

Participation and support in everyday life over a decade

Perspectives of persons with rheumatoid
arthritis and their significant others

Maria Bergström



This is an updated version of the thesis

Participation and support in everyday life over a decade: perspectives of persons with rheumatoid arthritis and their significant others

Maria Bergström

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| 2023-06-09 | The thesis was first published online. The online published version reflects the printed version. |
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Kappa

s. 9: The correct reference for Study III should be: Bergström, M., Larsson Ranada, Å., Sverker, A., Thyberg, I., & Björk, M. (2023). A dyadic exploration of support in everyday life of persons with RA and their significant others. *Scandinavian Journal of Occupational Therapy*, 30(5), 616-627.

s. 9: Study IV should be **[In manuscript]**

s. 30, Heading Participation... , row 5: Reference (Sverker et al., 2020) should be moved to the end of the sentence.

s. 46, Table 3: The following text should be added: **DAS28: Disease Activity Score in 28 joints; HAQ: Health Assessment Questionnaire; SSIA data: Swedish Social Insurance Agency data; VLA-swe: Valued Life Activity Scale – Swedish version**

s. 63, Last part of paragraph 3, the following text should be added: On this basis, **and in relation to Study II**, support from significant others as part of the early rehabilitation process in RA can be considered beneficial.

Study II

s. 428, Heading The TIRA project, row 10, the following text should be added: ...small joints, **or had positive Anti-CCP and at least one peripheral joint with synovitis.**

Study IV

s. 4, Heading Participants, row 5, the following text should be added: ...small joints, **or had positive Anti-CCP and at least one peripheral joint with synovitis.**

s. 16, Heading Integration... , last paragraph: ...issues with basic needs were expressed by **two** patients during the interviews...

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Participation and support in everyday life over a decade

- perspectives of persons with rheumatoid
arthritis and their significant others

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Linköping 2023



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To my grandmother, a person with rheumatoid arthritis
And in loving memory of my grandfather,
her significant other for more than six decades

- *Jag töcker om dej, Kal Oska. Har allti gjort'at. Vi ä di goaste vänner...*
- *Jaa...Di goaste vänner, dä ä vi...!*

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ABSTRACT

Introduction: The treatment of rheumatoid arthritis (RA) has evolved over recent decades. Today, many previous limitations related to, for example, joint damage have become rare, and persons with RA can often continue to work and engage in different aspects of everyday life. Nonetheless, persons with RA still report restrictions in everyday life, as they can be negatively impacted by symptoms like pain, stiffness and fatigue. As these symptoms might be invisible to others, the significant others of persons with RA can find it difficult to comprehend the effect of the disease. As a consequence, both the person with RA and the significant other may be affected, despite today's effective treatment.

As participation is a central concept within healthcare, it is also a prominent factor within rehabilitation and its goals. Despite access to contemporary treatment during the whole disease course, persons with RA still report participation restrictions. Since RA is a chronic disease, these remaining restrictions are of particular interest from a longitudinal perspective. However, support from the social environment, such as significant others, has the possibility to positively influence participation in everyday life. Therefore, it is essential to explore the influence of significant others and their support with the goal of enhanced participation in the everyday life of persons with RA, from a longitudinal perspective.

Aim: The general aim of this thesis is to explore participation in the everyday life of persons with RA over a decade, and in relation to this investigate the influence of significant others and their support.

Methods: This thesis consists of four studies that used different methodological approaches: qualitative, quantitative and mixed methods.

Study I was a qualitative study where 59 persons with RA participated in semi-structured interviews approximately three years after diagnosis. Questions covered experiences in everyday life and participation. The material was analysed through content analysis.

In **Study II**, longitudinal data from 274 persons with RA were analysed regarding disease activity (assessed by DAS28), grip force (assessed by Grippit), pain intensity (VAS mm) and activity limitations (assessed by HAQ). The data were collected at inclusion, year one and year two after diagnosis. Data related to sickness absence were also obtained, as well as self-assessed perceptions of experienced support. Through regression

analyses, associations between disease-related variables and sickness absence were investigated, with support as a moderator.

The data in **Study III** comprise semi-structured individual interviews with 16 persons with RA and their significant others, conducted approximately a decade after diagnosis. The interview guide was developed with Study I in mind and included similar topics, with the addition of support. This material was analysed using dyadic analysis, where a person with RA and the significant other comprised a dyad.

Finally, in **Study IV**, a convergent mixed methods approach was used. Longitudinal data regarding disease-related variables (same as Study II) were collected during the first decade after diagnosis and analysed through linear mixed models. The qualitative material consisted of individual interviews conducted three and ten years after diagnosis and analysed by directed content analysis. The quantitative and qualitative results were integrated in accordance with the chosen method.

Results: Significant others of persons with RA could encompass both facilitators and hindlers to participation in the everyday life of persons with RA. Through the provision of support and helpful attitudes towards needed adaptations, they had a positive influence on participation in the everyday life of persons with RA. This was a continuous process since the persons with RA were still affected by the disease a decade after diagnosis, and adaptations by the significant others might also still be needed.

Experiences of RA were found to differ between men and women over the first decade after diagnosis. Moreover, through a mixed methods design, discrepancies were found between the persons' own descriptions in interviews and the quantitative results. For instance, women expressed issues related to grip force and disease activity in the interviews, but these issues were not detected in the same way in the quantitative results. These discrepancies were additionally not seen in men; however, both men and women still showed signs of disability a decade after RA diagnosis. Nevertheless, over time, the persons with RA and their significant others had learned to live with the disease and there was a sense of togetherness in everyday life with RA. Namely, they approached the disease together as a unit.

Support was identified as a positive aspect that facilitated everyday life. It entailed both the support between the person with RA and the significant other, as well as the support from others outside of the dyad. Support could also come in different forms. For example, the person with RA could receive emotional support from a significant other, or healthcare professionals (HCPs) could provide informational support to either or both of the parties. In connection to the latter, a continuous need for knowledge was identified

in both the persons with RA and the significant others. Support from significant others also proved to have an impact on work life specifically, as more perceived support was associated with an increased risk of sickness absence.

Conclusively, significant others and their support can influence participation in the everyday life of persons with RA, and this influence can be facilitated through positive attitudes and different types of support during the first decade after diagnosis.

Conclusions: Significant others are essential providers of support as facilitators for participation in the everyday life of persons with RA, including many years after diagnosis. However, they must also be attentive towards the further need for adaptations and possible emotional burden in the persons with RA. It is also important for significant others to find a balance between overprotecting and contributing to independence.

The significant others in their turn might need support in understanding the impact of the disease. In this case, HCPs should be providers of support to both persons with RA and their significant others and consult with both of them as a unit in the rehabilitation process. This also exemplifies the need for support from outside the dyads of persons with RA and their significant others.

Support is requested both at an early stage and throughout the disease course. Different types of support from significant others can therefore preferably be part of the rehabilitation process as a way to enhance participation in the everyday life of persons with RA.

Keywords: activities, everyday life, longitudinal research, participation, rehabilitation, rheumatoid arthritis, significant others, support, work

SVENSK SAMMANFATTNING

Svensk titel: Delaktighet och stöd i vardagen under ett decennium – upplevelser från personer med reumatoid artrit och deras närstående

Bakgrund: Rutiner för tidig diagnos och tidigt insättande av sjukdomsmodifierade läkemedel vid reumatoid artrit (RA) har utvecklats under de senaste decennierna. Effekten av dessa rutiner är mindre sjukdomsaktivitet, mindre funktionshinder och mer delaktighet i vardagen för personer med RA som idag ofta kan fortsätta sitt yrkesarbete. Trots detta uttrycker ändå personer med RA hinder i vardagen som kan vara negativt påverkad av symtom som smärta, stelhet och trötthet (fatigue). Då denna typ av symtom även kan vara osynliga för andra kan det vara svårt för närstående till personer med RA att till fullo förstå sjukdomens påverkan. Det innebär att både personen med RA och närstående kan påverkas av sjukdomen, trots dagens effektiva behandling.

Delaktighet är ett centralt begrepp inom hälso- och sjukvård, och även en framträdande faktor i rehabilitering och dess målsättningar. Personer med RA uttrycker fortsatt delaktighetsinskränkningar trots att de under hela sjukdomsperioden haft tillgång till samtida behandling. Eftersom RA är en kronisk sjukdom är dessa kvarstående inskränkningar av särskilt intresse ur ett longitudinellt perspektiv. Dock har stöd från den sociala miljön, som t.ex. närstående, på olika sätt möjlighet att ha en positiv påverkan på delaktighet i vardagen. Det är därför av stor vikt att undersöka vilken påverkan närstående och deras stöd har i relation till målet att öka delaktighet i vardagen för personer med RA, även ur ett longitudinellt perspektiv.

Syfte: Avhandlingens övergripande syfte är att undersöka delaktighet i vardagen hos personer med RA under ett decennium, samt att undersöka vilken påverkan närstående och deras stöd kan ha.

Metod: Denna avhandling består av fyra delstudier där olika metoder använts; kvalitativa, kvantitativa och mixad metod.

Delstudie I var en kvalitativ studie där 59 personer med RA deltog i semistrukturerade intervjuer ca tre år efter insjuknande. Frågor under intervjun berörde upplevelser av vardagen och delaktighet. Materialet analyserades genom innehållsanalys.

I **Delstudie II** insamlades longitudinella data från 274 personer med RA gällande sjukdomsaktivitet (genom DAS28), handkraft (mätt med Grippit), smärtintensitet (mm på VAS-skala) och funktionshinder (enligt HAQ). Data inhämtades vid inklusion, år ett och år två efter diagnos. Även data relaterad till sjukfrånvaro inhämtades, liksom självskattning av upplevt stöd. För att undersöka associationer mellan sjukdomsvariabler och sjukfrånvaro genomfördes regressionsanalyser där stöd figurerade som moderator.

Materialet i **Delstudie III** innehöll semistrukturerade intervjuer med 16 personer med RA och deras närstående, genomförda uppskattningsvis ett decennium efter diagnos. Intervjuguiden var utformad med Delstudie I i åtanke och bestod av samma ämnen, med stöd som tillägg. Detta material analyserades genom dyadanalys, där en person med RA och dennes närstående utgjorde en dyad.

Avslutningsvis användes en konvergent mixad metod i **Delstudie IV**. Longitudinell data relaterad till sjukdomsvariabler (samma som i Delstudie II) samlades in under ett decennium efter diagnos och analyserades genom linjära mixade modeller. Det kvalitativa materialet bestod av individuella intervjuer genomförda tre och tio år efter diagnos och analyserades genom riktad innehållsanalys. Det kvantitativa och kvalitativa materialet integrerades sedan i enlighet med vald metod.

Resultat: Närstående till personer med RA kunde utgöra både möjliggörare och hinder för delaktighet i vardagen för personer med RA. Genom att erbjuda stöd och positiva attityder gentemot nödvändiga anpassningar, hade de en positiv påverkan på delaktighet i vardagen för personer med RA. Detta var en kontinuerlig process eftersom personerna med RA fortfarande var påverkade av sjukdomen ett decennium efter diagnos och anpassningar kunde ännu vara nödvändiga, även för närstående.

Upplevelser av RA skiljde sig mellan män och kvinnor under första decenniet efter diagnos. Genom mixad metoddesign hittades också diskrepanser mellan personernas egna beskrivningar i intervjuer och resultaten från kvantitativa mätningar. Exempelvis uttryckte kvinnor problem relaterat till handkraft och sjukdomsaktivitet, vilket inte hittades i det kvantitativa resultatet. Denna typ av diskrepanser sågs inte hos män. Däremot uppvisade både män och kvinnor funktionshinder ett decennium efter diagnos.

Personerna med RA och deras närstående hade över tid lärt sig leva med sjukdomen och det fanns en vi-känsla i vardagen med RA. De båda parterna bemötte sjukdomen som en enhet.

Stöd identifierades som en positiv aspekt och möjliggörande i vardagen. Detta innebar både stöd mellan personen med RA och dennes närstående, men även stöd från utanför dyaden. Stöd kunde också finnas i olika form. T.ex. kunde personerna med RA få emotionellt stöd från närstående, eller hälso- och sjukvårdspersonal kunde ge informativt stöd till någon eller båda av parterna. I relation till det senare identifierades också ett fortsatt behov av informativt stöd både från personerna med RA och närstående. Stöd från närstående visade sig också påverka arbete specifikt, då mer upplevt stöd var associerat med ökad risk för sjukfrånvaro.

Sammanfattningsvis kan närstående och deras stöd påverka delaktighet i vardagen för personer med RA. Denna påverkan kan vara möjliggörande genom positiva attityder och olika typer av stöd under det första decenniet efter diagnos.

Slutsatser: Under många år efter diagnos är närståendes stöd en viktig möjliggörare för delaktighet i vardagen för personer med RA. Däremot måste de också vara uppmärksamma på ytterligare behov för anpassningar och möjlig emotionell påverkan på personen med RA. Det är också viktigt att närstående hittar en balans mellan att överbeskydda och att bidra till självständighet.

Närstående i sin tur kan behöva stöd i att öka förståelsen av sjukdomens påverkan. I dessa fall kan hälso- och sjukvårdspersonal bidra med stöd till både personen med RA och närstående, och bör bemöta dem som en enhet i rehabiliteringsprocessen. Detta utgör också exempel på behovet av stöd från personer utanför dyaden av personen med RA och dennes närstående.

Behovet av stöd finns både tidigt och senare under sjukdomstiden. Olika typer av stöd från närstående kan därför med fördel utgöra en del av rehabiliteringsprocessen som ett sätt att öka delaktighet i vardagen för personer med RA.

Nyckelord: aktiviteter, arbete, delaktighet, longitudinell forskning, närstående, rehabilitering, reumatoid artrit, stöd, vardagliga livet

LIST OF PAPERS

- I. Bergström, M., Sverker, A., Larsson Ranada, Å., Valtersson, E., Thyberg, I., Östlund, G., & Björk, M. (2020). Significant others' influence on participation in everyday life – the perspectives of persons with early diagnosed rheumatoid arthritis. *Disability and Rehabilitation*, 42(3), 385-393.
- II. Bergström, M., Dahlström, Ö., Thyberg, I., & Björk, M. (2021). The role of support from significant others in the association between disease-related factors and sickness absence in early rheumatoid arthritis: a longitudinal study. *Scandinavian Journal of Rheumatology*, 50(6), 427-434.
- III. Bergström, M., Larsson Ranada, Å., Sverker, A., Thyberg, I., & Björk, M. (2021). A dyadic exploration of support in everyday life of persons with RA and their significant others. *Scandinavian Journal of Occupational Therapy*, 1-12.
- IV. Bergström, M., Larsson Ranada, Å., Sverker, A., Thyberg, I., & Björk, M. Disability during the first decade after rheumatoid arthritis diagnosis – a longitudinal mixed methods study. [Submitted for publication]

ABBREVIATIONS

| | |
|---------|---|
| ACR-87 | American College of Rheumatology classification criteria of rheumatoid arthritis |
| ADL | Activities of Daily Living |
| CIT | Critical Incident Technique |
| DAS28 | Disease Activity Score in 28 joints |
| DMARD | Disease-modifying antirheumatic drug |
| EULAR | European Alliance of Associations for Rheumatology, formerly European League Against Rheumatism |
| HAQ | Health Assessment Questionnaire |
| HCPs | Healthcare professionals |
| ICF | International Classification of Functioning, Disability and Health |
| RA | Rheumatoid arthritis |
| RMDs | Rheumatic and musculoskeletal diseases |
| SRQ | The Swedish Rheumatology Quality Register |
| SSIA | Swedish Social Insurance Agency |
| TIRA-2 | Early Interventions in Rheumatoid Arthritis (Tidiga Interventioner vid Reumatoid Artrit) |
| VAS | Visual Analogue Scale |
| VLA-swe | Valued Life Activity Scale – Swedish version |
| WHO | World Health Organization |

PREFACE

Tidaholm, March 2004:

My grandma sits up straight and smiles at me.

- Well, I do have quite a lot of problems with my ankles, she says.

We are sitting in the living room at my grandparents' place. A house I have known my whole life, in chairs that have been used for playing as well as sitting during Christmas. Right now, I am here as an occupational therapy student, writing a report on a person's life. I chose my grandma since she in my eyes is a strong and positive person, living with multiple diagnoses and an extensive social environment. She gives me a good amount of information for my report, and I find out things about my grandma that I did not know before.

She tells me that she is having problems with her joints, especially her ankles. I am familiar with her diagnoses and her age, but not her problems as such, this even though I am a significant other of hers and have my whole life considered our relationship to be very close. My grandma is simply a person who never nags. She has never shared her issues.

This was my first interview with a person with rheumatoid arthritis (RA). As a significant other, I would have experienced this conversation in a different way. We would have talked about my new experiences as a university student and what happened last time my cousins stayed the night at our grandparents' house.

But as an occupational therapy student I suddenly ask questions about her medical conditions and health. She answers honestly, of course, and I realise that despite being so close to her, I do not really know how she experiences her RA.

