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# Sexual Health in Rheumatoid Arthritis

– a physiotherapeutic approach

Kristina Areskoug Josefsson



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Physiotherapy, Faculty of

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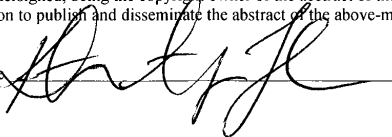
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Abstract <p>The overall aim of this thesis was to study how persons experience the influence of Rheumatoid Arthritis (RA) on their sexual health and their experiences of communication about sexual health, in order to improve physiotherapy within the field of rheumatology. Sexual health is an integrated part of life, and persons with Rheumatoid Arthritis, RA, often experience decreased sexual health, which can affect their overall quality of life. RA is a chronic systematic inflammatory disease with physical, social and psychological impact on the functioning of the patient. Common symptoms of RA are pain, fatigue, morning stiffness, reduced physical capacity and joint swelling. Symptoms during flares are complex and experienced in different ways. They can be described as multilayered symptoms affecting the whole body experience. Physiotherapy for persons with RA is usually directed towards improving activities of daily living, dealing with specific symptoms, such as pain or limited joint mobility, and it is important to widen this context to also include sexual relations.</p> <p>The thesis has a mixed paradigm design in a fixed multiphase model, including qualitative, quantitative and psychometric methods, in order to respond to the research question and the aims of the thesis. The first study explored the views of persons living with RA concerning sexual health in relation to physiotherapy, and covered how the body and the total life situation affected sexual health. The impact of RA was experienced as multidimensional. The findings consisted of three themes: 1) Sexual health – physical and psychological dimensions, 2) Impacts of RA and 3) Possibilities of increasing sexual health – does physiotherapy make a difference? The findings from the first study were used as a base for the questionnaire used in the second study in order to further investigate views and experiences of the impact of RA on sexual health, experiences and needs of physiotherapy in this context as well as communication between patients and health professionals concerning sexual health. The results of the second study clarified the need to improve communication and interaction between healthcare professionals and persons with RA concerning sexual health. This was investigated in the fourth study, where the question of whether decreased sexual health can be detected with a standard outcome measurement tool was explored. In order to perform the fourth study, the Multi Dimensional Health Assessment Questionnaire had to be validated and tested for reliability in a Swedish context, which was performed in the third psychometric study.</p> <p>To conclude, sexual health is affected in different ways for persons with RA, and there is a lack of communication concerning sexual health between health professionals and persons with RA. Physiotherapists can play an active role in improving sexual health for persons with RA by being aware that pain, fatigue, decreased mobility, and level of physical capacity can affect sexual health negatively. Improvement of communication concerning sexual health between persons with RA and their partners, as well as with health professionals, may improve sexual health among persons with RA.</p> <p>The Swedish version of the Multi Dimensional Health Assessment Questionnaire (MDHAQ-S) was found to have acceptable reliability and validity, and can be used as a base for sexual health communication since it correlates significantly with results of the Questionnaire of Sexual Health in persons with RA. The MDHAQ-S covers issues concerning sexual health in a multiple way to deepen the prerequisites for sexual health communication, but to uncover sexual health difficulties an in-depth clinical interview or a more specific sexual health questionnaire is needed.</p>		
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# Sexual Health in Rheumatoid Arthritis

– a physiotherapeutic approach

Kristina Areskoug Josefsson



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**Appendix 1 – Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy**

**Appendix 2 – Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy, Swedish version**

**Appendix 3 – Multi Dimensional Health Assessment Questionnaire, Swedish version (MDHAQ-S)**

**Appendix 4 - Questionnaire of sexual health for persons with RA**

**Appendix 5 - Questionnaire of sexual health for persons with RA, Swedish version**

## **Papers**

**Paper I - Women's experiences of sexual health when living with Rheumatoid Arthritis**

**Paper II – Sexual health in patients with Rheumatoid Arthritis – experiences, needs and communication with health care professionals**

**Paper III – Swedish version of the MDHAQ – Translation and psychometric evaluation**

**Paper IV – Detecting decreased sexual health with MDHAQ-S**

# List of publications

- I. Josefsson, K. A. & Gard, G. Women's experiences of sexual health when living with Rheumatoid Arthritis - an explorative qualitative study. *BMC Muskuloskelet Disord.* 2010 Oct 15;11:240.
- II. Josefsson, K. A. & Gard, G. Sexual health in patients with Rheumatoid Arthritis - experiences, needs and communication with health care professionals. *Musculoskeletal Care.* 2012 Jun;10(2):76-89. doi: 10.1002/msc.1002.
- III. Areskoug-Josefsson, K., Ekdahl, C., Jakobsson, U., Gard, G. Swedish version of the multidimensional health assessment questionnaire – translation and psychometric evaluation. *BMC Musculoskeletal Disorders* 2013, 14:178(4 June)
- IV. Areskoug-Josefsson, K., Ekdahl, C., Jakobsson, U., Gard, G. Detecting decreased sexual health with MDHAQ-S. *Health* 2013 (5)38-47

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# Abstract

The overall aim of this thesis was to study how persons experience the influence of Rheumatoid Arthritis (RA) on their sexual health and their experiences of communication about sexual health, in order to improve physiotherapy within the field of rheumatology. Sexual health is an integrated part of life, and persons with Rheumatoid Arthritis, RA, often experience a decreased sexual health, which can affect their overall quality of life. RA is a chronic systematic inflammatory disease with physical, social and psychological impact on the functioning of the patient. Common symptoms of RA are pain, fatigue, morning stiffness, reduced physical capacity, and joint swelling. Symptoms during flares are complex and experienced in different ways. They can be described as multilayered symptoms affecting the whole body experience. Physiotherapy for persons with RA is usually directed towards improving activities of daily living, dealing with specific symptoms, such as pain or limited joint mobility, and it is important to widen this context to also include sexual relations.

The thesis has a mixed paradigm design in a fixed multiphase model, including qualitative, quantitative and psychometric methods, in order to respond to the research question and the aims of the thesis. The first study explored the views of persons living with RA concerning sexual health in relation to physiotherapy, and covered how the body and the total life situation affected sexual health. The impact of RA was experienced as multidimensional. The findings consisted of three themes: 1) Sexual health – physical and psychological dimensions, 2) Impacts of RA and 3) Possibilities of increasing sexual health – does physiotherapy make a

difference? The findings from the first study were used as a base for the questionnaire used in the second study in order to further investigate views and experiences of the impact of RA on sexual health, experiences and needs of physiotherapy in this context, as well as communication between patients and health professionals concerning sexual health. The results of the second study clarified the need to improve communication and interaction between healthcare professionals and persons with RA concerning sexual health. This was investigated in the fourth study, where the question of whether decreased sexual health can be detected with a standard outcome measurement tool was explored. In order to perform the fourth study, the Multi Dimensional Health Assessment Questionnaire had to be validated and tested for reliability in a Swedish context, which was performed in the third psychometric study.

To conclude, sexual health is affected in different ways for persons with RA, and there is a lack of communication concerning sexual health between health professionals and persons with RA. Physiotherapists can play an active role in improving sexual health for persons with RA by being aware that pain, fatigue, decreased mobility, and level of physical capacity can affect sexual health negatively. Improvement of communication concerning sexual health between persons with RA and their partners, as well as with health professionals, may improve sexual health among persons with RA.

The Swedish version of the Multi Dimensional Health Assessment Questionnaire (MDHAQ-S) was found to have acceptable reliability and validity, and can be used as a base for sexual health communication since it correlates significantly with results of the Questionnaire of Sexual Health in persons with RA. The MDHAQ-S covers issues concerning sexual health in

a multiple way to deepen the prerequisites for sexual health communication, but to uncover sexual health difficulties, an in-depth clinical interview or a more specific sexual health questionnaire is needed.

# Summary in Swedish - Svensk sammanfattning

Reumatoid artrit (RA) även kallat ledgångsreumatism, är en ledsjukdom som innebär inflammationer i kroppens leder. Sjukdomens symptom är smärta, trötthet, nedsatt fysisk kapacitet med svullna, ömma leder. Kvinnor drabbas i större utsträckning av ledgångsreumatism än män. Sjukdomen är kronisk och behandlas med antireumatiska läkemedel samt kompletterande teambaserad behandling som vanligtvis innefattar även sjukgymnastik, social vägledning och arbetsterapi. Sjukgymnaster som arbetar med patienter med ledsjukdomar arbetar vanligtvis med att stödja patienter för att förbättra sin fysiska aktivitet, öka den fysiska kapaciteten (styrka, kondition, rörlighet) och med smärtlindrande behandling. Behandlingen kan vara individuell eller i grupp. Under mitt kliniska arbete som sjukgymnast för patienter med ledsjukdomar funderade jag på hur nyttan av sjukgymnastik upplevdes av patienterna. Var det enbart förbättring av muskelstyrka/ledrörlighet, minskning av smärta eller fanns det andra sätt att se på nyttan av sjukgymnastik? Det kändes viktigt att få fram vad som faktiskt var den upplevda nyttan med mitt arbete, så jag genomförde patientintervjuer med patienter med ledgångsreumatism (RA) för att få svar på frågan. Ett av resultaten av intervjustudien var att sjukgymnastik upplevdes ha positiv effekt på det sexuella livet. Denna nya spännande infallsvinkel blev starten på mitt avhandlingsarbete. Det övergripande syftet med mitt avhandlingsarbete var att utforska hur patienter med ledgångsreumatism upplevde att deras sjukdom hade påverkat deras sexuella hälsa och deras erfarenheter av kommunikation om sexuell hälsa,

med målet att förbättra det sjukgymnastiska omhändertagandet av patientgruppen.

Delmålen för de inkluderade studierna var; 1) att beskriva och analysera sexuell hälsa i relation till sjukgymnastik för kvinnor med RA, 2) att utforska upplevelser och påverkan av RA på sexuell hälsa, upplevelser och behov av sjukgymnastik och kommunikation mellan patienter med RA och sjukvårdspersonal gällande sexuell hälsa, 3) Att skapa en valid och reliabel svensk version av Multi Dimensional Health Assessment Questionnaire (MDHAQ-S), som möter den psykometriska standard som den ursprungliga MDHAQ har, 4) Att undersöka om MDHAQ-S korrelerar med ett frågeformulär om sexuell hälsa och om de inkluderade frågorna i MDHAQ-S kan fånga upp nedsatt sexuell hälsa hos patienter med RA.

Avhandlingens resultat är tänkta att användas i den kliniska vardagen, i mötet mellan patient och sjukvårdspersonal, för att förbättra kommunikationen kring sexuell hälsa och därigenom förbättra omhändertagandet av patienterna som inom området sexuell hälsa. Målet är även att ge sjukgymnaster ett bredare perspektiv på sina rehabiliteringsinsatser för denna patientgrupp, genom att påvisa hur sjukgymnastik upplevs påverka sexuell hälsa. Definitionen av sexuell hälsa kommer från Världshälsoorganisationen, WHO, och innebär att "sexuell hälsa är ett tillstånd av fysiskt, emotionellt, mentalt och socialt välbefinnande relaterat till sexualitet, inte endast frånvaro av sjukdom, dysfunktion eller svaghet. Sexuell hälsa kräver ett positivt och respektfullt närmande till sexualitet och sexuella relationer, liksom möjligheter att få njutbara och säkra sexuella erfarenheter, fria från förtryck, diskriminering

och våld.” Det är en bred definition som har använts som grund i avhandlingsarbetet.

Denna breda definition ligger till grund för den övergripande slutsatsen av avhandlingen, vilken är att information, kommunikation och sjukgymnastiska användas i kombination, inte som enskilda strategier för att förbättra sexuell hälsa, för att ge ett mer övergripande stöd för att förbättra sexuell hälsa för patienter med ledgångsreumatism.

För att få bred kunskap om sexuell hälsa för patienter med RA och sjukgymnastens roll har både kvantitativa (enkäter) och kvalitativa metoder (intervjuer) använts i avhandlingsarbetet. Förfarandet kallas ”mixed methods research” och används för att ge ett brett och fördjupat perspektiv på forskningsområdet.

Sexuell hälsa är en viktig del av livet, och nedsatt sexuell hälsa kan i sig påverka den allmänna hälsan negativt. Detta gör att det är viktigt att sjukvårdspersonal har kunskap om hur de kan kommunicera om sexuella problem och vad det finns för möjligheter att förbättra sexuell hälsa. Sjukgymnastik och en förbättrad kommunikation, både mellan patient och partner och mellan patient och sjukvårdspersonal kan underlätta möjligheten att hitta fungerande lösningar.

I de studier som har ingått i avhandlingen har det visat sig att sjukvårdspersonal nästan aldrig pratar om sexuell hälsa med patienter med RA, trots att en stor andel patienter upplever att deras sexuella hälsa har försämrats på grund av ledsjukdomen. För patienternas del är det framför allt viktigt att de känner förtroende för den de pratar med, detta är viktigare än yrkesroll. Vikten av sexuell hälsa förändras genom livet

beroende på ålder, livshändelser och sjukdom. De genomförda studierna visar att de deltagande patienterna vanligtvis tycker att det sexuella livet är viktigt för deras välbefinnande även om de har en kronisk sjukdom och är medelålders eller äldre. Gällande sjukgymnastik så tycker patienter att det finns ett starkt samband vad gäller förbättrad kondition, minskad smärta och förbättrad sexuell hälsa. Patienterna upplever även att sjukgymnastik ger självförtroende och en ökad tillfredsställelse med sig själva och sin kropp, vilket de tycker påverkar sexuell hälsa positivt. Detta överensstämmer med tidigare forskning, om sambandet mellan en fysiskt aktiv livsstil, god kroppskänning och en god sexuell hälsa.

För att underlätta kommunikation mellan patienter med RA och sjukvårdspersonal har ett frågeformulär om sexuell hälsa och hur ledgångsreumatism påverkar den sexuella hälsan skapats (QSH). Ett frågeformulär som används för att följa upplevelsen av den reumatiska sjukdomen generellt (MDHAQ-S) har översatts till svenska och testats under svenska förhållanden, med syfte att undersöka om frågeformuläret kan användas för att visa på nedsatt sexuell hälsa. Frågeformulären har jag valt att arbeta med eftersom användandet av frågeformulär kan underlätta kommunikationen kring känsliga ämnen, såsom sexuell hälsa. Resultaten av arbetet med frågeformulären visar att det generella frågeformuläret MDHAQ-S kan användas för att påvisa nedsatt sexuell hälsa, men att ett mer specifikt frågeformulär eller en utökad anamnes behöver användas för att få fram på vilket sätt den sexuella hälsan har påverkats till exempel om det gäller nedsatt sexuell lust, sexuell tillfredsställelse eller sexuell funktion.

En av slutsatserna i avhandlingen är att sexuell hälsa kan påverkas på olika sätt av ledgångsreumatism under sjukdomens progression, samt beroende

på ålder. Därför bör sexuell hälsa vara ett ämne som lyfts regelbundet vid möte mellan patient och reumatologisk sjukvårdspersonal för att möjliggöra ett förbättrat omhändertagande och ge stöd för att förbättra den sexuella hälsan hos patienterna. Ett sätt att uppnå detta, med respekt för patientens integritet, är att använda ett frågeformulär som MDHAQ-S för att utforska om den sexuella hälsan är nedsatt. De symptom som vanligtvis är sammanlänkade med nedsatt sexuell hälsa är negativ kroppsuppfattning, trötthet, värk och nedstämdhet. Sjukvårdspersonal måste ha kunskap om hur ledgångsreumatism kan påverka sexuell hälsa negativt, samt ha en medvetenhet om hur de med sin yrkeskunskap kan medverka till att förbättra patienternas sexuella hälsa för patienterna. Ett viktigt redskap är kommunikation om sexuell hälsa i den kliniska vardagen. I denna kommunikation ingår att ge information om hur den sexuella hälsan kan påverkas av ledgångsreumatism samt hur mediciner och rehabilitering kan förbättra sexuell hälsa. Strategier för kommunikation om sexuell hälsa behöver införas i de reumatologiska teamen, förslagsvis i kliniska riktlinjer.

Som sjukgymnast går det att stödja patienter att förbättra sin sexuella hälsa genom att motivera dem att öka sin mängd fysisk aktivitet, förbättrad fysisk kapacitet och rörlighet samt genom smärtlindrande behandling. Dessa behandlingar ingår i sedvanlig rehabilitering av patienter med ledgångsreumatism, men som sällan diskuteras utifrån perspektivet att förbättra sexuell hälsa. Patienter med ledgångsreumatism bör bli informerade om sambandet mellan sexuell hälsa och en fysiskt aktiv livsstil.

