between the categories independence, empowerment, and participation focused on and physical, psychological, and social aspects that influence the quality of life in patients with established RA. The categories were related as parts of a whole and the variations that emerged were not hierarchically related.

Papers II and III highlighted the importance of how patients related to lifestyle habits in order to handle the functional limitations from their established RA. This led to paper IV, where we concentrated on the question of whether there had been lifestyle-related discussions during the patients' healthcare visits.

Discussions about lifestyle habits as an integral part of care management in patients with established RA (Paper IV)

Papers II and III highlighted the importance of how patients related to lifestyle habits in order to handle the functional limitations from their established RA. This led to paper IV, where we concentrated on the question of whether there had been lifestyle-related discussions during the patients' healthcare visits.

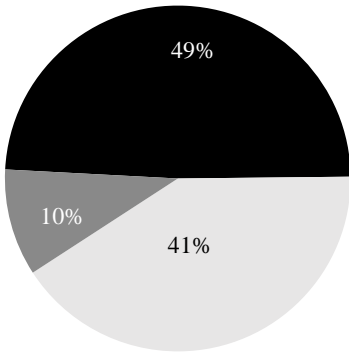
Physical activity had been discussed a least once with every second patient, with no significant differences between women and men (48% vs. 53%; $p = 0.121$). Ten per cent of the patients who did not have a discussion reported that they would have wanted one (Figure 6A). Those 46% who reported that they were active at the recommended physical activity level had discussed physical activity with health professionals more often than those who did not fulfilled the recommendations (55% vs. 45%; $p = 0.002$), with an OR of 1.47 (95% CI: 1.55–1.88).

Diet had been discussed with about a quarter of the patients, with no significant difference between women and men (22% vs. 27%; $p = 0.085$). Fifteen per cent of the patients who had not had a discussion would have wanted it (Figure 6B). Most patients (81%) reported that they had a traditional mixed diet, but it was more common that those who reported having a non-traditional mixed diet (low-glycaemic, Mediterranean, vegetarian, or vegan) stated that they would have wanted a discussion (31% vs. 20%; $p = 0.002$).

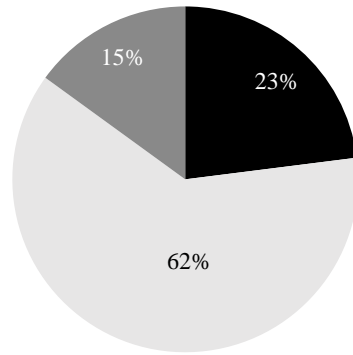
Smoking had also been discussed with a quarter of the patients, with no significant difference between women and men (26% vs. 27%; $p = 0.731$). Only 1% of the patients who had not had a discussion would have wanted it (Figure 6C). Thirteen per cent reported that they were current smokers. A higher proportion of ever-smokers than never-smokers had discussed smoking habits with healthcare professionals (32% vs. 17%; $p = 0.000$), and a higher proportion of them would also have wanted to discuss smoking (7% vs. 2%; $p = 0.001$).

Alcohol use was less often discussed, and more commonly with men than with women (22% vs. 15%; $p = 0.008$). Of the 19% who had a hazardous drinking pattern, 77% did not report that they had had a discussion regarding alcohol. Only 2% of them reported that they would have wanted such a discussion (Figure 6D).

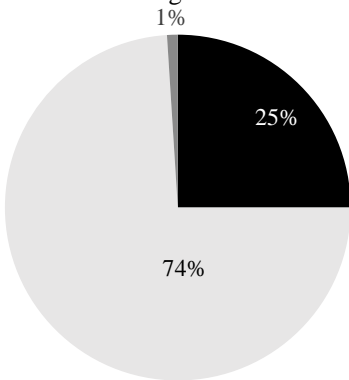
A Physical activity discussed?



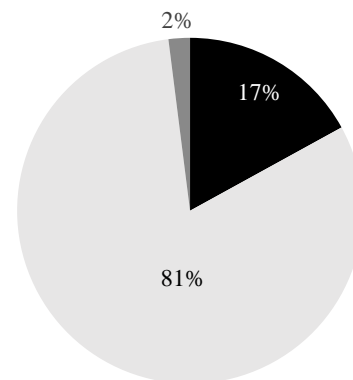
B Diet discussed?



B Smoking discussed?



D Alcohol discussed?



■ Yes □ No, it was not needed ■ No, but i wanted.

Figure 6. Rate of patients reporting that they had had a discussion regarding lifestyle-related habits and whether they had wanted to have a discussion. Panel A relates to physical activity, panel B relates to diet, panel C relates to smoking, and panel D relates to alcohol.

Discussion

This thesis explores health and quality of life in relation to lifestyle habits in patients with established RA. Paper I presents the studied patient group in a long-term follow-up, where pain, function, and general health at disease onset predicted measures of physical function, but not the level of physical activity at follow-up 5 to 18 years later. Since a further (unpublished) analysis using data from the follow-up revealed that a high quality of life at could be reported despite a worse physical function, it was decided to explore how patients with established RA experienced the influence of lifestyle habits on quality of life (Paper II), and also how they understood the concept quality of life (Paper III). It was found that quality of life in relation to lifestyle habits was a constant balancing between ideality and reality. The understanding of quality of life could be categorized as independence, empowerment, and participation, which could correlate to biological, psychological, and social aspects of life. Although different aspects of lifestyle habits appear to be important for quality of life, they are seldom discussed with the patients in the clinical situation (Paper IV), and this discussion is not always requested by the patients.

The 5- to 18-year follow-up study in Paper I, with baseline at disease onset, confirms results from previous research that worse function, as measured by HAQ and SOFI at baseline, is a predictor of worse function over time (Thyberg et al. 2012). This highlights the importance of clinical assessment of function at disease onset as a supplement to standard treatment. Other predictors of worse function, were having worse pain, having poorer general health, having a greater number of tender (but not of swollen) joints, being a woman, being older at inclusion, and having a longer disease duration at follow-up. The predictive value of mainly pain-related measurements and being a woman suggest that function at follow-up not only relates to the inflammatory process, but also to the widespread pain problem that has previously been reported to be common in this cohort of patients with RA (Andersson et al. 2013a). Although function and pain at disease onset were found to be prognostic measures of worse patient-reported physical function, it did not predict whether the patients achieved the recommended physical activity level according to WHO recommendation. Factors other than functional impairment may be of greater importance for prediction of physical activity levels (Eurenius et al. 2005). The benefits of physical activity on RA are well documented, and regular physical activity is also associated with a reduced risk of cardiovascular disease (Veldhuijzen van Zanten et al. 2015). Still, in the present Paper, one-third of all patients were not physically active at a recommended level, indicating that healthcare professionals need to assess and discuss physical activity habits from the patient's viewpoint of the disease (Iversen et al. 2015). It is necessary to identify ways to encourage patients to improve functional status and improve disease activity, and to maintain regular physical activity (Knittle et al. 2015). Earlier studies with low levels of physical activity in patients with RA have suggested the need to focus on promoting a physically active lifestyle, and to use behaviour change techniques (Nordgren et al. 2012). A patient centred approach is more

important when coaching patients with a more severe RA (Sjoquist et al. 2010). Lifestyle habits such as being physically active are usually based on long-standing behavioural patterns that also rely on support from the social environment (Knittle et al. 2012), in agreement with the bio-psycho-social model. Since the average age at onset of RA is the mid-fifties or older, lifestyle habits are probably already well established. It has been reported that older women with RA choose a more sedentary lifestyle and that there is a need to discuss and promote a more active lifestyle (Eurenius et al. 2005). A sedentary lifestyle is also one of the major risk factors for cardiovascular disease independently of participation in physical activity (Piepoli et al. 2016). It was found in Paper IV that physical activity was the most discussed lifestyle habit in healthcare, although only with half of the patients.

The finding that physical function, pain, and general health at disease onset predicted function but not the level of physical activity at follow-up led to further discussions in the research group regarding the relationship between limitations due to established RA and physical activity, but also with regard to other lifestyle habits (diet, smoking, alcohol use). These four habits have been put forward in the Swedish national recommendations (Socialstyrelsen 2012) as being important to discuss with patients during healthcare visits, regardless of medical speciality. In a previously unpublished analysis of data from the same cohort as the study in Paper I, it was found that patients with high or low levels of function as measured by HAQ could either have a high or a low quality of life as measured by EQ5D (Figure 4, page 39). These findings led to research questions regarding the patient's view of lifestyle habits and quality of life in the context of living with established RA. This was explored further in two qualitative studies (Papers II and III).

The overall finding in Paper II was that the experience of quality of life depended on a constant balancing of lifestyle habits between the ideal situation (ideality) and the actual situation (reality), described in terms of *limitation*, *self-regulation*, and *companionship*.

A habit such as smoking could be expressed as a pleasure and described as contributing to quality of life, despite the fact that it is known to be unhealthy. Sometimes there was too much of limitations and insufficiency to handle everyday life, or there was a sense of guilt for not being physically active enough or having a proper diet, which also affected quality of life. These somewhat paradoxical findings should also be seen in light of the biological, psychological, and social aspects of quality of life when living with a long-standing disease, as expressed by the patients in Paper III.

In Paper II, the patients described a *limitation* in physical activity in everyday situations that affected their quality of life. This is in line with the fact that the symptoms in RA mainly relate to biological factors such as morning stiffness, pain, and fatigue (Keefe et al. 2002, Thyberg et al. 2012), and that disease can lead to impaired physical functioning (Eurenius et al. 2005). Limitations in physical function were also reported to affect the ability to prepare food, which—together with a lack of knowledge of what diet that was positive for their RA—also had an effect on quality of life. The patients also expressed a fear of having

an unhealthy diet and of gaining weight, reflecting psychological aspects of quality of life, and expressed by the category *self-regulation*. These psychological aspects and the relation between limitations and self-regulation were also expressed by patients who smoked, although they knew about the harmful effects. They expressed a feeling of insufficiency and a fear of not being able to stop smoking. Living with a long-standing disease such as RA means that the patient has to cope, change priorities, and manage functional limitations on a daily basis (Thomsen et al. 2015). The patients with RA have to take active control of their limitations by self-regulation (Flurey et al. 2014). In Paper II, this is expressed by the overall theme of balancing between ideality and reality.

Quality of life in paper II was also influenced by social aspects, represented by the category *companionship*. This was expressed for each of the four lifestyle habits studied, but especially in relation to diet and alcohol use, where there was a sense of pleasure when eating and drinking in a social situation. These social aspects are important to address in the clinic, since patients with RA may have difficulty in leaving their homes and in being able to participate in valued activities (Feldthusen et al. 2013).

To further explore and understand the results from Paper II, it was important to find out how patients with established RA understood the concept of quality of life. It is known that patients, healthcare professionals, and researchers can have different conceptions of this term (Stamm et al. 2005). The overall finding in Paper III was that quality of life could be categorized as *independence* in terms of physical functioning and personal finances, *empowerment* in how to manage life, and *participation* as an experience of belonging in a social context, representing biological, psychological, and social aspects.

Being dependent on help from family or friends in everyday activities could affect one's quality of life. This finding is supported by the results of previous studies which found that patients who were married or cohabiting sometimes had feelings of gratitude and guilt because of being dependent (Kristiansen et al. 2012). Another aspect of independence was related to financial considerations. One consequence of the RA disease compared to the general population may be the inability to stay in paid work (Uhlig et al. 2007). Besides giving financial resources, the ability to work gives a sense of normality and a meaning in life (Gronning et al. 2010). Inadequately treated RA leads to less ability to work and a sizeable economic burden for the patients and their families, which has also been described in other studies (Ahlmen et al. 2005, McCarron 2015). Patients in the present paper described problems in staying employed, and in managing the working situation. According to previous studies, the ability to work depends on the kind of work (Birnbaum et al. 2009) and on physical and psychological health issues (Odegard et al. 2005). Patients with RA have reported that managing paid work can also be difficult when trying to find the right balance between work and rest (Simpson et al. 2005).

Impaired physical function in the lower extremities were reported to affect independence and to reduce quality of life. The relationship between physical function and emotional well-

being is important for patients with RA, since both contribute to the perceived burden of the disease and to quality of life (Gossec et al. 2015). There is an interaction between physical functioning and emotional well-being, and it is important to encourage and educate patients to cope with their current situation (Englbrecht et al. 2013). The experience of living with a long-standing disease such as RA makes the patient strive to accept to live with the fact that RA is part of who he or she is. This experience is in line with a previous study (Sverker et al. 2015).

In Paper III, the empowered patient described quality of life as how to manage everyday life and how to use different psychological strategies, in order to be empowered to take care of oneself and learn to live and cope with different symptoms. Being empowered is closely related to having high levels of self-management, and interventions focusing on self-management are patient-centred and have the possibility to improve both health and quality of life (Iversen et al. 2010, Arvidsson et al. 2011). Healthcare professionals put strong emphasis on enabling patients to self-manage some aspects of their condition and to make informed treatment choices (Luqmani et al. 2009). Empowerment occurs when healthcare professionals increase the ability of patients to think critically and to make autonomous informed decisions (Anderson et al. 2010). Offering patient education is one way of giving the patients an opportunity to take more control over decisions and actions that affect their own lives. Patients have reported having stronger empowerment and have implemented lifestyle changes after participating in a self-care program (Arvidsson et al. 2011).

To be part of a community and being able to participate in different contexts was experienced as quality of life in paper III. A variation in the concept participation was described as a sense of loneliness and of not being needed. Belonging in a social context has been expressed as important for maintaining quality of life in patients with RA (Pitsilka et al. 2015). The findings in Paper III confirms previous studies that have reported that the ability to meet people on equal terms is important for quality of life, and that one consequence of impaired physical function could be a reduced participation (McCarron 2015, Benka et al. 2016). For many patients, as also expressed in Paper III, work is an important social arena in everyday life (Kristiansen et al. 2012).

Since Papers II and III highlighted the importance of how patients handle lifestyle habits in relation to their long-standing RA to improve their quality of life, the study in Paper IV explored the extent to which lifestyle habits were discussed with healthcare professionals. Half of the patients had discussed physical activity but only about a quarter of them had discussed diet, smoking, and alcohol use. Previous research has indicated that health professionals seldom discuss physical activity with their patients (Wilcox et al. 2006, Manning et al. 2012), and that patients' motivation for physical activity is not understood (Iversen et al. 2015). Many patients with RA do not communicate with their healthcare professionals about their disease burden and treatment goals (Strand et al. 2015). In the present study, it was more common that patients who met the recommendations about

physical activity had these discussions. Also, a higher proportion of patients with a non-traditional mixed diet had discussed diet with their health professionals. Regarding both physical activity and diet, this could indicate that such patients had a special interest in the topic. As expected, smoking was more often discussed with smokers, and not at all with non-smokers. This is of some concern, since smoking is a well-known risk factor for RA and especially for RA with heredity. Alcohol use was discussed more commonly with men than with women. Most of those with a hazardous drinking pattern had not had any discussion about alcohol use. This indicates that healthcare professionals must take the initiative for such discussions, and Paper IV supports earlier findings that there is still a need to improve lifestyle discussions and to give non-pharmacological advice to patients (Sokka et al. 2009). Individualized counselling is the basis for motivation and commitment, and decision-making should be shared between the healthcare professional and the patient (Oliver 2011). One benefit of using the biopsychosocial approach is an understanding of the patient's subjective experience (Borell-Carrio et al 2004), and allows the healthcare professional to guide every patient in a person-centred way. This thesis highlights the importance of a biopsychosocial approach and patient-centred care in order to recognize the patients who may be in need of extra support from healthcare professionals over the course of the disease.