Living close to a person with an RA diagnosis can take different shapes. One might have to change one's way of living, adapt housework, give up travelling or not have to make any sudden changes at all. Either way, the people surrounding us are important parts of how we experience our everyday life.

As an occupational therapist, I am interested in the whole person, meaning her activities; her prerequisites and possibilities; her everyday life; and the environment surrounding her. I know that all this can come with positive and negative aspects, and I am familiar with the influence and importance of it all in relation to participation, a central concept within my field of occupational therapy.

In this thesis, I have focused on the person and her significant others as part of the social environment.

Maria Bergström

Kristinestad/Kristiinankaupunki, July 2019

and

Kolmården, May 2023

INTRODUCTION

Over recent decades, the treatment for RA, and thereby the preconditions for persons with RA, have changed. Previously, the diagnosis of RA could lead to substantial joint damage and the need for assistive aids, something that is commonly not the case today due to effective and early initiated treatment. Instead, persons with RA can often continue their work life as well as other parts of everyday life, such as leisure activities, domestic chores and social activities.

However, despite these improvements, persons with RA still report that they sometimes feel hindered in everyday life and cannot engage in activities in a desired way. Symptoms such as pain, stiffness and fatigue might interfere in different ways. For example, it can take time to get out of bed in the morning before your joints have “warmed up”, or you may need to lay down when you get home from work, instead of preparing dinner as planned. It can also involve your knees stopping you from sitting down on the floor to play with your grandchild, or a flare causing you to withdraw from the gathering with your friends that you had been looking forward to for so long. Yet, due to today’s effective treatment, these symptoms may be invisible to others.

The attitudes from others are thereby an important aspect. Because of the invisibility of RA, it might be difficult for others to comprehend the situation. In addition, assumptions from the era before the new type of treatment may persist, and one might imagine extensive consequences. Significant others of persons with RA may therefore perceive an uncertainty about the circumstances of the disease, and their everyday life is also impacted. In other words, both the persons with RA and significant others can be affected by the disease, despite contemporary treatment and a good prognosis. Additionally, the emotional impact of a chronic disease is to be taken into consideration. This highlights a need for further investigating both the perspective of the persons with RA and significant others.

Furthermore, the effective and early initiated treatment of today has been around for about two decades. It is therefore of great value to examine the everyday life of persons with RA from a longitudinal perspective. Even though they have had access to the new type of treatment during their whole disease course, are they doing as well as can be expected?

Valuable to health and well-being is participation, meaning to be free to engage in activities and everyday life and choose how and what to engage in. Due to today's treatment, persons with RA have the possibility to engage in activities and thereby experience participation. However, restrictions are still reported among persons with RA, despite effective treatment. Nevertheless, there are a range of possible facilitators for participation, starting with the people closest to the person, namely the care and support they can perceive from their significant others. Therefore, it is important to further examine the importance of significant others and what relation they can have to participation in everyday life. Hence, this thesis does not solely put focus on persons with RA, but also the significant others.

Pre-understanding and context of the thesis

The PhD student/author of this thesis is a registered occupational therapist with a background in different areas of the profession. These are primarily municipal rehabilitation and higher education, but also orthopaedics and people with dementia. During both the author's bachelor's studies and master's studies, a common research interest was persons with rheumatic or pain-related diagnoses. Thus, experience in research concerning persons with RA was accumulated.

The master's thesis, which is now published (Bergström et al., 2017), investigated persons with RA and how they describe and manage pain in everyday life. One part of the results considered significant others and how they can affect the persons with RA, for example, a wish to hide symptoms and that social life can be negatively affected. This raised the question of which role the social environment actually plays in the persons' lives. What sort of influence do the significant others have?

In relation to the master's studies, an opportunity for doctoral studies arose that would further deepen the knowledge and understanding of the research world in general, as well as persons with RA in particular. This opportunity was, without much further ado, eagerly seized. The results from the master's thesis show the importance of significant others, thereby witnessing of the need for a deep-dive into this particular aspect of the everyday life of persons with RA. Therefore, significant others will play a substantial role in this doctoral thesis.

Considering the author's background, the persons in this thesis and their everyday life are viewed through the lens of an occupational therapy perspective. This means that the persons with RA are considered in the context of activities, environment and the interaction between them. Focus is moreover put on what the persons can and want to do in everyday life, where the experience of participation is central, making it a preferable perspective in this thesis.

BACKGROUND

The Background section of this thesis will start by focusing on the person and her context, activities and environment. It will further cover the concepts of participation and support in everyday life. These concepts will later be explained in specific relation to persons with RA. Since the persons exist in a context of social environment, the importance of significant others and their influence on everyday life and participation will also be covered.

As a backdrop, concepts from occupational therapy theory have been used to explain the person's context, with a specific basis in the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2013). Additionally, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) has been part of clarifying components such as participation and environmental factors in relation to the persons.

The person in her everyday life

This thesis acknowledges people as occupational and social beings, and that engagement in occupations is an essential part of life, in accordance with the occupational therapy perspective formulated by Wilcock and Hocking (2015). Occupations contribute to a social identity as well as self-identity, and each occupation is experienced in a unique way by the individual (Townsend & Polatajko, 2013).

Before continuing, it might be important to consider the concepts of 'occupation' and 'activity'. According to Townsend and Polatajko (2013), the relationship between the two is hierarchical, where occupation encompasses a broader meaning. In relation to this, White and colleagues (2020) conceptualised the meaning of human occupation from the perspective of people with chronic conditions as follows: "doing activities and actions with meaning, in the context of one's life, health condition(s) and world" (White et al., 2020, p. 61). They further described human occupation as an abstract concept, where both activity and occupation explain human doing, but at different abstraction levels. This is also discussed by Njelesani and colleagues (2014), where occupations connect with levels of doing and relate to health and well-being. In this thesis,

activity is the primary concept chosen to explain doing. This choice is based on the hierarchical order described by Townsend and Polatajko (2013).

To be able to perform activities is connected to one's health and well-being (Townsend & Polatajko, 2013; Wilcock & Hocking, 2015). In relation to this, one's occupational identity is closely connected to the meaning of doing, and if disrupted, new ways of doing can be employed to reconstruct this sense of self (Hansson et al., 2022). If encountered with a chronic disease, the individual might need to reconstruct one's occupational identity as well as go through an adjustment process of occupational adaptation (Walder & Molineux, 2017). Moreover, the opportunities to engage in activities for a person with a chronic disease can be limited, and thusly hinder expressions of one's identity (White et al., 2020).

The person is a part of a dynamic interaction together with the activities she performs and the environment. One occupational therapy model that describes this interaction is the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2013). The model puts the individual in the centre with her affective, cognitive and physical characteristics. It illustrates how each individual lives within a distinctive environmental context, comprising a physical, institutional, cultural, and social environment. It also depicts the person as interacting with the environment through activities (Figure 1). To shed light on this interaction, in particular the interaction between the person and the social environment, this model is chosen for viewing the persons included in this thesis.

Moreover, a person's environment influences what she can access and do (Hocking, 2021). The social environment closest to the person encompasses the people they encounter in everyday life, for example, family members they can turn to for support. Within the social environment, the person is also confronted with norms and expectations (Townsend & Polatajko, 2013). These norms influence one's occupational identity, and not being able to live up to expectations can have a negative impact (Hansson et al., 2022). Further, the social environment has influence on a person's participation in everyday life (Townsend & Polatajko, 2013).

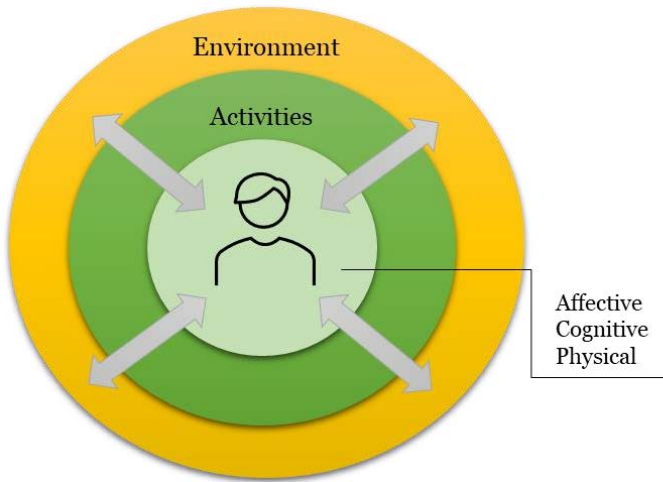


Figure 1. Illustration of the person interacting with the environment through activities, with inspiration from CMOP-E (Townsend & Polatajko, 2013). Please see Figure 2 (p. 28) for an example of a person with RA's interactions.

Participation in everyday life

We all have a relation to participation, as it is an important and wide concept. It is part of countless guidelines on different levels, such as those provided by the United Nations (2007) and the Swedish Agency for Participation (2023). The concept is also likely to have different meanings for different persons and disciplines, which is what the following sections will comprise.

One focus is specifically on 'patient participation' rather than sole participation. For example, the research field of nursing has been found to encompass the aspect of sharing and interaction in the form of communication (Eldh et al., 2010). In relation to older adults and 'social participation' in particular, the concept has been connected to involvement in activities that provide interactions with others (Levasseur et al., 2022). The authors also emphasise the importance of social participation in relation to well-being, as the COVID-19 pandemic shed light on, and stress that it should be considered a human right. In the case of children with disabilities, participation in its wider term has also been identified as for example involvement, a sense of inclusion and having choice and control (Hoogsteen & Woodgate, 2010). Sharing, inclusion and interactions seems to be common denominators in these cases. This Background section will later return to the concept of participation in relation to persons with RA.

The concept of participation is central in healthcare and often explained through the International Classification of Functioning, Disability and Health (ICF), a framework based on a biopsychosocial model (WHO, 2001). It uses the definition “engagement in a life situation” (WHO, 2001, p. 10). This definition has previously been criticised for not being particularly useful, since the term “life situation” involves all parts of life, making the theoretical definition unclear and also difficult to measure (Dijkers, 2010). In addition, the important subjective aspect of participation has been claimed as neglected in the ICF definition, enhancing the difficulty of measuring (Hemmingsson & Jonsson, 2005).

Since then, researchers have been working on conceptualising participation further. Moving into the field of occupational therapy, in a study by Borell and colleagues (2006), people living with chronic pain described participation in light of actively performing something and with an emphasise on doing: *doing* something physical, *doing* something social, or *doing* something for others. Further, Cogan and Carlson (2018) used the three dimensions ‘performance’, ‘subjective experience’ and ‘interpersonal connection’, where the subjective experience is essential since it signifies the person’s own perception. But they also encompass participation as a sense of belonging in a social context. One central aspect has also been described by Law (2002) as sharing, in particular when it comes to activities.

Participation has been explained as an interaction and transaction between person, activity, and environment (Mallinson & Hammel, 2010), an aspect that has been further identified by people with disabilities. They depict participation as a dynamic process and furthermore as being a part of something, having a choice and control, access and opportunity, supporting others and social connection. The dynamic process is ongoing between the person, the social and the societal (Hammel et al., 2008). Looking at participation in this way, a social dimension is needed to experience full participation. This becomes an issue when going back to the aspect of measuring participation. Firstly, it is measured on an individual level and, secondly, through individual performance. Assessments mentioned in relation to participation are often more focused on actual performance (Björk et al., 2020), but also the degrees to which a person fulfils roles and has relationships (Dijkers, 2010). Yet, more clearly adding a social aspect to participation has previously been stressed, where, for example, Piškur et al. (2014) discuss the need to include social roles in the context of participation. Moreover, as stated earlier, the definition includes the social context to which one belongs (Cogan & Carlson, 2018).

As participation is valuable for both health and well-being (Law, 2002), it is still considered an important outcome measure of healthcare’s success,

even though it may not be the initial main target (Wilkie et al., 2011). It is also an important outcome of rehabilitation (Mallinson & Hammel, 2010).

Several facilitators and barriers have been mentioned in relation to participation. The social environment and support are often defined as facilitators (Cogan & Carlson, 2018; Hammel et al., 2015; Law, 2002). However, the same factor can constitute both a facilitator and barrier under different circumstances, e.g., self-efficacy (internal) or a family situation (external) (Cogan & Carlson, 2018). Equivalently, while support can be a major facilitator, it can also have a negative influence through attitudes (Hammel et al., 2015). In agreement with this, even though the ICF framework's definition of participation has been criticised, the ICF in itself acknowledges that environmental factors, such as attitudes, either hinder or facilitate activities and participation (WHO, 2001).

In relation to the concept of participation, this thesis emphasises the subjective experience of performing and engaging in an activity rather than observable performance.

Receiving and providing support

Support in itself is a broad term. It is often referred to as instrumental, emotional and/or informational resources that are provided by the social environment (Helgeson, 2003). The emotional type of support encompasses people who listen, sympathise, provide reassurance, care and make you feel valued and loved. Instrumental support, on the other hand, incorporates concrete assistance, like household chores, whereas informational support signifies providing information or guidance. Emotional support is suggested to have the strongest relation to quality of life; however, this also depends on the stressor connected to the support provided. Namely, if the stressor is controllable, informational support is suggested to be most helpful, whereas emotional support could be more beneficial if the stressor is uncontrollable. The amount of support can also be an issue, since it is suggested that the social environment can provide too much support.

Apart from the amount of support, it has also been indicated that the timing and type of support is important (Hupcey, 1998). Moreover, recipients and providers of support may have different perceptions of the support that should be given, which might in turn lead to the recipient not being content with the support provided as they may not have received what was needed. This does not mean that the provider is purposefully inadequate, just that the experience or ability to provide what is needed is lacking in that particular situation. If not reciprocated, support may also be considered negative: either providing more support than what is received, or receiving more support than what is provided. On that note, Untas and

colleagues (2020) give the further example of support switching to overprotection.

Nevertheless, support is important for positive health-related outcomes (Hupcey, 1998) and has been exemplified as a coping method (Poh et al., 2015). It is also an important part of environmental factors according to the ICF framework (WHO, 2001). Furthermore, surrounding oneself with people who can offer support is of value when managing disease symptoms, such as pain (Bergström et al., 2017). Consequently, significant others, as part of the social environment, can constitute different types of support.

Rheumatoid arthritis

Rheumatoid arthritis (RA) is a chronic inflammatory disease, primarily involving the joints and often causing swelling, pain, stiffness and/or joint damage. For the person, and because of musculoskeletal deficits, RA is often related to decreased physical function and quality of life. Furthermore, it can lead to reduced work capacity and less participation in society. Environmental factors associated with RA are smoking and low socioeconomic status (Smolen et al., 2016a). In addition, comorbid risks associated with RA are for example cardiovascular disease and pulmonary disease (Figus et al., 2021; Innala et al., 2016). Examples of the prevalence of co-morbidities in a Swedish study were that 53% of patients had at least one co-morbidity at disease onset. Moreover, after five years, 41% had developed at least one new co-morbidity (Innala et al., 2016).

The incidence of RA is 0.5-1% worldwide (Smolen et al., 2016a), and in Sweden it is estimated at 41 per 100 000 per year (Eriksson et al., 2013). It is more common in women than men, with generally 70% of a studied population consisting of women (Sokka et al., 2009). Also, women tend to exhibit more disease activity, pain and activity limitation (Iikuni et al., 2009; Shin et al., 2021) than men, as well as achieve remission less frequently (Shin et al., 2021; Sokka et al., 2009).

Diagnosis and treatment

To assess the disease activity of RA, the Disease Activity Score in 28 joints (DAS28) can be used, which takes into account tender and swollen joints, as well as the person's overall health and a measurement of the erythrocyte sedimentation rate. This results in a score from 0-10 (the lower the score, the lower the disease activity) (Porter et al., 2011). There is a relationship between disease activity and activity limitation, where a higher disease activity tends to indicate greater activity limitation (Smolen et al., 2016a). For example, moderate disease activity has been related to more activity

limitation, as well as poorer health-related quality of life and pain (Scott et al., 2020). In addition, joint damage is reported to be associated with activity limitation, and such already in early RA (Eberhard et al., 2023).

Treatment of RA is guided by a treat-to-target approach, where the main goal is to optimise health-related quality of life (Smolen et al., 2016b). To achieve this, the aim is to control symptoms, prevent joint damage, and enhance function and participation in activities. Further, the primary target for treatment is clinical remission. This signifies “the absence of signs and symptoms of significant inflammatory disease activity” (Smolen et al., 2016b, p. 6) or disease activity <2.6 according to DAS28 (Porter et al., 2011; Smolen et al., 2016a). If remission cannot be accomplished, low disease activity is the next goal (Smolen et al., 2016b), and when reached, it should sustain over time. However, a Swedish nationwide study found that sustained remission over six months did not occur in even half of the patients, and further, the majority who did reach remission did so within three years (Einarsson et al., 2019). In relation to disease activity, Smolen and colleagues (2016a) describe work ability and quality of life as related to lower disease activity. Additionally described is that low disease activity at six months tends to indicate a better long-term outcome. Moreover, a target is preventive elements rather than early interventions in disease that is already manifest. Treatment should also prevent structural changes and minimise disability. Through regular assessment of disease activity, adaptations are made concerning treatment, e.g., changes of medication (Smolen et al., 2016a). The treat-to-target approach has exhibited higher rates of remission compared to previous routine care. For example, a Norwegian study showed a twofold increased odds of achieving remission, together with a significant improvement in health-related quality of life (Brinkmann et al., 2019). Furthermore, in a longitudinal study, function and quality of life were significantly improved in persons with RA who reached remission (DAS28 <2.6), compared to those with low disease activity (DAS28 2.6–3.2) over five years (Nikiphorou et al., 2020), highlighting the goal of remission.