# Thesis at a glance

<b>Paper I: <i>Women's experiences of sexual health when living with Rheumatoid Arthritis - an explorative qualitative study</i></b>	
<b>Aim</b>	The aim of the study was to explore sexual health in relation to physiotherapy in women living with RA. An explorative qualitative interview study with a phenomenological approach was performed.  The main theme that emerged in the data was that the body and the total life situation affected sexual health. Three categories were included in the theme: 1) Sexual health – physical and psychological dimensions, 2) Impacts of RA and 3) Possibilities of increasing sexual health – does physiotherapy make a difference?  <ul style="list-style-type: none"> <li>• Sexual health was affected by RA in different ways according to the informants.</li> <li>• The possibilities of improving sexual health were improved partner communication and physiotherapy.</li> <li>• Physiotherapy can play an active role in improving sexual health for patients with RA.</li> </ul>
<b>Methods</b>	
<b>Results</b>	
<b>Conclusion</b>	
<b>Paper II: <i>Sexual health in patients with Rheumatoid Arthritis - experiences, needs and communication with health care professionals</i></b>	
<b>Aims</b>	<ul style="list-style-type: none"> <li>• To further explore the experiences and views of impacts of RA on sexual health and experiences, and needs for physiotherapy;</li> <li>• To explore experiences of communication between patients with RA and health professionals concerning sexual health;</li> <li>• To analyse internal consistency of a sexual health questionnaire, the Questionnaire concerning sexual health for persons with RA.</li> </ul>
<b>Methods</b>	

<p><b>Results</b></p> <p><b>Conclusion</b></p>	<p>Quantitative study. Development and testing of a sexual health questionnaire. Exploration of experiences of sexual health among persons with RA.</p> <p>The questionnaire had good internal consistency. The results of the questionnaire showed that sexual health was not discussed between patients and health professionals. The frequency of patients experiencing decreased sexual health due to RA was similar to studies in other contexts.</p> <p>Physiotherapists need to be aware that pain, fatigue, decreased joint mobility and physical capacity can affect sexual health in patients with RA.</p> <p>Health professionals and patients with RA do not discuss sexual health. It is important to have a strategy about how to bring up sexual health in meetings between the patient with RA and the health professional to achieve the best possible care.</p>
<p><b>Paper III: <i>Swedish version of the MDHAQ – Translation and psychometric evaluation</i></b></p>	
<p><b>Aims</b></p> <p><b>Methods</b></p> <p><b>Results</b></p> <p><b>Conclusion</b></p>	<p>To find out whether sexual health difficulties can be screened by factors included in the MDHAQ-S for persons with RA.</p> <p>Quantitative study. Translation and adaptation of the MDHAQ-S to a Swedish context.</p> <p>Test-retest with intra-class correlation coefficient (ICC) gave a coefficient of 0.85 for physical function and 0.79 for psychological properties. Reliability test with Cronbach's alpha gave an alpha of 0.88 for the physical dimension and an alpha of 0.65 for the psychological dimension of the MDHAQ-S.</p> <p>The average sum of the content validity index for each item was of the MDHAQ-S was 0.94. The MDHAQ-S had mainly a moderate correlation with the AIMS2-SF, except for the social dimension of the AIMS2-SF, which had a</p>

	<p>very low correlation with the MDHAQ-S.</p> <p>The MDHAQ-S is an acceptably reliable and valid tool, and can be of use in clinical care for patients with RA, even if there are items that should be further developed to improve the MDHAQ-S. Further research is recommended concerning sensitivity to change.</p>
<p><b>Paper IV: <i>Detecting decreased sexual health with the MDHAQ-S</i></b></p>	
<p><b>Aims</b></p> <p><b>Methods</b></p> <p><b>Results</b></p>	<p>To investigate whether the MDHAQ-S correlates with a sexual health questionnaire and whether questions in the MDHAQ-S can detect decreased sexual health for persons with Rheumatoid Arthritis.</p> <p>A mixed methods design combining quantitative and qualitative data. Comparison between the MDHAQ-S and Questionnaire of sexual health (QSH). The collected data from the QSH and the MDHAQ-S were analysed using descriptive statistics, frequencies and proportions. They were also analysed for correlation with Spearman's rank correlation for the items included as well as for the physical and psychological dimensions of the MDHAQ-S. Multiple regression analysis was performed to identify associated factors to sexual wellbeing. The criterion variable was sexual wellbeing from the QSH, and the independent variables included from the MDHAQ-S were total score of physical function, total score of psychological function, pain, fatigue, and general wellbeing. The qualitative findings were analysed with content analysis.</p> <p>There were significant correlations between the MDHAQ-S and the QSH. The qualitative analysis led to the theme "change". The analysis of "<i>How has RA affected my experience of my body?</i>" included the categories <i>physical changes (weight, appearance, physical function)</i>, <i>changed experience of the body (changed body image, changed acceptance of the body, discontentment with the body)</i>, and <i>effect of medication on the body</i>. The categories included in "<i>How has RA affected my sexual health?</i>" were <i>changed physical functioning (pain, fatigue, changes</i></p>

<p><b>Conclusion</b></p>	<p><i>in arousal, effects of age, decreased ability of intimacy), and effects on intimate relationships (acceptance within the relationship, worsening relationship, improved relationship).</i></p> <p>The MDHAQ-S covered sexual health issues, not only by using the question concerning sexual health, but also by using other questions included in the questionnaire such as increased pain, fatigue, depression, anxiety, physical capacity, level of physical activity, and body weight. To explore decreased sexual arousal, decreased sexual satisfaction and decreased sexual wellbeing, there is a need to conduct a deeper interview of persons with RA, either using a sexual health questionnaire or in a clinical interview. Improving communication about sexual health with respect for the person's integrity is essential, and further research into how this can be done is needed to improve sexual health in persons with RA.</p>
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# Abbreviations

ACR = American College of Rheumatology

AIMS = Arthritis Impact Measurement Scale

AIMS 2 = Arthritis Impact Measurement Scale 2

AIMS2SF = Arthritis Impact Measurement Scale 2 Short Form

CDAI = Clinical Disease Activity Index

CVI = Content Validity Index

DAS-28 = Disease Activity Scale 28

DMARD = Disease Modifying Anti Rheumatic Drug

HAQ = Health Assessment Questionnaire

HAQ-DI = Health Assessment Disability Index

ICF = International Classification of Functioning, Disability and Health

MDHAQ = Multi Dimensional Health Assessment Questionnaire

MDHAQ-S = Multi Dimensional Health Assessment Questionnaire, Swedish version

PAS = Patient Activity Scale

PAS II = Patient Activity Scale II

QoL = Quality of Life

QSH = Questionnaire of Sexual Health

QSHP = Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy

RA = Rheumatoid Arthritis

RADAI = Rheumatoid Arthritis Disease Activity Index

RAPID3 = Routine Assessment of Patient Index Data with 3 measures

SDAI = Simplified Disease Activity Index

WHO = World Health Organization

# Definitions

Sexual Health = “Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.” [1]

Physiotherapy/Physical therapy = “Physical therapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in circumstances where movement and function are threatened by ageing, injury, diseases, disorders, conditions or environmental factors. Functional movement is central to what it means to be healthy. Physical therapy is concerned with identifying and maximizing quality of life and movement potential within the spheres of promotion, prevention, treatment/intervention, habilitation and rehabilitation. This encompasses physical, psychological, emotional, and social wellbeing. Physical therapy involves the interaction between the physical therapist, patients/clients, other health professionals, families, care givers and communities in a process where movement potential is assessed and goals are agreed upon, using knowledge and skills unique to physical therapists.”[2]

# Rationale

In my clinical work as a physiotherapist working with persons with rheumatologic diseases, I met women with Rheumatoid Arthritis (RA) who described that according to their experience, common physiotherapeutic interventions had a positive effect on their sexual life. The subject of sexual health is rarely communicated between physiotherapists and persons with RA, which motivated me to explore this field further with questions like: What is the role of the physiotherapist in this field? How can physiotherapy enhance sexual health?

The primary intention of the thesis was to investigate sexual health and RA from the women's perspective. In connection with the start of the thesis, a literature review was performed with the aim of exploring both the literature concerning the effects of RA on sexual health of female patients as well as the recommended strategies to improve sexual health of women with RA [3]. The conclusion of the review was that sexual health problems are common for women with RA. The problems can occur before, during and after sexual activities, and affect women's sexual health in several different ways. To ensure a broader perspective on how RA could affect sexual health, both men and women were included in the thesis.

Physiotherapy was one of the few mentioned recommendations in the literature review on how to improve sexual health. The findings of this literature review were used as a base for current research when planning the work of the thesis.

# Introduction

Sexual health is an integrated part of life, and persons with Rheumatoid Arthritis, RA, often experience decreased sexual health, which can affect their overall quality of life [3]. RA often leads to limitations in physical ability and function, areas that might affect sexual health in a negative way. Those areas are regularly addressed by physiotherapy interventions both as single therapy and in multidisciplinary team rehabilitation. Physiotherapy for persons with RA aims to maintain good quality of life and to reduce the burden of disease, for example, by improving muscle strength, joint mobility and physical capacity [4].

## Sexual health from a bio-psychosocial perspective

Sexual health is a broad field with biological, psychological and social perspectives. Sexuality in itself is complex and multidimensional consisting of biological, affective, cognitive and motivational parts, and not only limited to the act of sexual intercourse. Intimacy, proximity and sexuality are involved parts of life through the lifespan. Sexual health is defined as “...a state of physical, mental and social well-being in relation to sexuality. To obtain sexual health, a positive and respectful approach to sexuality and sexual relationships is required, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence” [5].

Sexual health can be described from a bio-psychosocial perspective, including the following aspects: biological (hormonal and vascular systems, illness/treatment), psychological (sexual information, attitudes towards

sexual expression, mental health and depression/treatment) and social (availability of a partner, length of relationship, quality of relationship and income) [6]. All of those aspects can be involved in the quality of a person's sexual health.

Psychological, interpersonal factors and life experiences are involved in a person's sexual health and sexual health difficulties. Sexual dysfunction can be due to predisposing, precipitating, maintaining as well as contextual factors [7]. Predisposing factors consist both of constitutional factors and earlier life experiences. Triggers for impaired sexual health are precipitating factors. Maintaining factors can be impaired self-esteem, anxiety, poor communication and fear of intimacy. Contextual factors can be stressful situations in daily life, as for example, poor economic status. Income can be affected for persons with chronic illness due to sick-leave from work or inability to work full-time [8]. Self-reported poor general health is associated with increased sexual dysfunctions for both men and women [9]. Sexual desire is affected by good health, good self-esteem and good sexual function [10].

Sexual health as concept was originally mainly discussed with focus on reproduction and function of sexual organs [11]. During the past few decades, this has gradually changed [11]. The World Health organization (WHO) has played an important role in bringing sexual health into health promotion and has organized symposiums in sexual health since 1974 [12]. In 1974 WHO also defined three levels of clinical interventions in sexual health: sexual information, counselling and sexual therapy [12]. A good sexual life requires absence of sexual diseases and is connected to self-esteem, intimate relationships and overall quality of life. To many people, a

good quality of life is strongly connected to good sexual health. However, the definition of what defines good sexual health is individual and might also change during one's life. The changes can be due to many circumstances in life, such as aging, illness or loss of a partner. Sexual health incorporates intimate relationships, and the quality of the relationship can affect the sexual health as well as vice versa.

Chronic diseases frequently affect sexual health negatively, both directly and indirectly [13, 14]. An example of direct negative effect on sexual health is a disruption of sexual response and desire due to pain. An indirect negative effect can depend on impaired mobility or reduced energy [13]. A chronic disease often has a negative impact on several dimensions in life and can be experienced as stressful. Chronic stress has a negative impact on sexual health, since chronic stress reduces the sexual response. Sexual response is also reduced by marked tiredness and depression, which are common for persons with chronic diseases [15]. Pain can also reduce the willingness to participate in sexual activities [16]. Chronic illness can challenge and affect a person's sexual health in several ways, such as influencing the perception of identity and self-esteem, the ability to change roles in the relationship and/or affecting somatisation of symptoms [17]. Sexual health problems or needs are often ignored due to the focus on the chronic illness itself [18].

In physiotherapy research concerning sexual function and intimate relationships, the research has been focused on sexual life, sexuality and sexual functioning [14, 19, 20]. In this thesis, the term sexual health has been used, since the thesis aims to focus on the broad spectrum of sexual health, as defined by the WHO [5]. Sexual health is also the term

recommended in sexology research according to Nordic Association of Clinical Sexology (NACS conference, 2011), due to its broad and inclusive character.

The International Classification of Functioning, Disability and Health (ICF) by WHO includes sexual health in two dimensions: sexual functions (b640) and intimate relationships (d770) [21]. These two dimensions are included in the ICF core sets for RA [22].

### **Sexual function**

Normal sexual functioning consists of sexual activity with transition through the phases from arousal to relaxation with a feeling of pleasure, fulfilment and satisfaction, according to the ICF [21, 23]. Recent studies showed that sexual dysfunction was experienced by 5-11% of people aged 16-95 years of age [24, 25]. There are difficulties in measuring prevalence of sexual dysfunction, depending on which instruments used, thus the prevalence might differ [26]. Research is lacking concerning the epidemiology of female sexual dysfunction [18, 27]. Due to gender differences, sexual function is described separately for women and men. Women's sexual function concerns desire, arousal, orgasm, and sexual satisfaction. Female sexual dysfunction includes hypoactive sexual desire disorder, female sexual arousal disorder, and pain disorders including dyspareunia and vaginismus [28]. Women in general often experience that feelings of intimacy are more important than sexual arousal [29].

Male sexual function can be described in five different areas: erection, orgasmic function, sexual desire, sexual satisfaction and satisfaction with sexual life. Sexual dysfunction can occur in all those fields. Among older

men, good health and good self-esteem are important factors influencing how the frequent they continue with sexual activities [10]. There is research considering erectile dysfunction in men, but there is a lack of research considering other male sexual dysfunctions [18, 27].

### **Intimate relationships**

Intimate relationships are described by the ICF as creating or maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners [21]. Intimate relationships can be affected both in a negative and a positive way by chronic disease, since changes in life due to the disease can either be a source for stress or for relational growth [18]. Sexual satisfaction affects intimate relationships positively, and problems within the intimate relationship affects sexual function negatively [30, 31]. In this thesis, we have had an open definition of intimate relationships, made by each participant. However, intimate relationships are often considered as sexual and/or marital relationships.

### **Addressing sexual health**

Sexual health is a field that should be addressed multidisciplinary and is not the responsibility of a single profession [32]. Sexual health issues have traditionally been addressed by physicians, therapists, counsellors and educators. This has not generally included physiotherapists, even though physiotherapy aims at being holistic and working towards maintaining, restoring and promoting physical function and quality of life [32, 33]. There are, however, some fields where physiotherapists have been directly involved in sexual health, such as the treatment of pelvic disorders and incontinence. Other rehabilitative fields where physiotherapy interventions

are more indirect are cardiac, neurological and orthopedic rehabilitation. Since sexual health issues are best discussed in context, physiotherapists might address sexual health issues when discussing body posture or physical function.

There are several possible reasons for the lack of discussion of sexual health with the patient by health professionals, such as the sensitivity of the subject; that health professionals are unsure on how to bring up the subject; that they are unsure of how they can support their patients; and/or believing that somebody else in the health care team is responsible for discussing sexual health with patients [34-37]. There can also be more practical reasons such as lack of time or lack of privacy during the meeting between the patient and the health professional [38]. One study [39] examined possible differences between health care professionals concerning their ability to address sexual health with their patients. All health professionals seemed to have similar reluctance in addressing the subject, but physiotherapists and occupational therapists were the least likely to discuss sexual health with their patients [39]. On the other hand, the patients themselves might also be unwilling to discuss sexual health, especially if they do not think that the health care professionals can offer any support [37, 40]. There are methods that can be used in order to increase and improve the communication concerning sexual health between health professionals and patients, such as the PLISSIT model [41] and the Recognition model [34]. However, they do not seem to be commonly used in rheumatologic or physiotherapeutic care.

The PLISSIT model has been used for patients with various physical and mental diseases. The PLISSIT model provides a graded counselling

approach allowing health professionals to deal with sexual issues at their own level of comfort and competence [41]. The four steps included in the model are the following:

- P-Permission: This step is the introduction of sexual health into the communication between the healthcare professional and the patient. Examples of permission giving could be having leaflets with information about sexual health in the waiting room of the clinic or by asking the patients if they want information about sexual health.
- LI- Limited Information: Limited information can be given by handing out information leaflets or by providing information verbally about how specific professional expertise can be of assistance concerning sexual health. In this step, it is important to have learnt what type of information the patient is interested in, instead of giving information that the health professional thinks is relevant.
- SS – Specific Suggestions: This is a step with a problem solving approach, and the type of solutions that can be discussed in this step depends on the expertise of the health professional. For example, the physiotherapist can inform about positions that are less strenuous to the joints, the occupational therapist can give advice on planning daily activities in life (including sexual activities), and the rheumatologist can give advice concerning medication.

- IT – Intensive Therapy: This level requires special training and is usually performed by a psychiatrist, psychologist or counselor.

The PLISSIT model gives guidance when the health professional should refer the patient to colleagues with more experience or expertise concerning sexual health. As a standard, persons with psychosexual problems should be referred to a psychosexual therapist, and persons with relationships difficulties should be referred to a counselor. For many patients, the permission-step and the limited information-step are sufficient to improve their sexual health [40].