Methodological considerations

This thesis is entirely based on patients included in the BARFOT study, giving the major strength in being a well-defined cohort with prospectively collected data and a tight and comprehensive long-term follow-up. The data used in the thesis is based on patients with a new RA diagnose fulfilling the ACR criteria from 1987 at six geographically spread rheumatology clinics, included over a period of 14 years. The use of ACR 1987 criteria gave a homogenous cohort of patients with a clearly defined diagnose.

The register with clinical data forms a robust base, and is in thesis complemented by patient-reported data from two postal surveys and qualitative data from interviews with a strategical sample of patients from all six clinics. The response rates in the two surveys were also high, 73% and 68% of those still alive and eligible.

To thoroughly answer the research questions of this thesis it was decided to use both quantitative (Paper I and IV) and qualitative methods (Paper II and III). Quantitative and qualitative methods complement each other since they generate different kind of knowledge. Trustworthiness is defined differently in quantitative and qualitative research and different procedures are needed to achieve it (Polit et al. 2012).

The internal validity in register data is considered to be very good since they are prospectively collected at clinical visits, and regularly controlled for quality against medical records and national quality register.

Outcome data in Paper I and IV were patient-reported in the two postal surveys, with questions mainly based on established, valid and reliable instruments. The complete questionnaires were discussed with patient partners, patients with special education in research, for feasibility and face validity. However, we did not do a test-retest of the whole questionnaire, which could be a limitation with regard to reliability. Although some bias could be introduced due to loss of follow-up of patients with high disease activity and worse health, the findings could be considered valid for most patients with established RA. The international generalisability could be affected by that it is a cohort mainly of Swedish born patients.

It is a strength for the qualitative papers that the interviews were conducted with patients from all six rheumatology clinics participating in the BARFOT study. The interviews were also conducted by the same researcher (the author of this thesis), who also transcribed all but two of the 22 interviews. This contributed to the trustworthiness of the qualitative papers. In qualitative research, trustworthiness is defined according to the four criteria of credibility, dependability, confirmability, and transferability (Polit et al. 2012).

The main author's profession as a physiotherapist and extensive experience of rheumatologic care enabled her to receive rich data from the participants, adding to the credibility of studies. The main author had no caregiver contact with the participants which

meant that the participants could answer the questions open and honest. The credibility was enhanced by careful description of data collection and analysis, and by the fact that the researchers worked on the data analysis both individually and together. The interviews were deemed rich, which improved the credibility.

Dependability was strengthened by using the same open-ended questions for all the participants, in order to assist them to reflect and explain.

Confirmability was achieved by the systematic and conscientious data analysis where all the steps in the analyses were reported. Inclusion of a patient research partner in the design and data analysis enhanced the confirmability of the studies in papers II and III.

Transferability was strengthened by that the interviews were performed at all of the six BARFOT clinics in Sweden. A qualitative approach does not attempt to generalize the result to a whole population, but it is probable that the categories could be transferable to other patients with long-standing diseases. All participants in the qualitative studies were born in Sweden, and this could be a limitation with regard to transferability.

Conclusions

- High levels of pain, worse general health and worse reports of physical function at RA onset increased the risk of being in the most disabled tertile of patients 5-18 years later.
- None of the studied variables at RA onset could predict if the patients fulfilled WHO recommendations for health-enhancing physical activity 5-18 year later.
- Quality of life in relation to lifestyle habits was influenced by a constant balancing between an ideal situation and the reality caused by living with an established RA.
- Patients with established RA conceived quality of life as being independent, empowered and participating, representing a biopsychosocial complexity in ways of understanding the concept.
- Physical activity had been discussed with half of the patients with established RA, but diet, smoking and alcohol use had only been discussed with a quarter of the patients.
- Patients with established RA did not actively ask for a discussion on lifestyle habits, although they could be expected to have such a need.
- It is important that health care professionals actively discuss lifestyle habits from a biopsychosocial perspective as an integral part of RA management.

Clinical implications

It is important to already at disease onset pay attention to high levels of pain and decreased physical function, despite well managed inflammatory activity. Patients with high levels of pain and impaired function at disease onset should be considered for multidisciplinary treatment to minimize disease burden over time.

In order to support quality of life in relation to lifestyle habits in patients with established RA, there is a need for a biopsychosocial approach from the health care professionals. These discussions should address the balance of lifestyle habits with regard to an ideal situation and the reality when living with established RA.

Recommendations for further research include an evaluated intervention with structured lifestyle discussions.

Summary in Swedish - Sammanfattning på Svenska

Reumatoid Artrit (RA) är en livslång, inflammatorisk sjukdom av okänd orsak som förekommer hos ca 0,5-0,7 % av befolkningen. Sjukdomen påverkar vanligtvis kroppens leder men kan också engagera kroppens inre organ. RA debuterar vanligtvis i 55-60 års ålder och drabbar kvinnor i dubbelt så stor utsträckning som män. Trötthet, smärta och nedsatt fysisk funktion är vanliga symtom, men RA kan även ha en stor påverkan på patienternas livskvalitet. Basen i behandlingen består av mediciner, men regelbunden fysisk aktivitet och träning har framkommit som ett nödvändigt komplement. Vårdpersonal uppmanas att samtala kring levnadsvanor med patienterna för att öka kunskapen kring dess påverkan på sjukdomen. De levnadsvanor som är i fokus är fysisk aktivitet, rökning, kost och alkohol. Studier har visat att patienter med RA löper större risk att utveckla hjärt-kärlsjukdom. Ytterligare risk föreligger hos de som är fysiskt inaktiva. För att bibehålla hälsa rekommenderar världshälsoorganisationen (WHO) fysisk aktivitet på moderat intensitet (t.ex. rask promenad) motsvarande 20-30 minuter 5-7 dagar i veckan och detta gäller även för patienter med RA. Studier har visat att patienter med RA inte når upp till dessa rekommendationer. Rökning, kost och alkohol har också visat sig ha betydelse för utveckling, prognos och effekt av behandling vid RA där rökning bland annat ger sämre behandlingseffekt. Hos många patienter saknas det kunskaper kring hur levnadsvanor faktiskt kan påverka sjukdomen.

Syftet med avhandlingsarbetet var att utforska och få större kunskaper kring de patienter med RA som efter en längre tids sjukdom har en starkt nedsatt fysisk funktion och identifiera faktorer som redan vid sjukdomsdebut kan förutsäga en sämre prognos. Ett annat syfte var att öka kunskapen kring hur patienter med en längre tids sjukdom uppfattar och hanterar de olika levnadsvanorna fysisk aktivitet, kost, rökning och alkohol, beskriva hur dessa levnadsvanor påverkar livskvaliteten och huruvida levnadsvanor diskuteras vid kontakt med vården eller ej.

Patienterna har hämtats från en större multicenterstudie (Bättre AntiReumatisk FarmakOTerapi, BARFOT), som följt patienter med nydebuterad RA sedan 1992, där sex reumatologiska kliniker i Sverige deltagit. Avhandlingen bygger på fyra delstudier med såväl kvantitativ som kvalitativ metodik. I delstudie I och IV användes registerdata och information från uppföljande frågeformulär som skickades ut år 2010 och 2017, medan datainsamlingen i delstudie II och III samlades in genom intervjuer.

I delstudie I som baseras på drygt 1300 patienter, undersöktes vilka faktorer som redan vid sjukdomsdebut kan förutsäga en sämre fysisk funktion 5-18 år senare. Resultatet visade att de som redan vid sjukdomsdebut har en sämre fysisk funktion och hög smärta bör uppmärksammas eftersom de på sikt i högre grad riskerar få mera besvär. Vårdpersonal bör därför tidigt uppmärksamma patientrapporterad fysisk funktion och smärta t ex med hjälp av patientrapporterade frågeformulär. Det framkom också att endast 65 % uppnådde WHO's

rekommendation om rekommenderad nivå av fysisk aktivitet. Dessutom bör patienter med etablerad RA rekommenderas en hälsosam livsstil tidigt eftersom patienternas rapporterade funktion och deras utförd fysisk aktivitet inte alltid överensstämmer.

Delstudie II och III är kvalitativa studier, som baseras på 22 enskilda intervjuer av patienter hämtade från BARFOT kohorten.

Delstudie II syftade till att beskriva hur levnadsvanor, fysisk aktivitet, kost, rökning och alkohol, påverkade livskvaliteten hos patienter med RA, där deras egna berättelser låg till grund för resultatet. De beskrev olika strategier inom de fyra olika levnadsvanorna som påverkade livskvaliteten. Det framkom att levnadsvanor påverkade patienternas livskvalitet, genom upplevelser som kunde sorteras till en av de tre kategorierna: *begränsningar*, *självhantering* och *gemenskap*. *Begränsningar* kunde t ex handla om en känsla av otillräcklighet för att hantera sina levnadsvanor. *Självhantering* handlade om känslor av skuld och motivation kopplat till levnadsvanorna och i kategorin *gemenskap* framkom upplevelser av tillhörighet och njutning förenat med levnadsvanor. Livskvaliteten påverkades av levnadsvanorna fysisk aktivitet, kost, rökning och alkohol genom att patienterna ständigt fick balansera mellan ideal och verklighet.

I delstudie III var fokus att beskriva olikheter och variationer i patienternas uppfattningar av begreppet livskvalitet. Patienterna beskrev livskvalitet som känsla av *oberoende*, *egenkraft* och *delaktighet*. Den *oberoende* patienten beskrev livskvalitet i termer som att vara fri och obehindrad i vardagsaktiviteter hemma, på arbetet, på fritiden och att ha en ekonomisk trygghet. *Egenkraft* fokuserade på psykologiska aspekter om hur man hanterar och bemästrar livet. *Egenkraft* var att tro på sin egen förmåga. Patienter med egenkraft beskrev en känsla av en mental och kroppslig säkerhet att kunna hantera olika situationer. Den *delaktiga* patienten beskrev vikten av att tillhöra ett socialt sammanhang.

I delstudie IV undersöktes i vilken utsträckning patienter med RA hade diskuterat levnadsvanorna fysisk aktivitet, rökning, kost och alkohol med vårdpersonal eller om de hade önskat ett sådant samtal. Delstudien baseras på det frågeformulär kring levnadsvanor som skickades ut under 2017 till samtliga patienter i BARFOT-kohorten, där svar från drygt 1000 patienter ligger till grund för resultatet. Sammanfattningsvis så hade hälften av patienterna med RA haft samtal kring fysisk aktivitet. Däremot hade levnadsvanorna rökning, kost och alkohol endast diskuterats med en fjärdedel av patienterna. Patienter med etablerad RA efterfrågade inte aktivt samtal kring levnadsvanor även om detta behov föreligger.

Vårdpersonal bör vara medveten om att det finns en grupp patienter med RA med nedsatt fysisk funktion och svårare smärta redan vid sjukdomsdebut som ger dem en ökad risk för uttalad funktionsnedsättning 5-18 år senare. Vidare har levnadsvanor en stor inverkan på patienter med RA och deras upplevelse av livskvalitet. Att tidigt hitta de med uttalade besvär,

svåra smärtor och ohälsosamma levnadsvanor är därför av största vikt så att dessa patienter tidigt kan få ett mer omfattande omhändertagande.

Vi bör också förstå att patienter med etablerad RA uppfattar begreppet livskvalitet på olika sätt och att de olika levnadsvanorna påverkade livskvalitén. För att på bästa sätt stödja patienterna är det viktigt att levnadsvanesamtal är en integrerad del av behandlingen. Patienter bör erbjudas att diskutera sina levnadsvanor på olika sätt genom individuella samtal eller genom gruppsamtal. Detta kan ske under olika perioder av sjukdomsförloppet för att t ex få hjälp att anpassa den fysiska aktiviteten samt få information om och möjlighet att förändra sina levnadsvanor till mer hälsosamma.

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Blood is thicker than water but love is thicker than blood.

Love

Karina

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Appendix

Questions on physical activity

Nedan följer några frågor om **Din fysiska aktivitet, stillasittande och träning**. Sätt ett kryss för det alternativ som **bäst stämmer in** på Dig.

7. Hur mycket tid ägnar du en vanlig vecka åt fysisk träning som får dig att bli andfådd, till exempel löpning, motionsgymnastik eller bollsport?

- | | |
|----------------------|--------------------------|
| 0 minuter/ingen tid | <input type="checkbox"/> |
| Mindre än 30 minuter | <input type="checkbox"/> |
| 30-60 minuter | <input type="checkbox"/> |
| 60-90 minuter | <input type="checkbox"/> |
| 90-120 minuter | <input type="checkbox"/> |
| Mer än 120 minuter | <input type="checkbox"/> |

8. Hur mycket tid ägnar du en vanlig vecka åt vardagsmotion, till exempel promenader, cykling eller trädgårdsarbete? Räkna samman all tid (minst 10 minuter åt gången).

- | | |
|---------------------------------|--------------------------|
| 0 minuter/ingen tid | <input type="checkbox"/> |
| Mindre än 30 minuter | <input type="checkbox"/> |
| 30-60 minuter (0,5-1 timme) | <input type="checkbox"/> |
| 60-90 minuter (1-1,5 timmar) | <input type="checkbox"/> |
| 90-150 minuter (1,5-2,5 timmar) | <input type="checkbox"/> |
| 150-300 minuter (2,5-5 timmar) | <input type="checkbox"/> |
| Mer än 300 minuter (5 timmar) | <input type="checkbox"/> |

Questions on diet

Nedan följer några frågor om **Dina levnadsvanor**. Sätt ett kryss för det alternativ som **bäst stämmer** in på Dig.

6. Vilken typ av kost anser du att du äter idag?

- Vanlig kost/blandkost *Äter det mesta dvs. alla typer av kött, fisk, grönsaker, mejeriprodukter och spannmål*
- Medelhavskost *Kost bestående av mycket frukt, grönsaker, baljväxter, magert kött, fisk, skaldjur, olivolja och nötter. Feta mejeriprodukter minimeras*
- GI-kost *Kost med lågt glykemiskt index, innehållande lite eller inga snabba kolhydrater*
- Vegetarisk kost *Vegetarisk kost med vissa animalier dvs. äter ägg och mjölkprodukter*
- Vegetarisk kost + fisk & skaldjur *Vegetarisk kost med vissa animalier dvs. äter ägg och mjölkprodukter samt fisk och skaldjur*
- Vegankost *Vegetarisk kost utan animalier dvs. äter inte fisk, ägg och mjölkprodukter*
- Annat, nämligen _____

Questions on smoking

10. Mina rökvanor

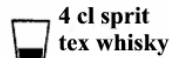
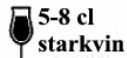
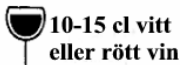
- Jag har aldrig varit rökare
- Jag har slutat röka för **mer** än 6 månader sedan
- Jag har slutat röka för **mindre** än 6 månader sedan

Vilket år slutade du röka? _____

- Jag röker, men inte dagligen
- Jag röker 1-9 cigaretter per dag
- Jag röker 10-19 cigaretter per dag
- Jag röker 20 cigaretter eller fler per dag

Questions on alcohol use

Med ett "glas" menas:



12. Har du aldrig druckit alkohol (sätt ett kryss i rutan och gå vidare till fråga 18)

Jag har aldrig druckit alkohol

13. Har du slutat dricka alkohol?

Ja

Nej

14. Hur ofta har du druckit alkohol under de senaste 12 månaderna?

4 gånger/vecka eller mer

2-3 gånger/vecka

2-4 gånger/månad

1 gång/månad eller mer sällan

15. Hur många "glas" dricker du en typisk dag då du dricker alkohol?

(för definition av "glas" se figur överst på sidan)

Mindre än 2 glas

3-4 glas

5-6 glas

7-9 glas

10 eller fler glas

Vet inte

16. Hur ofta dricker du sex "glas" eller fler vid samma tillfälle?

Dagligen eller nästan varje dag

Varje vecka

Varje månad

Mer sällan än en gång i månaden

Aldrig

Vet inte

17. Hur ofta har du under de senaste 12 månaderna druckit så mycket alkohol att du varit berusad?

Dagligen eller nästan dagligen

Några gånger/vecka

1 gång/vecka

2-3 gånger/månad

1 gång/månad

Någon eller några gånger per halvår

Mer sällan eller aldrig

Vet inte

Questions on lifestyle discussion

Nedan följer frågor om Du haft samtal kring levnadsvanor vid något besök på reumatologmottagning, vårdcentral etc.