There are different types of therapeutic approaches to RA. Most prominent are disease-modifying antirheumatic drugs (DMARDs) that are targeted at inflammation and reducing joint damage (Smolen et al., 2016a). The current recommendation in RA is to start therapy with DMARDs early, as soon as the diagnosis is made (Smolen et al., 2023).

Within a Swedish setting and national guidelines, the overall goal of care in persons with RA is to increase the number of persons who quickly reach remission or low disease activity (SKR, 2021), which is in line with the targets in the international guidelines set by the European Alliance of Associations for Rheumatology (EULAR) (Smolen et al., 2016b). Further,

the goals from the Swedish guidelines (2021) include increasing the number of persons with good functional status and enhancing the person's involvement in treatment. However, it is important to mention that persons with RA put emphasis in several factors when it comes to remission. Through focus group discussions, van Tuyl and colleagues (2015) conclude that remission is characterised by decreased daily impact on the condition as well as the absence or reduction of symptoms. Another factor mentioned in a recent review (Khoo et al., 2022) is independence. Additionally, from a patient perspective, even though DMARDs are often described as essential, they can be perceived as strong with troubling side effects (Kelly et al., 2018). Moreover, a recent Danish review (Damgaard et al., 2023) pointed out that non-pharmacological approaches are requested to self-manage pain and fatigue. From a longitudinal perspective, a Swedish study described that preferences develop over time, as persons with RA in the acute phase focused on controlling symptoms, but later in the disease course put more emphasise on non-pharmacological treatment (Landgren et al., 2020). This indicates a further need for other types of interventions.

Rehabilitation in RA

Rehabilitation incorporates prioritising participation in both social and meaningful activities. It also involves teamwork and a biopsychosocial approach. As a result, it might be difficult to define a core ingredient in rehabilitation, as several aspects and interventions co-exist as different components (Wade, 2020). Effective rehabilitation has been described as a way “to optimize a patient's self-rated quality of life and degree of social integration through optimizing independence in activities, minimizing pain and distress, and optimizing the ability to adapt and respond to changes in circumstances” (Wade, 2020, p. 579). This fits well into the rehabilitation of RA since there is a focus on adaptation, quality of life and minimising pain.

The provision of rehabilitation services looks different around Europe and across the globe, for example, regarding the structure of the institutional processes and responsibility for the person with RA (Prodinger et al., 2014). Nonetheless, it is an important aspect of care, and a higher dose of rehabilitation has recently been connected with improved physical function (Thoma et al., 2022). Concerning goals in rehabilitation, a Norwegian study (Valaas et al., 2022) displayed a good attainment of goals related to everyday routines and social and work participation during rehabilitation. Although, this positive trend was more difficult to maintain after rehabilitation, indicating that follow-up care should be reflected in the goals.

Further, in a person-centred approach, interventions are to be tailored individually, and different aspects may be of varying importance to different persons. For example, the interaction between the person and the rehabilitation provider might be more important than the amount or content of the interventions (Wade, 2020), implying the importance of the social environment. This was further stressed in a recent mixed methods study that acknowledged good conversation as important in relation to quality improvement in rehabilitation (Sand-Svartrud et al., 2023).

From a patient perspective, a person-centred approach to rehabilitation is emphasised by Feddersen and colleagues (2022). Their interview study showed that healthcare professionals (HCPs) who are interested in the person's values, preferences and experiences are perceived as facilitators in the rehabilitation process. They also found that the person's own influence over the rehabilitation process is valuable. Acknowledging the person as a unique individual with personal needs and wishes, rather than focusing on standards, was also expressed as important. Emphasising the uniqueness of every individual is also important when considering patient education (Mäkeläinen et al., 2009).

The active role of the patient is further highlighted in relation to patient-centeredness as mentioned by Voshaar and colleagues (2015). They further stipulate that patient education should include both disease information as well as impact on everyday life, and interventions should also involve the person's social environment.

In Sweden, the national guidelines state that the goal of team-based rehabilitation is to restore, as far as is possible, the person's capacity so that she can lead the life she wants (Socialstyrelsen, 2021), which is in line with the previously described definition by Wade (2020). These goals are accomplished through pain relief, improving movements and muscles, or offset impairment. Common strategies are physical exercise and patient education, and drug therapy is often provided simultaneously (Socialstyrelsen, 2021). In relation to occupational therapy, educational programmes have recently been shown to be positive in relation to pain and function (Gavin et al., 2023). In addition, patient education and joint protection are examples of interventions beneficial to self-management as well as social interactions. Subsequently, improvements in aspects such as mental status and overall well-being are also important, besides factors like disease activity (Siegel et al., 2017).

The Swedish National Board of Health and Welfare emphasise the importance of several HCPs working together with the person, such as rheumatologists, nurses, occupational therapists, physiotherapists and social workers. Further, they believe that diagnosis, treatment and

rehabilitation should be initiated early, together with close follow-ups (Socialstyrelsen, 2021). Goals set within rehabilitation are reported to be covered and closely related to the ICF framework (Küçükdeveci, 2019), and further to the comprehensive ICF core set for RA (Stucki et al., 2004).

As a result of contemporary treatment, persons with RA today have greater possibilities for a well-functioning everyday life. Improvements are in most cases seen from the introduction of treatment and onwards. However, despite the goals of rehabilitation, a longitudinal meta-analysis by Carpenter and colleagues (2020) displayed that, although statistically significant improvements were seen in disease activity, only small improvements were noticed concerning pain, fatigue, activity limitations and mental well-being, five years after diagnosis. Further, Svensson and colleagues (2020) showed in their study that unacceptable pain (≥ 40 mm VAS) still persisted 15 years after diagnosis, also in persons in remission. Moreover, Ahlstrand and colleagues (2015) found that both pain and activity limitations were still pronounced in contemporary treated persons with RA. Compared to those diagnosed in the 1990s and before the more effective treatment, improvements were seen but the impact was still prominent. Similar results have been reported from the Swedish BARFOT study, where disease activity decreased but activity limitations and pain persisted when comparing cohorts from the 1990s and 2000s (Andersson et al., 2017).

Living with RA

After receiving a chronic disease diagnosis, it is not uncommon to have a negative view of life. Benkel and colleagues (2020) reported that 67% of their participants experienced it as negative after receiving such diagnosis. Feelings of mainly sadness and worry were reported, and examples of negative outcomes were difficulties in managing work and how the disease controlled their lives.

This comes back in the case of RA specifically. Usually with RA, and despite today's effective treatment, difficulties still remain in aspects such as relationships, daily activities and work (Alten et al., 2019). Symptoms like pain and stiffness, and the occurrence of flares, have a negative impact on performance of activities. Particular reasons for withdrawing from, for example, physical activities, have been identified as fatigue, pain and swollen joints in a recent European survey (Metsios et al., 2023). Similarly, pain, fatigue and stiffness have been identified as the primary barriers to a normal life (Alten et al., 2019). In comparison, "being normal" is connected to being able to engage in activities and roles the same way as before the disease (Barns et al., 2015). "Normality" is also what persons with RA connect to the disease being in remission (Van Tuyl et al., 2015). Symptoms can further entail withdrawal from social events (Fairley et al., 2021), social

isolation (Brignon et al., 2020), and the unpredictable nature of the diagnosis adds to the challenges of living with RA (Bergström et al., 2017; Brignon et al., 2020; Flurey et al., 2014; Poh et al., 2015).

As mentioned, effective treatment has caused disease activity to decline and is further associated with decreased activity limitations (Shadick et al., 2019). In addition, the probability of difficulties in activities of daily living (ADL) does not increase within ten years of RA onset (Myasoedova et al., 2022), indicating the benefits of contemporary treatment. Furthermore, in a recent observational Swedish study, most persons with RA reported good health status. Still, 15% exhibited higher levels of pain, fatigue and distress three years after diagnosis (Lindqvist et al., 2022). In other words, even though most people with RA have few issues in everyday life, a fair amount still present restriction. Preferences also change over time, as persons with RA initially expressed a fear of a very restricted life, but later in the disease course might experience their everyday life as easier (Landgren et al., 2020).

Adaptations in everyday life might, however, be necessary for persons with RA, for example, due to pain (Bergström et al., 2017). This does not always come easy, as adaptations can be associated with disability and thereby threaten the longed-for normality. Examples of this, as found by Barns et al. (2015), is that adapting and changing an activity could change its meaning and significance, where the person simply no longer enjoys performing it.

Environmental modifications might also be necessary (Fairley et al., 2021), but a reluctance to use assistive aids has been identified, which can relate to things' significance. This reluctance can be due to a fear of being given disadvantages at work (Prodingner et al., 2014) or a fear of reinforced impairments. In addition, the usage of aids or assistive tools is connected to the loss of independence (Landgren et al., 2020). It is also something that can cause individuals to accept pain and discomfort rather than make adaptations (Barns et al., 2015). However, men with RA have expressed the use of assistive aids in a sort of grey area, where they tend to use tools/aids, but not the type directed towards disability, such as walking aids. Instead, they may use, for example, smaller screwdrivers as aids (Flurey et al., 2017). Women, on the other hand, put effort into hiding RA as they do not want to be assumed less productive with a chronic disease (Prodingner et al., 2014) or defined as "sick" (Barns et al., 2015). Assistive aids have, however, been identified by persons with RA as helpful in the process of adapting to pain. For example, a crutch or orthoses, but also the use of societal solutions such as ergonomically developed kitchen equipment or self-scanning systems in supermarkets or driving a car with an automatic gearbox (Bergström et al., 2017). Further, performing activities as such

have been expressed as sources of support, where physical activity is perceived as providing the most support (Benkel et al., 2020). It has also been described as a way to ease pain (Bergström et al., 2017). Moreover, the interactions between the person and environment previously described in this Background section, are further illustrated in specific relation to persons with RA, in Figure 2.

When it comes to the intimate part of life, sex life is also affected in persons with RA. This can be due to factors such as difficulties with mobility or side effects from medication (Negrón et al., 2023). Östlund and colleagues (2015) found that half of their study participants state that their sex life is affected in a negative way, and this was seen in both women and men. Things that affected them were tiredness and possible side-effects from medication. Regarding intimate life, the study participants also had found ways to make adaptations; however, RA was described as negatively affecting relationships. These negative effects are further stated by Fairley and colleagues (2021) who describe strained relationships and intimacy. On the other hand, in connection to relationships as such, opposite experiences have also been reported, for example, that there has been no change to relationships and that in fact the two parties have become closer through the disease (Brignon et al., 2020).

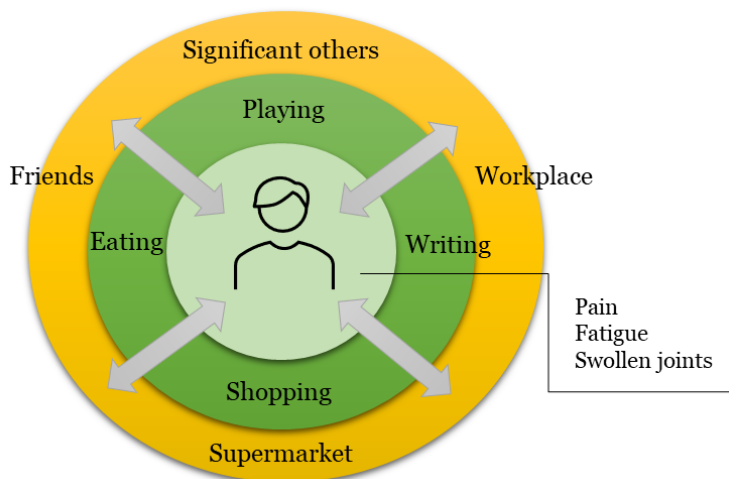


Figure 2. Interactions between the person, activities and environment. Examples of activities performed by persons with RA in their physical and social environments. With inspiration from CMOP-E (Townsend & Polatajko, 2013).

Work and RA

Work is often a prioritised activity and part of everyday life (Fairley et al., 2021; Holland & Collins, 2018; Madsen et al., 2021). This means that other activities and roles come second, such as for example parenthood (Feddersen et al., 2017; Feddersen et al., 2019), and this “work first” mindset can cause changes in other roles with the potential of disrupting normal occupational balance (Codd et al., 2022). However, work contributes to well-being and a sense of normality in RA, as well as maintaining social and professional relationships (Fairley et al., 2021; Feddersen et al., 2017). Further, work provides a sense of status (Feddersen et al., 2019) and self-worth, and distraction from symptoms (Purc-Stephenson et al., 2018) like pain and fatigue (Holland & Collins, 2018).

In connection with a disrupted occupational balance, prioritising work often comes at the expense of other activities. To be able to function at work and fulfil the worker role, persons with RA not seldom withdraw from social activities (Feddersen et al., 2019; Purc-Stephenson et al., 2018), as their energy has been prioritised for work, energy for other activities is thereby lacking, which has consequences for their family (Madsen et al., 2021). Additionally, there is a common understanding that informing one’s employer and co-workers about the disease might lead to negative results (Codd et al., 2022; Sverker et al., 2014) and interfere with one’s role as a stable employee (Feddersen et al., 2019). However, it has also been stated that disclosing one’s condition at work tends to lead to fewer psychological and emotional implications in work (Codd et al., 2022) and positively influence the capacity of sustained work (Codd et al., 2023). Moreover, supportive attitudes from employers and colleagues are essential for people with rheumatic and musculoskeletal disease to both acquire and maintain work. Further, workers should be encouraged to discuss work-related challenges with both employers and HCPs (Boonen et al., 2023).

With today’s more effective and early treatment, it can be expected that work life is less impacted, which in many ways is the case. Yet, Codd and colleagues (2022) recently reported that work-based participation restrictions are still present in inflammatory arthritis, despite the use of effective drug therapy. Moreover, in a longitudinal study, persons with rheumatic disease who reported persistent high pain, fatigue and disease activity reported significantly greater workplace activity limitations compared to those with low reported outcomes (Jetha et al., 2023). Also, several aspects related to RA have been identified as connected to sickness absence, for example, higher levels of pain and disease severity (Lenssinck et al., 2013). Activity limitation has time and again been reported as strongly related to the development of sickness absence (Gonzalez-Lopez et al., 2013) and decreased productivity (Bertin et al., 2016; Sruamsiri et

al., 2018). Moreover, remission defined by DAS28 yields less presenteeism (working while ill) than low disease activity (Kim et al., 2017), indicating that remission is both a preferable and achievable goal.

Compared to the general population, persons with RA suffer an increased risk of negative work-related outcomes. For example, a Danish study reported an increased risk of long-term sickness absence and disability pension and a lower chance of return to work (Hansen et al., 2017). These risks are particularly seen in the first year after diagnosis and physically demanding jobs, increasing the risk of long-term sickness absence (Hansen et al., 2016). However, initiating effective treatment within five years of symptom onset gives a good chance of regaining work ability, according to a Swedish study (Olofsson et al., 2017). Results by Rogier and colleagues (2022) further suggest that impairments in work productivity is reversible. This as they found presenteeism apparent in the months pre-diagnosis of RA and worsening until diagnosis but improved upon symptoms resolution. Moreover, this implies that interventions in the pre-diagnosis phase could improve work participation.

On the subject of treatment and its effect on work participation, Butink and colleagues (2023) found in a recent review that non-pharmacological interventions indicate small but significant positive effects on sickness absence, work status and presenteeism in rheumatic and musculoskeletal diseases (RMDs), depending on contextual factors such as type of disease. Nonetheless, these results indicate that given a person-centred approach, non-pharmacological interventions have the potential to improve work participation in people with rheumatic diseases. At the same time, Blomjous et al. (2019) found sickness absence and improved work productivity as mainly predicted by non-disease-specific variables. In all, this illustrates the complexity of RA and work.

Participation in the everyday life of RA

As previously stated, participation has been described in different ways over the years, for example, with an emphasis on doing. On the other hand, participation has more recently been expressed by persons with RA to still include the dimension of doing, in performance of activities with others and paid work (Sverker et al., 2020) as well as the feeling of belonging to a group, being included, sharing chores and responsibilities, having an influence on activities and goals, and shared decision-making. The emphasis has then moved to a more social aspect and often been described as something experienced with other people. The social aspect of participation previously described (Cogan & Carlson, 2018; Piškur et al., 2014) is therefore also transferable to persons with RA.