The base of the step-wise Recognition Model is to recognize that disabled persons have sexual needs and desires [34]. The following steps are described in the Recognition Model [34]:

1. Recognition of the service user as a sexual being. This step requires patient centeredness and acknowledgement of the patient as a sexual being, with sexual needs and desires. All team members should be able to have a positive approach to direct questions of sexual health asked by the patient. If the team has a specific person with expertise in sexual health issues, a referral to this person, for example, could be done like this: “I understand you have sexual concerns that you wish to discuss. It is not my area of expertise, but I can ask my colleague to speak with you.”
2. Provision of sensitive, permission-giving strategies such as indirect questions, and printed information. An example of an indirect question that can be used is the following: “Some persons also have questions about sex. If you have anything you wish to ask, I am

happy to discuss your concerns.” The aim of this step is to invite persons to speak about sexual issues if they wish and still respect their privacy.

3. Exploration of the sexual problem/concern. This step includes exploring what issues are of importance to the patient. For some it might be issues of fatigue or pain and for others it might be maintaining an intimate sexual relationship. Other questions may concern how soon sexual intercourse can be resumed after hip replacement. This step of exploration is essential to give the appropriate advice and information to the person with RA.

The first three steps can be performed by all team members.

4. Address issues that fit within the team’s expertise and boundaries. This step includes the specific competencies of different professionals, for example, the occupational therapist can assist in fatigue management and enabling meaningful activities, and the physiotherapist can use their skills in managing pain and addressing biomechanical issues. In order to simplify the different roles and competencies in the teams, a useful question is:” What can your profession offer in the field of sexual health that cannot be offered by other health professions?” This step includes analysis of sexual concerns, planning of treatment and setting goals.
5. Referrals for further treatment, when necessary. This step demands that the team members have knowledge of wider resources that might be of use to the patient.

The step of recognition is important, especially if the health professionals' expertise is within disability rather than sexual health. The steps in the Recognition model might overlap, and it is important that the team ensures that all steps are included in the service given by the team around the patient. The Recognition Model identifies the existing skills among health professionals that can be useful to promote and protect sexual health for persons with disabilities. The Recognition Model is intended to be used by multi-professional teams. The Recognition model also aids in what is included in each professional role when it comes to addressing sexual health issues.

## **Rheumatoid Arthritis**

Rheumatoid Arthritis (RA) is a chronic systematic inflammatory disease with genetic, environmental and stochastic factors [42, 43]. The known risk factors for RA includes genetic, hormonal, medical and lifestyle factors as well physical/psychological trauma factors [44]. Smoking is a preventable risk factor for RA [45]. The prevalence of RA is 0.5-1.1% and the prevalence among adults in Sweden is 0.66-0.77% [43, 46-48]. The gender division in Sweden is 72.8% women and 27.2% men [48]. Women suffer worse consequences of RA, such as functional disability, than men [49-51]. A majority of the persons with RA in Sweden acquire the disease after the age of 40 and the incidence increases with age, with a peak around 70-79 years for both men and women [48, 52]. RA is characterized by inflammation in the synovial tissue. The diagnostic criteria from 1988, with criteria 1-4 having had to be present for at least six weeks, were the following [53]:

1. Morning stiffness in and around joints lasting for one hour before maximal improvement;
2. Soft tissue swelling (arthritis) of three or more joint areas observed by a physician;
3. Swelling (arthritis) of the proximal interphalangeal-, metacarpophalangeal- or wrist joints;
4. Symmetric swelling (arthritis rheumatoid nodules);
5. The presence of rheumatoid factor;
6. Radiographic erosions and/or periarticular osteopenia in hand and/or wrist joints.

Rheumatoid Arthritis was defined by the presence of four or more criteria [53]. The criteria were revised in 2010 in order to be more sensitive to the earlier stages of the disease [54]. The new RA criteria from 2010 are the following:

1. Confirmed presence of synovitis in at least one joint;
2. Absence of an alternative diagnosis better explaining the synovitis;
3. Achievement of a total score of 6 or greater (of a possible 10) from the individual scores in four domains: number and site of involved joints (range 0-5), serological abnormality (range 0-3), elevated acute-phase response (range 0-1) and symptom duration (two levels; range 0-1).

There are also extra-articular features of RA, such as nodules, vasculitis, pericarditis, neuropathy, interstitial lung disease and eye involvement [55]. The course of the disease is usually relapse-remitting, with periods of flares alternating with periods of lower disease activity [56]. Comorbidity, especially cardiovascular diseases, is common for persons with RA [57].

### **Symptoms of RA**

Common symptoms of RA are pain, fatigue, morning stiffness, reduced physical capacity and joint swelling [50, 58, 59]. Symptoms during flares are complex and are experienced in different ways. They can be described as multilayered symptoms, affecting the whole body experience [60]. The symptoms of RA can lead to a negative body image which in turn can lead to reduced self-esteem and physical function [61]. RA can also lead to rheumatoid cachexia, co-morbidity, depression and decreased quality of life [62-64].

### **RA – impact on life**

RA has a strong impact, physically, psychologically and socially, on the functioning of the patient, and patients often consider that their lives are being controlled by RA [65-67]. Persons with RA have reduced life expectancy, and RA is connected to several co-morbidities, in particular, cardiovascular- and respiratory diseases [43, 55]. Despite significant therapy improvements, RA still affects the Quality of Life (QoL) negatively, and patients with RA have lower QoL than the population in general [68]. Work and leisure-time activities are related to quality of life and are often affected by RA in a negative way [69, 70]. Both presenteeism and

absenteeism are more common among persons with RA than in the general population [71]. Often persons with RA adapt their activities in different ways in order to accept necessary changes of the disease on their activities in life [72]. Physical function might be decreased, and sexual function may be negatively affected by the symptoms of RA [73]. Disfigurements of the foot and hand are still common among persons with RA, and can give negative appearance concerns [74]. The disfigurements might be corrected with surgery, but can still add negative feelings towards the body. A negative attitude towards one's own appearance is connected to a lower self-esteem among persons with RA, and perceptions of body image may be associated to feelings of unattractiveness [75]. Depression and anxiety are common among persons with RA, and there is a correlation between anxiety and erectile dysfunction [7, 76]. Depression and decreased health are also correlated. There is also a link between decreased sexual health and depression, since both can affect each other negatively [7].

Basson et al described direct and indirect negative effects of chronic disease on sexual health [13]. Rheumatoid Arthritis and the medical treatment of RA involve direct negative effect on sexual health by reduced sexual desire and response due to pain. However, there are indirect negative effects on sexual health such as the reduction of self-image, depressed mood, impaired mobility, reduced energy, partnership difficulties, fear of sex and worsening medical condition. According to a recent study, one of the two main predictors of global life satisfaction for persons with RA is satisfaction with sexual life [77]. Living with a chronic disease might also lead to changes in a person's sexual life due to several reasons which will be further explored in this thesis [16].

## Treatment of RA

Untreated RA leads to tissue damage, severe disability and joint deformity, and the longer RA is left untreated, the greater the progress of the damage. As most joint damage is largely irreversible, persistent damage will inevitably result in greater disability. Early diagnosis and aggressive treatment are essential to patients with RA to prevent joint damage and to increase physical function as well as quality of life. Early treatment of RA is an important and accepted concept [78]. Early treatment reduces joint damage and long-term physical disability [79]. The treatment goals in RA, therefore, include: prevention or control of joint damage; prevention of disease progression; prevention of loss of joint function; a decrease of symptoms (for example, pain and stiffness); and achievement of remission or low disease activity [42]. Furthermore, improvement in quality of life (QoL) and maintenance of a healthy lifestyle; achievement of drug-free remission; and rapid control of underlying inflammation are treatment goals [78, 80]. According to persons with RA, the most common prioritized treatment outcome is reduction of pain [81].

Most patients with RA are treated with Disease Modifying Anti-Rheumatic Drugs (DMARD), methotrexate being the most commonly used drug [46]. In 1999 tumour necrosis factor- alfa (TNF- $\alpha$ ) blockers were introduced. There is evidence of good treatment results with TNF- $\alpha$  therapy, usually in combination with methotrexate [78]. The improved pharmacological interventions have further developed the treatment goals to early pharmacological treatment and to accomplish remission or at least low disease activity [82]. Improved pharmacological treatment is also probably one reason for reduction of the amount of surgical interventions for

persons with RA, such as synovectomies, arthroplasties and arthrodeses [83, 84]. However, there are patients with RA (approximately 30%), that do not achieve positive effect of DMARDS. These patients continue to have a significant impact of RA on their physical, social and psychological functioning [55, 85].

The treatment of RA involves several healthcare professionals, and team-based treatment is beneficiary [86, 87]. Despite new medical treatment, there are studies showing that many perceived functional problems remain two years after diagnosis of RA [88]. Medication should be combined with physical exercise in order to improve physical capacity, muscle function and reduce symptoms of RA [89, 90]. Physical exercise can also in itself reduce the inflammation [89]. There is also research showing that experience of quality of life and psychosocial factors also need to be assessed, since they add other knowledge to the physical status of persons with RA [91].

### **Measuring disease activity and progress of RA**

Measuring disease activity and disease progression continuously is essential to optimize treatment of RA. The recommendation is to use both patient reported outcome measures and provider assessment [92]. There are several ways to measure disease activity in RA, both by the health professionals and by the persons with RA. Common measures are the Disease Activity Scale (DAS-28) and the Health Assessment Questionnaire (HAQ) [93-95]. The DAS-28 is a clinical provider assessed index of RA, combining information of swollen joints, tender joints, the acute phase response and general health. The HAQ is a patient reported outcome measure used to evaluate physical function of patients with RA, and the

instrument is also considered to be able to determine disease activity in RA [42, 96, 97] when compared with DAS28. The HAQ has been revised and the newest revision is the Multi Dimensional Health Assessment Questionnaire (MDHAQ) [95]. New research has led to the recommendation of the following measures in routine clinical care: the Clinical Disease Activity Index (CDAI), DAS-28, Patient Activity Scale (PAS), Patient Activity Scale II (PAS II), Routine Assessment of Patient Index Data with three measures (RAPID3) and Simplified Disease Activity Index (SDAI) [92]. The PAS includes the HAQ, the PASII includes the Health Assessment Questionnaire II (HAQII) and the RAPID 3 includes the MDHAQ. Of those measures, it is solely the MDHAQ that includes questions concerning sexual health. Sexual activities are not included in the HAQ. In research concerning outcome measurements that are important to patients with RA, being able to perform sexual activities is included [98].

### *Sexual health, RA and gender*

There is a need for a gender perspective when discussing sexual health and RA, not only because RA is much more prevalent among women but also since men and women experience different sexual difficulties due to RA [99]. Gender is important in the social context and different gender roles are associated with different cultural demands. Physical strain during sexual activities differs between men and women. Some of the symptoms of RA are experienced differently by men and women, for example, pain and fatigue [14].

Women with RA experience sexual health difficulties concerning sexual desire, sexual functioning, sexual satisfaction and sexual performance [3]. Women with RA often experience more joint pain than men during sexual activities [100]. One possible reason for the increased pain for women during sexual activities could be differences in strain on joints in intercourse positions. Females with RA experience lower sexual satisfaction than men with RA [101]. There are other factors influencing sexual health, and the perspective of gender on sexual health is complex [102]. There are gender differences showing that men have higher levels of sexual activity, interest in sex and better quality of their sex life, and that those gender gaps increase with age [103]. However, a recent study of patients with RA showed that male gender was associated with a larger negative impact on sexual activity [104], which indicates that this field needs further exploration for both men and women with RA. Erectile dysfunction might be associated with RA, according to a recent study [105].

### **Communication about sexual health concerning persons with RA**

Sexual health among persons with RA is not routinely addressed by clinicians in the field of rheumatology, despite the fact that several persons with RA experience decreased sexual health [16, 106]. Knowledge and openness about sexual health issues are important for rheumatology health professionals [107] and must be attained if good communication about sexual health is to be established with RA patients. The first step is to recognise a person with RA as a sexual being [34]. Communicating about

sexual health is a key issue in order to find out whether the person with RA needs advice or treatment in order to improve their sexual health. In order to do so, it is important for the health professionals to know about the experiences and views of the persons with RA to facilitate communication about sexual health. Questions concerning sexual health are not included in the common questionnaires, such as HAQ, which often are used at clinical visits to staff working in the field of rheumatology.

Concerning what and how each profession can contribute to improve sexual health of persons with RA, the role of the physiotherapist will be further explored in this thesis. The reason for this is that physiotherapy has been mentioned as a strategy that could be used to improve sexual health for persons with RA [3, 14]. Physiotherapy interventions aimed at improving sexual health can include pelvic floor exercises, body awareness, cognitive behavioural physiotherapy as well as exercise interventions and treatment of symptoms indirectly connected to sexual health such as pain and decreased mobility [14, 108, 109]. Promoting a healthy lifestyle is also essential since unhealthy life style factors, such as physical inactivity, affect sexual health negatively [9]. The mentioned role of the physiotherapist has been further acknowledged by enhanced evidence for physiotherapy interventions, but further research is needed [108, 110].

## **Physiotherapy for persons with RA**

The World Confederation for Physical Therapy definition of physiotherapy is broad: *“Physical therapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in*

*circumstances where movement and function are threatened by ageing, injury, diseases, disorders, conditions or environmental factors. Functional movement is central to what it means to be healthy. Physical therapy is concerned with identifying and maximizing quality of life and movement potential within the spheres of promotion, prevention, treatment/intervention, habilitation and rehabilitation. This encompasses physical, psychological, emotional, and social wellbeing. Physical therapy involves the interaction between the physical therapist, patients/clients, other health professionals, families, care givers and communities in a process where movement potential is assessed and goals are agreed upon, using knowledge and skills unique to physical therapists.”[2]*

The American College of Rheumatology (ACR) medical treatment guidelines request a base of optimal non-medical treatment for RA (including occupational- and physiotherapy) in order to decide the best medical treatment strategies for each individual patient [111]. This indicates the importance of the non-medical treatment strategies for patients with RA. Despite large medical advances, there are still many persons with RA not achieving clinical remission [112]. Those persons are in need of support to cope with their disease consequences and to manage their condition. There has been a change in paradigm within physiotherapy for persons with RA, from passive treatment towards active treatment [4, 113]. This change has led to physiotherapists encouraging patients with RA to be physically active and to exercise regularly [114]. Recommended methods are exercise and educational interventions with a component of cognitive behavioural therapy [43, 85]. In order to improve health via physiotherapy, the interventions are recommended to be individually tailored. A person that has had RA for several years might have more joint

difficulties and functional limitations than a person with a newly diagnosed RA. Physiotherapy is usually directed towards improving activities of daily living, dealing with specific symptoms, such as pain or limited joint mobility, and sexual relations should be included in this context [14, 115].

Physiotherapy recommendations to increase physical fitness may contain aerobic capacity training and muscle strength training [90, 112, 116], as well as hydrotherapy, multidisciplinary interventions and physical modalities to reduce pain [65]. There is evidence supporting the use of those interventions for persons with RA [117, 118], and the interventions are often combined and changed over the total time of disease duration to have optimal effects. Information about joint protection and how to achieve a healthy life style with increased physical activity is included in physiotherapy interventions. This is important since physical activity is related to quality of life [43, 119]. Regular physical exercise and encouragement to increase physical activity have been proven to be effective in decreasing symptoms in persons with RA [120]. Persons with RA are recommended to exercise 30 minutes of moderate exercise per week or 30 minutes of strenuous exercise three times per week [43]. The described positive outcomes of regular physical activities are improved physical function including increased muscle strength and endurance, aerobic fitness, and joint range of motion as well as reduction of pain and fatigue [118, 121]. For example, RA patients who exercise on a regular basis have less fatigue and disabilities compared to non-exercisers [122]. Physiotherapy for persons with RA has been shown to improve self-confidence, increase the amount of daily activities and reduce depression [123-125]. When a person is confident about their physical ability, this is reflected in a higher self-esteem, a more positive body image, and increased

feelings of attractiveness [126]. Patient centredness plays an important role in physiotherapy, and it is important to understand the determinants of patient satisfaction [127]. It is also essential to acknowledge and understand the role of emotions in physiotherapy practice since they play an important role in supporting the interaction between physiotherapist and patient [128, 129]. The evidence of other physiotherapy interventions such as transcutaneous electrical nerve stimulation, acupuncture and massage is scarce due to few studies and their poor methodological quality [130-132]. Despite the lack of evidence such interventions might be used and evaluated on the individual level with the purpose of reducing pain.