18 a) Diskuterade läkaren eller någon annan ur personalen matvanor med dig?

- 1 Ja, vid något besök i vården
- 2 Ja, vid senaste besöket
- 3 Nej

Ja Nej

b) Hade du önskat få diskutera matvanor?

19 a) Diskuterade läkaren eller någon annan ur personalen motionsvanor med dig?

- 1 Ja, vid något besök i vården
- 2 Ja, vid senaste besöket
- 3 Nej

Ja Nej

b) Hade du önskat få diskutera motionsvanor?

20 a) Diskuterade läkaren eller någon annan ur personalen tobaksvanor med dig?

- 1 Ja, vid något besök i vården
- 2 Ja, vid senaste besöket
- 3 Nej

Ja Nej

b) Hade du önskat få diskutera tobaksvanor?

21 a) Diskuterade läkaren eller någon annan ur personalen alkoholvanor med dig?

- 1 Ja, vid något besök i vården
- 2 Ja, vid senaste besöket
- 3 Nej

Ja Nej

b) Hade du önskat få diskutera alkoholvanor?

Sorry!
The lifestyle you ordered
is currently out of stock
(Banksy)

RESEARCH PAPER

Predictors of severe self-reported disability in RA in a long-term follow-up study

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Abstract

Purpose: Identify factors predictive for severe self-reported disability in patients with rheumatoid arthritis. **Methods:** Patients ($n = 1910$) were sent a questionnaire 5–18 years after disease onset. Outcomes were the Health Assessment Questionnaire (HAQ), Rheumatoid Arthritis Outcome Score (RAOS) and physical activity. The tertile of patients most affected by the disease were compared to those less affected. Proposed predictive factors were function, pain, general health, radiographic joint damage, swollen/tender joints and disease activity measures at baseline. Age, gender and disease duration were controlled for in logistic regression analyses. **Results:** Seventy-three percent ($n = 1387$) responded to the questionnaire, mean age 65 years (SD 15) and 70% were women. Worse scores in function, pain, general health and tender joints at baseline increased the risk of being in the most affected group, as measured by HAQ and RAOS 5–18 years after disease onset ($p < 0.000$). **Conclusion:** High levels of pain and worse reports of function at disease onset were risk factors for being in the most disabled tertile of patients after 5–18 years. Pain and function proved to be predictors of the outcome while some measures of inflammation were not. It is important to recognize these patients who may be in need of multidisciplinary treatments already at disease onset.

Keywords

Functioning, pain, prognostic factors, rheumatoid arthritis

History

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► Implications for Rehabilitation

- Health care providers should be aware of the subgroup of patients with more severe symptoms of pain and impaired function at disease onset since they have an increased risk of being in the most disabled tertile of rheumatoid arthritis patients several years later.
- Health care providers should assess pain and function and act on high pain and impaired function already at disease onset as they proved to be predictors of patient-reported outcomes controlled for inflammatory parameters.
- These findings support European guidelines and research findings that patients with high pain and impaired function despite of well-managed inflammatory parameters should early in the disease course be referred to multidisciplinary treatment for supplementary regime.

Introduction

Rheumatoid arthritis (RA) is a chronic, inflammatory, and systemic disease of unknown cause that affects 0.5–1.0% of the population. The average age at onset is the mid-fifties and twice as many women are affected as men [1–3]. RA is characterized by morning stiffness, joint swelling, pain and fatigue resulting in impaired physical functioning with a relapsing–remitting disease course [4]. The disease is also associated with an increased risk of developing cardiovascular disease, colon cancer, osteoporosis and

diabetes, which would lead to even further reduction in functioning [5,6]. Early identification is of importance to improve long-term outcome of the disease and the severity at presentation in terms of inflammation and self-reported functioning is known to predict an increased mortality in subjects with RA [7].

Despite great improvements in pharmacological treatment for patients with RA, disease progression is unpredictable and the remission rates reported vary depending on both study design and definitions used. Targeting disease activity by sustained clinical remission over 5 years has shown less radiographic progression and greater improvement in patient reported outcome measures compared with those in a non-remission group [8]. However, even with well-controlled disease activity, long-term follow-up studies have reported deterioration in function [9]. Also, not all patients respond to the new biologic drugs and they are more often women [10,11]. In these patients with more severe disease progression or with longer disease duration, fatigue and intense pain are some of

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the most pronounced symptoms resulting in activity limitations seriously affecting quality of life [12–14]. A discrepancy between disease activity and impaired function indicates unmet needs throughout the disease course for multi-professional interventions to prevent progressing disability.

There have been few larger, long-term follow-up studies focusing on the most disabled patients in terms of functioning. The clinical focus is on treating disease activity, i.e. inflammatory parameters and its response to drug treatment. Patient reported outcome measures has not been used as valid predictors in general in the clinic and its usefulness as predictors for the most disabled patients are less often studied. The research question focused on in this article was to study if self-reported data, functional assessment data and disease activity data at baseline has the possibility to predict severe self-reported disability several years later in a large well-defined cohort of patients with RA.

Patients and methods

Subjects

Better Anti-Rheumatic Pharmacotherapy (BARFOT) are a multi-center study in southern Sweden including patients between 1992 and 2006, involving patients with early RA according to the American College of Rheumatology criteria (ACR) [15]. The patients are followed at a structured way which includes follow-ups at 3 and 6 months and thereafter at 1, 2, 5, 8 and 15 years. Details of the study have been published elsewhere [16,17]. In 2010, 5–18 years after the patients were included in the BARFOT study, a questionnaire concerning self-reported physical function, and physical activity was sent out to all BARFOT subjects who were still alive (disease duration ≤ 12 months at inclusion, $n = 1910$).

The survey included several well-used and validated questionnaires on physical functioning: the Stanford Health Assessment Questionnaire (HAQ), the Rheumatoid and Arthritis Outcome Score (RAOS) and questions on health-enhancing physical activity, which all served as our outcome variables [18–20].

Outcome variables

The HAQ is self-administered and consists of 20 questions distributed in eight categories with a sum score varying between 0 and 3 (best to worst) [18,19]. Most questions in the HAQ concentrate on activities involving the upper extremities, which is why two subscales from a questionnaire focusing on lower extremity function were included, the RAOS subscale activities of daily living (ADL) and the subscale sport and recreational activities (sport/rec) with the score ranging from 0 to 100 (worst to best). The RAOS subscales can be used independently [20].

Physical activity was collected by using three questions in accordance with the World Health Organization's (WHO) recommendation on how to measure self-reported health-enhancing physical activity at the time of the survey. This included information on duration of intensity and number of days [21–23]. Patients who reported activities 5–7 days a week at moderate intensity (defined as aerobic exercise that causes mild breathlessness, e.g. walking or gardening, for at least 30 min a day) were considered to meet the moderate-intensity physical activity recommendations (WHO MI-PA). Those who exercised with a vigorous intensity (WHO VI-PA) for at least 30 min 2–3 times a week or more were also considered to meet health-enhancing physical activity recommendations. The two recommendations were also merged and categorized into either meeting or not meeting the WHO recommendations (WHO_{rec}) for health-enhancing physical activity.

Possible predictive variables from baseline data

Possible predictive variables retrieved from baseline data (at entry into the BARFOT study) were measures of function (self-reported and observer assessed), radiographic changes, disease activity and pain.

Baseline data on function were assessed with the self-reported HAQ and with the observer-assessed measure Signals of Functional Impairment (SOFI). SOFI measures range of motion in the hand, arm and lower extremities and involves 12 functional tests (eight on the upper extremities and four on the lower extremities, yielding a total range of 0–44 (best to worst). SOFI has acceptable validity and reliability in patients with RA [24].

Radiographic joint damage (yes/no) was assessed at baseline by ACR criteria 1987 [15]. Disease activity was measured by studying the different components in the Disease Activity Score of 28 joints (DAS 28) separately. DAS 28 is a commonly used index that includes components from the point of view of the patient and the doctor. DAS 28 includes the number of swollen and tender joints, erythrocyte sedimentation rate (ESR) and the patients' global assessment (general health measured with visual analog rating scale, VAS 0–100 best to worst [25,26]. Pain was assessed with a numerical rating scale (NRS) 0–10 (best to worst) in the 2010 questionnaire and with a VAS 0–100 (best to worst) at baseline [27].

Statistics

In order to study those most affected by the disease at time for the questionnaire in 2010, the outcome data were split into tertiles. In a logistic regression analysis, the tertile with the worst score was analyzed and compared with the two better tertiles collapsed for the outcome variables HAQ and RAOS (ADL and sport/rec). Physical activity was split into two groups: those reaching recommended levels of physical activity compared to those who did not (WHO MI-PA, WHO VI-PA and WHO_{rec}). Proposed predictive factors were HAQ, SOFI, pain, presence of radiographic changes or not, the number of swollen and tender joints, ESR and the patient's global assessment at baseline. Age, gender and disease duration (time between baseline and questionnaire survey) were included as possible confounding factors. The statistical analyses were performed using SPSS version 19.0 (SPSS Inc., Chicago, IL). The level of statistical significance was set to 0.05.

Ethics

The study was approved by the Swedish Ethical Committee at Lund University (DNR LU 2009/670). All patients in the survey provided written informed consent to participate in the study.

Results

Of the 1910 eligible patients in the BARFOT cohort who received the 2010 questionnaire, 1387 (73%) responded. Mean age of the responders was 65 years (SD 15); 968 (70%) were women and 420 (30%) were men. Disease duration was 9 years (SD 3.7) and women reported worse outcome in function, higher pain, and more swollen and tender joints than men ($p = 0.000$) (Table 1).

Questions concerning physical activity were answered by 1076 patients and 65% met the WHO_{rec}, women more often than men ($p = 0.006$). There was also a sex difference in meeting the recommendations for WHO VI-PA; this was more common in women ($p = 0.023$) (Table 1).

Analysis of non-responders showed no differences in sex distribution. Non-responders had worse disease activity [DAS 28; mean 5.4 (SD 1.2) versus mean 5.2 (SD 1.2); $p = 0.009$], worse health [mean 48.1 (SD 26.0) versus mean 45.0 (SD 25.3);

Table 1. Patient descriptive from the 2010 questionnaire.

	All (n = 1387)	Women (n = 967)	Men (n = 420)	p Value
Age, years	65 (14)	64 (15)	68 (13)	0.000
HAQ (0–3)	0.6 (0.6)	0.7 (0.6)	0.4 (0.5)	0.000
RAOS ADL (0–100)	71.3 (21.9)	69.6 (22.4)	75.5 (20.3)	0.000
RAOS sport/rec (0–100)	40.0 (31.1)	36.5 (30.5)	48.7 (31.1)	0.000
WHO _{rec} ^a (%)	695 (65)	493 (67)	202 (58)	0.01
WHO ^a MI-PA (%)	665 (51)	472 (52)	193 (47)	0.11
WHO ^a VI-PA (%)	368 (34)	268 (36)	100 (29)	0.02
Swollen joints (0–28)	3.65 (5.5)	4.05 (5.7)	2.73 (4.9)	0.000
Tender joints (0–28)	5.82 (6.7)	6.34 (6.9)	4.62 (6.1)	0.000
NRS pain (0–100)	35.3 (25.6)	38.1 (25.7)	28.9 (24.27)	0.000
NRS GH (0–100)	31.7 (24.1)	33.6 (24.3)	27.6 (28.0)	0.000

Values are mean (SD) unless otherwise indicated. GH = general health NRS.

^aBased on 1076 responders, 732 women and 344 men.

Table 2. Patient descriptive at baseline.

	All (n = 1387)	Women (n = 967)	Men (n = 420)	p Value
Age (years)	55 (14.1)	54 (14.48)	58 (12.68)	0.000
RF (%)	62	62	63	0.72
X-ray (%)	23	22	26	0.14
HAQ (0–3)	0.98 (0.6)	1.06 (0.6)	0.83 (0.6)	0.000
SOFI (0–44)	7.69 (5.8)	7.57 (5.8)	7.96 (5.8)	0.33
VAS pain (0–100)	46.28 (23.9)	47.86 (23.7)	42.60 (24.0)	0.000
VAS GH (0–100)	45.00 (25.4)	46.64 (25.3)	41.20 (25.1)	0.000
Swollen joints (0–28)	10.25 (5.7)	10.02 (5.6)	10.77 (5.7)	0.033
Tender joints (0–28)	8.14 (6.2)	8.58 (6.3)	7.15 (5.8)	0.000
CRP	30.85 (35.9)	28.86 (34.5)	35.43 (38.6)	0.002
ESR	34.45 (24.2)	34.54 (24.4)	34.23 (23.8)	0.83
DAS 28 (0–10)	5.21 (1.24)	5.28 (1.2)	5.06 (1.2)	0.003

Values are mean (SD) unless otherwise indicated. RF = rheumatoid factor; X-ray = radiographic joint damage; GH = general health; CRP = C-reactive protein.

$p = 0.020$] a higher number of swollen joints [mean 11.03 (SD 5.8) versus mean 10.25 (SD 5.7); $p = 0.013$] and tender joints [mean 8.8 (SD 6.6) versus mean 8.1 (SD 6.2); $p = 0.05$] than responders at study inclusion. There was no difference in X-ray changes at baseline, while 57% of the non-responders were RF positive as compared to 62% of the responders ($p = 0.021$).

Patient characteristics at baseline

At baseline, women reported a worse HAQ, higher pain levels, and more swollen and tender joints than men ($p = 0.033$). However, there was no difference between the sexes in observer-assessed function (SOFI, $p = 0.330$) and in ESR ($p = 0.826$) (Table 2).

Regression analysis

In order to study those with worse disease, the patients were split into tertiles based on information from the 2010 survey. Those in the tertile with the worst outcome scores were compared with those in the two tertiles with better outcome scores. The cut-off in the HAQ was >0.75 , for RAOS ADL it was <60 and for RAOS sport/rec it was <25 . Physical activity was studied in terms of whether the patients met or did not meet the WHO_{rec}.

Worse scores at baseline in, SOFI, pain, general health, number of tender joints and higher ESR increased the risk of

having worse physical function as measured by the HAQ in the 2010 survey. Findings were similar for the RAOS ADL and sport/rec scales where worse function (HAQ and SOFI), higher pain, lower general health, a larger number of tender joints were found to be predictive of worse outcome (Table 3).

None of the variables studied were predictive of who did or did not meet WHO_{rec}, or who met the moderate-intensity (WHO MI-PA) or vigorous-intensity (WHO VI-PA) recommendations (Table 4).

All variables were controlled for confounding by age, sex and disease duration at follow-up. Also these factors had predictive values with regard to the outcome variables (data not shown). For example, a worse outcome in HAQ was also predicted by age (OR: 1.03, 95% CI: 1.02–1.04), female sex (OR: 2.53, 95% CI: 1.85–3.46) and disease duration (OR: 1.08, 95% CI: 1.04–1.12).