The experience of belonging in relation to participation has also been connected to quality of life in persons with RA (Malm et al., 2017). However, participation restrictions have been expressed, with examples of activities related to domestic life such as gardening and repairing houses, and further, activities related to recreation and leisure (Sverker et al., 2015). In a study by Benka and colleagues (2016), it was found that the ones who reported more participation restrictions also tended to report more pain, fatigue and disability, regardless of whether they had early or established RA. In addition, participation restrictions were found to be significantly and negatively associated with mental and physical health in persons with RA.

In relation to participation restrictions, persons with RA describe strong feelings, such as hopelessness, anger, sadness and shame. This in connection to being unable to perform valued activities, refraining from activities with children or grandchildren, and embarrassment in public. This could also lead to feelings of social exclusion (Östlund et al., 2014). Concerning this type of isolation, a lack of empathy has been stated as a contributing factor (Negrón et al., 2023). Several strategies have been identified to handle participation restrictions in both men and women with RA. For example, adjusting time and pace, the use of equipment, and timing and dosage of medication. Further, avoiding physically demanding or social activities as well as intimate contact were also part of the strategies. Another important aspect was to accept the disease, including pain and participation restrictions as such (Östlund et al., 2016). It has also been reported that by feeling more able to participate in social life, the person with RA can be more comfortable with her own disease (Negrón et al., 2023).

From a longitudinal perspective, physical limitations and negative effect on life seems to be more in focus early in the disease process, whereas in established RA, the persons tend to perceive their mental well-being as more important (Parenti et al., 2020). Further, negative feelings, such as being a burden to others, have been expressed as prevented by the support of partners (Brignon et al., 2020).

The perspective of significant others

First and foremost, definitions of the term ‘significant other’ include “a person who is important to one’s well-being” (Merriam-Webster’s Dictionary, 2023) and “a person who the individual considers close” (Socialstyrelsen, 2023). Therefore, a significant other does not necessarily encompass a relative, which for the sake of this thesis is important to keep in mind.

As previously stated, a person's social environment can both constitute facilitators and barriers for participation (Cogan & Carlson, 2018; WHO, 2001). Hence, significant others as part of the person's social environment is an important influence. In Sweden, a patient's significant other should by law be given the possibility to take part in health care as long as it does not interfere with professional confidentiality (SFS 2014:821). This further emphasises the importance of the significant other in the person's life.

Being a significant other to a person who is long-term ill or disabled has previously been connected to high burden, but at the same time, a good quality of life. Spouses of persons with chronic illnesses have expressed a need for teamwork together with family and friends (Eriksson & Svedlund, 2006). Even though they receive informational support from HCPs as well as instrumental and emotional support from family, more support from family is requested. In addition, significant others depict a failure of understanding from the extended family (Eriksson et al., 2019). Moreover, being a female significant other has been connected to higher care burden (Baanders & Heijmans, 2007) and higher levels of distress (Harris et al., 2016), and more females report mental illness. Yet, female significant others can also adapt rather quickly to a new situation (Liedström et al., 2014). However, Eriksson and colleagues (2019) point out that significant others' situations are potentially overlooked by both healthcare and the family. They conclude that HCPs must recognise their needs and provide efficient support.

With a chronic disease, new routines are established for spouses (Autio & Rissanen, 2018; Eriksson et al., 2019) who wish to continue normally and pursue previous interests (Aasbø et al., 2016). Further, it has been stressed as important that they generate time and space for their own social and recreational activities (Eriksson & Svedlund, 2006). Still, in couples where one person is chronically ill, negative effects on social relationships are reported (Pretter et al., 2014), and closeness and intimacy are expressed as changed (Eriksson & Svedlund, 2006). However, chronic diseases are also described as putting things in perspective, strengthening relationships (Baanders & Heijmans, 2007; Pretter et al., 2014), and positive emotions can increase quality of life and well-being in spouses (Autio & Rissanen, 2018; Eriksson et al., 2019). In addition, warm social relationships as such have been expressed by significant others as substantial (Eriksson et al., 2019). Furthermore, social relationships have been identified as important for health and even survival, which is why social relationship-based interventions are discussed as highly potential for positive health outcomes (Holt-Lunstad et al., 2010).

Significant others of persons with RA

In relation to RA, even though it is a chronic disease, the prognosis is in most cases good. Nevertheless, others can be triggered and concerned if the disease is visible in the person's appearance (Parenti et al., 2020). Also, significant others of persons with chronic pain are reported to be affected by possible side effects from medication as well as emotional strain (Brown & Newton-John, 2022). Family members of persons with RA experience the exclusion of the person from family activities as well as a lack of shared activities (Fallatah & Edge, 2015). On the other hand, persons with RA describe friends as looking for ways to include them in activities (Negrón et al., 2023).

While interviewing both persons with RA and their significant others, Tiwana and colleagues (2015) found that significant others of persons with RA often deal with mood changes in the person with RA, as well as assist in situations like cutting up food and getting dressed. At the same time, the sometimes invisibility of RA could cause a lack of understanding, along with symptoms being attributed to normal ageing or laziness. In addition, the person with RA could withhold information about their condition. On the subject of withholding information, Untas and colleagues (2020) report that a lack of communication may appear between the person and the significant other, which has an impact on their relationship. Moreover, persons with RA have previously been reported to hide their pain in company of, e.g., older people, children and grandchildren in order to not become someone's burden (Bergström et al., 2017). On the other hand, the consequences of an arthritis diagnosis have also been characterised as the partner becoming more empathetic, and the couple becoming emotionally closer (Gullickson & LaChapelle, 2018). Concerning relationships as such, they tend to be affected specifically at the onset of RA, as well as spouses' social lives (Landgren et al., 2020). Further, Negrón and colleagues (2023) exemplify how spouses become closer as they have learned to understand the disease together.

Factors such as fatigue and pain do have an impact on the life of persons with RA, described as not fully comprehended by their partners. Lehman and colleagues (2011) reported that partners both under- and overestimate its impact. For example, 34% of partners tend to underestimate the extent of physical limitations, and that underestimation of experiences of fatigue, pain and physical limitations are connected to problematic spousal support. In turn, this has been reported as more profound in newer relationships or when the person with RA is more recently diagnosed, as they learn to live with RA in the context of the relationship (Beggs et al., 2016). Furthermore, underestimation or overreaction, as well as distrusting or not comprehending the person's disability, has been

identified as the most unhelpful reaction from, for example, family members (Kostova et al., 2014). On the other hand, significant others of persons with chronic disease in their turn express that other people outside struggle with understanding (Eriksson & Svedlund, 2006), albeit it has also been reported that persons with RA who perceive support from family and friends who understand the disease are better able to adjust to the new way of living (Negrón et al., 2023).

In other words, significant others appear to be important influences. At the same time, it is widely stated that it is challenging for significant others to fully comprehend the disease and its effects (Alten et al., 2019; Bergström et al., 2017; Dures et al., 2017; Fairley et al., 2021; Kostova et al., 2014; Lehman et al., 2011; Poh et al., 2015; Tiwana et al., 2015; Untas et al., 2020). Relationships between the person and the significant other have further been characterised as strained or negatively affected (Dures et al., 2017; Fairley et al., 2021; Östlund et al., 2015), yet it is also reported that adjusting to the new situation can have a positive effect on the relationship (Brignon et al., 2020; Fallatah & Edge, 2015). All things considered, significant others are an important part of the social environment and their somewhat mixed impact on the person calls for further inquiry.

Support from significant others

As previously stated, support comes in different forms: emotional, instrumental (or practical) and informational (Helgeson, 2003). Different types and sources of support play important roles in different aspects of the disease. In rheumatic diseases, emotional support has been identified as the most prevalent, followed by instrumental support, mostly provided by family and partner (Brooks et al., 2014). Support from family and friends has been stated as important in the everyday life of persons with inflammatory arthritis (Damgaard et al., 2023), and crucial in the acceptance process of RA since they provide both emotional and practical support. Simply put, persons with RA are able to accept the disease when they feel accepted by their families and thereby establish a new way of life (Kostova et al., 2014).

When it comes to chronic pain conditions, significant others' support has been stated as an important encouragement to continue with treatment (Brown & Newton-John, 2022). Moreover, experienced support in persons with RA has been connected to positive outcomes concerning mental well-being, namely reduced stress (De Cock et al., 2022), lower depression scores (Hung et al., 2017) and lower levels of psychological distress (Benka et al., 2012). Emotional support is also found to be prospectively beneficial, particularly in individuals with more disability (Benka et al., 2014), and connected to decreased pain (Pow et al., 2018). In addition, pain has been stated as worse in persons with RA with low support, compared to those

who report better support (Hedenstierna et al., 2022). What effect the support gives may also depend on the type of relationship between the person with RA and the person providing support, according to Hung and colleagues (2017), as support from both spouses and children were found to be connected to reduced symptoms of depression.

In contrast to support, persons with RA have also given examples of non-supportive behaviours. For example, underestimating or overreacting to the person's situation, as well as distrusting or not understanding disability, in which case the person with RA might feel misunderstood and accused of escaping chores (Kostova et al., 2014). Further, others pretend like the symptoms of, e.g., pain do not exist and friends stop involving persons with RA, which has a negative impact (Bergström et al., 2017). Also, the assistance that the person with RA needs to ask for, instead of being offered, can be perceived as a lack of support instead of help. Significant others may need to both be present and allow the person with RA some space in order to provide practical support without the person feeling invaded but instead useful, as a way to not encroach upon the person's autonomy (Kostova et al., 2014; Untas et al., 2020).

Support from significant others is also required specifically in work-related parts of everyday life. Encouraging and supportive attitudes are defined as positive influences on work life, including when it comes to returning to work (Snippen et al., 2019). Furthermore, support and recognition has been expressed as essential when it comes to the ability to continue working despite an RA diagnosis (Feddersen et al., 2017).

From the perspective of significant others of persons with chronic diseases, support from family is appreciated and even essential (Eriksson & Svedlund, 2006), although Liedström and colleagues (2014) reported that few significant others have support of their own. Moreover, significant others of persons with inflammatory arthritis describe a need for knowledge about the disease and symptoms due to its invisibility and unpredictability. They also find it difficult to balance the support they provide (Brignon et al., 2020). This identifies another need for further investigation in relation to the perspective of significant others.

Rationale

Even though contemporary RA treatment has resulted in improvements regarding disease activity and abilities to perform activities, hindrances are still experienced in participation. As a way for HCPs to provide beneficial and effective rehabilitation, ways to enhance participation in the everyday life of persons with RA needs to be further scrutinised from different perspectives. Today, many persons with RA have had access to the modern type of treatment during their whole disease course, stressing the importance of viewing their participation in everyday life from a longitudinal perspective. Furthermore, as both guidelines and previous research acknowledge that care and rehabilitation should be built on the preferences and wishes of the persons with RA, one central aspect is to explore the persons' own experiences.

Significant others have an important influence on the person's everyday life and are valuable providers of support. In addition, previous studies reveal needs from the significant others' perspective. Hence, their role and experiences should be further examined.

By exploring the views of persons with RA and their significant others, and additionally examining them from a longitudinal perspective, possibilities for environmental interventions can be provided. This should further be achieved by focusing on the significant others, their influence and support, in the quest for enhanced participation in the everyday life of persons with RA.

AIMS

General aim: The general aim of this thesis is to explore participation in the everyday life of persons with RA over a decade, and in relation to this investigate the influence of significant others and their support.

Study I: To describe the meaning of significant others in relation to participation in everyday life of persons with early diagnosed and contemporary treated RA.

Study II: To analyse how support from significant others affects the associations between disease-related variables (disease activity, activity limitations, pain intensity, and grip force) at the time of RA diagnosis and sickness absence during the two years after diagnosis.

Study III: To explore how support is expressed in the dyadic relationships between persons with RA and their significant others, and how this support can influence participation in everyday life of persons with RA.

Study IV: To explore how men and women with RA experience their everyday life over the course of the first decade after diagnosis of RA, and how this relates to quantitative measures of disability and disease activity.

METHOD

Design

This thesis encompasses four studies with varying study designs: qualitative interviews (Study I and III), a longitudinal cohort study (Study II) and a mixed methods study (Study IV) (Table 1).

Table 1. Overview of Study I-IV.

| | Design | Participants | Data collection | Data analysis |
|------------------|----------------------------------|--|--|---|
| Study I | Qualitative interview study | 59 persons with RA in working age (18-63 years), three years' experience of living with RA | Individual interviews using the CIT technique | Content analysis |
| Study II | Quantitative longitudinal cohort | 274 persons with RA in working age (18-63 years) | The TIRA-2 cohort | Regression analysis |
| Study III | Qualitative interview study | 16 persons with RA who took part in Study I, and their significant others | Individual interviews | Dyadic analysis |
| Study IV | Convergent mixed methods | 31 persons with RA who took part in Study I and III | The TIRA-2 cohort Two sets of individual interviews | Descriptive statistics Linear mixed model Directed content analysis |

The thesis undertook an exploratory design (Polit & Beck, 2017), where participation and support in everyday life from the perspectives of persons with RA and their significant others were investigated through different methodological approaches. The individuals' subjective experience was captured through a constructivist worldview, whereas objectivity added to the entirety of their everyday life through a positivistic approach (Polit & Beck, 2017).

To start up the project, we sought an understanding of the persons' participation in everyday life by focusing on holistic and dynamic aspects

as well as subjective experiences (Polit & Beck, 2017). To capture this, individual qualitative interviews were conducted.

From the results in Study I, where the influence of significant others was prominent, we hypothesised that a positive influence from significant others in the form of support would facilitate participation in work life. This was examined through self-reported and observational longitudinal data and statistical analysis in a larger sample to enhance generalisability (Polit & Beck, 2017).

As Study II displayed the impact of support in relation to work life, yet without specifying types of support, we aimed to further explore support and additionally add the perspective of significant others. To enhance the understanding of how support is expressed between the persons with RA and their significant others, the subjective experiences were investigated through individual interviews (Patton, 2015) and subsequently dyadic analysis (Eisikovits & Koren, 2010).

Finally, we aimed to investigate the everyday life of persons with RA through different approaches. To gain insights on a level deeper than qualitative and quantitative information separately, a convergent mixed methods design was chosen (Creswell & Creswell, 2018). Additionally, a longitudinal perspective was applied. Hence, self-reported and observational data collected during a decade were analysed, as well as individual interview data. The different focuses in the studies are illustrated in Figure 3.

The TIRA project and registry data

The persons with RA in Study I-IV were recruited from the multicenter project Early Interventions in Rheumatoid Arthritis (Swedish acronym TIRA), which was conducted through a cooperation between rheumatology units in southeast Sweden (Thyberg et al., 2005a). The main aim of the TIRA project was to establish clinical routines for early diagnosis and early instituted multi-professional interventions.

The first TIRA cohort (TIRA-1) included 320 persons with RA recruited during the period 1996-1998 (Thyberg et al., 2005a), and in the second cohort, TIRA-2 (Thyberg et al., 2017), 522 persons with RA were included from the period 2006-2009. Everyone included in the cohorts was clinically diagnosed and belonged to one of the participating rheumatology units. In this thesis, the sample of persons with RA were part of the TIRA-2 cohort.

Persons with RA were consecutively included in TIRA-2 at the time of diagnosis (baseline) between 2006 and 2009. Regular follow-ups were performed yearly from baseline and 10 years onward. To be included in the cohort, persons with RA needed to fulfil at least four of the criteria

according to the American College of Rheumatology (ACR-87) (Arnett et al., 1988), or at least morning stiffness ≥ 60 minutes, symmetrical arthritis, and arthritis of the small joints, or had positive Anti-CCP and at least one peripheral joint with synovitis. There were no exclusion criteria. A total of 522 persons with RA were included in the TIRA-2 cohort.

At time of inclusion in the TIRA cohort and the follow-ups, data for serological markers, disease activity, health economics, medication and activity limitation were registered online in The Swedish Rheumatology Quality Register (SRQ) by both HCPs and patients. The SRQ database contains data for approximately 89 000 persons with rheumatic diseases and is aimed to guide clinical decisions and improve treatment and follow-ups. SRQ is further used to develop quality of care and for research (SRQ, 2023). The majority of the quantitative TIRA-2 data analysed in this thesis are imported from SRQ, whereas some data were registered solely in the regional TIRA database. In addition, sickness absence was obtained from the Swedish Social Insurance Agency.