## **In summary**

This thesis regards sexual health difficulties as possibly connected to RA and aims to detect whether/how such problems are experienced among persons with RA as well as how those difficulties should be approached. Several questionnaires and interview guides in the field of sexual health are specific and cover a special area within sexual health. Those questionnaires can be seen as too specific for this group of patients, since their sexual health issues are experienced to be mainly connected to RA. Questionnaires measuring female and male sexual dysfunction are not applicable in general to this thesis since it aims to cover sexual health in RA context, not sexual dysfunction. Most questionnaires concerning female sexual health are intended for heterosexual women with a partner and cover engagements in sexual activities [28]. This thesis has a broader and different scope. It aims to be a stepping stone connecting the fields of rheumatology and sexual health. When sexual health problems are uncovered, there is a need for further exploration with more specific aims within the field of sexology or

rheumatology in order to identify and recommend adequate interventions and counselling. This thesis focuses on the communicative process concerning sexual health problems due to RA and how physiotherapy as an intervention can be used in this field.

Only women were included in the first qualitative study. In the planning of the second study, the inclusion criteria regarding sex were changed in order to broaden the perspective of the studies. Therefore, studies II-IV include the views of both men and women.

# Aims of the thesis

The overall aim of this thesis was to study how persons experience the influence of Rheumatoid Arthritis on their sexual health and their experiences of communication in order to improve physiotherapy within the field of rheumatology.

The aims in detail were to:

1. Describe and analyse sexual health in relation to physiotherapy in women living with RA (Study I);
2. Explore experiences and views of impacts of RA on sexual health, experiences and needs of physiotherapy, and experiences of communication between patients with RA and health professionals concerning sexual health (Study II);
3. Develop a valid and reliable version of the MDHAQ under Swedish conditions, equivalent to and meeting the same psychometric and acceptability standards as the original MDHAQ (Study III);
4. Investigate whether the MDHAQ-S correlates with a sexual health questionnaire and whether questions in the MDHAQ-S can detect decreased sexual health for persons with Rheumatoid Arthritis (Study IV).

# Methods

The thesis has a mixed paradigm design in a fixed multiphase model, including qualitative, quantitative and psychometric methods, in order to respond to the research question and the aims of the thesis. The methodological pluralism of mixed methods research can lead to a deeper understanding of the research field than mono method research [133-136]. A broader and more inclusive way of research is recommended concerning sexual health research since the base of mixed methods research as “multiple ways of seeing” broadens the perspective of the planned research [18, 136]. The qualitative part in mixed methods focuses on exploring underlying issues and gaining insights of the research field [134]. The quantitative part investigates “how many” and “how strong”, that is, measures, predictions and correlations [134]. Physiotherapy aligns theoretically with both qualitative and quantitative research models [135]. The mixed methods research is used both in the planning and performance of the included thesis as a whole and in the individual studies.

The first study investigated the views of persons living with RA concerning sexual health in relation to physiotherapy. The findings of this study were used as a base for the questionnaire used in the second study in order to further explore views and experiences of the impact of RA on sexual health, experiences and needs of physiotherapy in this context as well as communication between patients and health professionals concerning sexual health. The results of the second study clarified the need to improve communication and interaction between healthcare professionals and persons with RA concerning sexual health. This was investigated in the

fourth study where the question whether decreased sexual health can be detected with a standard outcome measurement tool was explored. In order to perform the fourth study, the MDHAQ had to be validated and tested for reliability in a Swedish context, which was performed in the third psychometric study.

## **Design of the studies**

Study I was a qualitative study. The results were analysed with a phenomenological approach according to Giorgi [137-139].

Study II was a primarily quantitative study. A questionnaire with both closed and open questions was used. The questionnaire was based on the earlier performed interview study and on existing questionnaires in adjacent research fields.

Study III was a methodological psychometric study aiming to adapt and test a questionnaire in a Swedish context. The included questionnaires were the MDHAQ-S and the AIMS2-SF.

Study IV was a mixed methods study aiming to explore if and how the MDHAQ-S could detect decreased sexual health associated with RA. The study included the following questionnaires: MDHAQ-S and the developed questionnaire from study 2, the Questionnaire of Sexual Health for persons with RA (QSH).

Table 1. Overview of design, participants, data collection and data analysis of the included papers in the thesis

	<i>Study I</i>	<i>Study II</i>	<i>Study III</i>	<i>Study IV</i>
<i>Design</i>	Descriptive	Explorative and descriptive	Psychometric	Psychometric
<i>Participants</i>	10 women with RA, age span 42-66 years, median 59.5 years old. Years with a RA, range 2-31 years. The HAQ-levels of the informants varied between 0-2.13	150 persons with RA, 122 women and 28 men, response rate 42%. Age span 19-77 years, median 57 years old. Years with RA, range 1-50 years.	30 persons with RA, 100% response rate (reliability test group) 100 persons with RA, response rate 83%, (validity test group) Age span 20-83 years.	80 persons with RA, response rate 68%. Quantitative study group, age span 28-77 years, median 59 years old. Qualitative study group, age span 19-77 years, median 59 years old.
<i>Data collection</i>	Individual interviews	Questionnaire	Questionnaires	Questionnaires
<i>Instruments</i>	HAQ	QSHP	MDHAQ-S, AIMS2-SF	MDHAQ-S, QSH

	<i>Study I</i>	<i>Study II</i>	<i>Study III</i>	<i>Study IV</i>
<i>Data analyses</i>	Phenomenological approach	Statistical correlation analysis with Spearman's rank correlation. Internal consistency by Chronbach's alpha. Explorative factor analysis with principal component analysis, rotated.	Internal consistency by Chronbach's alpha. Test-retest with weighted kappa statistics and intra-class correlation. Analyses of floor and ceiling effects. Content validity with the content validity index (CVI). Concurrent validity with Spearman rank order correlation.	Descriptive statistics, Spearman's rank order correlation, multiple regression analysis, and independent sample t-test. Qualitative content analysis.

## Participants

The inclusion criteria for the studies were similar:  $\geq 18$  years of age, diagnosed with RA and having a clinical contact with the included clinics. Both the diagnostic criteria from 1988 and 2010 have been used, depending

on when the participants were diagnosed with RA. The first study had two additional prerequisites for gender and disease duration, since the study only concerned women who had been diagnosed with RA for more than two years. The participants were recruited from the south of Sweden at rehabilitation and rheumatology clinics.

## **Instruments used in the study I-IV (See appendix 1-5)**

### **Study I**

*Health Assessment Questionnaire Disability Index* (HAQ -DI) was used to describe the functional status of the informants in order to ensure diversity [97, 140]. The HAQ-DI is the functional section of the Stanford Health Assessment Questionnaire (HAQ). The HAQ-DI is a questionnaire that is regularly used in research within the field of rheumatology and has been used in studies of sexual health for persons with RA [104, 141, 142]. The original Health Assessment Questionnaire (HAQ) included a question about sexual health, but the HAQ-DI has excluded this question. The HAQ-DI is an instrument intended to measure a person's level of functional ability in daily activities, and the instrument is considered valid and reliable [140].

### **Study II & IV**

The developed questionnaire used in study II, Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy (QSHP), was also used in study IV after revision, Questionnaire of Sexual Health for persons with RA (QSH). The Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy consisted of 33 questions within the following fields: impact of RA, experiences of physiotherapy, sexual health and information/communication

with health professionals concerning sexual health. The questionnaire includes closed questions, but with a possibility for respondents to answer the questions with further comments.

### **Study III**

*The Arthritis Impact Measurement Scale 2 Short Form (AIMS2-SF)* was used in study III. The Arthritis Impact Measurement Scale (AIMS) was developed to assess outcome of healthcare for patients with RA [143], and it has been further developed and shortened to the Arthritis Impact Measurement Scale 2-Short Form (AIMS2-SF) [144]. The AIMS measures the individual's functional, social, emotional and physical status. The AIMS2-SF is a shorter and less time consuming version of the Arthritis Impact Measurement Scale -2 (AIMS2) with similar psychometric properties, convergent validity, content validity, reliability, and sensitivity to change [144-146]. The AIMS2-SF has shown to have good factorial validity, [145] and it is easier for the patients to administer since it consists of fewer questions, 26 instead of 57. In order to achieve best possible symptom agreement concerning arthritis pain between AIMS2 and AIMS2-SF, item 42 was replaced with item 38 in AIMS2-SF, which has been recommended in earlier studies [146, 147].

The AIMS2-SF is a self-administered questionnaire covering the ICF components activity limitations and participation restrictions within five domains: physical function, role function, social function, symptoms and mood [144]. Each item is answered by a 5-point scale. Higher scores indicate higher level of impairment. The time it takes to perform the AIMS2-SF is estimated to be 10 minutes. The AIMS 2 is a valid and reliable

instrument in Swedish [148]. The AIMS has also been used to test validity of other outcome measurement tools for patients with RA [149].

The QSH includes 21 closed questions with the possibility for respondents to add further comments. The revision of the Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy led to the exclusion of questions concerning experiences of physiotherapy and the rephrasing of some of the original questions. Areas covered by the questionnaire are: sexual health, the effect of the disease on sexual health, and needs for information about how the disease might affect sexual health.

### **Study III & IV**

The MDHAQ-S, which was used in study III and IV, is a revised version of the HAQ, the Multi Dimensional Health Assessment Questionnaire (MDHAQ) tested in a Swedish context. Study III included testing of reliability and validity of the MDHAQ-S. The MDHAQ-S consists of the following parts: function, psychological status, pain, global health, fatigue, morning stiffness and exercise habits. It includes the Routine Assessment of Patient Index 3 (RAPID3) and Rheumatoid Arthritis Disease Activity Index (RADAI) self-report joint count [95] as well as a symptoms list and recent medical history. The RAPID3 and the RADAI have high reliability [150]. The RADAI is a valid instrument [151, 152], and patient reported tender joint count has a moderately to high correlation to assessments by health professionals [153]. The test-retest reliability, internal consistency reliability and face validity have been shown to be good for the MDHAQ [154, 155]. The criterion and construct validity of the MDHAQ have also been investigated in earlier studies translating the instrument, with good

results [155, 156]. Criterion validity of the activities of daily living questions included in the MDHAQ, derived from the original HAQ, has been tested under Swedish conditions with good results [140]. The added questions concerning advanced function: "Can you walk 3 km if you wish?" and "Can you participate in recreational activities and sports as you would like, if you wish?" are more difficult to test for criterion validity.

The MDHAQ-S is estimated to be performed in five minutes. The first section "function" of the MDHAQ-S (questionl. a-j) includes ten activities of daily living scored 0-3 (0="without any difficulty", 1="with some difficulty", 2="with much difficulty", and 3="unable to do."). The sum of the answers is divided by three giving a score between 0-10. The questions concerning psychological status (questionl.k-m) are scored 0="without any difficulty", 1.1="with some difficulty", 2.2="with much difficulty", and 3.3="unable to do." The sums are added to a total sum of 0-9.9. The MDHAQ-S includes visual analogue scales with 21 circles measuring pain, global health and fatigue with a total score of 0-10 in 0.5 units. The RADAI includes eight joints or joint groups scored 0, 1, 2 or 3. The RAPID3 scores (0-30scale) include four categories: High Severity >12, Moderate Severity=6.1-12, Low severity=3.1-6, and Remission <=3. The review of symptoms (question 5) is a checklist of symptoms where the checked boxes are counted. Morning stiffness (question 6) is rated by yes or no and the amount of time in minutes. Change in status (question 7) is scored: 1 = Much better, 2 = Better, 3 = Same, 4 = Worse, 5 = Much worse. Exercise frequency (question 8) is scored 3 = 3 or more times a week, 2 = 1-2 times per week, 1 = 1-2 times per month, 0 = Do not exercise regularly, 9 = Cannot exercise due to disability/ handicap. The MDHAQ-S also includes questions about recent medical history, which are not scored.

## Data processes and analyses

### Study 1

Phenomenology aims to reveal the phenomena from the experiences and the views of the persons being studied [137], which is the reason why this method of analysis was chosen in this first explorative study.

Phenomenology also encourages the participants to describe the phenomena as they were experienced and construct the structure of the phenomena as they appeared. In qualitative research the researcher's pre-understanding of the phenomena should be described. In this case both the researchers were physiotherapists, and one of them was also a psychologist, the other one specialized in rheumatology. The study was performed as individual interviews instead of group interviews, due to the deeply personal and sensitive subject.

During the interviews an interview guide was used, which consisted of different themes of discussion as well as questions concerning the informants' background. The base for the interview guide was earlier research in the field, and further themes were added if new themes were brought forward in the interviews. Included themes were definition and importance of sexual health and intimate relationships, experiences of living with RA, experiences of physiotherapy, relations between RA and sexual health/sexual activity/intimate relationships as well as suggestions for improvement of sexual health. The use of an interview guide is recommended in qualitative studies [157] in order to deepen the interviews.

Validation and reliability in phenomenology, according to Giorgi, are obtained when the described phenomena are captured by the intuited essence, and this description can be used consistently [138]. The analysis of the material, according to Giorgi, consists of the following steps [137, 139]:

1. Reading through the material to obtain a general sense of the whole statement;
2. Re-reading of the material to discriminate meaning units from a holistic perspective and to focus on the experience of sexual health when living with RA;
3. Going through the meaning units and expressing deepened insight contained in them more directly;
4. Synthesizing of the transformed meaning units into a consistent statement regarding the subjects' experience.

Trustworthiness includes credibility, transferability, dependability and confirmability [158]. Credibility is the truth value of the qualitative research, and with high credibility other persons experiencing the same phenomena will recognise the described experiences of the phenomena [159]. The credibility is enhanced by following a described method and doing the analysis accordingly [159]. Transferability was possible to other groups in a similar context [158, 159]. The informants in this group come from the same region and are of the same cultural origin, which must be taken into account when discussing the transferability of the results. However, there were differences in disease duration, marital status, work ability and their level of physical capacity in activities of daily living. The amount of informants is not as important in qualitative research as the amount of given information during the interviews [160]. Pragmatically, ten informants were included in this study. Dependability is the stability of the data over time and conditions [158]. Dependability was enhanced by the

informants' checking of the transcribed interviews. Confirmability refers to the objectivity of the data [158]. The confirmability was strengthened by the analysis being first performed by the two researchers independently and then discussed until consensus was reached. Quotations from the transcribed interviews were used to confirm trustworthiness for each category.

## **Study II**

The statistical methods in paper 2 were: descriptive statistics, statistical correlation analysis with Spearman's rank order correlation, Internal Consistency by Cronbach's alfa and explorative factor analysis with principal component analysis (varimax rotated method). Statistical correlation analysis was necessary to use a non-parametric test due to the relatively low sample size and because ordinal variables were used. Cronbach's alfa is a widely used method measuring intercorrelation of items [161], and an alfa > 0.7 shows good internal consistency [158].

Validity is a measure of how well the instrument measures what it is intended to measure. Construct validity was performed with explorative factor analysis with principal component analysis, rotated method (varimax rotation, Eigen value >1). This method is used to identify clusters of related items on a scale and to reduce the amount of items to reveal clear factors [158]. Items with high factor loadings define each dimension. Explorative factor analysis showed that the items in the questionnaire belonged to three meaningful factors: sexual well-being, body image and relationship.

To be a clinically meaningful item in one of these factors, it was considered that each item must have a loading over .50 in accordance with Hair et al.

[162]. Each item was also, to be clinically meaningful, referred to the factor in which it had the highest loading. In accordance with these principles the factor “sexual well-being” contained five items, the factor “Body image” contained two items, and the factor “relationship” contained two items.

Face validity was tested in a group of RA-patients prior to the study, and the validity of the study was enhanced by the fact that the questionnaire was built on earlier qualitative results as well as questionnaires used in other studies.

Reliability is a measure of the proportion of the variability in measures, due to the true differences between individuals. Reliability is affected by clarity and precision of language in order to produce results repeatedly. This is expressed numerically as a value between 0 (no reliability) and 1 (perfect reliability). Reliability can be measured by internal consistency, which measures how well each item correlates with scores on all other items [158]. Internal consistency by Chronbach’s alpha was analysed for all items on ordinal level in the questionnaire, in total 10 items, showing a Chronbach’s alpha of 0.74. If the item 21 was deleted, the Chronbach’s alpha increased to 0.85. Cronbach’s alfa should be between 0.70-0.90 and the coefficient is an important indicator of an instrument’s quality [158]. SPSS version 17.0 was used in the analyses.

### **Study III**

Content validity indicates whether the items in the questionnaire are representative of the researched phenomena and reflect relevant areas, as well as whether the intended measure of the included scales is fulfilled [163]. Content validity was performed by letting the test-retest group rate

the relevance of each question included in the MDHAQ-S by using a content validity index for each item. The content validity index was dichotomized to relevant and not relevant. The items were considered to be relevant if the content validity index was  $>0.78$  [163, 164]. The average of the sum of the content validity index for each item should be  $> 0.90$  [163].

Face validity is a part of validity and can be performed by a group giving their opinions of whether the questionnaire measures what it is intended to measure [165, 166]. In this study face validity was performed by a rheumatologic team consisting of a rheumatologist, a nurse, a physiotherapist and an occupational therapist with several years of experience in the field of rheumatology. No further additions were made, but two questions concerning ethnic origin and medical insurance were removed from the Swedish version of the MDHAQ, according to the recommendations from the face validity group.