Discussion

In this longitudinal study, self-reported and observer-assessed function and pain at onset of disease in patients with RA were found to be prognostic measures of a worse self-reported physical function outcome several years later; however, none of the variables studied could predict who did or did not meet WHO_{rec} for health-enhancing physical activity in 2010. Our findings highlight that measures of pain and function can be useful for early identification of patients who are at increased risk of being severely disabled.

Worse scores in function at baseline, both self-reported (HAQ) and observer-assessed (SOFI), predicted a worse self-reported outcome in HAQ and RAOS 5–18 years later. In a study by Bjork et al. [28], the HAQ score 5 years after disease onset was explained by disease activity and function at baseline, where the most important factors at inclusion were HAQ (dichotomized over/under 1.0), grip force, SOFI (lower limb), sex and walking speed at inclusion [28], which is in accordance with our findings. It has been suggested that a HAQ cut-off of 1.0 should be used as a clinical indicator, to identify patients who are at risk of having a worse outcome [29,30]. The subjects in the most disabled tertile in our study had a mean HAQ at baseline close to 1.0.

In the present study, worse pain, worse general health and a greater number of tender joints were also found to predict a worse outcome in HAQ and the two RAOS subscales. These variables are all interrelated; the number of tender joints reflects the pain level and pain is a well-known predictor of general health perception [31]. Also, the total HAQ score reflects a patient's disease activity and is associated with both pain and swollen and tender joint counts [32] and high correlations between HAQ, pain and general health has been published earlier [33]. It is well known that pain in RA shows higher correlations with functional scores and with DAS 28 than with radiographic scores from the small joints [34].

Being a woman, having higher age at inclusion and having longer disease duration at follow-up were also predictive of a worse function in the HAQ and both RAOS subscales. In one long-term follow-up study, function deteriorated – especially in women – even though disease activity had been well managed and there was no significant difference in self-reported function between genders at disease onset [35]. Disease activity and disability appear to have different predictors [36]. This is in accordance with the results of the present study, where swollen joints and radiographic changes at baseline were not able to predict a worse outcome. This highlights the importance of clinical assessment of function at disease onset as a supplement to standard treatment. According to European guidelines, patients

Table 3. Results from the multiple regression analysis showing odds ratios (ORs) for outcome with regard to explanatory baseline variables.

	HAQ OR (95% CI)	p Value	RAOS ADL OR (95% CI)	p Value	RAOS sport/rec OR (95% CI)	p Value
HAQ (0-3) n = 973-1301	3.57 (2.838-4.487)	0.000	2.37 (1.864-3.013)	0.000	2.33 (1.826-2.961)	0.000
SOFI (0-44) n = 765-1025	1.09 (1.066-1.121)	0.000	1.09 (1.057-1.118)	0.000	1.08 (1.053-1.114)	0.000
Pain ^a (0-100) n = 1003-1337	1.02 (1.015-1.025)	0.000	1.02 (1.013-1.026)	0.000	1.01 (1.008-1.020)	0.000
GH ^a (0-100) n = 1009-1345	1.02 (1.012-1.022)	0.000	1.01 (1.009-1.020)	0.000	1.01 (1.005-1.01)	0.000
Swollen ^b (0-28) n = 919-1231	1.02 (0.994-1.039)	0.15	0.98 (0.955-1.005)	0.11	1.00 (0.973-1.023)	0.84
Tender ^b (0-28) n = 917-1229	1.05 (1.029-1.072)	0.000	1.03 (1.009-1.056)	0.006	1.03 (1.009-1.057)	0.01
ESR n = 1014-1355	1.01 (1.002-1.012)	0.004	1.00 (0.996-1.006)	0.74	1.01 (1.002-1.013)	0.01
X-ray (0/1) n = 914-1224	1.24 (0.927-1.660)	0.15	1.15 (0.825-1.606)	0.41	1.32 (0.938-1.854)	0.11

Predictive variables were included separately in the multiple logistic regression analysis and controlled for age, sex and disease duration. X-ray = radiographic joint damage; GH = general health. ^aMeasured with VAS. ^bNumber of swollen and tender joints (of 28).

Table 4. Results from the multiple regression analysis showing odds ratios (ORs) for WHO_{rec} with regard to explanatory baseline variables.

	WHO _{rec} OR (95% CI)	p Value	WHO MI-PA OR (95% CI)	p Value	WHO VI-PA OR (95% CI)	p Value
HAQ (0-3) n = 973-1301	0.90 (0.718-1.125)	0.35	0.84 (0.698-1.022)	0.08	1.28 (1.018-1.609)	0.04
SOFI (0-44) n = 765-1025	0.99 (0.966-1.020)	0.6	1.00 (0.977-1.022)	0.97	1.02 (0.990-1.047)	0.2
Pain ^a (0-100) n = 1003-1337	1.00 (0.992-1.002)	0.27	1.00 (0.991-1.001)	0.1	0.999 (0.993-1.004)	0.67
GH ^a (0-100) n = 1009-1345	1.00 (0.994-1.004)	0.73	1.00 (0.993-1.002)	0.32	1.00 (0.997-1.007)	0.47
Swollen ^b (0-28) n = 919-1231	0.98 (0.955-1.002)	0.07	0.98 (0.957-0.998)	0.03	1.01 (0.985-1.033)	0.47
Tender ^b (0-28) n = 917-1229	0.99 (0.972-1.015)	0.52	0.98 (0.965-1.002)	0.08	1.01 (0.986-1.030)	0.48
ESR, n = 1014-1355	1.00 (0.995-1.006)	0.95	1.00 (0.997-1.006)	0.56	1.00 (0.995-1.01)	0.8
X-ray (0/1) n = 914-1224	1.10 (0.800-1.512)	0.56	1.04 (0.785-1.366)	0.81	1.04 (0.747-1.438)	0.83

Predictive variables were included separately in the multiple logistic regression analysis and controlled for age, sex and disease duration. X-ray = radiographic joint damage; GH = general health. ^aMeasured with VAS. ^bNumber of swollen and tender joints (of 28).

with RA should be given the opportunity to meet a team of health care professionals at disease onset [37].

The WHO has published recommendations for a health-enhancing lifestyle, which has been widely endorsed and also adapted for people with arthritis. Physical activity has been considered a safe, efficacious and widely advocated method of controlling disease consequences in RA [38,39]. From earlier cross-sectional studies, we know that people with RA are less physically active, and physical inactivity is associated with female sex, older age, worse pain, higher levels of disease activity, co-morbidity and low physical function [39,40]. The present study shows that people with RA are just as active as people in general are in Sweden, in terms of meeting the WHO_{rec} [41]. Still, more than one-third of all subjects were physically inactive, which is why healthcare workers should enhance and support physical activity in patients with RA.

None of the variables studied could predict which subjects met the WHO recommendations concerning physical activity. This indicates that factors other than functional impairment may be of greater importance for prediction of physical activity levels. There have been few true predictive studies on health-enhancing physical activity in the RA population, and more are needed. Also, self-reported function such as the HAQ, observer-assessed performance measures (e.g. SOFI), self-reports of physical activity as well as portable activity monitors represent different constructs of functioning [42]. However, psychosocial factors such as self-efficacy, social support and outcome expectations are factors associated with current and maintained self-reported physical activity [43]. We found that being able to perform certain activities and actually participating in physical activities were different entities, which indicates that physical activity must be assessed and discussed frequently with the patient.

Strengths of the study were the 73% response rate, the well-defined cohort with a substantial amount of documented material,

and the tight and comprehensive long-term follow-up. Some limitations can be mentioned. Since outcome data were derived from a questionnaire, there are no data of inflammatory parameters as ESR included and swollen and painful joints are self-reported. In a research setting, patient-reported swollen and tender joints can be used instead of physician-reported data [44]. However, the baseline numbers of swollen and tender joints that were included as predictors in the analyses were physician-reported. Yet, another limitation and possible confounder to our findings is the lack of information concerning comorbidities at baseline. This was not registered at disease onset why we could not adjust our data accordingly.

The clinical implications of our study highlight the importance of early identification of RA subgroups at increased risk. The combination of high pain and worse function at disease onset despite well-managed inflammatory parameters may need regime supplementary to medication. Patients at risk who are identified at disease onset should be referred to multidisciplinary treatments to minimize the disease burden. Multidisciplinary rehabilitation has the possibility to improve pain and function in addition to medication, especially in the most affected patients [45]. This knowledge is important, and can help healthcare professionals to reduce pain in order to enhance function and encourage patients to be physically active.

In conclusion, we found that worse physical function and worse pain at disease onset can predict worse physical function several years later, which some parameters of inflammation could not. However, none of the studied variables predicted the amount of physical activity actually being performed. It is important – especially at disease onset – to recognize patients with impaired function and higher pain levels who are in need of multidisciplinary treatments. It is also important to recommend a healthy lifestyle early in the course of the disease, since good function and being physically active are not the same thing.

Declaration of interest

The authors report no declarations of interest. This study was supported by grants from the Stig Thune Foundation, the Berger Foundation, the Norrbacka-Eugenia Foundation, the Swedish Rheumatism Association and the Region Halland.

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Paper II





HEALTH AND WELL-BEING IN HUMAN VULNERABILITY

The influence of lifestyle habits on quality of life in patients with established rheumatoid arthritis—A constant balancing between ideality and reality

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Abstract

Introduction: Rheumatoid arthritis (RA) is a chronic, inflammatory, and systemic disease with symptoms that limit activities and affect quality of life. RA is associated with an increased risk of developing comorbidities, some of which are also known to be associated with lifestyle habits such as physical activity, diet, smoking, and alcohol. There has been an augmented focus on the implementation and maintenance of healthy lifestyle habits even for patients with RA in the past decade, but little is known about the link between patients' experiences of lifestyle habits and quality of life. The aim of the study was thus to describe and explore how patients with established RA experience the influence of lifestyle habits on quality of life.

Methods: The study had a descriptive and explorative design, based on qualitative content analysis. Strategic sampling was used in order to achieve variations in experiences. Twenty-two patients with RA (14 women and 8 men) from 30 to 84 years old, with a disease duration ranging from 8 to 23 years, were interviewed.

Results: The analysis of the influence of lifestyle habits on quality of life resulted in the theme *balancing between ideality and reality*. Three categories emerged about how lifestyle habits influenced quality of life by *limitations* (including insufficiency and adaptation), *self-regulation* (including guilt and motivation), and *companionship* (including belonging and pleasure).

Conclusions: Quality of life for patients with established RA was influenced by the balance between ideality and reality in the lifestyle habits: physical activity, diet, smoking, and alcohol. This is important new knowledge for health professionals when discussing lifestyle habits with RA patients.

Key words: *Lifestyle habits, quality of life, qualitative content analysis, rheumatoid arthritis*

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Rheumatoid arthritis (RA) is a chronic, inflammatory, and systemic disease of unknown etiology with a prevalence of 0.5–1.0% in the western world. The average age at onset is the mid-50s, and the female to male ratio is three to one (Englund et al., 2010; Scott, Wolfe, & Huizinga, 2010). Because the disease is chronic, the patients have to live with lifelong effects from their RA and early diagnose and treatment will improve the long-time prognosis (Monti, Montecucco, Bugatti, & Caporali, 2015). Based on disease duration, the term early RA is generally defined as having less than 2 years of disease duration,

whereas a longer disease duration is referred to as established RA (Conaghan, Green, & Emery, 1999).

Pain, physical disability, fatigue, and sleep disturbances are some of the most pronounced symptoms in patients with a more severe disease progression or with a longer disease duration, resulting in activity limitations seriously affecting health-related quality of life (Uhlir, Moe, & Kvien, 2014). RA is also associated with an increased risk of developing comorbidities (Dougados et al., 2014; Turesson & Matteson, 2007), some of which are known to be associated with lifestyle habits such as a sedentary lifestyle,

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unhealthy diets, smoking, and alcohol (Beaglehole et al., 2011).

Studies have shown that patients with RA do not reach health-enhancing levels of physical activity which affects their cardiovascular health (Sokka et al., 2008). Diet and obesity are closely linked, and obesity is associated with worse disease severity and a larger number of comorbidities in patients with RA (Ajeganova, Andersson, & Hafstrom, 2013). Patients with cachexia (loss of muscle mass and strength and concomitant increase in fat mass) also have an increased risk of cardiovascular diseases (Elkan, Hakansson, Frostegard, Cederholm, & Hafstrom, 2009).

Substance use, such as smoking and alcohol, has disease-specific effects, besides well-known general health effects. Smoking, which is the known environmental factor that has the greatest significance for the development of RA, is associated with a worse prognosis and is also a negative factor in terms of response to therapy (Soderlin, Petersson, Bergman, Svensson, & BARFOT study group, 2011; Soderlin, Petersson, & Geborek, 2012). A moderate consumption of alcohol may have a positive effect on disease activity, and prognosis and may decrease the risk of developing RA (Maxwell, Gowers, Moore, & Wilson, 2010). The importance of a healthy lifestyle in addition to antirheumatic drugs and other treatment modalities is well known for patients with RA, and health professionals are encouraged to prioritize discussions on lifestyles habits when supporting patients (Dean & Gormsen Hansen, 2012).

There is limited knowledge about the impact of lifestyle habits such as physical activity, diet, smoking, and alcohol on quality of life. In the general population, physical activity has been reported to be positively associated with quality of life (Bize, Johnson, & Plotnikoff, 2007; Tessier et al., 2007). Both a vegetarian diet and a Mediterranean diet may improve quality of life in patients with established RA (Li & Micheletti, 2011; Skoldstam, Hagfors, & Johansson, 2003). Smoking is negatively associated with quality of life and the association is related to the number of cigarettes smoked, whereas smoking cessation is associated with an improved quality of life (Goldenberg, Danovitch, & IsHak, 2014). There are studies reporting moderate alcohol use having a beneficial effect on quality of life, but there is no consensus whether it is the alcohol or the social context affecting the quality of life (Bergman, Symeonidou, Andersson, & Soderlin, 2013; Kim et al., 2013).

The aim of the study was thus to describe and explore how patients with established RA experience the influence of lifestyle habits on quality of life.

Method

Design

The study had a descriptive and explorative design, based on qualitative content analysis, with an inductive approach. Qualitative content analysis is a method that provides a systematic way of making valid inferences from verbal or written data in order to describe a specific phenomenon (Krippendorff, 2013). The method is often used in healthcare research (Graneheim & Lundman, 2004). Although described as lacking a solid theoretical background (Krippendorff, 2013), qualitative content analysis is useful for providing knowledge and understanding of a studied phenomenon and for analyzing a person's experiences, reflections, and attitudes (Krippendorff, 2013). The intention is to describe variations by identifying differences and similarities in the content, both the manifest content (describing what the text says) and the latent content (exploring the interpreted meaning) (Graneheim & Lundman, 2004).

Participants

A total of 2800 adult patients over 18 years old were enrolled in the BARFOT (Better anti-Rheumatic Pharmacotherapy) study from 1992 to 2006; a multi-center longitudinal observational study of patients with early RA in southern Sweden. All patients in the BARFOT study ($n = 2100$) received a postal questionnaire in 2010 concerning lifestyle factors, including physical activity, diet, smoking, and alcohol habits. The interviews for the present study were conducted with 22 of them, a common number of informants in qualitative content analysis (Graneheim & Lundman, 2004; Mason, 2010). The informants were selected by using a strategic sampling procedure in order to get variation in physical function (Health Assessment Questionnaire, HAQ), quality of life (EuroQol5D, EQ-5D), sex, age, marital status, education, disease duration, employment, and all six BARFOT centers which cover both urban and rural patient referral areas (Table I).