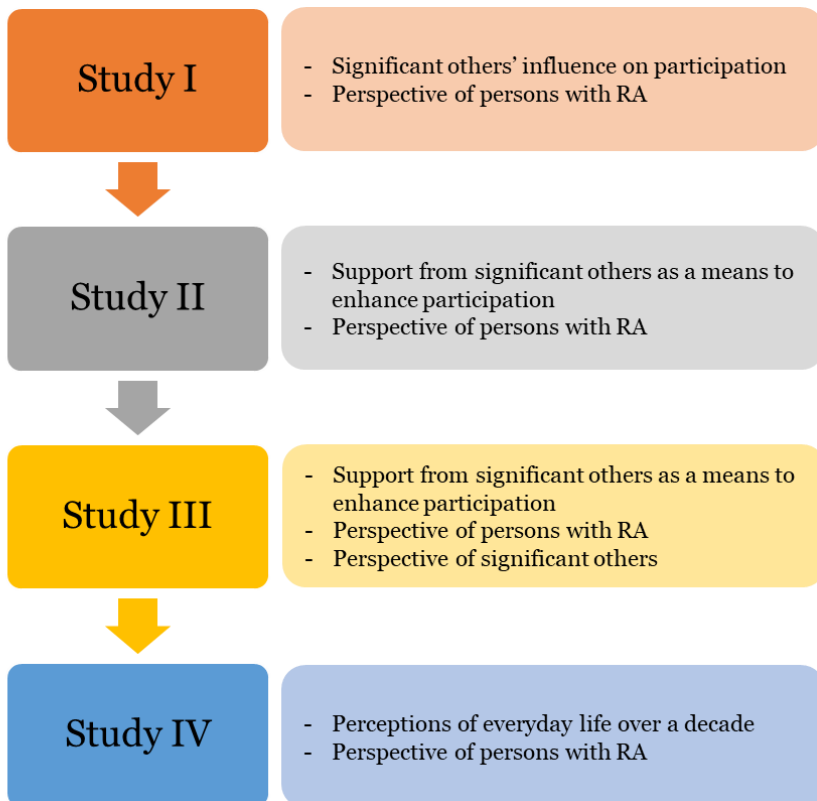


Figure 3. The perspectives and focuses of Study I-IV.

Participants

All persons with RA in Study I-IV are participants from the TIRA-2 cohort. In Study III, significant others of these persons also took part. Hence, the participants consist of both persons with RA (I-IV) and significant others of persons with RA (III) (Table 2, Figure 4).

Table 2. Overview of participants in Study I-IV. Persons with RA in Study I-IV, and significant others in Study III. Study I and III: age at time of interview. Study II and IV: age at time of inclusion. N=number of participants.

| | Study I N=59 | Study II N=274 | Study III N=16 | Significant others, Study III N=16 | Study IV N=31 |
|--|-------------------------------|---------------------------------|---------------------------------|---|--------------------------------|
| Female/male (N) | 34/25 | 201/73 | 8/8 | 11/5 | 16/15 |
| Age (mean years) | 53 | 50 | 62 | 59 | 49 |
| Length of relationship (mean years) | - | - | - | 35 | - |

Study I

In Study I, inclusion criteria were being of working age at time of inclusion (18-63 years of age) and having three years of experience of RA. In order to include persons who had lived with the disease for three years, recruitment started in 2009. Fifty-nine persons met the inclusion criteria and were invited to participate in individual interviews. Eleven of these persons (eight women, three men) declined, leaving 48 participants. To increase the number of men, 15 men from TIRA-2 who had lived with the disease for three years during 2010 were subsequently invited. Four of them declined, leaving 59 persons with RA participating in Study I.

Study II

The inclusion criteria for Study II were based on working age (retirement age in Sweden is 65 years), due to the aim of the study and that it concerned work life data. In addition, data from two years after inclusion were analysed. Therefore, the participants in Study II consist of the persons from TIRA-2 who were 63 years or younger at inclusion, leaving 274 persons.

Study III

In 2018, approximately a decade after taking part in Study I, contact was again made with the involved rheumatology units. At this point, one unit declined, five persons were deceased and five were terminated from TIRA-2, leaving 42 persons. These persons were invited together with someone they considered to be a significant other. In total, 16 persons with RA and their significant others took part in Study III. Together, they are referred to as “dyads”. Most of the dyads were formed by heterosexual couples, either married or co-habiting, who had known each other for decades. Parent-child-dyads also existed, as well as close friends.

Study IV

While collecting the data for Study III, persons with RA who could not for different reasons provide a significant other were interviewed. This means that a larger number of persons with RA were interviewed than who took part in Study III. Inclusion criteria for Study IV were to have participated in the two sets of individual interviews, 2009-2010 and 2018-2019, leaving 31 persons with RA in Study IV.

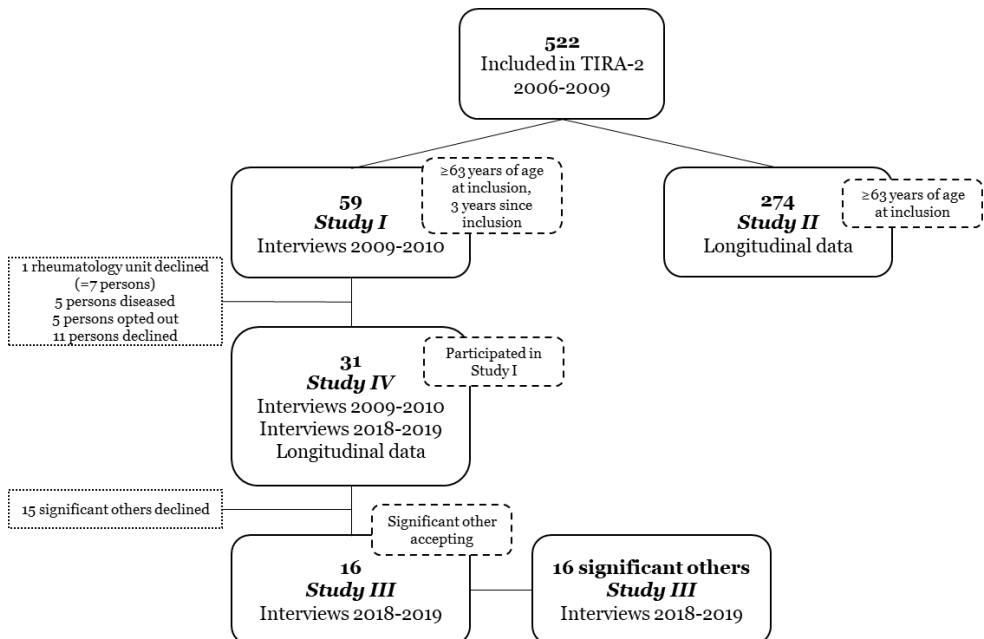


Figure 4. Flowchart of participants in Study I-IV. Number of participants, inclusion criteria, drop-outs and type of data collection.

Data collection

The data in this thesis were collected through qualitative individual interviews (I, III and IV) as well as from the TIRA-2 cohort (II and IV) partly via SRQ, and the Swedish Social Insurance Agency (II) (Table 3).

Qualitative interviews

In Study I, III and IV, individual interviews constituted the data material.

In Study I, interviews were conducted approximately three years past diagnosis. Three of the study's authors conducted the interviews using the Critical Incident Technique (CIT) (Flanagan, 1954), which is a flexible method where problematic situations are explored. The interview questions were shaped accordingly with the aim to capture critical events in the everyday life of the participants. A semi-structured interview guide was followed by all the interviewers, containing open-ended questions about participation restrictions related to RA in everyday life. Examples of questions were: 'How is your everyday life?' and 'Can you describe a situation, preferably during the past week, when you were hindered or reminded of your RA?'. These interviews were conducted between October 2009 and May 2010. They lasted between 45 and 90 minutes, and were audio recorded and transcribed verbatim.

In Study III, individual semi-structured interviews were conducted by two of the study's authors and one research assistant approximately ten years after diagnosis. The interview guide was based on the guide from Study I and included topics such as 'participation' and 'support', with follow-up questions. There were two separate guides that included these topics, with minor formulation differences depending on whether the interviewee was the person with RA or the significant other (together referred to as "dyads"). Two people within the same dyad were never interviewed by the same researcher in order to be able to enter each interview as objectively as possible. The interviews with the persons with RA lasted between 18 and 71 minutes, and the interviews with the significant others between 17 and 55 minutes. All interviews were audio recorded and transcribed verbatim. Data were collected between October 2018 and November 2019.

The qualitative data material in Study IV consisted of the individual interviews from the 31 participants, both three years and ten years after diagnosis.

Quantitative outcomes

Data from the TIRA-2 cohort, obtained through SRQ, were collected regarding disease activity, grip force, pain intensity and activity limitation

(disease-related variables) at baseline (time of inclusion in TIRA-2), one year and two years after diagnosis (II), and three, five, eight and ten years after diagnosis (IV).

Disease activity was assessed by Disease Activity Score in 28 joints (DAS28), which is a scale from 0-10 with the following values: > 5.1 indicating high disease activity, < 3.2 low disease activity, and < 2.6 remission (Porter et al., 2011). It considers tender and swollen joints, as well as the person's overall health, and, in the case of TIRA-2, measurement of erythrocyte sedimentation rate. DAS28 is a commonly used and valid tool for assessing disease activity in RA (Gaujoux-Viala et al., 2012).

Grip force was tested in newtons (N) with a Grippit™ (AB Detektor, Gothenburg, Sweden), measuring the right hand's mean score over ten seconds, which is a reliable assessment used in RA (Nordenskiöld & Grimby, 1993).

Pain intensity was reported in millimetres (mm) using a Visual Analogue Scale (VAS).

Activity limitation was self-reported using the Health Assessment Questionnaire (HAQ), which consists of questions related to the ability to perform certain activities, such as dressing, eating and walking. For each activity, the individual has the following response alternatives: "without any difficulty (scoring 0), "with some difficulty" (scoring 1), "with much difficulty" (scoring 2), and "unable to do" (scoring 3). This results in a total score between 0 and 3: the higher score, the more disability (Ek Dahl et al., 1988). Activity limitation measured by HAQ has previously been reported as associated with grip force measured by Grippit (Björk et al., 2007; Thyberg et al., 2005b).

In Study II, data relating to sickness absence were obtained from the Swedish Social Insurance Agency as the number of days with absence from work during year one and year two after diagnosis. Additionally in Study II, the perception of support from family and friends was obtained yearly through a postal survey within TIRA-2. On two separate scales, one for family and one for friends, the participants were asked to mark the provided support in accordance with the following questions: 'Do you receive practical and/or emotional support from family?' and 'Do you receive practical and/or emotional support from friends?'. Zero mm on the scale indicated no perceived support, and 100 mm indicated full perceived support.

Further, in Study IV, the participants reported their performance in valued life activities using the Swedish version of the Valued Life Activity Scale (VLA-swe), which is a validated assessment aimed towards participation in valued life activities. It consists of 33 activities, self-reported on a four-point scale (0 = no difficulty to 3 = unable to perform).

The individual has the option to rate activities as not applicable, and if so, the particular activity is not included in the final scoring (Björk et al., 2016). If an activity was reported as “unable to perform”, “a little difficulty” or “lot of difficulty”, it was considered “affected” in Study IV.

Table 3. Qualitative and quantitative data collection in Study I-IV.

| | Study I | Study II | Study III | Study IV |
|--------------------------------------|---------|----------|-----------|----------|
| Interview I, at 3 years | X | | | X |
| Interview II, at 10 years | | | X | X |
| DAS28 | | X | | X |
| Grippit | | X | | X |
| Pain intensity | | X | | X |
| HAQ | | X | | X |
| SSIA data | | X | | |
| Perception of support | | X | | |
| VLA-swe | | | | X |

Data analysis

The material in this thesis has been analysed using several different methods. The qualitative material has been analysed through different content analysis procedures (Study I and IV) as well as dyadic analysis (Study III), while the quantitative material has been analysed using different statistical procedures (Study II and IV).

Content analysis

In Study I, the material from the 59 interviews was analysed by content analysis using the steps described by Graneheim and Lundman (2004) and applying a manifest focus. These steps involve dividing the text into meaning units, which are then condensed and abstracted into codes, which are in turn sorted into sub-categories and categories. The PhD student performed the initial analysis, and the suggested codes, sub-categories and categories were discussed with supervisors and additional co-authors until consensus was reached. This was a back and forth moving process between the different steps in the analysis.

In Study IV, the qualitative material from the 31 participants was analysed using directed content analysis as described by Hsieh and Shannon (2005). In this process, the open question ‘Over the course of a decade, how is everyday life affected by RA?’ guided the process, together with predetermined codes from the quantitative material (outcomes). In this analysis, the PhD student performed the larger part and after discussion with the supervisors one more subcategory was added.

Dyadic analysis

The dyadic analysis conducted in Study III was guided by the procedure of Eisikovits and Koren (2010). This process started with analysing each individual interview while allowing themes to emerge. Secondly, an analysis was performed within each dyad, in this case comprising the persons with RA and their significant others. This way, contrasts and overlaps were identified, and new themes emerged on a dyadic level. Thirdly, an overarching analysis was performed across the dyads, identifying common conceptual patterns (Figure 5).

In the first phase of the dyadic analysis, the PhD student and two co-authors read through the material, and patterns were identified and discussed. In the second phase, each dyad was analysed, and contrasts and overlaps were searched for. Thus, themes on a dyadic level were suggested by the PhD student and further discussed and validated by the two co-authors and adjusted accordingly. Continuing, the remaining two co-authors as well as a research partner read material from 13 dyads in total as a way of triangulation. Suggested themes were thereafter adjusted and further discussed. All co-authors joined in a final discussion about the results until consensus was reached.

Statistical analysis

The analysis in Study II was performed using zero-inflated negative binomial regression with disease-related variables (disease activity, activity limitation, pain intensity and grip force) as independent variables. As the association between these disease-related variables and sickness absence was examined, support was included as a moderator in the model. Figure 6 illustrates the conceptual model. Direct associations between each of the disease-related variables at baseline and sickness absence during year one were tested. In the case of sickness absence, direct associations between the disease-related variable and number of days were also tested. In the next step, moderations of these associations were tested, namely if support from family and friends moderated the associations. The same analyses were then performed for disease-related variables at year one and sickness absence during the second year after diagnosis.

Statistical analyses were performed using IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, N.Y., USA) and Mplus v. 7.4 (Los Angeles, CA., USA).

In Study IV, descriptive statistics were used to describe the participants. To determine changes between men and women over time (baseline, three years, five years, eight years and ten years after inclusion), linear mixed models were used.

In both Study II and IV, statistical significance was set to $p < 0.05$.

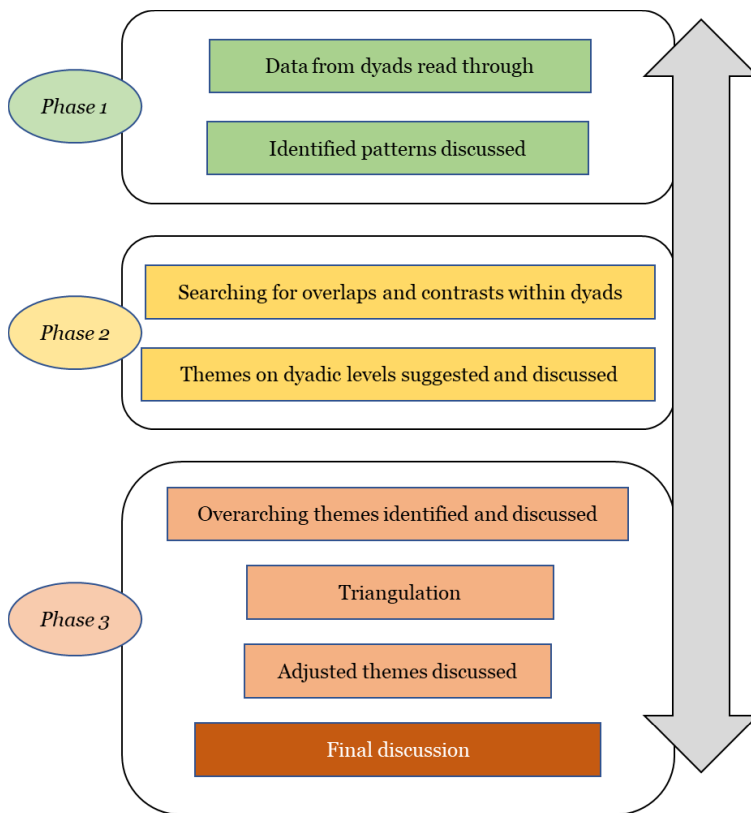


Figure 5. Dyadic analysis, divided into three phases and a constant moving back and forth between the different phases.

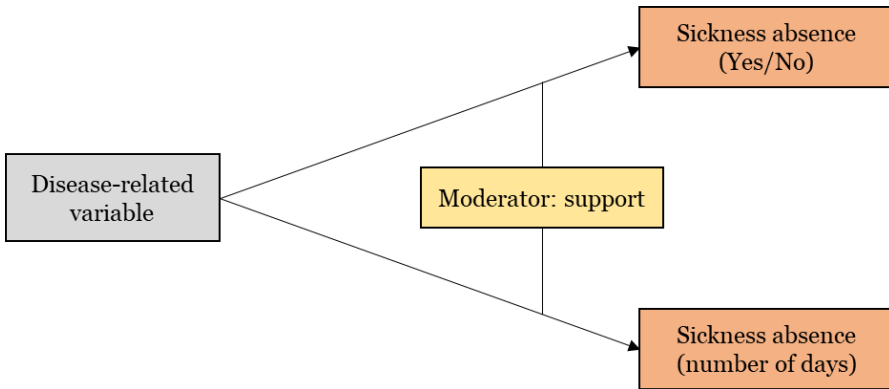


Figure 6. Illustration of associations between disease-related variables and sickness absence, and the moderator of support.