Concurrent validity measures how well an instrument relates to another external measure at the same time [167]. In this study the Swedish version of the MDHAQ was tested in relationship with the AIMS2-SF. Spearman's correlation coefficient was used to evaluate the relationship. Correlation coefficients of 0.1-0.3 is considered to be a weak relationship, 0.3-0.5 a moderate relationship, and  $>0.5$  a strong correlation [158].

Floor and ceiling effects had a cut-off point at 15%, which are levels that have been used in other tests of the MDHAQ [155, 156, 168, 169].

Reliability was measured with test-retest by the study group of 30 participants. The retest was performed one week after the first test. The

time limit between test-retest should be long enough for the respondents not to remember their answers, but not so long that their original status has changed [166]. The higher the reliability coefficient (closer to 1.00), the more reliable is the instrument. Reliability coefficients of 0.70 are considered to be satisfactory, but coefficients between 0.85-0.95 are preferable [158]. Reliability was also tested with Cronbach's alfa and item total correlation. Cronbach's alfa should be higher than 0.70, but not above 0.90, since too high an alfa might represent redundancies [166]. SPSS version 18.0 was used in the analysis.

#### **Study IV**

A mixed methods design combining quantitative and qualitative data was chosen to complement, deepen the understanding of, and support the findings of how different factors might affect sexual health [134, 135]. The use of mixed methods research demands rigour to the quantitative and qualitative methods included [170]. The study was performed with the quantitative data and the qualitative findings analysed separately, with a final mixed methods interpretation.

#### **Quantitative analyses**

The collected data from the QSH and the MDHAQ-S were analysed using descriptive statistics, frequencies and proportions, and were analysed for correlation with Spearman's rank correlation for the items included as well as for the physical and psychological dimensions of the MDHAQ-S. Multiple regression analysis was performed to identify associated factors to sexual wellbeing. The criterion variable was sexual wellbeing from the QSH, and the independent variables included from the MDHAQ-S were total

score of physical function, total score of psychological function, pain, fatigue, and general well-being. Descriptive statistics and independent sample test were used to describe the subgroup expressing decreased sexual health on the MDHAQ-S review of symptoms, as well as the subgroups with high levels of regular exercise and high Body Mass Index (BMI). The subgroup of those describing decreased sexual health was chosen since it is a direct question about sexual health, the exercise subgroup was chosen due to the known positive effects of a physically active lifestyle on sexual health, and the subgroup of overweight ( $BMI \geq 25$ ) was chosen on the basis of the results from the open answers in the questionnaire.

### **Qualitative analyses**

In the QSH, participants had the opportunity to describe their experiences in their own words as to whether and how RA had affected their sexual health. The open answers of the QSH were analysed with content analysis [171]. Content analysis has been used in other studies that have analysed open answers in questionnaires in combination with quantitative data analysis [172-174].

Each question was analysed separately, and the content analysis consisted of the following procedure [171]:

- Reading and re-reading all answers to get a sense of the material;
- Sorting the material into meaning units;
- Coding meaning units;
- Comparing codes concerning similarities and differences;

- Differences between the two researchers concerning coding and categorisation were discussed from the view of the question and the completion of the answer.
- Categorizing codes and comparing similarities and differences;
- Differences between the two researchers concerning coding and categorisation were discussed from the view of the question and the completion of the answer.
- Transforming the categories into a theme.

The trustworthiness in qualitative studies depends on the credibility, confirmability, transferability and dependability of the results [159]. Credibility in qualitative studies concerns the truth value of the collection of data and analysis process. In order to gain high credibility, the data collection process and analysis have been thoroughly described with methodological references. The researchers discussed the categories and themes together to gain consensus. These discussions strengthened the confirmability of the results. The analysis of the open questions resulted in a theme with underlying categories. The transferability of the results was enhanced by including data from two groups of informants from different regions in Sweden. The transferability is also strengthened by the combination of quantitative and qualitative data in this study. The dependability of the results is difficult to predict, but the results show similarities to other studies within the research field.

## **Ethical considerations**

In research of sexual health, ethical reasoning is essential since it is a sensitive subject. All projects were approved by the Regional Ethical Committee in Linköping or Lund and have been thoroughly discussed so that they could be conducted with appropriate ethical considerations.

Paper I was limited to include women, but papers II-IV were changed to also include men with RA.

Study I - project number M48-09, the Regional Ethical Board of Linköping

Study II – project number M222-09, the Regional Ethical Board of Linköping

Study III – project number 2011/142-31, the Regional Ethical Board of Linköping

Study IV – project number 2012/14, the Regional Ethical Board of Lund

# Results

The overall aim of this thesis was to study how persons experience the influence of Rheumatoid Arthritis on their sexual health and their experiences of communication in order to improve physiotherapy within the field of rheumatology. The results of the included studies are described from the view of the aim.

## Sexual health

In study I the informants described their views of what sexual health was to them. In studies II and IV the participants rated the importance of sexual health and changes in their views and experiences of sexual health.

Sexual health was experienced and described as containing both a physical and a psychological dimension. The physical dimension included touch, caressing, showing love and tenderness as well as sexual intercourse. The psychological dimension of sexual health was experienced as being there for another person, psychological closeness, feeling loved and caring for someone. Different emotional experiences related to their definitions of sexual health. Pleasure, happiness, joy and the opportunity to release emotions were experienced, but also increased pain and psychological pressure. Being attractive, feeling attractive and feeling attracted to a partner were also included in sexual health.

The importance of sexuality and sexual health was rated as very important or important by 56% of the participants in study II and by 58% of the participants in study IV. The importance of sexual intercourse differed in

their intimate relationship, and was not always present. Those that described an acceptance of this by their partners or an increased acceptance over time also described less strain on their relationships. Coping with the impact of RA on sexual health was important. Closeness and caring were important aspects of a relationship as well as a close sexual companionship, doing things that felt good for each other, and having pleasurable sexual experiences with the partner. To achieve good sexual health, understanding and communication between the partners were vital, as well as honesty with each other, and willingness to participate in the sexual relationship.

### **Influence of RA on sexual health**

In the qualitative interviews in study I, the informants described their experiences of whether RA had affected their sexual health and if so, how. The impact of the disease was multidimensional and covered how the body and the total life situation affected sexual health. This aspect consisted of three themes: 1) Sexual health – physical and psychological dimensions, 2) Impacts of RA and 3) Possibilities of increasing sexual health – does physiotherapy make a difference?

Questions concerning the impact of RA on sexual health were also included in study II and study IV, giving further information on this theme. Those two studies added information concerning the physical influence of RA on sexual health, and the effect of the emotional experience of living with RA on sexual health. In study II 37 % of the participants experienced that RA had affected their sexual health in a negative way and 50% had this experience in study IV.

## Physical influence of RA on sexual health

Common symptoms of RA with a negative impact on sexual health were pain, fatigue, stiffness and swollen joints, with varying severity. Decreased physical ability, deformed joints, and reduced muscle strength and limitations in activities of daily living were also experienced. The informants described a large variety of direct negative impact on sexual health: deformed hip joints which made sexual intercourse impossible, hip mobility problems during intercourse, decreased mobility in sexual activities and fewer possible positions for sexual intercourse. Pain was a major factor with direct negative influence on sexual health. There were different types of pain: pain before, during and after sexual activities, pain when being touched and pain when caressing the partner.

Body image was experienced to be affected by RA for some of the informants, and the most common negative impact was increased weight, loss of body shape and loss of muscle mass, which was experienced to be due to medication and inability to be as physically active as the informants wanted to be. In study II 29% of the respondents experienced a negative or very negative body image. Their view of their bodies changed after their RA diagnosis, 38% in a negative way and 14% in a positive way. A negative body image was significantly correlated in study II with an increased negative body image and decreased sexual desire since the onset of the disease, as well as with low sexual desire, low sexual well-being and a feeling that the disease had had a negative effect on their ability to function sexually. In study IV several participants mentioned increased body weight due to RA in their open answers, and that this in turn

affected their sexual health in a negative way. Therefore, the group with a BMI representing overweight (>25) was compared to the rest of the participants in study IV. The comparison showed a significant difference only for QSH, question 19: *"I think there is a strong connection between improved physical capacity and improved sexual health"* (p=0.00).

The categories included in the open answers in study IV for the question: *"How has RA affected my experience of my body?"* were *physical changes (weight, appearance, physical function)*, *changed experience of the body (changed body image, changed acceptance of the body, discontentment with the body)* and *effect of medication on the body*. The body image was experienced to be less attractive after the diagnosis of RA. Increased body weight and feelings of being fat were mentioned by several participants as reasons for decreased sexual health, and were experienced to be due to decreased physical ability owing to RA or to medical impacts. Loss of muscle and posture and developing a less attractive body shape were also considered to be effects of RA that had a negative effect on the participants' sexual health. The participants also described negative feelings and aggression towards themselves and their body both in connection to sexual health and in general.

## **Emotional and psychological experiences of RA on sexual health**

There was a wide variety in descriptions of negative emotions and psychological experiences due to RA that affected sexual health: sleeping difficulties, anxiety, worry, frustration, depression, fear of being abandoned

by their partner, feeling old, feelings of being unattractive, sadness, loss of sexual arousal, decreased sexual satisfaction and being angry. The negative emotions could lead to decreased intimacy and avoidance of sexual activity.

In study II and study IV 62% of the participants experienced decreased sexual arousal since the onset of RA. Sexual satisfaction after engaging in sexual activities was affected by RA for 43% of the participants in study II and 42% in study IV.

## **Experiences of communication about sexual health**

Study I, study II and study IV explored the experiences of how communication with health care professionals concerning sexual health had been performed/should be performed, as well as how the participants wished to be informed about impacts on sexual health by RA.

An important aspect to achieving sexual health was increased communication between partners and knowledge about the impacts of RA concerning sexual health. Written information, shared with the partner, could be used as a basis to discuss and thereby possibly improve their own mutual sexual life. Long-lasting relationships were experienced to have increased the possibilities of having an open communication concerning sexual health between partners.

In study II a majority (75%) of the patients had not discussed sexual health with staff or eventual effects of RA on sexual health when they were diagnosed with RA. Only one patient reported that sexual health was

sometimes discussed with their rheumatologic team, and none of the patients discussed sexual health often or regularly with them.

Concerning the way in which sexual health should be brought up, the participants had different preferences, and the question allowed multiple choices in the response. Some of the participants did not want any information concerning sexual health and RA by health professionals, others wanted to bring up the subject themselves when necessary and wanted medical staff to address the subject. Written information about sexual health in the waiting room and having information about sexual health available on the Internet were considered to be good ways to spread information about RA and sexual health.

According to the results in study II, there was a greater need for advice and information about sexual health in four groups: 1) patients with a negative body image, 2) patients with a poorer body image since the onset of the disease, 3) patients with decreased sexual desire since the onset of the disease, and 4) patients with reduced ability to function sexually due to the disease.

The patients wanted to talk to different health professionals about sexual health. Some patients preferred not to talk about sexual health even if they had experienced difficulties in this field.

Some patients had written additional comments in the questionnaire in study II and study IV. Several comments concerned the patients having wished that the topic had been brought up when they were younger or earlier in the development of the disease. This could indicate a greater need for support for those considering having children. There were also

comments indicating that sexual health had never been brought up by their rheumatologic team. Further comments had to do with the importance of information about RA being given to the spouse and how the disease can affect sexual health.

### **Improvement of sexual health**

Most of the informants in study I had not reflected on whether their sexual health was affected by RA or thought it possible to improve it. However, in the interview situations and in the questionnaires, possibilities of increasing sexual health were explored. Besides improving symptoms of RA that the study participants considered affected their sexual health in a negative way, there were other factors of importance as well. The partner's own health also affected the sexual health for the informants, and a healthy spouse increased the possibilities of having good sexual health.

### **Physiotherapy to improve sexual health for persons with RA**

During the interviews in study I the informants expressed how they believed that they, and other persons with RA, could benefit concerning sexual health from physiotherapy. There were descriptions of the importance of decreasing physical symptoms such as pain and fatigue. There were experiences of positive effect of physiotherapy on sexual health among the informants. The positive effects were diverse: knowledge of their physical capacities, increased physical ability and increased sexual fantasies. A better physical ability could make sexual activities easier and increase options of sexual intercourse positions. The increased sexual fantasies were connected to being able to be in different body positions during physical exercise. Touch was also important, since being touched

could be experienced as increasing pain. Several physiotherapy interventions include touching the patient, such as passive joint mobility stretching. This therapeutic touch led to a greater acceptance of being touched and lessened the worry of increased pain from touch. Relaxation exercises were also mentioned as having a positive effect on being able to relax during sexual activities. Positive emotions during and after physiotherapy, such as joy, feeling appreciated and cared for were also expressed. These emotions increased the experienced positive effects of physiotherapy.

The experienced positive emotions, during and after physiotherapy sessions gave an increased attention for the partner and more energy to the relationship. Sexual attractiveness was experienced to increase with physiotherapy, due to increased self-esteem and improved body image. The informants experienced the physiotherapist to have an important role and described their physiotherapists as a coach, a provider of information concerning the body and the disease, and someone who gave them feedback and back-up in their daily activities.

In study II and study IV believed connections between sexual health and decreased pain, and decreased fatigue and increased physical capacity were explored. The results showed that a large majority of the participants agreed/strongly agreed that there were strong connections between decreased pain, stiffness, fatigue, physical capacity and improved sexual health.

## Questionnaire of Sexual Health (QSH)

The QSH was used in study II and study IV, and was validated and tested for reliability in a Swedish context. The questions concerning earlier experiences of physiotherapy and communication of sexual health with health care professionals were removed in the revised version of the QSH for study IV in order to get a more focused view on sexual health issues.

### Reliability

Internal consistency was measured with Chronbach's alpha, which was 0.74. Chronbach's alfa increased to 0.85 if item 21 was deleted (*"I experience that RA has affected my relationship with my partner"*).

### Validity

Explorative factor analysis was performed with principal component analysis, rotated method (varimax rotation, Eigen value >1). Items with high factor loadings define each dimension. Three meaningful factors emerged from the results: sexual well-being, body image and relationship. Two parts had to be fulfilled in order for the factor to be considered as meaningful: each item must have a loading over 0.50 in accordance with Hair et al. (Hair et al. 1998), and each item was to be referred to the factor in which it had the highest loading. In accordance with these principles, the factor "sexual well-being" contained five items, the factor "body image" contained two items, and the factor "relationship" contained two items.

The validity of the questionnaire was enhanced by using knowledge gained in the previous qualitative study (Josefsson et al. 2010) and by using relevant questions from earlier studies in the field (Majerovitz et al. 1994; Fugl-Meyer et al. 1999; Hill et al. 2003). A face validity check was also done on a group of RA patients before study II.

## **Swedish version of the Multi Dimensional Health Assessment Questionnaire (MDHAQ-S)**

The MDHAQ-S was tested for validity and reliability in a Swedish context in study III.

The translation and adaption process of the MDHAQ led to the removal of two items as they were not considered applicable to the Swedish context. The questions were “ethnic group” and “change of medical insurance” – part of question 10 (“Over the last 6 months you have had...”). Questions concerning ethnic group are unusual in Swedish health care questionnaires and were excluded according to the recommendation of the multi professional committee review, in step 3 of translational process. The other parts of the original MDHAQ were kept, and no additional items were included in the Swedish version. None of the participants in the reliability test group wanted to add items to the MDHAQ-S.

There were 100 patients who were invited to participate in the validity test group, and 83 persons agreed to participate. There were 58 (70%) women and 19 men (23%) who participated. Six persons did not describe their

gender. The results for each item with mean, standard deviation, range, response rate, floor effects and ceiling effects are presented in table 2.

Table 2. Characteristics for the MDHAQ-S items and scores

Item/Scale score	Mean (SD)	Range	Response rate %	Floor, % <sup>1</sup>	Ceiling, % <sup>2</sup>
1a. Dressing yourself, including tying shoelaces and doing buttons?	0.49 (0.59)	0-3	99%		
1b. Getting in or out of bed?	0.28 (0.45)	0-3	99%		
1c. Lifting a full cup or glass to your mouth?	0.29 (0.48)	0-3	99%		
1d. Walking outdoors on flat ground?	0.27 (0.52)	0-3	99%		
1e. Washing and drying your entire body?	0.39 (0.52)	0-3	99%		
1f. Bending down to pick up clothing from the floor?	0.48 (0.65)	0-3	99%		
1g. Turning regular taps on and off	0.51 (0.74)	0-3	99%		
1h. Getting in or out of a car, bus, train, or airplane?	0.46 (0.61)	0-3	98%		
1i. Walking 3km?	0.90 (1.00)	0-3	98%		
1j. Participating in sports and games as you would like	1.35 (1.03)	0-3	94%		
Mean 10-item physical function score	1.76(1.56)	0-3	93%	14.5%	0%
1k. Getting a good night's sleep?	1.05 (0.86)	0-3	96%		
1l. Dealing with feelings of anxiety or being nervous	0.42 (0.52)	0-3	94%		
1m. Dealing with feelings of depression or feeling blue?	0.46 (0.55)	0-3	95%		
Mean 3 item psychological score	1.96(1.52)	0-3	93%	21.7%	0%
2. How much pain have you had because of your condition over the past week?	4.03 (2.31)	0-10	98%	6%	0%
3. Amount of pain in joints	13.12 (7.94)	0-54	99%	3.6%	0%
4. Considering all the ways in which illness and health conditions may affect you at this time, please indicate below how you are doing	3.69 (2.30)	0-10	98%	6%	0%
5. Amount of symptoms	10.05 (6.18)	0-60	99%	3.6%	0%
6. Morning stiffness, yes-no	1.32 (0.47)	1-2 (yes/no)	95%		
7. How do you feel today compared to one week ago?	2.59 (0.76)	1-5	98%	7.2%	1.2%
8. How often do you exercise aerobically?	1.36 (1.25)	0-4	93%	38.6%	21.7%
9. How much of a problem has unusual fatigue or tiredness been to you over the last week?	4.30(2.79)	0-10	94%	8.4%	2.4%
10. Amount of other events	1.37 (1.32)	0-12	90%	28.9%	0%

<sup>1</sup> Worst possible value of the item or minimum total value of the scale. <sup>2</sup> Best possible value of the item or maximum total value of the scale.