Data collection

Data collection took place at the participant's BARFOT clinic in a private room between May 2014 and June 2015. The interview started with the main author (KM) clarifying the aim of the study. All interviews were initiated with an open-ended question: How do your lifestyle habits influence your quality of life? The focus was on the lifestyle habits: physical activity, diet, smoking, and alcohol. In order to encourage the patients to think more profoundly about the question and to obtain in-depth data,

Table I. Characteristics of the participants (N=22).

Participant (P)	BARFOT Clinic	HAQ	EQ-5D	Sex	Age	RA-duration (years)	Married/Co-habiting	Education	Employment
1	3	1.13	0.59	Female	63	14	Yes	Compulsory comprehensive school	Retirement-disease
2	3	0.88	0.73	Female	52	16	No	Upper secondary school	Retirement-disease
3	3	1.38	0.73	Male	68	20	Yes	Upper secondary school	Retirement
4	5	1.38	0.73	Female	65	20	Yes	Undergraduate studies	Part time
5	6	0.63	0.73	Male	66	17	Yes	Compulsory comprehensive school	Retirement
6	6	1.13	0.80	Female	77	8	Yes	Compulsory comprehensive school	Retirement
7	4	0.63	0.73	Female	63	21	No	Undergraduate studies	Full time
8	2	0.75	0.66	Male	65	22	No	Upper secondary school	Retirement
9	4	0.38	0.66	Female	65	11	Yes	Upper secondary school	Retirement
10	4	1.0	0.52	Male	63	18	Yes	Compulsory comprehensive school	Part time
11	3	0.50	0.73	Female	64	22	Yes	Upper secondary school	Sick leave
12	1	1.0	0.52	Female	51	12	Yes	Upper secondary school	Sick leave
13	1	0	1.00	Male	84	18	Yes	Compulsory comprehensive school	Retirement
14	1	0	0.85	Female	77	17	Yes	Upper secondary school	Retirement
15	1	0	1.00	Male	38	19	No	Upper secondary school	Full time
16	5	0	0.80	Male	68	19	Yes	Compulsory comprehensive school	Retirement
17	2	0	0.80	Female	30	10	Yes	Compulsory comprehensive school	Part time
18	2	0.50	0.66	Male	74	14	No	Compulsory comprehensive school	Retirement
19	2	0.88	0.69	Female	58	23	No	Upper secondary school	Sick leave
20	3	0	0.80	Female	37	14	No	Undergraduate studies	Full time
21	3	0	0.85	Female	32	9	Yes	Undergraduate studies	Full time
22	3	0	1.00	Female	40	13	Yes	Upper secondary school	Full time

follow-up questions such as "Please, can you tell me more about ...?", or "How do you mean? ..." were asked. Two pilot interviews were conducted to test the opening question and these interviews were included in the study because no amendment was required. Each interview lasted 30–70 min and was audio recorded.

Data analysis

Qualitative content analysis was used, and both the manifest and latent content were analyzed in accordance with Graneheim and Lundman (2004). The analysis was performed by the authors KM, BA and IL. The authors AB, MA, and SB reviewed the analysis and discussions were held until consensus was reached. The main author (KM) transcribed the interviews verbatim. The interviews were read through several times in order to gain familiarity, and meaning units related to the aim of the study were identified, resulting in 526 meaning units. These were condensed to shorten the text while retaining the content. The condensed meaning units were abstracted to codes that were compared, based on similarities and differences, after which they were grouped into seven subcategories and three categories on a manifest level. The content of these categories was brought together and an overall theme emerged, which expressed the latent meaning of the content.

Ethical considerations

The Regional Ethical Review Board at Lund University, Sweden, approved the study LU 2014/146. The participants received a letter regarding the aim of the study, its design, and the voluntary nature of participation and gave their informed consent. The participants were guaranteed confidentially and informed that they could withdraw at any time without giving an explanation and without any consequences for future care. The study was carried out in accordance with the ethical principles of the Declaration of Helsinki 2013 (WMA, 2013).

Findings

Balancing between ideality and reality

The quality of life for participants with established RA was influenced by the balance between ideality and reality in the performance of lifestyle habits: physical activity, diet, smoking, and alcohol. These could be described in terms of limitation, self-regulation, and companionship, which influenced their experience of their quality of life, whilst they constantly balanced between ideality and reality (Table II). Their experiences of these were individual and diverse, and their quality of life was influenced both positively and negatively. These habits were performed automatically, without continually analyzing the potential effect on their quality of life.

Limitation

The category limitation included the subcategories insufficiency and adaptation. Limitations in terms of insufficiency and adaptation in the performance of their lifestyle habits affected the balance between ideality and reality and thus influenced the quality of life.

The participants described a limitation in *physical activity* in everyday situations because of flashes of pain in their joints, stiffness, and fatigue affecting quality of life. They were not able to walk in some environments and to perform some activities, which led to a sense of *insufficiency* affecting quality of life. They expressed an *insufficiency* in terms of trying certain activities, of being physically active, of a fear of falling, and not being able to manage the situation. The participants indicated how they used different types of strategies and *adaptations* to overcome their limitations and to be able to become, or to remain physically active. They talked of different types of adapted training equipment and technical aids to facilitate walking, which influenced quality of life.

I know that I'm very limited. I can't, I can't go out in the woods because I can't walk on such uneven ground, I just can't (P 4).

In relation to *diet*, the participants expressed a limitation with feelings of *insufficiency* by having a

Table II. The themes, categories, and subcategories reflecting the influence of lifestyle habits on the quality of life of patients with rheumatoid arthritis.

Theme	Balancing between ideality and reality		
Categories	Limitation	Self-regulation	Companionship
Subcategories	Insufficiency	Guilt	Belonging
	Adaptation	Motivation	Pleasure

lack of knowledge about how diet affects their health and thus their quality of life. There was a fear of having an unhealthy diet and of gaining weight. The participants *adapted* themselves by active decisions to avoid food that could cause them to gain weight. They adapted their diet after the family's needs even if it affected their health and therefore their quality of life.

Now when I live alone and can decide that this food makes me feel good, it works for me, so my quality of life in terms of food has become much better (P 2).

Participants who *smoked* felt a limitation through *insufficiency*. They knew about the harmful effects of smoking and expressed a feeling of insufficiency and a fear of not being able to stop smoking. There were participants who had *adapted* themselves to the recommendations and stopped smoking.

I have to stop smoking now and I've had, I've tried several times before but it hasn't worked properly (P 9).

The participants spoke of a limitation through an *insufficient* knowledge about the effects of *alcohol* on their health and thus quality of life. They expressed a concern about drinking alcohol because of the harmful effects. There were also informants who had *adapted* their use of alcohol after disease onset and drug treatment, even if it resulted in a restriction on their lives and affected their quality of life.

Too much would most likely be negative for . . . for my quality of life, but a limited amount of alcohol would, I think, raise my quality of life (P 20).

Self-regulation

The category self-regulation included the subcategories guilt and motivation. Self-regulation in form of guilt and motivation in the performance of their lifestyle habits were factors that influenced the quality of life.

The self-regulation in *physical activity* was affected by a feeling of *guilt* about being physically inactive. The participants expressed a desire and *motivation* to be physically active, in spite of not being physically able to, because they saw an opportunity to improve their quality of life. Their motivation to perform physical activity at home, at work, and during leisure time was based on individual experiences.

Well, without physical activity, there is no quality of life either. Then you will just be on

the couch, and that is the worst thing you can do, so it hangs together (P 19).

The participants experienced that their self-regulation was affected by *guilt* if their *diet* was unbalanced. Opinions of family and friends concerning what diet would be the best for the participants made them feel guilty. The opposite also emerged and there were participants who expressed a *motivation* to change to a healthy diet and they experienced an effect on their quality of life.

But, I don't perhaps eat enough fish, it may be so, but we have it once a week at least (P 5).

The *smoking* induced a sense of *guilt* because smoking affected their health and RA treatment. The participants described that self-regulation was driven by a *motivation* and an opportunity to influence their health and thus their quality of life by stopping smoking.

Perhaps because it could affect my RA, it's not so good and it's perhaps because of smoking that I got RA. But I never really did enough (P 9).

Self-regulation in relation to *alcohol* was described by the participants with varied emotions. Those who consumed alcohol, knowing that it was dangerous for their health in combination with their medication, felt *guilty*. It appeared that they were *motivated* to abstain from alcohol in order to achieve better quality of life, but that they also experienced an opportunity for good health and improved quality of life by drinking small amounts of alcohol.

I just will not feel better if I have a glass of wine. It doesn't really matter or so. And I have stopped partying because it did actually have a negative impact [on quality of life]. I often got more pain after a night out than if I didn't party (P 21).

Companionship

The category companionship included the subcategories belonging and pleasure. Companionship in terms of belonging and pleasure in the performance of the lifestyle habits influenced the quality of life and was a part of the balancing between ideality and reality for patients with established RA.

The participants experienced that *physical activity* was based on a sense of *belonging*, a feeling of being in a companionship. The participants also expressed the opposite, a sense of loneliness if they were limited in carrying out physical activity. To be able to participate in activities was described as a source of *pleasure* with an impact on quality of life.

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It feels great and you cycle a little and feel quite good and greet a few people (P 10).

Companionship in relation to *diet* was perceived as a sense of *belonging*. The participants described a sense of *pleasure* when eating together with family and friends that had a positive impact on their quality of life.

When one can cook something that tastes really good and everyone is satisfied. That's life quality (P 3).

The participants who *smoked* experienced a sense of *belonging* to the companionship of smokers. They describe a pleasure with the smoking and an influence on quality of life. A sense of *belonging* even emerged among those participants who did not smoke and a *pleasure* from not being exposed to smoking.

There's no one in my neighborhood who smokes, not anyone, no neighbors or anything. That's good (P 4).

Companionship also emerged in relation to *alcohol*, where the participants expressed that alcohol created a sense of *belonging*, with an impact on quality of life. The participants experienced *pleasure* and enjoyed eating and drinking in a social companionship.

It can be very cosy when you're together in a group or when you get a really good liqueur with a cup of coffee and a piece of cake or something (laughter) ... then it's fine, then I think it's nice and cosy (P 1).

Discussion

This study explored the influence of lifestyle habits on quality of life in patients with established RA. The result showed that the experience of quality of life depended on a constant balancing of performed lifestyle habits between the ideal situation (ideality) and the actual situation (reality), including limitation, self-regulation, and companionship. Lifestyle habits, such as physical activity, diet, and substance use, can be referred to as health-related habits and are internalized health determinants carried out automatically. They may contribute to positive health or to ill health and are targets for health improvement (Salvador-Carulla et al., 2013).

There has been an augmented focus on the implementation and maintenance of healthy lifestyle habits even for patients with RA in the last decade, but little is known of the link between patients' experiences of lifestyle habits and quality of life. From earlier studies, we know that lifestyle habits, such as physical activity and diet, can be included in

patients' understanding of both the health concept and of the concept quality of life (Fagerlind, Ring, Brulde, Feltelius, & Lindblad, 2010).

For patients with RA, quality of life is considered as a composite of several dimensions of health consequences, including pain, fatigue, physical functioning, and social functioning (Kvien & Uhlig, 2005). This is in line with findings in the present study and previous research (Fagerlind et al., 2010). The findings indicate that living with established RA means a continuous balancing between ideality and reality. Patients with RA are vulnerable and relate individually to lifestyle habits and their impact on quality of life. There is an individual understanding of health and quality of life. They express a need to take active choices and to change priorities in everyday life and in lifestyle habits in order to enhance quality of life, which is consistent with previous findings by Thomsen et al. (2015). There is a constant balancing in everyday life and a need for adaptation in lifestyle habits. In order to maintain the balance in everyday life, with a fluctuating RA, patients try to regain control over their limitations by self-regulation (Flurey, Morris, Richards, Hughes, & Hewlett, 2014). Coping with arthritis is a balancing process, where patients redefine what they considered to be normal life throughout the disease (Gronning, Lomundal, Koksvisk, & Steinsbekk, 2011).

In this study, patients with established RA experienced different limitations in relation to lifestyle habits (physical activity, diet, smoking, and alcohol). They expressed insufficiency, fear, and adaptation in everyday life and how it affected their quality of life. Limitations in relation to physical activity affect various activities in everyday life, due to lack of energy, presence of pain, and fear of joint damage (Van den Berg, De Boer, le Cessie, Breedveld, & Vliet Vlieland, 2007). The limitations can be influenced by biological factors, such as cartilage damage, joint degeneration, inflammation, swelling, and deconditioning (Keefe et al., 2002). It is known that pain and impaired function affect everyday activities in patients with early and longstanding RA (Malm, Bergman, Andersson, & Bremander, 2015; Thyberg, Dahlstrom, Bjork, Arvidsson, & Thyberg, 2012). Patients expressed an insufficiency about diet and special dietary recommendations to reduce RA symptoms. They state that these are hard to follow and sustain for a longer duration and they express limitations about cooking two dishes, one for the family and one for themselves (Ryden & Sydner, 2011). In this study, the patients who smoked expressed an insufficiency and fear of not being able to quit smoking, and they also said that they did not know how smoking affected the RA disease, which is in accordance with the findings of Aimer, Stamp,

Stebbing, Valentino, et al. (2015), who described key barriers or limitations for smoking cessation. Patients are unaware of the relationship between smoking and RA, smoking is a distraction from pain and is used like a coping mechanism to handle the symptoms from the RA disease (Aimer, Stamp, Stebbings, Valentino, et al., 2015). The patients in the present study expressed a fear and an ambivalence in relation to alcohol and RA, which can be due to an association between alcohol and quality of life (Bergman et al., 2013).

The patients in this study described a self-regulation, including both guilt and motivation, in their way of handling or not being able to handle the lifestyle habits in order to gain quality of life. The findings showed that patients with established RA felt guilty when being physically inactive and quality of life was affected in a negative way. This result differs from a comparative study reporting that generalized feelings of guilt and shame are not major issues for patients with established RA and that they do not experience more feelings of guilt than their peers without RA. Guilt and shame are associated with demographic and psychosocial characteristics and not with physical functions and pain (Ten Klooster et al., 2014). The patients expressed a motivation to be physically active in improving quality of life. Lifestyle interventions are important for enhancing quality of life and motivation for physical activity among patients with RA (Knittle et al., 2015). The patients spoke of quality of life being influenced both by guilt and motivation in relation to physical activity, a healthy diet, smoking cessation, and by having a low alcohol consumption. Implementation of healthier dietary habits is difficult. Patients with RA are sometimes recommended a dietary change but find it difficult to achieve it outside their home. Their motivation for sustained dietary changes is individual, and the patients' view on dietary changes is often that they are a temporary change during a specific period of time and not a permanent change of lifestyle habits. This supports the need for and the importance of sustainable lifestyle interventions in the context of dietary change (Ryden & Sydner, 2011) and RA-specific smoking cessation intervention in order to influence quality of life, and to avoid comorbidities and less effective therapy response (Aimer, Stamp, Stebbings, Cameron, et al., 2015).

The present study shows the importance of being a part of a companionship in order to experience quality of life in relation to lifestyle habits. Patients' experiences of how lifestyle habits influenced quality of life in the social context of interacting with others included a sense of belonging and pleasure, which is in line with an earlier study stating that being

physical active was an opportunity to experience a sense of companionship (Loeppenthin et al., 2014). It also included a duality, however, where an improved quality of life could be related to "unhealthy" behavior, such as physical inactivity, unhealthy eating, smoking, and drinking in a positive social context. Companionship sometimes contributed to physical inactivity, where patients with RA often spent time together with family and friends eating or just talking instead of being physically active (Thomsen et al., 2015). It has also been maintained that inactivity affects companionship negatively, when patients have high levels of pain and fatigue and difficulties leaving their homes, and do not have the energy to participate in valued social activities (Feldthusen, Bjork, Forsblad-d'Elia, & Mannerkorpi, 2013; Thomsen et al., 2015).