Integration of qualitative and quantitative results

Study IV employed a convergent mixed methods design. This means that the qualitative and quantitative data were collected and analysed separately at first. Then, in the integration phase, the results were merged, interpreted and compared (Creswell & Creswell, 2018). To guide the process of integration, visual means were used in the form of joint display (Fetters et al., 2013). This assisted in getting an overall view of both the qualitative and quantitative results and performing the merging. The directed qualitative analysis was as previously mentioned guided partly by the outcomes as predetermined codes.

Ethical considerations

Study I-IV were approved by The Regional Ethics Committee at Linköping university. Prior to the PhD project, Study I (Dnr. M168-05 T84-09) and Study II (Dnr. M168-05) were approved. Ethical application for Study III was carried out during the PhD project by the PhD student (Dnr. 2018/158-31 2019-00733). Due to few participants, an additional application was carried out, resulting in a larger number of participants for Study III – and consequently for Study IV.

In conducting research involving persons, it is of utmost importance to take ethical regulations and guidelines into account. As stated in The Declaration of Helsinki (The World Medical Association, 2013), the rights and well-being of the individuals must always come first. In relation to beneficence, it is considered vital that the participants are never in any

specific risk of harm during the data collection, and that the benefits from the research results would outweigh these potential risks, should there be any (SFS 2003:460).

Since interviews are part of the data collection methods, anonymity has not been achievable in Study I, III and IV. However, confidentiality can be achieved through careful handling of the data. For example, no names of persons or places have been used in quotes in manuscripts, and the material has been made inaccessible to others.

In accordance with The Declaration of Helsinki (The World Medical Association, 2013) all participants have been informed about the aims of the studies, and consent has been a prerequisite for participating in them. To participate has been voluntary and the option of withdrawal at any point without specific reasons has also been stated to the individuals. In the case of these studies, all participants were a minimum of 18 years of age and capable of understanding and giving their consent. Further, no dependent relationship existed between the participants and the researchers obtaining the consent, since none of the researchers were involved in treatment or rehabilitation.

In relation to participating voluntarily and giving consent, it is also important to mention that some individuals did not get the opportunity to make this decision themselves. In Study III, all clinics who took part in Study I were contacted, although one clinic declined. This means that persons connected to this particular clinic were not given the opportunity to participate. The same goes for the significant others in Study III. The invitation letter that was sent to the persons with RA had an additional letter to a significant other attached. It was the persons with RA who defined and invited significant others, which means that all potential significant others may not have been invited. Hence, in Study III, accepting or declining was not consistently the person's own choice.

RESULTS

A brief summary of the results (Study I-IV)

Study I had the aim to describe the meaning of significant others in relation to participation in the everyday life of persons with early diagnosed RA. The results revealed four categories encompassing: 1) RA causing activity adaptations for both the persons with RA and the significant others, which could be approached with both unwillingness and positive attitudes; 2) a balance between needing assistance and experience participation, where the persons with RA distinguished between needing help and feeling involved in activities; 3) problematic and manageable physical interactions with significant others; and 4) feelings in relation to activities with others, such as anxiety and failing others. All this considered, significant others can be both hindering and facilitating for participation in the everyday life of persons with RA. It is therefore of value to continue exploring how significant others can be solely facilitating and what they in turn need to achieve this.

With the aim of analysing how support from significant others affects the associations between disease-related variables and sickness absence during the first two years after RA diagnosis, the hypothesis of **Study II** was that support is a positive influence associated with lower sickness absence despite the impact of disease-related variables. Although, conversely, higher perceived support increased the odds of sickness absence during the first year after diagnosis. Higher disease activity was additionally directly related to sickness absence during both the first and second year after diagnosis (strengthened by support during the first year). This indicates that sickness absence must not be considered altogether negative, and that support from significant others can encourage a sustainable work life. Moreover, since support was more influential during the first year, it should be taken into account early in the disease process, meaning that the amount, type and timing of support are also important factors.

In **Study III**, the aim was to explore how support is expressed by persons with RA and their significant others, and how support relates to participation in everyday life. The results showed that both RA and support had become a natural part of everyday life, and in particular emotional

support. Also, the reciprocal dynamics of support were stressed. In addition, support from others outside of the dyad of the person with RA and the significant other facilitated everyday life, as well as a well-functioning communication. These results showed the profound impact that the significant others as part of the social environment can have on persons with RA. It further showed that the aspects of time, open communication and the constant exchange of support were things that facilitated the dyads' participation in everyday life.

Finally, **Study IV** aimed to explore how men and women with RA experience their everyday life during the first decade after diagnosis, and how this relates to quantitative measures of disability and disease activity. Through mixed methods, discrepancies were found between the qualitative and quantitative results, in addition to differences between men and women. In the interviews, women expressed more issues in relation to disease activity and grip force, which did not concur with the quantitative results. Moreover, the women's pain intensity changed quantitatively over time, but this was not expressed in the interviews. Disconfirming results such as these were not seen in men. Also, issues regarding participation in basic activities were more visible quantitatively than through what the participants expressed in the interviews. Furthermore, the results stated that both men and women still exhibit disability a decade after RA diagnosis. To conclude, Study IV shows a further rehabilitation need for persons with RA in order to facilitate participation in everyday life, and additionally that thorough patient interviews can add valuable information to clinical assessments.

In relation to the aim of the thesis, attention was focused towards meaningful and important content from the results of the four studies. Content that was considered unifying of the results were systematically grouped into the following headlines: *Adapting everyday life*, *A need for knowledge*, *The aspects of support*, *'We are in this together'* and *Participation in the everyday life of RA*. Thus, they constitute the overall results of this thesis. The results are additionally illustrated in Figure 7, depicting participation as the central element.

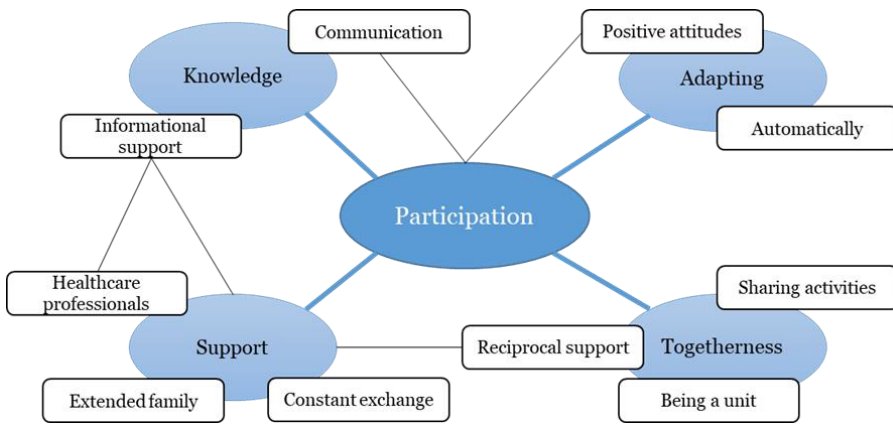


Figure 7. Illustration of the interconnection of the results and how the concepts relate to each other. They are all part of facilitating participation in the everyday life of persons with RA.

Adapting everyday life

Both the person with RA and the significant others need to adapt to the disease (I, III). Also, people around them need to adapt, including after years of living with the disease (III). The approach to adaptation can take different shapes, such as unwillingness to adapt, or a more positive approach, which facilitates participation (I) and where the adaptations are made more or less automatically (III). As seen in Study II, persons with RA also need to adapt their work life, in some cases in the form of sickness absence. But even when still present at work, women express feeling limited and in need of adaptations, such as changing work hours (IV). Study IV also made it evident that both men and women with RA adapted their everyday life in different ways, still after living with RA for a decade. Examples include planning carefully ahead or even avoiding or giving up activities. Additionally, men chose to give up hobbies, and both men and women felt limited in social activities, so much so that several withdrew from such activities. The fact that the persons with RA articulated problems in social activities was evident through both interviews and self-rated assessments (VLA-swe), showing confirming results in this matter (IV).

Even though all persons with RA in our studies have had access to the new and improved treatment from the start, they still made adaptations a decade after diagnosis. Interestingly, Study IV displayed, for example, that women's disease activity had decreased ten years after diagnosis, but they still pronounced problems in relation to disease activity (stiffness, pain, flares) at this point.

The limitations – and thereby the imposed adaptations – could be hard on persons with RA, as well as their significant others, for example, when the physical aspect hindered interaction with their loved ones, such as carrying or playing with small children, or intimate life with their partner (I).

A need for knowledge

Study IV displayed that persons with RA still exhibit disability even after a decade with the disease, although it is not always easy for significant others to understand the needs of persons with RA (I, III). In cases when persons with RA do not want to ask for help (I), or do not share how they feel (III), significant others might offer assistance without asking (I, III), or act overprotective (I), which is comprehended as a barrier for participation in everyday life. Persons with RA express that significant others cannot fully understand the situation, whereas significant others experience that they are not provided with enough information (III). In turn, persons with RA might then perceive the significant other as not interested (III). To avoid this vicious circle, it is preferable that significant others find a balance between when to offer assistance and when to step aside and let the person with RA handle activities, alternately performing the activity together (I). Also, that they strive for an open and honest communication from both sides (III).

In addition, both the persons with RA and their significant others request support from the healthcare system in the form of information (III). This can be a way of providing significant others with more information about the condition and how they can behave on their part. For example, to identify when to step in and offer practical assistance (I), and how and when to offer the preferable type of support (II, III). It is also suggested that HCPs can more actively invite significant others to take part in the rehabilitation process, such as clinical visits, or information meetings and patient education sessions (III), even continuously.

Activities are still affected and adapted a decade into the disease, including basic activities (IV), which is important to communicate to significant others. In this way, they can be provided with information and resources in order to act as facilitators for participation in the everyday life of persons with RA.

The aspects of support

To enhance participation, support is vital (I), and in different aspects, it is present in the everyday life of persons with RA and their significant others. Study III shows that there is often a constant exchange of support between the two parties, and that it can move from a more practical nature early in the disease course to mostly emotional later (III). This is also important due to the persistent symptoms and disability later in the disease course (IV). Support is also often exchanged automatically and becomes a part of the routines of everyday life. Further, that support stretches outside of the persons with RA and the significant others, and also involves extended family, friends and the healthcare system (III). The results from Study I depicted support as particularly facilitating when persons with RA expressed feelings like aggression towards others, as a result of, for example, pain. In these situations, the significant others could meet these feelings with understanding and support and thereby facilitate participation in everyday life.

Although the hypothesis for Study II was that support from family and friends would decrease sickness absence, the results show the complete opposite. This adds another interesting aspect of support. Namely, the potential of persons with RA getting supported in a decision of claiming sickness absence if that is what they need at that point in time. As mentioned, full employment might not be the overall primary goal, and one should therefore be open to support having a different impact. Instead, we can look into what quality, type and timing might be optimal for the person with RA at the time. In addition, from a rehabilitation point of view, interventions regarding support can also be beneficial at an early stage, since support from family and friends had the most impact during the first year after diagnosis (II).

‘We are in this together’

From the qualitative studies (I, III), it is evident that the persons with RA and the significant others are a unit. When making adaptations together and when the attitude from the significant other is that it is “not a big deal”, it facilitates participation in the everyday life of persons with RA (I). When helping each other out, sharing domestic tasks and ensuring the person with RA feels involved, needed and able to contribute also facilitates participation (I). As expressed in Study III, the person with RA and the significant other can have ‘grown together’ and learned to live with the disease. In addition, RA itself was pronounced as a natural part of everyday life, and in positive cases, having no interference with roles or relationships (a decade after diagnosis). The fact that support is viewed as reciprocal also

adds to the feeling of togetherness. Additionally, although not part of the aim of this thesis, Study IV showed differences between men and women in their experiences of RA, which is important to take into consideration as a significant other.

Study II showed that higher perceived support from family and friends increased the odds of sickness absence one year after diagnosis of RA. Sickness absence should therefore not be seen as solely negative, but we should instead look at the different types of support that significant others can offer. Also, the timing and quality of support can be further investigated. In order to do this, significant others will preferably be included in the rehabilitation process, enhancing the togetherness in the disease as well as the process of healthcare and rehabilitation.

Participation in the everyday life of RA

To provide a complete view of the complex everyday life of persons with RA, it is important to include participation in assessments and follow-ups (IV). Persons with RA experience both facilitators and barriers when it comes to participation in everyday life, significant others being included in both aspects (I). From the results of Study I, it is revealed that significant others unwilling to adapt, acting overprotective, providing unrequested assistance and being uncaring in physical contact can be experienced as barriers for participation in everyday life. At the same time, they can also provide facilitation by showing a willingness to adapt, involving the person with RA, showing understanding attitudes and support.

Further, by providing good support at a convenient time, significant others can also act as facilitators for participation in work life for persons with RA (II). This might not solely mean a 100% employment, or any employment. Even as work is an important part of life, it may not be the best or a goal for everyone. Therefore, by the right support provided by significant others, there is a potential to reach a well-functioning work life, and in particular participation in a sustainable work life for persons with RA.

A good foundation for participation is to engage in reciprocal relationships, which Study III exhibited examples of. By a constant exchange of support and open, honest and well-functioning communication, participation in everyday life can be facilitated.

DISCUSSION

The overall aim of this thesis was to explore participation in the everyday life of persons with RA over a decade, and in relation to this, to investigate the influence of significant others and their support.

The results show that persons with RA are still affected by the disease a decade after diagnosis, and they still need to make adaptations in everyday life. This also goes for their significant others. Additionally, restrictions in everyday life are still evident a decade after diagnosis.

Furthermore, a continuous need for knowledge was identified, namely a facilitating communication between both the persons with RA and their significant others, as well as HCPs. A way forward here is for significant others to be actively invited as part of the rehabilitation process.

The positive aspects of support were also evident through the results. This was needed both between the persons with RA and the significant others, as well as others outside of their dyads. Further, the quality, type and timing of the provision of support is of importance.

It was also apparent that there was a sense of togetherness between the persons with RA and their significant others in the disease and everyday life. Over time, they had learned to live with RA, and they approached it as a unit.

Finally, significant others are prominent influences on participation in everyday life of persons with RA. Their behaviour and attitudes can constitute both hindrances and facilitators for participation, and by providing their support, they can have a highly positive influence on participation in the everyday life of persons with RA.

Still in need of adaptations after a decade

Being forced to alter, adapt or adjust activities could have different consequences for the persons with RA and their significant others (I, III, IV). Cases where a negative attitude was seen are unsurprising when looking at the circumstances from an occupational therapy perspective. Activities are uniquely experienced by the person engaging in them and are associated with specific personal meanings (Townsend & Polatajko, 2013). In addition, Barns et al. (2015) found that adapting and changing an activity could mean that both the meaning and significance altered, and consequently, the person might no longer enjoy performing it. Therefore,

the challenge in adapting activities is in a way expected. This is an important point to consider, both in relation to the person with RA, but also the significant others, since both parties are part of the adjustment process and might both have to change or give up valued activities. However, there are differences in as to what kind of activities they might need to alter or withdraw from. Significant others can be forced to give up different types of leisure activities, such as skiing, or alternatively perform them without the person with RA. Whereas the person with RA can be forced to give up activities altogether, such as the example of skiing, it can also interfere with their closeness to others, like holding or playing with children or grandchildren. This often comes with feelings of sorrow. On the other hand, interacting during intimate activities of course affects the significant other in a direct way. However, understanding attitudes and a willingness to adapt were perceived as facilitating (I). These results add valuable information to previous research, such as Matheson et al. (2010) who stated that there might be both an adjusted and restricted life for partners of persons with RA.

Adapting activities can also mean that RA becomes more visible, while the persons do not want to be defined by their disease, as identified in previous research (Flurey et al., 2014; Landgren et al., 2020). Also, engaging in activities and roles the same way as before the disease can be challenging due to flares and periods of more active disease. As mentioned by Kostova and colleagues (2014), it can further be difficult to accept the loss of independence and no longer be able to manage life roles as before. To experience independence, e.g., choose and manage activities, has been further described as an important part of quality of life (Malm et al., 2017). This can be connected to an unwillingness to accept assistance that has previously been issued (Fairley et al., 2021). The need of assistance in itself can shed light on the symptoms of the disease, which can cause negative feelings for the persons with RA. This, in turn, can be connected to the imbalance between adequate assistance and overprotection, mentioned by our participants (I, III).