## Reliability

The reliability test with Cronbach's alpha gave an alpha of 0.65 for the psychological dimension of the MDHAQ-S and an alpha of 0.88 for the physical dimension of the MDHAQ-S. Testing item total correlation showed that, if the item concerning sleep was removed from the psychological dimension, the Cronbach's alpha increased to 0.91. In the physical dimension of the MDHAQ-S, Cronbach's alpha remained stable when testing item total correlation for the items included (variance 0.86-0.87).

The reliability test group had 27 fully responded questionnaires which were used for the calculations. Test-retest was performed in two ways. The items for physical function item 1a-1j were first summarized to one score, and the items for psychological function were also summarized to one score. Test-retest with intra-class correlation coefficient (ICC) gave a coefficient of 0.85 for physical function and 0.79 for psychological properties, which showed a good reliability of the MDHAQ-S for the functional and the psychological properties.

The second analysis of test-retest was performed for all items in the MDHAQ-S separately. The kappa statistics of the items 1a-1m showed a range between 0.35 and 0.82. The items with the highest scores were "Dealing with feelings of depression or feeling blue?" ( $K_w=0.82$ ) and "Turning regular taps on and off?" ( $K_w=0.72$ ), both showing excellent reliability. The items with the lowest scores were "Walking three kilometers, if you wish" ( $K_w=0.35$ ), "Dealing with feelings of anxiety or being nervous?" ( $K_w=0.39$ ). These two items show poor reliability. The other items in the first question have kappa values varying between 0.46 and 0.73, which is considered to be fair to good reliability [175].

Items 2-5 and 9-10 had an ICC of 0.75-0.86, which indicates very good reliability (items 5 and 10 concerning the amount of difficulties experienced). Items 6-8 were measured with kappa statistics and showed acceptable to very good results. Item 6 had a kappa of 0.51. This item also included a question concerning the duration of morning stiffness, which had an ICC of 0.28. Item 7, "How do you feel today compared to one week ago?", had a kappa of 0.41. Item 8, "How often do you exercise aerobically (sweating, increased heart rate, shortness of breath) for at least one-half hour (30 minutes)?", had a kappa of 0.95.

### **Validity**

The floor and ceiling effects of the MDHAQ-S are below the cut-off point of 15% for the physical dimension, showing that RA has had a negative effect on their physical capacity. The psychological dimension has a floor effect of 21.7% and a ceiling effect of 0%, which means that the participants has scored low effect of RA on their psychological function. There were floor and ceiling effects in question 8 concerning exercise habits, and floor effects for question 10. Question 10 concerned changes in their medical history, such as having experienced a medical trauma, and in their social life, for example, changed their medical status, during the last six months. The floor effect of this item shows that the participants had quite stable medical and social status.

The items were considered to be relevant if the content validity index was  $>0.78$  [163]. Item 10 in the MDHAQ-S had an item-level CVI of 0.75. The range of the item-level CVI of the other items in the MDHAQ-S was 0.89-1.00, which indicates that those questions in the MDHAQ-S are highly relevant for persons with RA. The MDHAQ-S was considered to be

relevant since the average of the sum of the content validity index for each item was 0.94.

None of the items in the MDHAQ-S and the AIMS2-SF had a very high correlation. Item 2 (pain) of the MDHAQ-S and the symptoms dimension of the AIMS2SF had a high correlation ( $r=0.77$ ). There was a moderate correlation between the physical component of the MDHAQ-S ( $r=0.65$ ) and item 4 (general well-being) ( $r=0.58$ ) to the symptoms dimension of the AIMS2-SF. The psychological component of the MDHAQ-S had a moderate correlation with the dimension of mood in the AIMS2-SF ( $r=0.57$ ). The dimension of symptoms of the AIMS2SF also had a moderate correlation with item 3 (amount of painful joints) of the MDHAQ-S ( $r=0.58$ ). The items of the MDHAQ-S showed a very low correlation with the social dimension of AIMS2-SF.

The MDHAQ-S physical component had a moderate correlation with item 3 (amount of painful joints) ( $r=0.55$ ), item 2 (pain) ( $r=0.62$ ) and item 4 (general well-being) ( $r=0.59$ ) in the MDHAQ-S. The latter two items also had a high correlation with each other. The MDHAQ-S psychological component had a moderate correlation with item 9 (fatigue) ( $r=0.53$ ) in the MDHAQ-S. Item 3 (amount of painful joints) had a moderate correlation with item 4 (general well-being) in the MDHAQ-S.

Item 8 (level of physical exercise) had a very low correlation with all items in the MDHAQ-S and the AIMS2-SF.

The MDHAQ-S was used in study IV with the aim of detecting decreased sexual health for persons with RA. The MDHAQ-S did detect decreased sexual health in level with earlier studies, but there were more participants

with decreased sexual health according to the QSH than the MDHAQ-S. However, the MDHAQ-S showed other factors that are important in order to detect decreased sexual health, such as increased pain, fatigue, depression, anxiety, physical capacity, level of physical activity and body weight.

## **Summary of results**

RA affects sexual health in different ways: physically, psychologically and emotionally. Persons with RA consider sexual health to be important, but health professionals rarely bring up the subject during clinical visits. According to persons with RA, sexual health can be improved by physiotherapy and improved information as well as communication about sexual health. The MDHAQ-S and the QSH are valid and reliable instruments that can be used to detect decreased sexual health for persons with RA. The MDHAQ-S correlates with the QSH and brings forward issues of importance concerning sexual health.

# General discussion

The message of this thesis is that sexual health is a neglected, but important topic when treating persons with RA. Strategies to improve sexual health for persons with RA are needed, and this thesis brings forward communication, information and physiotherapy as possible suitable interventions. Sexual health has been defined in this thesis by the WHO definition [5]. The term sexual health was first mainly used as a description of being free from sexually transmitted diseases, but has changed to a more inclusive term, where the level of sexual health is defined by each individual. This definition also includes the choice of being sexually healthy by choosing not to have a sexually active life. In the included studies this has not been investigated, but the items in the questionnaire have focused on if the informants have experienced whether or not RA has affected their sexual health, and if so, how, and not on issues describing their amount of sexual activities. Still, it is important to have awareness, that being asexual can be combined with experiencing good sexual health. A common risk factor for decreased sexual health in the general population is chronic diseases [18, 27, 176]. In the included studies, the participants have described their perceived effects on sexual health due to RA.

It is necessary to be flexible in communication and to have strategies within the rheumatologic team to deal with both men's and women's sexual health, and to acknowledge the gender differences. Those gender differences should be taken into consideration when communicating about sexual health with persons with RA. In accordance with considering gender differences, the subject of transgender should also be brought into

consideration [177]. In this thesis there has only been the option to answer the questionnaires used in studies I-IV with the choices “male” or “female”, which is discriminative towards those not distinguishing themselves as either [178]. The included studies would have improved if an additional alternative had been included. As the questionnaires were already developed, the only option was to neglect the question of gender for those not comfortable with describing themselves as male or female. In order to be able to assist persons with reduced sexual health, a structured interview is useful to assess sexual dysfunction associated with chronic illness [13].

Earlier studies have shown that communication with persons with RA is scarce among health professionals in the field of rheumatology [179, 180]. To enhance sexual health for persons with RA, it is important that all professions within the team have knowledge and communicative skills concerning sexual health. Among the participants in study I and study II, the results showed that there were differences in which health professional they preferred to discuss sexual health with; personal impression and feelings of mutual understanding were more important than profession. There is a need for collaboration between different health professionals when treating sexual health difficulties, since the competence of different professions may contribute to support and improve sexual health [7]. To empower patients there is a need for information according to each individual's need and to respect the individual's integrity, as well as best possible care from all health professionals in order to assist in improving a person's sexual health. In study II this was evident by some participants answering that they experienced sexual difficulties due to RA, but they did not want to discuss this issue with health care professionals. Information is an important part of improving sexual health according to the results from

study I and study II, since persons with RA can lack information about how RA and DMARDs might affect sexual health. Several patient organizations provide information about issues concerning sexual health and intimate relationships, but the included studies indicated a need for patients as well as health professionals to be informed about this. In study II the participants described how they wanted information about sexual health and RA to be available mainly in the waiting room, on the Internet and in written folders that they could share with their partners.

Persons with RA are less physically active than their counterparts, and introduction of physical activities as well as coaching towards increased physical activity is a basic, but important part, of physiotherapy [43]. The change in physiotherapy paradigm with the encouragement of physical activities and coaching of regular exercise for persons with RA further increases the reason why physiotherapists should be more active in working with sexual health. There are several reasons for this: 1) a person's level of physical activity can affect their sexual health, since increased physical activity can improve the amount of sexual intimacy, 2) a higher amount of active leisure time activities decreases feelings of pain and fatigue, which can also indirectly improve a person's sexual health, and 3) a person's level of daily activities is positively correlated with sexual functioning [181-184]. The level of physical fitness is also related to the level of sexual activities, which is an argument for physiotherapists to promote and coach physical activity in rehabilitation for persons with RA [181]. Men with a physically active lifestyle may decrease their risk of sexual dysfunctions, and physically active women may develop a greater sexual desire [27, 176]. Thus, a healthy lifestyle with regular exercise habits may be related to better sexual health. Persons who exercise regularly have

enhanced attractiveness and increased energy levels, which often make them feel better about themselves, which in turn can also enhance sexual health [185]. Physiotherapists regularly coach persons with RA towards being more physically active and to continue with physical activity after onset of the disease [120]. The relation between levels of sexual activity and physical activity shows that physical activity coaching may be done not only to improve physical fitness, but also to improve sexual health. Physiotherapists need to be aware of this. Moreover, they also need to inform their patients about the connection between an active lifestyle and sexual health in order to be able to promote a healthy lifestyle also from the perspective of sexual health. Knowledge about how physical activity can improve sexual health might also serve as a motivator towards increasing a person's level of physical activity, since perceived benefits increase engagement in physical activity [43]. Promotion of a healthy lifestyle is important, both for the individual and for society, in order to increase health and to reduce healthcare costs. Sexual well-being is connected to general well-being, and an increase of a healthy active lifestyle might be beneficial in a larger perspective [18]. To further enhance sexual health within clinical physiotherapy is a future challenge for the profession, as with health behaviour changes, which are a challenge to all health care professionals [114]. Exercise habits are included in the MDHAQ-S, but the results in study IV showed no significant differences for the group exercising three times per week or more concerning sexual health. The question concerning exercise habits in the MDHAQ-S (study III) showed both ceiling and floor effects. Therefore, it is possible that a more thorough description of the participants' exercise habits, including both intensity and type of exercise could have been useful when investigating how and

whether level of exercise can show significant differences for persons living with RA.

The interaction between health professionals and patient requires effective communication in order to achieve the wanted positive treatment results. A good base for communication concerning sexual health is the PLISSIT model [41]. The model has four steps: Permission, Limited Information, Specific Suggestions and Intensive Therapy. Each step demands increased knowledge and competence by the health professional, and the model can be used to identify the level of therapy needed for the individual.

Permission includes being open for communication about sexual issues, and this is essential for all health professionals [186]. Limited information means simple but relevant information, for example, "Physical exercise can improve sexual health". Specific suggestions include more precise advice for a mentioned sexual difficulty. Intensive therapy includes specific interventions performed by a sexologist or a psychologist. The physiotherapist not only has to be comfortable and active in the first step, Permission, but also feels confident and has enough knowledge to be able to act on the level of limited information in order to improve sexual health. There is a need for education about sexual health for all healthcare professionals in their basic training in order to gain knowledge, confidence and comfort in discussing sexual health with patients [106]. If the health professional lacks the essential knowledge, there is a risk for both continued decreased and worsened sexual health [187]. According to studies in other countries, there is a lack of education in sexual health in medical education [106, 186, 188] Owing to the results concerning sexual health communication in study II, there is reason to believe that the situation is similar in Sweden.

There is a large age span among the participants in the included studies. This is of interest since individuals may differ in how important sexual health and sexual activities are over time and from a gender perspective [18]. In addition, the incidence and reoccurrence of sexual dysfunctions increase with age. 40-45% of adult women and 20-30% of adult men in general population have sexual dysfunction [176, 189, 190]. In older age there is also a higher risk of having lost a partner, which might lead to excluding sexual activities. For younger women with RA, pregnancy can be an issue that affects sexual health, since pregnancy can cause a remission of symptoms, but this relapses in 90% of the cases within six months post-partum [191, 192]. Communication about sexual health could possibly be more present for younger persons with RA, where pregnancy could be an issue. However, in our studies, we have not seen this. It is possible that impact of RA on the informants' sexual health would have been seen differently if the studies were performed on more similar age groups.

Body image might also change with age, and the participants in the studies might have changed their view of their body due to disease or age [193]. There is also discussion within the scientific field of sociology concerning "erotic capital", where physical appearance is a major factor [194]. It is reasonable to believe that a person might feel a loss in their erotic capital, that is, in physical sexual attraction, when having a chronic disease, especially if the symptoms of the disease are visible to others [195]. The participants in studies II and IV have described negative body images, such as feelings of unattractiveness and feelings of being fat and ugly, as consequences of RA. Increased body weight was brought up in particular by the participants in the included studies. This is understandable, since body weight is considered not only to be a predictor of physical

attractiveness, but also since obese persons with RA have worse disease severity [196-198]. Obesity is also in itself a risk factor for decreased sexual health [195]. There are gender differences concerning obesity for persons with RA, with more men being more obese than women, but obese women report higher ratings of pain and fatigue [198]. Physiotherapy for persons with RA has been shown to improve self-confidence, increase the amount of daily activities and reduce depression [123-125]. When a person is confident about his or her physical ability, this is reflected in a higher self-esteem, a more positive body image and increased feelings of attractiveness [126]. All of these factors can affect sexual health in a positive way [109]. Body awareness is connected to self-esteem, trust in oneself, and the satisfaction of physical and mental needs [199]. Body awareness is part of the embodied identity, which states the importance of the strong connection between body awareness and identity [199]. A high self-perceived body attractiveness and self-esteem increase romantic self-confidence as well [200]. Physiotherapists working with the body have to be aware of and consider the embodied identity in their daily practice. The focus on physical appearance should be considered when communicating about sexual health with persons with RA, since participants in our studies who had a more negative body image often described deterioration in their sexual health, and needed more advice and information about sexual health.

Changes in medication might influence sexual health positively as well as negatively, according to the informants in the included studies. Participants in studies I, II and IV have described that their sexual health improved with new medication when their other symptoms of RA decreased. Other patients have, however, described a loss of sexual arousal and loss of ability to reach orgasm after starting with DMARDs. The type of DMARDs was

not registered in the included studies, which is a limitation of the studies, especially since use of biologic DMARDs has showed to have a negative impact on participation in sexual activity [67]. A study by Palmer and El Miedany [99] did not show any significant correlation between usage of DMARDs and sexual problems for persons with RA, but this issue needs to be explored further.

The use of questionnaires to explore the symptoms and health status of persons with RA is common. However, some questionnaires have been used during a long period of time and might have lost relevance due to changes in society. The items in the MDHAQ-S were considered to be highly relevant by the participants, according to CVI of 0.94 in study III. The development from the HAQ to the MDHAQ has followed changes in the treatment paradigm of RA, with inclusion of physical activity and changes from bathing in a tub to washing yourself, for example [154]. Therefore, the MDHAQ-S should be more relevant than the HAQ to use in clinical practice for persons with RA.