Methodological consideration

Trustworthiness in a qualitative study should be based on the four criteria: credibility, dependability, confirmability, and transferability (Graneheim & Lundman, 2004; Polit & Tanto Beck, 2012). In order to strengthen the credibility, a strategic selection of participants was chosen. Credibility was also supported by the fact that two pilot interviews and a total of 22 interviews were conducted and that no new content in the subcategories emerged after the 16th interview. Rich descriptions are not primarily based on the number of participants but are obtained by qualitative inquiry into the experiences of the phenomenon in question. The interview text was deemed rich and contained great variety. Dependability was strengthened by the interviews being performed with the same main question, and that the informants were encouraged to talk openly (Graneheim & Lundman, 2004; Polit & Tanto Beck, 2012). Confirmability was demonstrated because of the systematic treatment of data. As a researcher, it is important to reflect on one's own attitudes and pre-understanding of the phenomena in question. When analyzing the interviews KM read individually all the written interviews and thereafter discussed the findings with two of the other authors (IL and BA). In the final process, all the co-authors participated in the construction of the final findings but no member check was done. This process required a genuine openness, flexibility, reflection, and critical discussion within the research group. The chosen quotations reflecting the content of each category provides the reader with an opportunity to determine the confirmability of the study (Polit & Tanto Beck, 2012). Transferability means that the study identifies the phenomenon that is set out to study, that is, how patients with established RA experience the influence of lifestyle habits on

health-related quality of life. The transferability is strengthened because the study was performed among a national sample of BARFOT-clinics in Sweden. The findings could be transferable to another context (Graneheim & Lundman, 2004; Polit & Tanto Beck, 2012). A limitation could be that all the participants were born in Sweden.

Conclusion

Quality of life for patients with established RA was influenced by the balance between ideality and reality in the lifestyle habits: physical activity, diet, smoking, and alcohol. These lifestyle habits could be described in terms of limitation, self-regulation, and companionship, all influencing the perception of quality of life, with a constant balancing between ideality and reality. The patients experience a struggle to determine the right balance of lifestyle habits in order to enhance quality of life and to try to achieve a normal life, independent of the established RA. This is important new knowledge for health professionals when discussing lifestyle habits with RA patients.

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Paper III



Quality of life in patients with established rheumatoid arthritis: A phenomenographic study

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Abstract

Objective: Patients with rheumatoid arthritis perceive reduced quality of life in several domains, such as physical health, level of independence, environment and personal beliefs, compared with the healthy population. There is an increasing interest in quality of life in clinical and medical interventions. Few studies have explored patients' individual conceptions of quality of life, and interviews can thus complement quantitative studies. There is a need for a deeper understanding of the patients' experiences of quality of life, with regard to living with a long-term condition such as rheumatoid arthritis. The aim of this study was to explore the variation of ways in which patients with established rheumatoid arthritis understand the concept of quality of life.

Methods: The study had a qualitative design with a phenomenographic approach, which was used to describe variations in how individuals experience their quality of life. The study is based on interviews with 22 patients with established rheumatoid arthritis enrolled in the BARFOT (better anti-rheumatic pharmacotherapy) study.

Results: The concept of quality of life could be understood in three different ways: (1) independence in terms of physical functioning and personal finances, (2) empowerment in how to manage life and (3) participation as an experience of belonging in a social context.

Conclusion: The different conceptions of quality of life reflect the complexity in the concept, including physical, psychological and social aspects. This complexity is important to have in mind when health professionals support patients in enhancing their quality of life.

Keywords

Rheumatology/clinical immunology, rheumatoid arthritis, quality of life, qualitative study

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Introduction

Rheumatoid arthritis (RA) is a long-term, fluctuating, inflammatory and systemic disease of unknown etiology.¹ In recent years, there has been an increasing interest in incorporating the concept of quality of life (QoL) in the evaluation of clinical and medical interventions.²

The World Health Organization (WHO)³ defines QoL as 'a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, person's beliefs and their relationship to salient features of the environment'. QoL can be measured in various ways, and several generic and RA-specific questionnaires have been used.^{4–6} Patients with RA report reduced QoL in several domains, such as physical health, level

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of independence, environment and personal beliefs, compared with the healthy population. QoL in RA is affected by fatigue, pain, stiffness and impaired physical functioning.⁷⁻⁹ In addition, QoL is also influenced by socioeconomic factors such as age, employment, economic status and lifestyle habits.¹⁰

There are few qualitative studies exploring RA patients' perceptions of the concept of QoL. One previous study found that the patients' understanding included not only freedom from disease and good physical functioning but also psychosocial aspects of life.¹¹ There is a need for a deeper understanding of the patients' experiences of QoL, especially with regard to living with a long-term condition such as RA. This could be achieved by using qualitative research methods as a complement to previous quantitative research.¹² The aim of this study was to explore the variation of ways in which patients with established RA understand the concept of QoL.

Method

Design

The study had a qualitative design with a phenomenographic approach to describe the different ways the studied phenomenon of QoL could be understood.^{13,14} The variation in conceptions is important, because the conceptions are founded on the lived experience of the individuals. Phenomenography proposes that a phenomenon is understood by individuals in qualitatively different ways and that a group of individuals create an understanding of the phenomenon on a collective level.¹³

Participants

The study was based on interviews with 22 patients with established RA, defined as having more than 2 years of disease duration.¹⁵ All of these patients were enrolled in the BARFOT (better anti-rheumatic pharmacotherapy) study, in which 2800 adult patients with early RA were included from 1992 to 2006. The patients were registered at diagnosis (baseline) and at follow-up at 3, 6 and 12 months and 2, 5, 8 and 15 years. Details of the study have been published elsewhere.^{16,17} For this study, participants were selected by using a strategic sampling procedure in order to gain variations in the following: gender (14 females and 8 males); age (30–84 years); disease duration (8–23 years); marital status (15 married/co-habiting and 7 single); education (8 compulsory comprehensive school, 9 upper secondary school and 5 undergraduate studies); employment (8 employed and 14 on sick leave or retired); physical function assessed by health assessment questionnaire (HAQ)=0–1.38; health-related QoL assessed by Euroqol5D (EQ-5D)=0.52–1.0 and originating from all 6 BARFOT centres (2–7 participants/centre) which cover both urban and rural patient referral areas.

Data collection

Individual interviews were performed at the participant's BARFOT clinic in a private room, between May 2014 and

June 2015. The interviews started with the main author (K.M.), clarifying the aim of the study. In line with the phenomenographic method,¹⁸ all interviews were initiated with three open-ended questions aimed at ensuring similar data from all participants: 'What does QoL mean to you?', 'How do you conceive your QoL?' and 'How has your RA affected your QoL?' The aim of the interviews was to capture the participant's fundamental and genuine conceptions about QoL. The interviewer therefore returned to the main questions several times during the interview and by probing questions and reflecting comments encouraged the participants to focus on their own lived experience. Finally, the interviewer summarized the interview with the participants. Each interview lasted between 30 and 70 min, was audio-recorded and then transcribed verbatim by K.M. Two pilot interviews were conducted in order to check the questions. As no revision was necessary, these interviews were included in the study.

Data analysis

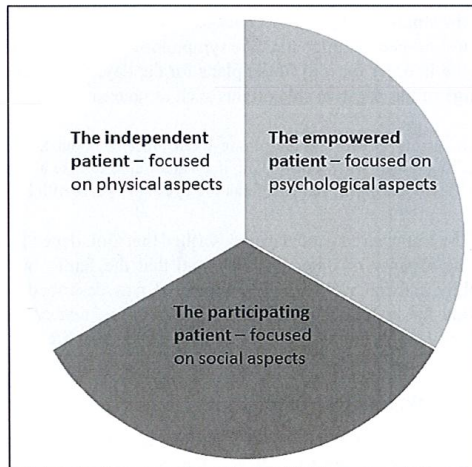
The aim of the phenomenographic method is to identify various ways of understanding a phenomenon, in this case, QoL. The analysis was performed manually in seven steps according to Larsson and Holmström¹⁹ by K.M., with the last author (I.L.) acting as co-assessor:

1. The entire text was read several times in combination with listening to the audio-recorded interviews.
2. When rereading, the whole text marks were made where participants gave information corresponding to the aim of the study.
3. The marks were then compared and discussed to identify the participant's dominant way of understanding QoL and how this was described, formulating a preliminary description of each patient's dominant way of understanding his or her QoL.
4. Based on similarities and differences, descriptions were categorized into three descriptive categories. These are reported in the form of text and illustrated by quotations.
5. The participant's non-dominant ways of understanding of the phenomenon were identified. This was undertaken to ensure that no aspect was overlooked (Table 1).
6. A structure was created of descriptive categories in order to find the internal relationship between the three categories, which created the outcome space, constituting the result of the phenomenographic study (Figure 1).
7. To each of the three descriptive categories, a metaphor was assigned.

To attain rigour and consensus in the data analysis, the authors, who had extensive experience of rheumatology and qualitative methodology, took part in several discussions regarding each step in the data analysis. The patient perspective was also taken into account by inviting a patient research

Table 1. Characteristics and dominating (++) and non-dominating (+) ways of how 22 participants with established RA experience ways of understanding quality of life.

Participant no.	Gender	HAQ	EQ-5D	Disease duration (years)	The independent patient	The empowered patient	The participating patient
1	Female	1.13	0.59	14	++	+	+
2	Female	0.88	0.73	16	+	++	+
3	Male	1.38	0.73	20	++	+	
4	Female	1.38	0.73	20	+	++	+
5	Male	0.63	0.73	17	+	++	+
6	Female	1.13	0.80	8	+	++	+
7	Female	0.63	0.73	21	++	+	+
8	Male	0.75	0.66	22	+	+	++
9	Female	0.38	0.66	11	++	+	+
10	Male	1.0	0.52	18	+	++	
11	Female	0.50	0.73	22	+	++	
12	Female	1.0	0.52	12	++	+	
13	Male	0	1.00	18	+	+	++
14	Female	0	0.85	17	++	+	+
15	Male	0	1.00	19	++	+	+
16	Male	0	0.80	19	+	+	++
17	Female	0	0.80	10	++	+	+
18	Male	0.50	0.66	14	++	+	+
19	Female	0.88	0.69	23	++	+	+
20	Female	0	0.80	14	++	+	+
21	Female	0	0.85	9	++	+	
22	Female	0	1.00	13	+	++	+

**Figure 1.** The outcome space illustrating the relationship between the categories independence, empowerment and participation and described physical, psychological and social aspects that influence the quality of life in patients with established RA. The categories are related as parts of a whole and the variations that emerged are not hierarchically related.

partner to participate in the design of the study and in the data analysis.²⁰

Ethical considerations

The participants received a letter regarding the aim of the study, its design and voluntary nature of participation and signed an informed consent. The participants were guaranteed confidentially and informed that they could withdraw at any time without giving an explanation. The study was carried out in accordance with the ethical principles of the Declaration of Helsinki 2013.²¹ The Regional Ethical Review Board at Lund University, Sweden, approved the study (LU 2016/896, KI 2014/1986-31/1).

Results

The patients spoke of a number of different ways of understanding the phenomenon of QoL in established RA, although one way of understanding was more dominant for each individual (Table 1). The following three ways of understanding emerged: the independent patient, the empowered patient and the participating patient.

The independent patient

In this descriptive category, the conceptions were focused on various physical aspects as being independent in terms of physical functioning and personal finances, and the metaphor of the independent patient emerged. The independent patient experienced QoL when being free and independent in the ability to choose and manage daily activities of living at

home, at work and in their leisure time. The patients could manage their life plan without asking for help. The independent patient talked of the importance of maintaining physical functioning, so they could remain physically active and have the ability to be outside the home. QoL for the independent patient entailed not being limited:

... physical activity means quite a lot to me, because I also relate it to quality of life ... (P20, female, 37 years, 14 years with RA)

... independence is thus also quality of life and then it's not having pain. Being able to cope oneself, stopping asking for help or not having to ask for help. (P19, female, 58 years, 23 years with RA)

QoL also entailed having financial security and possibilities for choosing where and how to live, in an apartment or in a house, what to eat and to be able to afford to continue with a self-chosen hobby, such as travelling or going to the theatre:

... I don't want to have a financial situation that means I'm unable to buy the food I like and so on or unable to go to some event if I like it, then it would be miserable. If I need to buy some clothes or something then I'd like to have the money for it. (P14, female, 77 years, 17 years with RA)

Being independent also meant not having the need to take medication or to be able to take as little medication as possible, but the patients could, on the other hand, conceive a sense of dependency by having the need to have a routine, a plan to take medication at a certain time of the day. When travelling abroad, some medications needed special handling, which was conceived as limiting:

... [quality of life] yes, to get rid of the pain, and avoid to use a lot of medication. (P1, female, 63 years, 14 years with RA)

... not being limited, yes, that's quality of life for me. it's not being limited. Yes being able to do what I feel like doing. Actually, it, that's quality of life. (P12, female, 51 years, 12 years with RA)

Variations in conceptions of QoL emerged with patients expressing that their freedom was restricted due to being dependent in their daily activities, which led to practical consequences such as being forced to cancel planned activities and stay at home. The patients felt that they became dependent because of fatigue, pain or limitations in their functioning, which affected how they handled and performed their everyday life activities:

... when it was the worst possible when I could hardly turn over in bed then I thought – shit is life going to be like this? This is completely worthless. (P15, male, 38 years, 19 years with RA)

The empowered patient

In this descriptive category, the conceptions were focused on different psychological aspects of how to manage life, and the metaphor of the empowered patient emerged. The empowered patient experienced that QoL meant to take charge of and use different resources, such as positive thinking, in order to manage fatigue, pain and physical functioning. The patients' conception of being empowered was to believe in their own capacity to self-manage their everyday life, to be flexible and to influence their situation:

... positive thinking, particularly even in difficult situations, so I always think there's a light at the end of the tunnel and then it is being a, yes how shall I answer, quality of life, yes that's what I'm doing. (P10, male, 63 years, 18 years with RA)

There were also conceptions about the empowered patient, that QoL entailed being able to see opportunities and to be able to continue with planned activities by using ordinary routines, and to accept the need for help in specific situations. The empowered patient talked of a sense of security in mind and body in order to cope with a situation in an individual way:

... Yes, but it's that I choose, I do easier things so that I don't have to feel sad that I am unable to do what I can't do. (P4, female, 65 years, 20 years with RA)

The empowered patient's conception of QoL was to adjust the use of medication to manage symptoms such as pain and fatigue in order for it to fit the plans for the day, and to take charge of the negative side effects such as nausea:

... quality of life, the only thing I can think of about that is taking tablets when I have pain, it sounds stupid or take a bath as I will feel better, yes. (P2, female, 52 years, 16 years with RA)

The empowered patient also described that QoL depended on the absence of other diseases, and that the family was healthy and felt well. Being empowered was described as having the knowledge and experience to adjust and create ordinary daily routines in order to handle everyday life.