The challenge of living with RA has been stated to result in role stress (De Cock et al., 2022), and the disease has been expressed as a threat to the person's identity (Flurey et al., 2014). By again applying an occupational therapy perspective, engaging in activities enables the expression of one's identity (White et al., 2020), and disruption in identity impacts meaningful roles (Hansson et al., 2022). In the case of our persons with RA, adaptations of or withdrawal from valued activities might therefore impact their identity and roles. This relates to their limitations in interactions and activities as, for example, grandparents (playing with grandchildren) or

friends (withdrawal from social activities) (I, III). These restrictions in fulfilling life roles have previously been stated by Landgren and colleagues (2020), and the redefinition of identities has been documented (Parenti et al, 2020). Also important to remember is that a person has different roles, which can end up in a conflict in relation to RA and the caused limitations. For example, as reported by Feddersen and colleagues (2017), being both a mother and a worker brings a willingness to fulfil one role, which can restrict managing the other. From the significant others' point of view, it is important to keep in mind that the person with RA might live with these conflicting feelings and be attentive of that. Considering the results specifically from Study II on significant others' influence on work life, this attentiveness might be even more important.

These issues and adaptations also still exist a decade after diagnosis, despite decreased disease activity. In this way, the goals of treatment are met in the sense that disease activity is lower, but the persons' everyday life is still strained (Ahlstrand et al., 2015). It is therefore of importance to thoroughly investigate and follow up the situation of the person, in many other ways than status of disease activity. For example, occupational balance has been related to satisfaction with life overall in RA, namely the higher the occupational balance, higher the life satisfaction (Wagman et al., 2020). This has also been exemplified by Flurey and colleagues (2014) as a balance between rest and activity, as well as a balance between independence and seeking assistance. They found that this type of balance is important to reduce the impact of RA. Balance in life is therefore also a valid aspect to consider.

Informational support in the form of knowledge

Both the persons with RA and the significant others talked about the need for good communication, both in order to provide knowledge but also to facilitate everyday life (I) continuously over time (III). If significant others remained uninformed, it could cause the person with RA to feel both helpless and overprotected, depending on the significant other's approach (I). Since the persons with RA still perceived that activities were affected a decade after diagnosis (IV), significant others need to be provided with this knowledge and in turn supported in how to handle this knowledge.

A vicious circle where the person with RA does not share status or feelings, the significant other feels unaware, and the person with RA considers the significant other uninterested, could appear due to a lack of information-sharing. This further affects the situations where support would be exchanged. As noted in previous research, understanding from

others facilitates the provision of support in adequate ways. Further, if understanding is non-existent, needs may not be anticipated at all, or support provided in the wrong way (Nyman & Larsson Lund, 2007).

In accordance with the participants of the qualitative study by Matheson and colleagues (2010), the significant others expressed a further wish and need for information about the disease (III). Even though some had been offered this sort of information early in the disease process, it seems that it was later either forgotten or not offered. In relation to the recommendations for patient education for people with inflammatory arthritis, patient education should be an integral part of standard care and continuous throughout the disease (Zangi et al., 2015). In comparison with this thesis' results, it is possible that patient education is somewhat forgotten further into the disease. Even though the recommendations are for patients in particular, they also highlight the importance of patient education directed towards significant others.

On the basis of this thesis' results, one preferable way forward can be to ensure a continuous flow of education both for people with RA as well as their significant others. To actively invite significant others to be part of the rehabilitation process throughout the disease course can also be a way to address this. Examples of previously conducted patient education include Mäkeläinen and colleagues (2009). They found that 24% of persons with RA were dissatisfied with patient education, primarily because the information was not individually focused nor met emotional support needs. Instead, focus was put on medical treatment, and information was only given after diagnosis, but not later. No differences were found between men and women concerning satisfaction. Furthermore, a British study (Ellard et al., 2009) reported that education including both persons with RA and their significant others were well-received, and several made changes in their daily management of RA after the education, although this was a small scale and local study. Additionally, in their longitudinal study, Grønning and colleagues (2022) found that education and thorough information was still requested several years after taken part in patient education. This is also supported by Landgren and colleagues (2020) who found that knowledge was requested both earlier and later in the disease. In the light of these study examples, focus should be on personal preferences, continuous patient education, and preferably involve significant others.

In relation to occupational healthcare specifically, the involvement of significant others has been investigated from the perspective of people with chronic diseases in the Netherlands (Snippen et al., 2022a). Researchers

found both positive and negative aspects of this. Positive aspects included that significant others, by being involved in the process, could provide emotional and informational support before, during and after consultations, as well as in everyday life, but also the risk of overburdening significant others and receiving unwanted support from them. Important however, is the fact that the participants in general expressed positivity when asked if they wanted a significant other to be involved in their occupational health care, and that they preferred them to join consultations over other ways of involvement. From these results, we can conclude positive effects when significant others attend consultations. This is also relevant in connection to our results showing significant other's support impacting work life (II).

From another point of view, namely the occupational health physicians', the same Dutch research group sought to find out knowledge and attitudes regarding involving significant others in the return-to-work process of people with chronic diseases. An e-learning module was implemented, which was found to improve both the knowledge and attitudes of the physicians (Snippen et al., 2022b). This further accentuates positive aspects of significant others joining consultations.

With respect to the persons with RA and their significant others in this thesis, similar implementations and results could be expected within a healthcare context. Our participants requested more knowledge and thorough informational support throughout the rehabilitation process, and via such implementations, these requests can be approached. For example, HCPs can actively invite significant others to join consultations, and/or offer sessions exclusively with the significant others, individually or in groups. This type of solutions could also help significant others in understanding how to balance their provision of support concerning amount and timing (II). The involvement of significant others in the rehabilitation process is also a potential quality improvement, according to a recent Norwegian study (Sand-Svartrud et al., 2023), emphasizing the relevance of this matter.

A further discussion in this matter is whether solutions like these should be provided in face-to-face sessions or via e-health. The question of web-based rehabilitation for persons with RA is relevant; however, evidence of effectiveness is limited. A review by Srikesavan and colleagues (2019) stated that there is space for further development of such treatment, but the evidence is of low quality. However, The Swedish National Board of Health and Welfare point to equity problems in terms of access to health care in different parts of the country (Socialstyrelsen, 2021). In addition, consultations have been suggested to proceed in ways other than face-to-face (SKR, 2020). These types of equity problems have also been identified

in other counties. For example, Barber et al. (2021) stated that the provision of rheumatology services differs across Canada and that potential solutions are travelling clinics as well as telehealth. In addition, they found that priorities for patients in regard to care were, for example, early access and multidisciplinary teams. Moreover, the EULAR recommendations for the implementation of self-management in inflammatory arthritis include the use of digital healthcare (Nikiphorou et al., 2021), and additionally, the patients might actually prefer interventions through the internet (Damgaard et al., 2023). It is therefore reasonable to provide support and meet the requests from our participants through both face-to-face sessions and e-health solutions.

Different ways to provide support

The results of this thesis show that support has different kinds of values. Support has become an important part of the everyday life of the persons with RA and their significant others over the years, but it is also needed from other sources (III), and it can have an impact on work status (II).

Quality of support has been reported as correlated with quality of life in persons with RA (Pitsilka et al., 2015). This can be viewed in light of our results since support was expressed as prominent in everyday life. In examining the effects of support, it is suggested to divide the different types, since only looking at total support might conceal the different effects from the different types (Pow et al., 2018). This has not been the case in Study II, where only an overall question was asked. However, in Study III, we dug a little deeper during the interviews, and achieved perceptions from both persons with RA and their significant others. According to Pow et al. (2018), this can provide complementary information that could be missed if only one part was assessed.

Regarding other sources of support, besides each other, HCPs were given as examples, which is in accordance with previous studies (Benkel et al., 2020; Bergström et al., 2017). HCPs can both constitute an understanding and supportive environment (Dures et al., 2017), as well as an informational type of support. From a longitudinal perspective, it is also valued at an early stage (Damgaard et al., 2023; Landgren et al., 2020), touching the results of Study II where support from significant others had the most impact during the first year after diagnosis.

However, as noted earlier, the participants of this thesis wished for more support than what was given. This relates to earlier research, such as persons with RA requiring more informational support from HCPs (Poh et al., 2015), patient education being desired later in the disease course

(Damgaard et al., 2023), and gaps found between support provided by HCPs and support requested by persons with inflammatory arthritis (Dures et al., 2016). Significant others of persons with RA have also previously been reported to occasionally receive emotional support by HCPs, but still be in need of more informational support, in order to, in turn, provide this to the person with RA (Fallatah & Edge, 2015). Again, this calls for HCPs more thoroughly providing information and involving significant others in the care and rehabilitation of persons with RA.

With respect to the results from Study II where support from significant others were found to have the biggest impact during the first year after diagnosis, two things are important to consider. Firstly, support from significant others have the potential to be used in the rehabilitation process of persons with RA. Secondly, this approach should be undertaken early in the process. An interesting side note here is that social support has been reported to not influence the likelihood of achieving remission in early RA, up to five years after diagnosis (Hedenstierna et al., 2022). However, such results also shows that the focus should be broadened from remission to, for example, the performance of meaningful activities in everyday life.

Going back to an occupational therapy perspective, the environment should be recognised as a means for interventions (Law, 2002), in this case the significant others in the social environment. By continuing, in relation to the aim of this thesis, the ICF framework emphasises that environmental factors influence participation (WHO, 2001), which should be considered when planning for interventions for persons with RA. Additionally, social influences as well as social interventions are part of the EULAR recommendations for pain management in inflammatory arthritis (Geenen et al., 2018). Significant others also have an influence on treatment adherence in persons with chronic pain, according to Brown and Newton-John (2022), who moreover suggest significant others as integrated in pain management. On this basis, support from significant others as part of the early rehabilitation process in RA can be considered beneficial. Moreover, specific types of support should be further investigated.

Togetherness in everyday life

The persons with RA and their significant others expressed a sense of unity and togetherness in their life with the disease. That they had learned to live with it as a natural part of everyday life (III).

One important aspect of partners living together with arthritis in the adjustment process is acceptance. According to Gullickson and LaChapelle (2018), this process tends to develop over time. In addition, a constant

readjustment is needed because of the uncertainty and fluctuations of the disease. In the case of this thesis' participants, they seem to exhibit this acceptance as a way of managing everyday life, as developed over time. Gullickson and LaChapelle (2018) further state that the first step in an adjustment process is to learn about the disease, and that this can be done through information from professionals, the person with the disease, or via print resources. This brings back the earlier discussion about informational support and the importance of HCPs offering this, as well as the person with the disease keeping an open dialogue. It thus seems like this informational support is a prominent factor in the acceptance and adjustment process of living in togetherness with RA, further highlighting the need for structural routines to continuously provide this to both persons with RA and their significant others throughout the disease course.

Additionally, the well-being of significant others is substantial in relation to the persons with RA and the disease itself. In related diseases, such as osteoarthritis, the life satisfaction of spouses has been found to be significantly associated with the severity of illness; meaning greater increase in illness severity related to greater decrease in spouses' life satisfaction (Polenick et al., 2015). In RA specifically, compared to the general population, family members of persons with RA have an increased prevalence of stress and depression (Chung et al., 2016). Also, depression in spouses have been connected to a worse disease course in RA (Lam et al., 2009), indicating that the treatment and rehabilitation should in fact be approached with a view of them together constituting a unit. Moreover, the mental health and self-efficacy of a person with inflammatory arthritis is, on one hand, connected to communication within a couple, but on the other, it is also connected to how satisfied both parties are with support. These findings by Rat and colleagues (2021) are discussed to relate to how the effect of the partner should be better taken into consideration. Yet again, both the person with RA and the significant other are important to attend to in the treatment and rehabilitation process.

Social relationships play an essential role in the mental health and well-being of persons with disabilities, such as those with RA (Tough et al., 2017). It is therefore of value to protect the existing social relationships of persons with RA, which according to the results of Study III specifically, are in most cases essential. One way to stimulate this is through the possibility of continuing to participate in joined activities. In the acceptance process, it is also important to find meanings in valued activities in different constellations (Gullickson & LaChapelle, 2018), namely modifying pre-arthritis activities and choosing activities that both parties can pursue and participate as a couple. But it is also important for partners to feel free to maintain valued activities either individually or with

family and friends, even without the person with the disease (Gullickson & LaChapelle, 2018). For the sake of the well-being of the significant other, this is an important point. At the same time, communication in situations like this should be considered of the outmost importance in order not to enhance any possible feelings of participation restrictions for the person with RA. So, yet again, including communication in the requested support and suggested patient (and significant other) education is a potential way forward.

The importance of facilitating participation

As seen in the results of this thesis, the significant others of persons with RA can both constitute facilitators and barriers for participation. This is in itself a rather natural statement, since, for example, the ICF framework (WHO, 2001) sees environmental factors as either facilitating or hindering both activities and participation. Nonetheless, it further determines the importance of significant others and their influence on the lives of persons with RA, not least since relationships in themselves are important factors for participation (Hammel et al., 2008).

The participants in this thesis expressed faith in each other and a constant exchange of support (III). From an occupational therapy perspective, this can be connected to participation as part of supporting and doing things for each other, contributing to others' well-being, and dimensions of belonging, as well as engaging in meaningful and reciprocal relationships. In turn, the sense of belonging is connected to one's own well-being, and the ability to contribute to others is associated with increased feelings of belonging (Hammell, 2014). The experience of belonging in relation to participation is also connected to quality of life in persons with RA (Malm et al., 2017). Thus, for the persons with RA to feel included and able to contribute and thus experience participation in everyday life, significant others should be encouraged to share activities and act in supportive and facilitating ways. Examples from the results of this thesis include positive attitudes and the willingness to adapt to the new life situation (I).

This is also important when considering symptoms that persons with RA experience, specifically since these are still experienced a decade after diagnosis (IV). It is reported that physical limitations due to RA symptoms restrict social participation in certain activities, which in turn leads to a threat of social exclusion (Bay et al., 2020). As noted earlier in this discussion, significant others should still be able to pursue activities individually, but at the same time should not exclude the person with RA

from activities or social events. There seems to be a balance needed between these aspects, for the sake of both parties' well-being.

Likewise, in order to facilitate participation in the everyday life of persons with RA, a balance needs to be established when it comes to assistance from significant others. Needing to ask for help is expressed as negative, but overprotection causes the same issue. These are examples of the opposite of facilitating, given by the persons with RA in this thesis, especially in the results of Study I. This relates to two earlier discussions. Firstly, communication between the person with RA and the significant other is of greatest importance. This has also been identified as a potential focus for interventions (Rat et al., 2021). The participants of this thesis have also articulated that a well-functioning communication facilitates participation (III), further enhancing the importance of such an intervention focus. Secondly, support may come in a negative form if not balanced, namely providing more support than received or vice versa (Hupcey, 1998). This means that the support needs to be balanced, which is of particular interest in Study II where the amount and type of support may be of importance.

Also in connection to Study II is the discussion of the timing of support. From the perspective of persons with RA, timing of assistance has previously been identified as important, as an adequate timing prevents the person from experiencing shortcomings, and an inadequate timing imposes dependency in an activity (Nyman & Larsson Lund, 2007). As Study II in particular illustrates, the timing of support is of importance, and further suggests that specific types of support should be investigated more thoroughly. If a right amount of the right type of support can be provided at the right time, this can constitute a good basis for participation. So, as previously stated, in order to be able to provide this balanced support, significant others need support themselves. Further stressing this issue is the fact that a lack of understanding has been connected to mental health in persons with disabilities (Tough et al., 2017), which is why it is important that significant others are kept informed, supported and viewed as part of the unit together with the person with RA within healthcare settings.

Apart from significant others, it is also important to note that other parts of the person's social environment are valuable for enhanced participation. HCPs are vital sources of different types of support; however, they have also been exemplified as not wanting to address emotional issues (Bay et al., 2020; Dures et al., 2017). But as previously suggested, they should be part of offering, for example, informational support both for persons with RA as well as significant others throughout the disease course. Also, when it comes to work life, HCPs are important partners in discussing work-related challenges, and supportive attitudes of employers and colleagues are

essential in order to sustain a functioning work life (Boonen et al., 2023). In relation to this, low support from colleagues and high physical demands might decrease work productivity (Lenssinck et al., 2013), meaning that the matter of support should also be applied on work places and work life, this since participation in work is important for one's identity (Landgren et al., 2020). Furthermore, the results of Study II have particularly demonstrated the impact support can have on work life, and moreover, work life is still adapted a decade after diagnosis, as seen in Study IV. Support as a strategy should therefore also be considered in work-related goals. As a way forward, Codd and colleagues (2023) suggest that the subjective experience is important in identifying work participation restrictions and finding the type of work support that is required. This indicates a further need for qualitative studies on the subject.