Items concerning body weight and exercise habits as well as changes in medication are included in the MDHAQ-S. Those items are useful to bring forward when communicating about sexual health with persons living with RA, according to our results in study IV. The MDHAQ-S might also be clinically useful for other rheumatological diseases such as osteoarthritis, systemic lupus erythematosus, spondylarthropathy and gout, since the original version has been used in clinical practice for those diseases [201]. Sensitivity to change of the original MDHAQ is also similar for those five diagnostic groups [202]. The MDHAQ has been considered to improve doctor-patient communication in clinical situations, due to the broad

perspective of the MDHAQ [203]. The results of study IV show that the MDHAQ-S covers sexual health issues, not only by using the question concerning sexual health, but also by using other questions included in the questionnaire such as increased pain, fatigue, depression, anxiety, physical capacity, level of physical activity and body weight. It will be of interest to research if clinics that regularly use the MDHAQ have a better patient-health care professional communication concerning sexual health, since our study II has shown a lack of communication about sexual health in this field [180]. However, to explore decreased sexual arousal, decreased sexual satisfaction and decreased sexual wellbeing, there is a need to conduct a deeper interview of persons with RA, either using a sexual health questionnaire such as QSH or in a clinical interview.

The QSH was used in study IV due to its validity and reliability in the Swedish context, which was tested in study III. There are different questionnaires that are used to measure the impact of RA on sexual health, but they differ in their scope. Some questionnaires focus on sexual dysfunction, others do not include whether the respondent experiences that the decreased sexual health is due to RA, or they cover only a specific short period time [99, 204]. Questionnaires concerning a specific time, for example, three months might be misleading if the respondents have felt their decreased sexual health since the onset of the disease. There are also non-disease specific questionnaires concerning sexual function, such as Female Sexual Function Index but they do not include intimate relationships [205]. The QSH includes both sexual function and intimate relationships, two areas of importance according to the ICF core sets for RA [22], and the questions are directed towards eventual impact of RA on

sexual health. The QSH does not cover a specific time, but is inclusive of the period of disease duration.

Other research questions that also have to be focused in future research are: How well are the sexual health care needs for chronically ill persons being met by healthcare professionals? Which strategies are the best to use by the individual and by healthcare professionals in order to improve sexual health? How can different healthcare professionals best enhance their work with sexual health issues?

## **Limitations of the included studies**

This thesis does not discuss issues of sexual preferences, but it is reasonable to believe that communication with healthcare professionals would be even more complicated if the person with RA also had a non-normative sexual preference. Non-normative sexual issues have been shown to be limiting sexual health discussions between healthcare professionals and patients in earlier research [206, 207]. In the included studies, the verbal and written phrasing concerning civil status of the person with RA could have been more inclusive. In some of the used questionnaires, terms such as "married", "living with someone" or "divorced" were used, but the terms of "having or not having a partner" would probably be more appropriate to use in future studies. In the verbal phrasing, the term "partner" was used in all studies.

The included studies did not approach Sjögren's syndrome with the participants in the studies, but it is reasonable to think that there have been participants who have had Sjögren's syndrome in the studied

population, since a suggested prevalence of Sjögren's syndrome among persons with RA is 10-55% [208, 209]. Recent studies have shown that Sjögren's syndrome correlates significantly with sexual dysfunction for women with RA. It is, therefore, reasonable to think that it might have affected the results of the studies since persons with RA and Sjögren's syndrome might experience more sexual health difficulties than persons with RA [179, 210]. However, since the prevalence of Sjögren's syndrome among persons with RA is common and will be present in the clinical everyday work, it is believed that the presented results are trustworthy despite this issue.

In our studies we have not discussed the issue of smoking, which might have been useful since smoking affects RA, sexual health and general health negatively [45, 211]. However, since a recent study could not find evidence that smoking was a risk factor for sexual dysfunction for persons with RA, it is possible that this would not have influenced the results of the included studies [212].

The first explorative qualitative study only included women living with RA, and it is reasonable to believe that the views of how men experience the impact of RA on sexual health might have deepened the understanding of the phenomena. In studies II, III and IV, the included groups of men were too small to explore results of gender subgroups. However, other studies with inclusion of men and women have shown similar results giving credibility to the results in study I [100, 142, 213].

Responsiveness to change has not been investigated for the QSH or the MDHAQ-S, which should be performed in future research, if the questionnaires were to be of use to follow up interventions.

## **Methodological considerations**

The choice of using mixed methods research in this thesis was due to the broad scope of the research theme. Mixed methods are a purposeful design in physiotherapy research. Quantitative design is not sufficient, especially when researching a person's experiences of pain and how it is to live with disabilities [214]. While working with the thesis, I have found that the use of both quantitative and qualitative methods has enlightened the performed research, in a way that it is doubtful that a single-method thesis would have done.

Both the diagnostic criteria of RA are included in the thesis, since several of the persons with RA involved in the included studies have been diagnosed according to the criteria from 1987, and the first study was performed before the criteria from 2010 were published [53, 54]. Several of the involved persons with RA in the included studies have had their diagnosis for many years, which is important to notice because they might have problems such as joint deformities due to the earlier years with the disease, even if they have experienced the benefit from improved medication in the more recent years. There are clinical discussions considering whether the criteria are more likely to over diagnose, that is, to diagnose mono arthritis as RA, but the criteria are so new that it is impossible to tell whether person who is diagnosed with RA according to the criteria from 2010 actually had mono arthritis. However, this should not have affected the general results since implications of new diagnostic criteria often take some time and therefore, it is possible that a majority of the informants were diagnosed according to the criteria from 1987.

## **Qualitative methodological discussion**

Since study I was descriptive and concerned sensitive issues such as sexual health and intimate relationships, a qualitative methodology was preferable. The researchers' pre-understanding as physiotherapists, one specialized in rheumatology and the other also a psychologist, was considered to be useful when analysing the data. The choice of a phenomenological approach was to truly highlight the lived experiences of the participants. Phenomenology has been used to explore different areas of impact of RA in qualitative research as, for example, quality of life, health quality and hospital admission [215-217]. Other qualitative methods have different aims and were not considered suitable due to the research question. The pragmatic choice of ten informants in study I was chosen since this selection was believed to adequately answer the research question. As study I progressed, it showed that the selection was sufficient to describe the studied phenomena. However, a larger sample could have given further views of the investigated phenomena. The selection procedure was a mixture between a convenience selection and a judgement selection, since there were physiotherapists asking patients if they could consider participating in the study after the patients had received written information about the study. In the selection there was an intention to have variation in factors such as age, functional ability, disease duration and marital status. The consideration of whether the person was suitable to be interviewed was thereby performed by the physiotherapist since all patients did not receive a personal question. According to Marshall, a judgement sample is preferable, and this should be considered in a future study [218]. All informants in study I had a Swedish background; inclusion

of informants with non-Swedish background could have contributed with more perspectives to the investigated phenomena.

Content analysis was chosen for study IV since this method has been used in other studies that have analysed open answers in questionnaires in combination with quantitative data analysis [172-174]. The transferability of the results of study I would have been improved if men had been included in the study, and for both study I and study IV, transferability could have been strengthened if the participants had been recruited from a more diverse population or broader region.

### **Quantitative methodological discussion**

The response rate is often low for questionnaires concerning sexuality and RA. A recent study in France had a response rate of 38% [219]. There is an increasing general trend towards lower participation in questionnaire surveys [220]. One way to increase participation is to offer a reward for participation [220]. This was not done in the included studies. The response rate in study II was fairly low, but other studies using questionnaires concerning sexual issues have shown even lower response rates, perhaps due to the sensitivity of the subject [100, 221, 222]. In a study of sexuality among Swedes, the lowest response rates were observed in older women [223]. Female gender and old age have also been shown to be factors that reduce response rates in questions about sexuality in other studies of the impact of rheumatologic disease on sexual health [100, 104, 224]. The sensitivity of the subject and the fact that the majority of the studied groups were elderly women can be reasons for the low participation, as well as the lack of any reward in those studies. However, the response rate in study IV was considerably higher than in study II. One

reason for this could be the difference between the study participants concerning education. In study IV the participants in general had higher education, which perhaps could have influenced the literacy of the questionnaire and the response rate [225]. Health literacy can affect the results of questionnaires [226]. This has, however, not been investigated concerning the QSH or the MDHAQ-S.

Spectrum bias was avoided in study III through the broad inclusion criteria of the studied group and the consecutive inclusion in the study. There is a risk for spectrum bias if the investigated sample does not reflect the clinically relevant population. The MDHAQ-S is primarily intended to be used in rheumatologic care, and the included participants come from this setting. AIMS2 has been used in other studies and has been considered to be of good reference standard, which, therefore, minimises misclassification bias [227-229].

Study III did not include age or disease duration, which could have been valuable in order to find eventual differences due to those factors considering validity and reliability of the MDHAQ-S. Information about the participants' age was instead found from the clinical visits record from the participating clinic. The age span found was in accordance with the studies I, III and IV, so a direct inclusion of age should not have affected the results of the study. However, age and disease duration should be included in future studies of the MDHAQ-S, preferably in combination with testing sensitivity to change of the instrument.

The size of the reliability test group in study III was in line with the size of earlier reliability test groups for the MDHAQ, but a larger group could have strengthened the results [155]. The results of test-retest group were

considered to be acceptable, and reliability was also tested for internal consistency with Cronbach's alfa.

The size of the study group in study IV was based on practical reality and therefore, power analysis was not performed prior to the study. The size of the sample in study III was slightly smaller than the sample size enrolled when testing the Korean and the Finnish version of the MDHAQ. However, the results showed resemblance [155, 156]. For kappa statistics in rehabilitation, which was used in study III, power calculations are not strictly relevant and they were not performed [230]. Multiple regression analyses have been performed on sample sizes equal to the sample size of study IV in physiotherapeutic research, but even so, a larger sample size would have strengthened the results [231, 232].

### **Mixed methods discussion**

Study IV was performed as a mixed methods study with a quantitative priority in order to complement the quantitative results with the qualitative findings. It is recommended that performers of mixed methods research have experience of both quantitative and qualitative research prior to using mixed methods, and research by groups of scientists is preferable [136]. The authors of this study have different expertise areas and have a broad qualitative and quantitative experience as a group, which covers the demand of knowledge for performing mixed methods research. The design was mixing during interpretation, that is, the qualitative strand and the quantitative strand were mixed after analysis of each collected data [136]. Among the reasons why mixed methods was considered the most suitable

approach to this study was the sensitivity of the research field – sexual health. In order to uncover the participants' feelings and lived experiences of decreased sexual health stemming from RA, with respect to the individual's integrity, the choice of set answers and open answers was considered preferable. The complement of the qualitative findings to the quantitative results was illustrative, and the analysis was supportive of each other.

# Conclusions

There is a lack of communication concerning sexual health between health professionals and persons with RA. Sexual health is affected negatively in different ways for persons with RA. Physiotherapists can play an active role in improving sexual health for persons with RA by increasing the patients' awareness that pain, fatigue, decreased mobility, low physical activity level and low physical capacity can affect sexual health negatively. There is a need to improve care concerning sexual health for persons with RA. In order to do so, health professionals need to recognise that sexual health can be negatively affected by RA. They also need to be aware and have knowledge of their professional possibilities of improving sexual health for persons with RA. An important part of improving sexual health is communication about sexual health. This also includes information of how RA, symptoms of RA, rehabilitation and medication might affect sexual health negatively and/or positively. Sexual health can be improved by information and increased communication between persons with RA and their partner, as well as with health professionals, and by physiotherapy. Physiotherapists can improve sexual health by promoting physical activities, physical capacity and mobility, and by reducing pain. Those interventions are common physiotherapy interventions, and have to be performed with the aim of improving sexual health. It is important to inform persons with RA about the connections between sexual health and a physically active lifestyle.

The Swedish version of the Multi Dimensional Health Assessment Questionnaire (MDHAQ-S) was found to be relevant, to have acceptable

reliability and validity, and can be used as a base for sexual health communication since it correlates with Questionnaire of Sexual Health and covers important dimensions of sexual health in a multiple way. However, to reach a deeper understanding of sexual health difficulties, an in-depth clinical interview or a sexual health questionnaire is needed.

## Clinical implications

New strategies of communication and information about sexual health need to be implemented by health care professionals in order to help persons with RA to improve their sexual health. A possible way to increase communication about sexual health between persons with RA and health professionals is to include the topic of sexual health in clinical guidelines. The present studies show that sexual health can be affected differently during the disease progression as well as during the lifespan due to aging and/or changes in the life situation. Therefore, sexual health issues have to be addressed routinely in clinical visits for persons with RA, in order for health professionals to be able to support those persons that experience decreased sexual health due to RA. One way to explore whether there are issues of sexual health that need to be addressed is to use the MDHAQ-S questionnaire. This questionnaire includes questions of sexual health as well as questions concerning symptoms that often are related to sexual health such as negative body image, fatigue and pain. For the best effect, information, communication and physiotherapy are recommended to be used in combination to improve sexual health.

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# Appendices

**Appendix 1 – Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy**

**Appendix 2 – Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy, Swedish version**

**Appendix 3 – Multi Dimensional Health Assessment Questionnaire – Swedish version (MDHAQ-S)**

**Appendix 4 - Questionnaire of sexual health for persons with RA**

**Appendix 5 - Questionnaire of sexual health for persons with RA, Swedish version**

## Appendix 1

### Questionnaire concerning sexual health for persons with RA and their experiences of physiotherapy

*Sexual health is defined from both a physical and psychological perspective, and may include close relationships with tenderness, touch and/or intimate sexual companionship. Having good sexual health is part of being well, physically and psychologically.*

*Below is a number of questions. Fill in, and off he answers that apply to you.*

1. My age is ..... years. I am  male  female
  
2. I am
  - Single
  - Living with someone
  - Married
  - Divorced
  - Widow/ widower
  
3. My partner
  - is healthy
  - suffering from.....
  - I don't have a steady partner
  
4. Disease debut
  - I felt the first symptoms in (year) .....
  - I got diagnosed with RA in (year).....

5. I often feel the following due to my disease (You may choose several alternatives)
- Pain
  - Swollen joints
  - Instability in joints
  - Stiffness
  - Fatigue
  - Sleeping difficulties
  - Other.....
6. Duration of the symptoms
- Constantly
  - Mainly in the mornings
  - Mainly during the day
  - Mainly in the evenings
  - Mainly at night
  - I have no symptoms one or several days in a row
  - Other.....
7. Except for RA, I also suffer from the following chronic symptoms
- .....
- .....

8. I have experience of (*You may choose several alternatives*)

- Group physiotherapy
- Individual physiotherapy
- I have no experience of physiotherapy

*Below are two statements about physiotherapy. Please cross off the alternatives that are in line with your views and experiences.*

9. Physiotherapy makes me (*you may choose several alternatives*)

- Happy
- Positive
- Depressed
- Tired
- Strong
- Other.....

10. I believe that physiotherapy is important for my (*You may choose several alternatives*)

- Physical capacity
- Wellbeing
- Self-confidence
- Strength
- Other.....

*Below are several statements about sexual health. Please cross off the alternatives that are in line with your views and experiences.*

11. When I see myself in a mirror I feel

- Very pleased
- Quite pleased
- Pleased
- Quite displeased
- Very displeased

Comment.....

12. Since I got RA, my attitude towards my body has changed

- Yes, I like my body better now
- Yes I like my body less now
- No, my opinion of my body has not changed

Comment.....

13. My disease has affected my possibilities of functioning sexually

- Yes, in a positive way
- Yes, in a negative way
- No, not at all
- Doubtful

Comment.....

14. My sexual health is affected negatively by (You may choose several alternatives)

- Pain
- Swollen joints
- Instability in joints
- Decreased motion
- Decreased physical capacity
- Stiffness
- Fatigue
- Sleeping difficulties
- Other.....

15. I would describe my sexual wellbeing as

- Very good
- Good
- Less good
- Unsatisfactory
- Very unsatisfactory
- Comment.....

16. I think my sexual desire is

- Normal
- Too strong or too often
- Too weak or too rare
- I have no sexual desire

Comment.....

17. If I compare my sexual desire today with before the start of rheumatoid disease, it is

- Much more
- A little bit more
- Unchanged
- Less
- Much less

Comment.....

18. After sexual activity I feel

- A strong satisfaction
- Quite a strong satisfaction
- A weak satisfaction
- No satisfaction at all

Comment.....

19. If I compare my sexual satisfaction today with before the start of my rheumatoid disease, it is

- Much better
- A little bit better
- Unchanged
- A little bit worse
- Much worse

Comment.....

20. I think the relationship I live in feels good and works

- Very well
- Quite well
- Ok
- Bad
- Very bad
- I don't have a relationship at present

Comment.....

21. I experience that RA has affected my relationship with my partner

- Very much
- Much
- A little
- Very little
- Not at all

Comment.....

22. To me, in my life, sexuality is

- Very important
- Quite important
- Quite unimportant
- Not important at all

Comment.....

23. I believe that there is a strong connection between decreased pain and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment.....

24. I believe that there is a strong connection between decreased stiffness and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment.....

25. I think that there is a strong connection between decreased fatigue and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment.....

26. I think that there is a strong connection between improved physical capacity and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment.....

27. I think that there is a strong connection between positive feelings and experiences and sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment.....

*Below are some statements about health professionals and sexual health. Please cross off the alternatives that are in line with your views and experiences.*

28. When I got RA, the rheumatologist/rheumatologic team discussed with me how my sexual health could be affected by the disease.