The participating patient

In this descriptive category, the conceptions were focused on different social aspects, such as having the experience of belonging and participating, and the metaphor of the participating patient emerged. The participating patient experienced QoL in terms of being part of a social community, participating in different projects at home, at work or in the community. QoL also entailed having the ability to meet old and new friends, and to have meaningful things to do. The participating patient took part in different contexts with other people of different ages and gender:

... being able to be together with younger people, I've always thought that it is fun to sort of keep my head above water [be alert and keep up with what is going in the world], that I've not only thought like a 65-year old but can understand how a 25-year old thinks and a 40-year old and perhaps even younger. I think that's also quality of life to be able to meet people of all ages. (P16, male, 68 years, 19 years with RA)

QoL for the participating patient entailed a sense of belonging to a family, a group of colleagues and friends, and being appreciated and valued:

... be together with friends and acquaintances. That's quality of life. (P13, male, 84 years, 18 years of RA)

The participating patient also conceived that QoL entailed being outside the home, in the garden or on a daily walk around the neighbourhood, talking to neighbours and being seen as a person:

... it's also quality of life being able to give back, pick up the kids at day nursery etc. We're actually busy with taking care of children. (P16, male, 68 years, 19 years with RA)

Variations emerged and were described as fears of not being able to participate in social relationships because of symptoms, such as limitations in functioning, fatigue and pain. The participating patient described conceptions of loneliness and a fear of not being needed and being left out. The conception of QoL was adversely affected if the patients always needed to eat and cook by themselves, not being able to visit family, friends or to have dinner at a restaurant:

... my quality of life has deteriorated through me being alone now so that ... well, in any case the one I lived with, then the quality of life is worse, I think. (P8, male, 65 years, 22 years of RA)

Outcome space

The result of this phenomenographic study does not only contain the categories but also the relationship between the categories, termed the outcome space. The categories are related as parts of a whole and the variations that emerged are not hierarchically related. The categories independence, empowerment and participation are physical, psychological and social aspects of the concept of QoL in established RA, reflecting the complexity of QoL in a long-term condition. Physical aspects included independence in terms of both physical and financial aspects. QoL was also influenced by psychological aspects, such as management and empowerment. Social aspects entailed having a sense of belonging and participation. The outcome space can be divided into three parts: independence, empowerment and participation with no overlap, representing the collective understanding of the participants' ways of understanding QoL (Figure 1).

Discussion

The study showed that patients with established RA understood the concept of QoL in three different ways: independence, empowerment and participation. These categories can be described as physical, psychological and social aspects and are in line with the WHO³ definition of QoL.

In this study, being independent was spoken of as a conception of freedom, a physical feeling of maintaining independence without bodily symptoms. Being able to continue with physical activities and exercise depended on the current level of physical functioning. To be independent in this study meant functioning physically and being physically active. These aspects have also been found to be very important for QoL in other studies,^{22,23} which report physical activity as an opportunity for experiencing independence and QoL. A variation in the conceptions of independence was dependence, experienced as limited physical functioning due to deformities and pain affecting QoL. A previous study has described how physical limitations in the lower extremities affect independence and reduce QoL.²⁴ It emerged in this study that the participants were aware of the benefits of being physically active and how physical activity affected QoL, which is consistent with the findings of previous research.²⁵ The ability to influence life and not having to plan ahead made life easier and was expressed as independency. It was also important not to feel limited in terms of medication administration, and the association between the conception of independence and the medication administration has been previously described.²⁶ Physical functioning was expressed in this study as being vital for maintaining mobility and being able to have leisure activities, as well as continuing with a self-chosen hobby. The latter was associated with QoL and expressed as a measure of independence. This is also in line with other studies where hobbies were described as an important domain for QoL in RA.²⁷

The independent patient's QoL was negatively affected when having to be dependent on help from family or friends in everyday activities. This is supported by other studies where it is reported that patients who were married or cohabiting sometimes had feelings of gratitude and guilt for being dependent.^{27,28} The independent patient described the value of having sufficient financial resources to be able to travel and to stay active in various hobbies, even if the hobby was an expensive one that entailed travelling or riding a horse or a motorbike. The financial situation could be affected by the disease, since inadequately treated RA leads to sizable economic costs for the patients and their families, which has also been described in other studies.^{29,30}

The experience of living with a long-term condition such as RA makes the patients strive to accept to live with the fact that RA is a part of who the person is. The empowered patient described how to manage everyday life and how to use different psychological strategies, in order to be empowered to take care of yourself and learn to live and cope with

different symptoms.²⁸ In a previous study, the patients' self-perception and identity were affected by reduced physical functioning, and the patients described a process of coping with physical barriers as a struggle between the mind and the body and the need to adjust new routines to handle different situations.³¹ The empowered patients used their knowledge of having had a long-term condition for several years, and had a belief in their own ability to manage different situations, and how to reset goals and expectations. A previous study about the experience of living with RA reported that the patients became their own experts in managing and coping with disease symptoms, which could be interpreted as empowerment.³² Another finding in our study is that the empowered patient expressed a need to take active choices and change priorities to enhance QoL. This indicates the importance of strengthening empowerment, and that health professionals continue to develop problem-based learning and give the patients individual support to enhance awareness and understanding of the consequences of their self-managing.³³ Empowerment helps the patients think critically to have the opportunity to make autonomous and informed decisions so they can get what they need, handle everyday life and enhance QoL.³⁴ The latter was affected if individual expectations could no longer be achieved and if previous presumptions about life could not be fulfilled, which was described in a study of everyday life in patients with RA as being a disruption in the individual's life project.³¹ The empowered patients spoke of having a sense of control and the knowledge to use ordinary everyday routines to handle different symptoms, which enhanced QoL, such as walking around the neighbourhood, relaxation techniques and how to ask for and receive help from others. This is in line with two qualitative studies that highlighted personal empowerment and individual resources for overcoming disease-related restrictions.^{35,36}

To be able to participate in different contexts was experienced as an aspect of QoL, and to be a part of a social context gave a sense of belonging. The participating patient expressed the importance of being part of a family and having friends to achieve QoL. A variation in the concept participation was described as a sense of loneliness and not being needed. To belong in a social context has been expressed as important for retaining QoL in patients with RA.³⁷ Overcoming conceived restrictions and limitations by having social support in everyday life improves QoL, which is in accordance with previous findings about the accessibility of different social relationships and participation with family, friends and colleagues.^{10,38} Most work situations involve social contacts, which enhance social participation.⁴⁰ Companionship at work or different types of social or voluntary networks appear to be important social arenas for social participation, and these findings are confirmed by other researchers.^{22,31,35} These studies indicate the importance of remaining in employment and being able to continue with self-chosen hobbies. Patients with RA become work-disabled at a greater

rate than the general population, which affects QoL.³⁹ As can be found in previous research, our study confirms the importance of having the ability to meet people on equal terms in different contexts, and one consequence of impaired physical functioning could be a reduced social participation and thus isolation.⁴⁰ Furthermore, symptoms such as pain and fatigue also affect the ability to participate.²⁵

The categories are separated parts of a whole, and occur in varying degrees for the same individual. In order to enhance QoL, it is important that the whole person is seen and heard, and supported in all the aspects described in the three categories: independence, empowerment and participation. By using a qualitative design, the patients' perspective is highlighted. The participants have the opportunity to describe with their own words the phenomenon, QoL, from personal experiences of living with a long-term condition, instead of being restricted to answer standardized questionnaires.¹²

Methodological considerations

The phenomenographic approach was chosen in order to gain variation in ways of understanding QoL in patients with RA.¹⁸ In qualitative research, trustworthiness should be based on four criteria: credibility, dependability, confirmability and transferability.^{41,42} Credibility was strengthened by two pilot interviews, and that a total of 22 interviews were conducted. The fact that the interview text was deemed rich and that the descriptive categories covered the data also increases credibility. Credibility was enhanced by careful description of data collection and analysis, and that the researchers worked both individually and together in the data analysis. Dependability was strengthened by using the same open-ended questions to all the participants to assist them to reflect and explain their understanding of the phenomenon of QoL. The strength was that the main researcher performed all interviews in the same way. Confirmability was demonstrated by the systematic and conscientious data analysis, where all steps have been reported. Including a patient research partner in the design and data analysis enhanced the confirmability of the study. Quotations of the participants' ways of understanding enhanced and illuminated the content. The transferability was strengthened since the study was performed among a national sample of BARFOT clinics in Sweden. A qualitative approach does not attempt to generalize the result to a whole population, but it is probable that the categories could be transferable to other patients with long-term condition. All the participants were born in Sweden, and this could be a limitation in the study with regard to transferability.

Conclusion

QoL in patients with established RA was conceived as independence in terms of physical functioning and financial resources, as empowerment in how to manage life and as

participation in the experience of belonging in a social context. This reflects the complexity in the concept of QoL, including physical, psychological and social aspects that are in line with the WHO definition. This study suggests a holistic approach from the health professionals, which is important when supporting patients with RA in different situations to increase their QoL. Research in QoL within rheumatology that focuses on narrative interviews from patients with both early and established RA is scarce and further qualitative studies are necessary. It would also be interesting in a clinical practice to investigate how independence, empowerment and participation can be maintained and enhanced in patient with RA.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

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Informed consent

Written informed consent was obtained from all subjects before the study.

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Paper IV



Lifestyle habits discussions as an integral part of care management in patients with established rheumatoid arthritis

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Running head: Lifestyle discussions in healthcare

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Abstract

Objectives: To explore whether lifestyle habits had been discussed during healthcare visits in patients with rheumatoid arthritis (RA).

Method: A postal questionnaire in 2017 sent to 1,542 eligible patients from the Better Anti-Rheumatic Pharmacotherapy (BARFOT) study included questions on lifestyle habits (physical activity, diet, smoking, and alcohol), on whether these habits had been discussed during healthcare visits, and on whether there was a desire for such discussion.

Results: 1,061 patients (68%) responded (mean age 67 years (SD 13); 73% women). Physical activity was discussed with 49% of the patients. Those who reported that they were active on a health-enhancing level were more likely to have discussed physical activity with health professionals. Diet had been discussed with 23% of the patients. Patients who reported a non-traditional mixed diet were more likely to want to have discussions about diet. Smoking was discussed with 25% of the patients. Smokers had more often discussed smoking habits with healthcare professionals (32% vs. 17%; $p=0.000$). Alcohol had been discussed with 17% of the patients. Of those patients with hazardous drinking habits, 77% had not had a discussion regarding alcohol.

Conclusions:

Physical activity had been discussed at least once with every second patient with established RA. Diet, smoking, and drinking habits had been discussed with about a quarter of them. There is a need for improvement, since lifestyle habits are especially important in a long-standing disease such as RA. Patient education concerning lifestyle habits should be an integral part of care management and an interactive process.

Introduction

Rheumatoid arthritis (RA) is a long-term autoimmune disease characterized by synovitis, systemic inflammation, and production of autoantibodies (1). The prevalence is 0.5–1.0% (2) in the western world, being higher in women and older individuals (3). Physical disability, pain, fatigue, and sleep disturbances are some of the most pronounced symptoms, resulting in limitations in activity that affect the patient's quality of life (4). RA is also associated with an increased risk of developing comorbidities (5), which are known to be associated with lifestyle-related habits such as having a sedentary lifestyle, having an unhealthy diet, smoking, and over-consumption of alcohol (6). In 2010, the European League Against Rheumatism (EULAR) published general guidelines on risk management in patients with RA, in which health professionals are encouraged to prioritize discussions with patients regarding their lifestyle (7).

Regular physical activity and exercise are necessary elements in the treatment of RA, and during the past decade interventional trials have shown that physical activity is well-tolerated and improves muscle function in established RA (8). In healthy individuals physical activity leads to decreased levels of pro-inflammatory cytokines, and individuals that are physically active before onset of the disease appear to present with milder RA. This adds to the evidence that physical activity has beneficial effects on inflammatory diseases (9, 10). Diet and obesity are closely related, and are associated with a higher risk of comorbidities and worse disease activity in RA (11). It is well known that smoking is a modifiable risk factor with important negative effects on health (12). In rheumatic diseases smoking has shown to be associated with the onset of RA, with smokers being more likely to develop RA than non-smokers (13). Current smokers of cigarettes are also less likely to respond to treatment of RA (14).

Studies regarding alcohol report divergent results for example that alcohol intake may protect against development of RA (15) and that alcohol intake is associated with less radiographic progression in men (16), and lower self-reported disease activity and better health-related quality of life (17). Though, alcohol consumption has many negative effects on health (18) and there is a hepatotoxic risk in alcohol use if treated with methotrexate (19).

A qualitative study in patients with RA showed that lifestyle habits affect their quality of life, resulting in a constant balancing act between reality and the ideal situation (20). The main difficulty is in changing behaviour, since well-motivated will do better than unmotivated patients with poor self-esteem, lower socioeconomic status which are associated with poor long-term outcome and increased mortality (21). Since there have been recommendations in healthcare to reach out to patients with discussions on lifestyle habits, it is of interest to study the extent to which these discussions actually occur.

The aim of this study was to explore whether the lifestyle habits physical activity, diet, smoking, and consumption of alcohol were discussed with patients during healthcare visits.

Methods

Subjects

This cross-sectional postal survey in 2017 included all 1,542 still living patients from the Better Anti-Rheumatic Pharmacotherapy (BARFOT) study, which involved patients with early RA according to the American College of Rheumatology criteria 1987 (ACR 87) (22), recruited from six rheumatology clinics. In the BARFOT study data from 2,800 adult patients were registered (with consecutive inclusion between 1996 and 2006) at diagnosis (baseline), at 3, 6, and 12 months, and after 2, 5, 8, and 15 years. Details of the larger study have been published elsewhere (23).

Questionnaire

All the patients received a postal questionnaire for self-completion, including questions concerning lifestyle-related habits: physical activity, diet, smoking, and alcohol consumption. The questionnaire also included sociodemographic data and questions on function and health status. We sent one reminder, and if necessary two, to those who did not respond to the first mailing.

The main outcome variables were based on questions that had been used previously in a national patient survey (Health on equal terms) (24): “Did a medical doctor or other health professional discuss physical activity and exercise/diet/smoking/alcohol habits with you during any of your healthcare visits?” The response alternatives were: (1) yes, during at least one healthcare visit; (2) yes, at my latest visit; and (3) no. In this study, both “yes” responses were labelled as “yes”. For each of the four lifestyle-related habits there was also a question regarding whether the patients would have wanted such a discussion, with an answer of “yes” or “no”.

The questionnaire also included questions regarding physical activity performed, diet, smoking habits, and alcohol consumption.

Physical activity and exercise

Physical activity and exercise was assessed with two questions concerning the frequency and duration during the previous 7 days (min/week): (1) vigorous intensity (jogging or intense exercise) and (2) moderate intensity (walking, gardening, or bicycling) (25).

Based on answers to these questions it was evaluated if recommendations for health-enhancing physical activity (HEPA) was met or not. The recommendation for HEPA includes that moderate-intensity aerobic physical activity should be performed regularly for a minimum of 30 min, at least five days a week (150 min/week) or substituted by 20 min of vigorous activity three days per week (60 min/week) (26). In this study, fulfilling HEPA at a moderate intensity was defined as moderate activity > 120 min/week.

Diet

The present diet of the patient was assessed by giving eight options: traditional mixed, Mediterranean, low-glycaemic (GI-diet), vegetarian, vegetarian with seafood, vegan, gluten-free, and other (free text).

Smoking

Smoking habits were also assessed and the responses were coded as never-smokers, previous smokers, or current smokers (27). When the smoking habits were dichotomized, previous and current smokers were called ever-smokers and compared with never-smokers.

Alcohol consumption

Alcohol consumption was assessed with the AUDIT-C questionnaire, a validated subset of items from the full alcohol AUDIT (28), consisting of three questions concerning (1) frequency per month, (2) volume per occasion, and (3) number of times with six or more drinks on one occasion. All questions are scored 0–4 (best to worst), with a total score of 0–12 points. The limit for hazardous drinking according to the Swedish National Institute of Public Health is AUDIT-C > 4 points for women and > 5 points for men (www.fhi.se), cut-offs that were also used in this study.