To make way for the most possible participation in the everyday life of persons with RA, the rehabilitation process in itself is also important to consider. Regardless of high or low disease activity, rehabilitation has been proven a necessity (Szewczyk et al., 2021). In this rehabilitation process, wishes expressed by persons with diagnoses include feeling in control and able to influence the process (Feddersen et al., 2022), and for optimal results, the individuals should be actively engaged in the goal-setting process (Sand-Svartrud et al., 2023; Yun & Choi, 2019). This sheds light on the importance of a person-centred approach, which should also involve family and friends as well as different types of support (Voshaar et al., 2015). Furthermore, effective non-pharmacological treatment including physiotherapy and occupational therapy have been expressed as preferred, and this with the background of experiences of positive health effects as well as the opportunity to meet peers (Landgren et al., 2020). With respect to this, the multidisciplinary composition of teams is accentuated. Also, the previously discussed patient education can therefore have several benefits, such as interacting with peers, which can in turn compose an additional source of support.

As the ICF framework emphasises that environmental factors influence participation (WHO, 2001), this is important to keep in mind while planning interventions. Therefore, significant others should be considered as a natural part of the rehabilitation process.

Methodological considerations

General methodological discussion

A large benefit in this thesis is the rich longitudinal data obtained from the regional TIRA database as well as from SRQ. It has provided the opportunity to thoroughly scrutinise the everyday life of contemporarily treated persons with RA in relation to participation and support. Additionally, adding the subjective view of the persons through interviews in a longitudinal perspective has nuanced the results even more. To explore the concept of participation and support even further, the perspective of the significant others increased the understanding and complemented the views of the persons with RA. The use of both quantitative and qualitative data can generate greater insights than the information from solely the former or the latter (Creswell & Creswell, 2018). Hence, through the use of different methodological approaches, the comprehension of the everyday life of persons with RA over a longer period of time has been deepened.

TIRA-2 as a cohort is representative of the population in general (Carpenter et al., 2020), and the usage of extracted data from SRQ within the cohort should be considered a strength since the quality register exhibits a good coverage of the persons with RA in Sweden (86% in 2021) (SRQ, 2023). Even though the TIRA-2 cohort is a representative sample as such, the sample sizes in the four studies differed. Since the aim and rationale of the study should direct the sampling method (Patton, 2015), no general accepted sample size exists for qualitative studies (Elo et al., 2014; Graneheim et al., 2017). The interview data is thereby considered to have provided a good amount of material. Likewise, the longitudinal observational and self-assessed data in Study II originates from a fair-sized sample, quantitatively speaking.

However, the purposeful sampling used in the qualitative studies can, of course, have an impact on the results, although, to increase credibility, it is essential that the participants are able to express their experiences of a phenomenon (Graneheim et al., 2017), which is why they need to have had experience of the phenomenon in question. In relation to sampling, reasons for declining were not always known and different results might have surfaced with different participants. For instance, in Study III, we can speculate that reasons for significant others declining were problematic relationships, this also since the dyads of Study III expressed good relationships in general. Nonetheless, the dyads constituted a substantial part in answering the aim of the thesis.

The participants of Study I, III and IV do not represent the sex distribution of RA, since most people with the disease are women (Sokka et al., 2009), whereas the distribution in the studies are closer to 50/50.

This is because the intention was an even number of participants between the sexes rather than the population distribution. Naturally, the studies' results might look different with another distribution, perhaps highlighting different issues or situations in the individual interviews. In Study II, however, the sample reflects the division between the sexes with 73% women, even though sex differences were not part of the aim of that study nor this thesis.

The first TIRA cohort started in the 1990s, when the existing criteria for RA were the ones according to the American College of Rheumatology (ACR-87) (Arnett et al., 1988). The cohort related to this thesis, TIRA-2, that started to include patients in 2006, also based inclusion criteria on ACR-87. Since then, a new approach to classifying RA has been developed: the 2010 ACR/EULAR criteria (Aletaha et al., 2010); however, these more recent criteria have not been used in this thesis. One can argue that this is a limitation, but in order to gain knowledge about the longitudinal perspective of persons with RA, cohorts initiated prior to 2010 must be applied, such as TIRA-2. In addition, classification and diagnosis is not the same thing. While diagnosis has the goal of being correct, classification focuses on providing large homogenous populations for study purposes. It can, however, be used to support diagnosis (Smolen et al., 2016a).

Study I

In Study I, three different researchers performed the interviews, which can be considered a limitation. However, interviewing 59 persons is demanding for one person for different reasons, and the interview guide had been developed by the whole research team. Further, the guide was followed during the interviews, increasing the consistency of the material. The interview guide was also tested in pilot-interviews, which is a way to increase trustworthiness (Elo et al., 2014). The fact that the PhD student who performed the larger part of the content analysis had not been involved in the interviews resulted in features such as body language not being taken into account in the analysis. This meant that the analysis focused on what was said rather than what the surrounding features might imply, thus keeping a manifest approach as intended (Bengtsson, 2016; Graneheim et al., 2017). It can also be argued that the material was approached without any preconceptions. In this analysis process, the sub-categories and categories formulated by the PhD student were checked and discussed with the supervisors to ensure credibility (Graneheim & Lundman, 2004). To increase trustworthiness, authentic quotes were further used (Elo & Kyngäs, 2008).

Study II

The choice to jointly analyse temporary sickness absence and disability pension should be considered positive since temporary sickness absence can progress into disability pension (Björk et al., 2010). A limitation of Study II is, however, that no power calculation was carried out prior to the study. Although the predefined sample consisted of patients from the TIRA-2 cohort and therefore constituted a certain number of participants. Due to how the Swedish Social Insurance Agency is organised, the only sickness absence data accessible was for longer than 14 days. We can therefore assume that more sickness absence days exist, but the longer periods in focus have certainly been analysed. In addition, sickness absence due to causes besides RA may also be in the analyses.

Not accounted for in the analyses of Study II is sex differences, type of work or age. Even though sex differences are known, and type of work affects sickness absence (Pekkala et al., 2018), they were not a part of the scope of the study. However, a follow-up analysis controlling for age was performed and only affected the results marginally.

In Study II, the scales used for obtaining perceived support from significant others were not common nor validated instruments. Instead, they were part of a yearly postal survey sent to participants of TIRA-2. Naturally, this can be considered a limitation. Moreover, the question asked encompassed support as a broad term, namely ‘practical and/or emotional support’, meaning that we could not differentiate the two types of support. It would have been of value in relation to the concept of support and different types of support might give different effects (Pow et al., 2018). However, the two types are established within the concept of support (Helgeson, 2003). In addition, even though not previously used, the scales were in the form of VASs which is a well-documented strategy.

The other assessments used in Study II are all established in rheumatic diseases. Self-reported pain by a VAS scale is widely used through its simplicity and reported to detect changes (Hawker et al., 2011). Possible hindrances due to cognitive abilities were not in question in our participants. HAQ has previously been suggested as a clinical indicator of rehabilitation (Thyberg et al., 2012), although its validity and reliability has not been tested in RA and a Swedish setting for a long time (Ekdahl et al., 1988). It can therefore be of interest to question whether HAQ is the best way to depict the persons’ limitations in activities. However, yet again, to be able to follow persons with RA for a longer period of time, assessments such as this must be possible to use. Furthermore, HAQ consists of basic activities, and assessments in relation to more complex activities could have been used. The VLA-swe used in Study IV is an example of this sort and will be discussed later in this Methodological considerations section.

The chosen method for assessing disease activity in TIRA-2, and hence in Study II, is DAS28. It is, however, important to notice that other variables and cut-offs for defining remission exist. Therefore, there can be inconsistency between the number of persons in remission, depending on the chosen definition (Einarsson et al., 2019; Verstappen, 2013). It is, nevertheless, widely used in research, making results easier to compare.

Study III

Persons with RA defined different individuals as their significant others. The most common was a spouse, but a parent, children and a close friend also participated as significant others. This broad definition, and leaving it up to the persons with RA to define significant other, enriched the material and shows that today one should not presume that a spouse is the undeniably closest significant other. Naturally, if we would have defined a significant other solely as a spouse, the results might have looked different.

Like in Study I, the interview guide was tested in a pilot-interview with one person with RA and one significant other, to enhance trustworthiness (Elo et al., 2014). As a way of triangulation, several researchers were involved in the analysis process of the study (Figure 5, p. 48). In addition, a research partner was involved in the process to ensure the patient perspective. These two points can be considered to increase credibility (Taylor, 2007). Decisions taken during the analysis process can also be considered more reliable due to the fact that most dyad reports were read through by three researchers or more (Polit & Beck, 2017). However, since the PhD student performed most of the interviews with the persons with RA, and conducted the initial analyses of the material, the transcribed material and analyses could not be approached with the same neutrality as in Study I. On the other hand, in accordance with confirmability, the material was approached with a reflexive view, and as mentioned, several researchers were involved in the analysis process, as well as a research partner (Taylor, 2007).

Study IV

The strengths of a mixed methods design is the development of a more comprehensive understanding of a phenomenon or group of people (Creswell & Creswell, 2018). Gaining knowledge from both perspectives is another strength of this study, which enhances its credibility (Taylor, 2007).

A potential issue with validity when using convergent mixed methods design is unequal sample sizes for the qualitative and quantitative material (Creswell & Creswell, 2018). As all data material in Study IV originated from the same sample, this was not an issue in this case. Additionally, as

recommended by Creswell and Creswell (2018), the same concepts were used in both types of materials, namely the quantitative outcomes constituted the predetermined codes in the qualitative analysis.

Even though 31 participants are not an optimal number quantitatively, it is a solid number qualitatively. In addition, the 31 participants have taken part in two interviews each, further enriching the material. When it comes to qualitative research, there are no rules for sample size, as it all comes down to what the researcher wants to know. This means that validity, meaningfulness and insights from qualitative data collection are more closely connected to the richness of the information, rather than the sample size (Patton, 2015).

When applying a deductive approach to qualitative analysis, as in Study IV, one question is how to treat data that does not fit into the pre-selected model or theory (Graneheim et al., 2017). In addition, by immediate coding, there is a risk of approaching data with bias (Hsieh & Shannon, 2005). However, in order to examine both quantitative and qualitative data, this type of approach seemed appropriate. Further, an overall question initiated the analysis process, so that no valuable data would be overlooked. In this way, the approach taken in Study IV concerning the qualitative analysis was more of an abductive type (Graneheim et al., 2017).

In terms of quantitative analyses in Study IV, to illustrate changes between men and women over time, a linear mixed model was used. This is preferable when working with a smaller sample as well as missing values (Krueger & Tian, 2004). The assessments used in Study IV are discussed earlier, apart from VLA-swe. This is the Swedish version of an originally American assessment and has been culturally adapted and tested for internal consistency and construct validity, with good results (Björk et al., 2016). As a central concept of this thesis is participation, using the VLA-swe that assesses participation in valued life activities is a strength. Compared to HAQ, VLA-swe adds a social dimension to activities, which is also relevant to this thesis. The assessment also includes activities that can be considered more updated and relevant to today's persons with RA in comparison to activities in HAQ. Moreover, Björk and colleagues (2016) demonstrated that an individual may score 0 (=no difficulty) in HAQ, while exhibiting disability according to VLA-swe. The original assessment (American version) has also previously captured discretionary activities, such as socialising, as most affected (Katz et al., 2006). VLA-swe furthermore covers a broad spectrum of activities that are relevant to persons with RA today and puts the person's preferences in focus (Björk et al., 2016), which is additionally in line with person-centred care. In conclusion, VLA-swe is considered a good assessment in the case of Study IV and this thesis.

CONCLUSIONS

This thesis concludes that significant others as part of the social environment can both hinder and facilitate participation in the everyday life of persons with RA. As a way to facilitate and enhance participation, understanding and support are important, including several years after being diagnosed with the disease. Significant others should also be attentive of the need for adaptations as well as the emotional burden and potential role stress in persons with RA. In addition, they need to find the balance between overlooking and overprotecting the person with RA. This is also important since these adaptations are still needed even after a decade with RA. As the longitudinal results show, disability is still evident and needs further attention.

In turn, significant others might need support in finding this balance, which relates to the need for well-functioning communication. One part of this is for HCPs to provide informational support to significant others and encounter the person with RA and the significant other as a unit in the treatment and rehabilitation process. HCPs should attend to both of them since persons with RA and their significant others live close together, both with each other and the disease. This is also an example of the support needed from outside the dyads of persons with RA and their significant others. Additionally, it exemplifies possible non-pharmacological interventions that need to be further developed and evaluated.

Moreover, the person with RA engaging in reciprocal relationships with well-functioning communication is a good foundation for participation in everyday life. Support from both outside and inside the dyad has been concluded as influential, sometimes crucial, both at an early stage and throughout the disease process. The provision of support has been proven important in everyday life, including a sustainable work life. Therefore, support from significant others can preferably be part of the rehabilitation process as a step towards enhanced participation in the everyday life of persons with RA.

Implications for practice

In relation to the rehabilitation process, the results from Study I-IV can give several suggestions with reference to participation. First of all, participation in itself is important to assess. This in order to reinforce the person's subjective experience, as the subjective experience and assessments do not always coincide (Study IV). Therefore, to paint an even

clearer picture, assessing participation as clinical routine can give even more comprehensive information about the person's experiences of everyday life. Additionally, it may raise the question of whether previous and commonly used assessments are measuring what is needed in the 2020s.

Further, Study I-III indicate that significant others should be invited to be a part of the process to a larger extent, in the interest of supplying information and tools to use and work with in their everyday life together with the person with RA. Additionally, it involves them in providing support with the purpose of enhancing participation in the everyday life of persons with RA. This can be performed in steps. Firstly, HCPs should provide informational (and emotional, if requested) support to the unit of the person with RA and the significant other, whereby, by being a part of the process and provided with this support, the significant other is given the opportunity to provide support to the person with RA in. This process is illustrated in Figure 8.

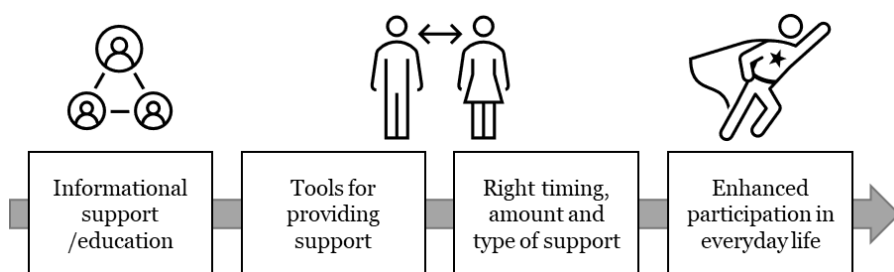


Figure 8. Process of significant others' involvement in order to provide support.

These suggestions regarding the involvement of significant others and the dyad working together outside of physical healthcare units are in line with the Swedish guidelines considering the management of RA. The guidelines emphasise the active involvement and responsibility of the person with RA, as well as support from outside healthcare, for example, in relation to continued work life (SKR, 2020). Moreover, the suggestions are part of the non-pharmacological interventions requested by persons with RA.

Looking beyond the diagnosis of RA, it is also of value to investigate the possibility of implicating this type of approaches when it comes to persons with other diagnoses. There are many other diseases that are chronic, with similar symptoms such as pain and fatigue, which result in activity limitations. In these cases, significant others might also be in need of different kinds of support and become involved in the process of care and/or rehabilitation. Therefore, there are no obstacles for transferring these suggestions to other diagnoses.

Future research suggestions

- As discussed, and as previous research suggests, it is of value to look further into different types of support, preferably over a longer time period. Our results show that support is needed both early and continuously, which should be further examined. Information about the support needs of persons with RA can be collected through both individual interviews, to gain a deeper and subjective understanding, as well as through, for example, surveys. Continuing from the results of such studies, interventions including support can be elaborated, with the possibility of pinpointing the type, amount and timing of the support.

- Even though the significant others of persons with RA are an important part of this thesis, their voices should be more extensively heard and listened to on different levels. A preferable strategy for this is to carry out qualitative interviews, but also by including larger samples and conduct surveys. As a part of including them in the rehabilitation process, their needs should also be taken into consideration.

- In the result from Study IV, we saw that the persons' perceptions and the assessments do not necessarily coincide. Therefore, it is of importance to examine whether the incorporation of more self-reported and subjective assessments, such as the VLA scale in clinical settings, can give a more thorough description of the person's experience in everyday life. In relation to this, it might also be of value to further develop questionnaires such as HAQ to make them relatable for today's patients.

- The implication of support from significant others as part of the rehabilitation process needs further investigation. To start, a deeper understanding of the type and timing of support (suggested in points above) can guide the development of educational modules regarding what different sets can contain and when they should be offered. One part of these educational interventions can be to develop and evaluate education modules specifically adapted for significant others. Another part might be to develop and incorporate the approach of the person with RA and significant other as a unit. Through this, HCPs can work together with the two parties in providing support and tools they can work with in everyday life. Another aspect is the possibility for web-based provision of this type of intervention. Considering today's needs for flexibility and accessibility, providing knowledge and educational modules in digital form is certainly of interest. In all cases, the effects of suggested educational interventions can be evaluated by looking into the experience of participation in everyday life, for example, by using the VLA scale as assessment.

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