The questionnaire also included well-used and validated questionnaires on physical function and health-related quality of life. Function was measured with the Stanford Health Questionnaire (HAQ)(29). Health-related quality of life was measured as health status according to EuroQol-5Dimensions (EQ-5D) (30). Patients' global assessment (general health), pain, and fatigue were assessed with numerical rating scales (NRSs) 0–10 (best to worst) (31). Self-administered assessment of the number of tender and swollen joints was based on the 28-joint count (32). Treatment with disease-modifying anti-rheumatic drugs (DMARDs), glucocorticoids, and biologics was registered.

Statistical analysis

Statistical analyses were performed using SPSS statistical software version 22.0. All significance tests were two-tailed and were conducted at the 5% significance level. Continuous data are given as mean and standard deviation (SD) and categorical data are shown as frequency (percentage). To study differences between groups, the independent t-test was used for continuous variables and the chi-square test was used for proportions.

Ethical considerations

All participants had provided their written informed consent. The present study was approved by the Ethical Review Board at Lund University, Sweden (DNR LU 2016/816) and was performed according to the ethical principles for medical research on human beings described in the Declaration of Helsinki as updated in 2013(33).

Results

Of the 1,542 patients who were eligible, 1,061 (68%) responded to the questionnaire. The mean age (SD) of the responders was 67 (13) years, the mean duration of disease was 15 (3.8) years, and 769 were women (73%). Demographics and patient-reported disease activity, quality of life, and function are given in Table 1, and treatments at the time of the questionnaire are given in Table 2.

Gender and age characteristics were not significantly different in responders and non-responders. However, inclusion data from the BARFOT cohort showed that a lower proportion of patients who did not answer the questionnaire were rheumatoid factor positive (57% vs. 66%; $p < 0.001$).

Physical activity

Physical activity was discussed with 49% of the patients, with no significant differences between women and men (48% vs. 53%; $p = 0.121$). Ten per cent of the patients who did not have a discussion reported that they would have wanted one (Figure 1A). Forty-six per cent of the patients pursued a health-enhancing physically activity at the HEPA level. Those who reported that they were active at the HEPA level had discussed physical activity with health professionals more often than those who did not fulfill HEPA requirements (55% vs. 45%; $p = 0.002$) with an OR of 1.47 (95% CI: 1.55–1.88). There was no significant difference between patients who fulfilled the HEPA criteria and those who did not, with regard to whether or not they wanted a discussion concerning physical activity (29% vs. 26%; $p = 0.366$).

Diet

Diet was discussed with 23% of the patients, with no significant difference between women and men (22% vs. 27%; $p = 0.085$). Fifteen per cent of the patients who had not had a discussion would have wanted it (Figure 1B). Most patients (81%) reported that they had a traditional mixed diet. A higher proportion of patients who reported having a non-traditional mixed diet (low-glycaemic, Mediterranean, vegetarian, or vegan) expressed that they would have wanted discussions on diet than those who had a traditional mixed diet (31% vs. 20%; $p = 0.002$).

Smoking

Smoking was discussed with 25% of the patients, with no significant difference between women and men (26% vs. 27%; $p = 0.731$). Only 1% of the patients who had not had a discussion would have wanted it (Figure 1C). Thirteen per cent reported that they were current smokers. A higher proportion of ever-smokers than never-smokers had discussed smoking habits with healthcare professionals (32% vs. 17%; $p = 0.000$), and a higher proportion of them would also have wanted to discuss smoking (7% vs. 2%; $p = 0.001$). There was no significant difference in medical treatment between those who had had a discussion on smoking and those who had not (Table 2).

Alcohol consumption

Alcohol was discussed with 17% of the patients, and more commonly with men than with women (22% vs. 15%; $p = 0.008$). Nineteen per cent reported having a hazardous drinking pattern, and of those, 77% did not report having a discussion regarding alcohol. Of those respondents who did not have a discussion on alcohol, 2% reported that they would have wanted such a discussion (Figure 1D). A higher proportion of those who reported having hazardous drinking habits would have wanted to discuss alcohol consumption (8% vs. 4%; $p = 0.018$). There was no significant difference in medical treatment between those who had had a discussion regarding alcohol and those who had not (Table 2).

Discussion

This study, based on patient reports, showed that physical activity had been discussed at least once with every second patient with established RA. However, diet, smoking, and alcohol consumption had only been discussed with about a quarter of the patients. EULAR recommended patient-centred standards of care for RA, encouraging health professionals to prioritize discussions on lifestyle habits in patients with RA (34). A goal of rheumatological care is to have well-informed patients who have sufficient knowledge to participate in decision making. Discussions on lifestyle habits from the patient's point of view can lead to valuable insights regarding their expectations (35).

The results show that lifestyle-habits discussions concerning physical activity had increased compared to a previous Swedish study in rheumatology, in which 28% of the patients from an outpatient clinic reported that physical activity had been discussed (36). The Swedish national patient survey from 2014 found that 36% of the patients in primary care had discussed physical activity (www.npe.skl.se), which is lower than what was found in the present study on patients with RA. Physical activity and exercise are discussed more frequently with RA patients, which could be due to the fact that many patients with RA meet a physiotherapist sometime during the course of the disease. This could also be the reason for why physical activity is discussed more often than the other lifestyle habits. In this study 46% of the responders were active according to HEPA criteria, which is lower than in a previous cross-sectional study from 2013, where 69% reported that they currently were active on a HEPA level (37). Comparisons between studies are problematic, due to different ways of presenting physical activity in relation to the HEPA recommendations (26, 38)

Previous research has found that patients with RA often ask for dietary recommendations to improve their symptoms (38) although in one previous study only 8% of the patients in a rheumatology outpatient clinic reported that diet had been discussed with them (36). This is considerably lower than the 23% found in the present study. In the present study, a higher proportion of patients who reported having a non-traditional mixed diet (low-glycaemic, Mediterranean, vegetarian, or vegan) wanted to be involved in dietary discussions.

Since environmental exposure has been implicated in the aetiology of RA (13) and the most prominent risk factor for RA is smoking (39), discussion of smoking should be prioritized. In this study, smoking was discussed with a quarter of the patients, but a lower proportion of non-smokers received information and had discussions about smoking, and they were also less interested in having such a discussion. Almost 65% of the rheumatologists are reporting that they are giving advice on cessation of smoking to patients with inflammatory diseases (40). In the clinical setting, it is common to address smoking and alcohol habits together with an introduction to medical treatment. In this study, there were no differences in having such discussions between patients who were given medication and those who were not. It is especially important to discuss smoking habits with patients with RA, because of the detrimental effect of smoking and the difference in response to disease-modifying anti-rheumatic therapy (14). It is also important to discuss smoking habits with non-smokers, since smoking is an important environmental risk factor for RA, particularly in patients with specific

genetics (39). There are still some patients who are unaware of how smoking can affect RA, and they have a right to have this information (20).

The definition of hazardous drinking patterns varies in different surveys, but use of AUDIT-C indicated that 17% of the Swedish population reported having a hazardous drinking pattern in 2016, which is slightly lower than the findings in the present study (19%) (17, 41). Alcohol was seldom discussed, and patients with a hazardous drinking pattern often reported that they had not had such a discussion. Alcohol consumption is known to be one of the most challenging subjects for healthcare professionals to bring up for discussion (42), but it is also well known that patients who take methotrexate and consume alcohol have an increased risk of liver disease (19), and alcohol abuse can be a major social problem (43). The relation between alcohol consumption and cardiovascular disease is complex. A population-based cohort study found heterogeneous associations between levels of alcohol consumption and initial presentations of cardiovascular diseases (CVD) (44), which highlights the importance of counselling of patients who are at higher risk of CVD, such as RA patients.

Evaluation of health promotion is complex, especially when the interventions provided are expected to achieve measurable improvements only several years after their introduction. There is growing evidence to suggest that only supporting patients with information and advice does not lead to changes in behaviour regarding health (45), but the main challenge is to change behaviour, not to impart knowledge (21). According to previous research regarding lifestyle-related counselling, one-third of the patients prefer individual counselling and a quarter of them would like to get information in leaflets (46). Health professionals are committed to offering the best evidence-based care to all patients (47) even though discussions on lifestyle are a complex issue (48). A previous pilot study regarding lifestyle counselling by a specialist nurse showed that most of the patients in the study had already discussed lifestyle-related habits with the general practitioner, and that additional advice only led to modest improvement (21). In the present study, the question did not refer to any particular unit that had held the discussions, but the healthcare staff in general, and the patients in the study had also had at least seven follow-ups at the rheumatology unit. As the patients who had wanted to discuss lifestyle-habits were already interested in the subject, successful discussions must rely on a patient-centred approach and have more than just information and facts—taking patients' attitudes, motivations, goals, readiness for change, and social support into account (45).

One can assume that many of the discussions on lifestyle-habits are held more as a way of giving information, when patients are starting their medical treatment or when a change in treatment is being made. Perhaps patients do not regard such occasions as being a discussion of lifestyle-related habits.

Many of the patients did not want to have any discussion regarding their lifestyle-habits, which is a problem. One reason for this could be that such habits are often discussed in the media and socially, but this kind of discussion is not directed at their RA, which itself has risk factors that must be taken account of when discussing lifestyle habits. Perhaps this issue could be solved if all the patients with RA were regularly invited to structured, person-centred discussions

conducted alone or in a group. It is most important, however, that patient education concerning lifestyle-related habits is an integral part of care management and an interactive process between patients and health professionals, to afford the patient better control over their situation and enable empowerment.

The main strength of this study was that it was based on a large number of closely followed BARFOT patients from six clinics. Self-reported questionnaires have shown both reliability and validity, but they can also be limited by factors such as inconsistent patient recall and over- and under-estimation of, for example, physical activity (49). Not all of the patients answered the questionnaire, but the non-responders did not differ significantly in characteristics from those who answered the questionnaire, except that a lower proportion had rheumatoid factor.

Conclusion

Physical activity had been discussed at least once with every second patient with established RA. Diet, smoking, and alcohol consumption had only been discussed with about a quarter of them. Although these are higher figures than has been reported previously, there is a need for further improvement—since lifestyle habits are especially important in a long-standing disease such as RA. Patient education concerning lifestyle issues should be an integral part of care management, and an interactive process between patients and health professionals.

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Disclosure statement

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Table 1. Demographics and disease activity variables in the 2017 postal questionnaire (n = 1,061)

	All	Women	Men	p-value
	Mean (SD)	Mean (SD)	Mean (SD)	
Age, years	67 (13)	66 (13)	70 (12)	< 0.001
Disease duration, years	15 (3.8)	16 (3.8)	16 (3.8)	0.6
HAQ	0.5 (0.6)	0.6 (0.6)	0.4 (0.5)	< 0.001
EQ-5D	0.7 (0.2)	0.7 (0.3)	0.8 (0.2)	< 0.001
NRS Pain (0–10, best to worst)	3.5 (2.5)	3.6 (2.5)	3.0 (2.5)	< 0.001
NRS Fatigue (0–10, best to worst)	4.0 (2.8)	4.4 (2.9)	3.4 (2.6)	< 0.001
NRS Global health (0–10, best to worst)	3.0 (2.4)	3.2 (2.5)	2.8 (2.4)	0.027
Tender joints, 28-joint count	5.6 (6.6)	5.6 (6.8)	4.3 (6.1)	0.003
Swollen joints, 28-joint count	3.0 (4.9)	3.3 (5.0)	2.3 (4.5)	0.002

HAQ, the Stanford Health Questionnaire; EQ5D, EuroQol-5 Dimensions; NRS, Numerical rating scale. Tender/swollen joints, self-administered assessment of number of tender and swollen joints based on the 28-joint count.

Table 2. Proportions (%) of current treatment at the time of the questionnaire

	All	Smoking habits*		Alcohol consumption**	
		Never	Ever	Non-hazardous	Hazardous
No DMARDS	23	24	22	23	19
Methotrexate	35	34	36	36	33
Sulphasalazine	2	2	2	2	4
Other mono	3	3	3	3	4
Combination	4	4	4	4	4
Biologic	33	33	33	32	36

DMARD, disease-modifying anti-rheumatic drug.

*Overall p-value = 0.956.

**Overall p-value = 0.610.

Figure 1 A-D

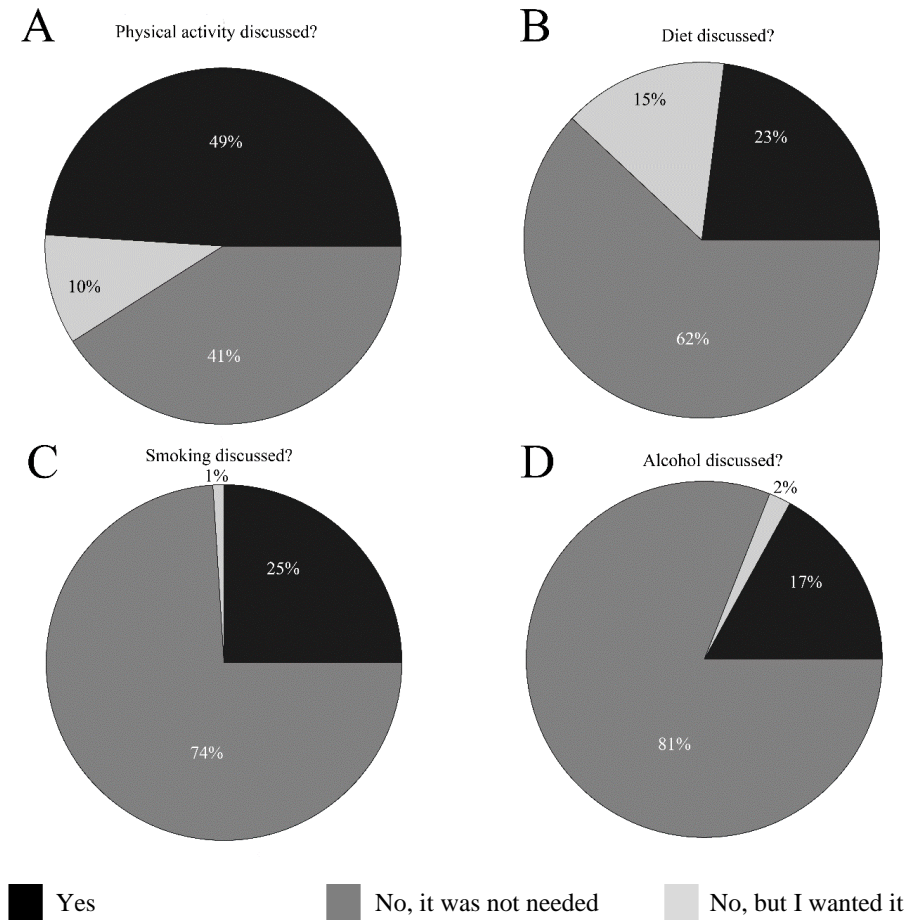


Figure 1. Rate of patients reporting that they had had a discussion regarding lifestyle-related habits and whether they had wanted to have a discussion. Panel **A** relates to physical activity, panel **B** relates to diet, panel **C** relates to smoking, and panel **D** relates to alcohol consumption.



Karina Malm

Karina Malm is a physiotherapist specialized in rheumatology, working at the rheumatology clinic at Capio Movement and at FoU Spenshult in Halmstad, Sweden.

From a physiotherapists perspective Karina has a special interest in inflammatory rheumatic diseases, with a focus on rheumatoid arthritis. As a clinically active physiotherapist with regular contact with this group of patients, she has experienced a need to improve patient care with regard to their lifestyle habits.

In her PhD-thesis Karina explores lifestyle habits, physical function and quality of life in established rheumatoid arthritis. This PhD-thesis presents the results from her research education in rheumatology at the department of Clinical Sciences, Lund, Faculty of Medicine, Lund University.