- Totally agree
- Partly agree
- Don't agree at all

Comment.....

29. In my contacts with health care professionals (within rheumatology), we discuss sexual health

- Every time
- Often
- Rarely
- Almost never
- Never
- When there is a need to discuss it

Comment.....

30. In my contacts with health care professionals (within rheumatology), I would like sexual health to be brought up the following way (*you may choose several alternatives*)

- I bring it up when there is need for it
- Health professionals bring up the subject
- Contact by e-mail
- Written information in the waiting room
- Information on the Internet
- I don't want sexual health to be brought up at all
- Other.....

31. If I had/have sexual problems I would talk to (*Choose several alternatives*)

- Partner
- Close friend
- Doctor
- Nurse
- Occupational therapist
- Physiotherapist
- Counsellor
- Other health professional
- I wouldn't talk about it
- Other.....

32. I have, due to my disease, felt a need for information and advice concerning my sexual life
- Yes, a major need
  - Yes, a certain need
  - No
  - Doubtful, don't know
33. I have asked for advice from health care professionals concerning sexual health problems
- Yes
  - No

## Appendix 2

### Frågeformulär om sexuell hälsa hos patienter med RA och deras upplevelser av sjukgymnastik

*Sexuell hälsa definieras här både ur ett kroppsligt och psykologiskt perspektiv och kan innefatta nära relationer av ömhet, beröring och/eller intim sexuell gemenskap. Att ha en god sexuell hälsa är en del i begreppet att må bra kroppsligt och psykologiskt.*

*Här följer ett antal allmänna frågor. Fyll i och kryssa i de svar som gäller för Dig.*

1. Min ålder är ..... År Jag är  man  kvinna
  
2. Jag är
  - Singel
  - Sambo
  - Gift
  - Skild
  - Änka/Änkeman
  
3. Min partner
  - är frisk
  - lider av.....
  - Jag har ingen stadigvarande partner

4. Sjukdomsdebut

De första symptomen kände jag av år .....

Jag fick diagnosen RA år.....

5. Jag känner ofta av följande på grund av min sjukdom (*här kan Du välja flera alternativ*)

- Smärta
- Ledsvullnad
- Ledinstabilitet
- Stelhet
- Trötthet
- Sömnsvårigheter
- Annat.....

6. Besvärens varaktighet

- Ständiga besvär
- Mest på morgonen
- Mest under dagen
- Mest på kvällen
- Mest under natten
- Jag är besvärsfri en eller flera dagar i följd
- Annat.....

7. Förutom RA, har jag också följande kroniska besvär

.....

8. Jag har erfarenhet av (*här kan Du välja flera alternativ*)

- Sjukgymnastik i grupp
- Individuell sjukgymnastisk behandling
- Jag har ingen erfarenhet av sjukgymnastik

*Här följer två påståenden om sjukgymnastik. Kryssa i de alternativ som överensstämmer med dina åsikter och upplevelser.*

9. Sjukgymnastik gör mig *(här kan Du välja flera alternativ)*

- Glad
- Positiv
- Nedstämd
- Trött
- Stark
- Annat.....

10. Jag tycker att sjukgymnastik är viktigt för min/mitt *(här kan Du välja flera alternativ)*

- Kondition
- Välbefinnande
- Självförtroende
- Styrka
- Annat.....

*Här följer ett antal påståenden om sexuell hälsa. Kryssa i de alternativ som överensstämmer med dina åsikter och upplevelser.*

11. När jag ser min bild i en spegel känner jag mig

- Mycket nöjd
- Ganska nöjd
- Nöjd
- Ganska missnöjd
- Mycket missnöjd

Kommentar.....

12. Sedan jag fick RA har min uppfattning om min kropp förändrats

- Ja, jag tycker bättre om min kropp nu
- Ja, jag tycker sämre om min kropp nu
- Nej, min upplevelse av min kropp har inte förändrats

Kommentar.....

13. Min sjukdom har påverkat mina möjligheter att fungera sexuellt

- Ja, positivt
- Ja, negativt
- Nej, inte alls
- Tveksamt

Kommentar.....

14. Min sexuella hälsa påverkas negativt av (*här kan Du välja flera alternativ*)

- Smärta
- Ledsvullnad
- Ledinstabilitet
- Nedsatt rörlighet
- Nedsatt kondition
- Stelhet
- Trötthet
- Sömnsvårigheter
- Annat.....

15. Jag vill beskriva mitt sexuella välbefinnande som

- Mycket gott
- Gott
- Mindre gott
- Dåligt
- Mycket dåligt

Kommentar.....

16. Jag tycker att min sexuella lust känns

- Lagom stark och lagom ofta
- För stark eller för ofta
- För svag eller för sällan
- Jag har ingen sexuell lust

Kommentar.....

17. Om jag jämför min sexuella lust idag med innan min reumatiska sjukdom började, är den

- Mycket större
- Något större
- Oförändrad
- Något mindre
- Mycket mindre

Kommentar.....

18. Efter sexuell aktivitet/ umgänge känner jag

- En stark tillfredsställelse
- En ganska stark tillfredsställelse
- En svag tillfredsställelse
- Ingen tillfredsställelse alls

Kommentar.....

19. Om jag jämför min sexuella tillfredsställelse idag med innan min reumatiska sjukdom började, är den

- Mycket bättre
- Något bättre
- Oförändrad
- Något sämre
- Mycket sämre

Kommentar.....

20. Jag tycker att det förhållande jag lever i känns och fungerar i stort sett

- Mycket bra
- Ganska bra
- Bra
- Dåligt
- Mycket dåligt
- Har ingen relation för närvarande

Kommentar.....

21. Jag upplever att RA har påverkat min relation till min partner

- Mycket
- Ganska mycket
- Ganska lite
- Mycket lite
- Inte alls

Kommentar.....

22. För mig är sexualiteten i mitt liv

- Mycket viktig
- Ganska viktig
- Ganska oviktig
- Inte viktig alls

Kommentar.....

23. Jag tycker att det finns ett starkt samband mellan minskad smärta och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

24. Jag tycker att det finns ett starkt samband mellan minskad stelhet och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

25. Jag tycker att det finns ett starkt samband mellan minskad trötthet och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

26. Jag tycker att det finns ett starkt samband mellan förbättrad kondition och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

27. Jag tycker att det finns ett starkt samband mellan positiva känslor och upplevelser och sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

*Här följer ett antal påståenden om sjukvårdspersonal och sexuell hälsa. Kryssa i de alternativ som överensstämmer med dina åsikter och upplevelser.*

28. När jag fick min RA diagnos diskuterade läkaren/reumateamet om/hur det kunde påverka min sexuella hälsa med mig

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

29. Vid mina kontakter med sjukvården diskuterar vi om/hur RA påverkar min sexuella hälsa

- Varje gång
- Ofta
- Ibland
- Nästan aldrig
- Aldrig
- Vid behov

Kommentar.....

Vid mina kontakter med sjukvården skulle jag vilja ta upp om hur RA påverkar min sexuella hälsa på följande sätt (*här kan Du välja flera alternativ*)

- Jag tar upp ämnet vid behov
- Sjukvårdspersonalen tar upp ämnet
- Kontaktmöjlighet via e-mail
- Skriftligt informationsmaterial tillgängligt i väntrummet
- Informationssida på internet
- Jag vill inte ha information om detta

Annat.....

30. Om jag har/har haft sexuella problem skulle jag prata med (*här kan Du välja flera alternativ*)

- Min partner
- Nära vän
- Läkare
- Sjuksköterska
- Arbetsterapeut
- Sjukgymnast
- Kurator
- Annan Sjukvårdspersonal
- Jag skulle inte prata om det

Annan.....

31. Jag har på grund av min sjukdom känt behov av information och råd för mitt sexuella liv

- Ja, ett stort behov
- Ja, ett visst behov
- Nej
- Tveksam, vet ej

32. Jag har sökt hjälp hos sjukvården för problem med sexuell hälsa

- Ja
- Nej





## Appendix 4

### Questionnaire concerning sexual health for persons with RA

*Sexual health is defined from a both physical and psychological perspective, and may include close relationships with tenderness, touch and/or intimate sexual companionship. Having good sexual health is part of being well, physically and psychologically.*

*Below is a number of questions. Fill in and cross off the answers that apply to you.*

1. My age is \_\_\_\_\_ years. I am  male  female

2. I am

- Single
- Living with someone
- Married
- Divorced
- Widow/ widower

3. My partner

- is healthy
- suffering from

---

- I don't have a steady partner

*Below are several statements about sexual health. Please cross off the alternatives that are in line with your views and experiences.*

4. When I see myself in a mirror I feel

- Very pleased
- Quite pleased
- Pleased
- Quite displeased
- Very displeased

Comment

---

5. Since I got RA, my attitude towards my body has changed

- Yes, I like my body better now
- Yes, I like my body less now
- No, my opinion of my body has not changed

Comment

---

6. My disease has affected my possibilities of functioning sexually

- Yes, in a positive way
- Yes, in a negative way
- No, not at all
- Doubtful

Comment

---

7. My sexual health is affected negatively by (You may choose several alternatives)

- Pain
  - Swollen joints
  - Instability in joints
  - Decreased motion
  - Decreased physical capacity
  - Stiffness
  - Fatigue
  - Sleeping difficulties
  - Other
- 

8. I would describe my sexual wellbeing as

- Very good
- Good
- Less good
- Unsatisfactory
- Very unsatisfactory

Comment

---

9. I think my sexual desire is

- Normal
- Too strong or too often
- Too weak or too rare
- I have no sexual desire

Comment

---

10. If I compare my sexual desire today with before the start of rheumatoid disease, it is

- Much more
- A little bit more
- Unchanged
- Less
- Much less

Comment

---

11. After sexual activity, I feel

- A strong satisfaction
- Quite a strong satisfaction
- A weak satisfaction
- No satisfaction at all

Comment

---

12. If I compare my sexual satisfaction today with before the start of my rheumatoid disease, it is

- Much better
- A little bit better
- Unchanged
- A little bit worse
- Much worse

Comment

---

13. I think the relationship I live in feels good and works

- Very well
- Quite well
- OK
- Bad
- Very bad
- I don't have a relationship at present

Comment

---

14. I experience that RA has affected my relationship with my partner

Very much

Much

Quite a little

Very little

Not at all

Comment

---

15. To me, in my life, sexuality is

Very important

Quite important

Quite unimportant

Not important at all

Comment

---

16. I believe that there is a strong connection between decreased pain and improved sexual health

Totally agree

Agree partly

Don't agree at all

Comment

---

17. I believe that there is a strong connection between decreased stiffness and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment

---

18. I think that there is a strong connection between decreased fatigue and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment

---

19. I think that there is a strong connection between improved physical capacity and improved sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment

---

20. I think that there is a strong connection between positive feelings and experiences and sexual health

- Totally agree
- Agree partly
- Don't agree at all

Comment

---

*Below is a statement about health professionals and sexual health. Please cross the alternatives that are in line with your views and experiences.*

21. When in contact with healthcare due to RA, I would like to be informed/discuss how RA can affect my sexual health in the following way (You may choose several alternatives)

- I bring up the subject if needed
- Health professionals bring up the subject
- Contact by e-mail
- Written information in the waiting room
- Information on the Internet
- I don't want information about how RA can affect my sexual health

## Appendix 5

### Frågeformulär om sexuell hälsa hos patienter med RA

*Sexuell hälsa definieras här både ur ett kroppsligt och psykologiskt perspektiv och kan innefatta nära relationer av ömhet, beröring och/eller intim sexuell gemenskap. Att ha en god sexuell hälsa är en del i begreppet att må bra kroppsligt och psykologiskt.*

*Här följer ett antal allmänna frågor. Fyll i och kryssa i de svar som gäller för Dig.*

1. Min ålder är ..... År Jag är  man  kvinna

2. Jag är

- Singel
- Sambo
- Gift
- Skild
- Änka/Änkeman

3. Min partner

- är frisk
- lider av.....
- Jag har ingen stadigvarande partner

*Här följer ett antal påståenden om sexuell hälsa. Kryssa i de alternativ som överensstämmer med dina åsikter och upplevelser.*

4. När jag ser min bild i en spegel känner jag mig

- Mycket nöjd
- Ganska nöjd
- Nöjd
- Ganska missnöjd
- Mycket missnöjd

Kommentar.....

5. Sedan jag fick RA har min uppfattning om min kropp förändrats

- Ja, jag tycker bättre om min kropp nu
- Ja, jag tycker sämre om min kropp nu
- Nej, min upplevelse av min kropp har inte förändrats

Kommentar.....

6. Min sjukdom har påverkat mina möjligheter att fungera sexuellt

- Ja, positivt
- Ja, negativt
- Nej, inte alls
- Tveksamt

Kommentar.....

7. Min sexuella hälsa påverkas negativt av (*här kan Du välja flera alternativ*)

- Smärta
- Ledsvullnad
- Ledinstabilitet
- Nedsatt rörlighet
- Nedsatt kondition
- Stelhet
- Trötthet
- Sömnsvårigheter
- Annat.....

8. Jag vill beskriva mitt sexuella välbefinnande som

- Mycket gott
- Gott
- Mindre gott
- Dåligt
- Mycket dåligt

Kommentar.....

9. Jag tycker att min sexuella lust känns

- Lagom stark och lagom ofta
- För stark eller för ofta
- För svag eller för sällan
- Jag har ingen sexuell lust

Kommentar.....

10. Om jag jämför min sexuella lust idag med innan min reumatiska sjukdom började, är den

- Mycket större
- Något större
- Oförändrad
- Något mindre
- Mycket mindre

Kommentar.....

11. Efter sexuell aktivitet/ umgänge känner jag

- En stark tillfredsställelse
- En ganska stark tillfredsställelse
- En svag tillfredsställelse
- Ingen tillfredsställelse alls

Kommentar.....

12. Om jag jämför min sexuella tillfredsställelse idag med innan min reumatiska sjukdom började, är den

- Mycket bättre
- Något bättre
- Oförändrad
- Något sämre
- Mycket sämre

Kommentar.....

13. Jag tycker att det förhållande jag lever i känns och fungerar i stort sett

- Mycket bra
- Ganska bra
- Bra
- Dåligt
- Mycket dåligt
- Har ingen relation för närvarande

Kommentar.....

14. Jag upplever att RA har påverkat min relation till min partner

- Mycket
- Ganska mycket
- Ganska lite
- Mycket lite
- Inte alls

Kommentar.....

15. För mig är sexualiteten i mitt liv

- Mycket viktig
- Ganska viktig
- Ganska oviktig
- Inte viktig alls

Kommentar.....

16. Jag tycker att det finns ett starkt samband mellan minskad smärta och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

17. Jag tycker att det finns ett starkt samband mellan minskad stelhet och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

18. Jag tycker att det finns ett starkt samband mellan minskad trötthet och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

19. Jag tycker att det finns ett starkt samband mellan förbättrad kondition och förbättrad sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

20. Jag tycker att det finns ett starkt samband mellan positiva känslor och upplevelser och sexuell hälsa

- Instämmer helt
- Instämmer delvis
- Instämmer inte alls

Kommentar.....

21. Vid mina kontakter med sjukvården skulle jag vilja ta upp om hur RA påverkar min sexuella hälsa på följande sätt (*här kan Du välja flera alternativ*)

- Jag tar upp ämnet vid behov
- Sjukvårdspersonalen tar upp ämnet
- Kontaktmöjlighet via e-mail
- Skriftligt informationsmaterial tillgängligt i väntrummet
- Informationssida på internet
- Jag vill inte ha information om detta

Annat.....

## **Papers 1-4**







RESEARCH ARTICLE

Open Access

# Women's experiences of sexual health when living with Rheumatoid Arthritis - an explorative qualitative study

Kristina Areskoug Josefsson<sup>1,2\*†</sup>, Gunvor Gard<sup>1,3†</sup>

## Abstract

**Background:** The ICF core sets for patients with Rheumatoid Arthritis (RA) acknowledge sexual function and intimate relationships as important since the patients' sexual health can be affected by the disease. About 36-70% of all RA-patients experience a reduced sexual health, and their perceived problems are directly or indirectly caused by their disease. Physiotherapy is often used as non-pharmacological treatment for RA. Mobility treatment, pain reduction, and physical activities are often included in physiotherapy for patients with RA. The aim of the study was to explore sexual health in relation to physiotherapy in women living with RA.

**Method:** An explorative qualitative interview study with a phenomenological approach was performed. The study consisted of ten interviews with women with RA. The analysis was performed according to Giorgi.

**Results:** The main theme that emerged in the material was that the body and the total life situation affected sexual health. Three categories were included in the theme: 1) sexual health - physical and psychological dimensions, 2) Impacts of RA, and 3) Possibilities to increase sexual health - does physiotherapy make a difference?

**Conclusions:** Sexual health was affected by RA in different ways for the informants. Possibilities to improve sexual health were improved partner communication and physiotherapy. Physiotherapy can play an active role in improving sexual health for patients with RA.

## Background

According to World Health Organization (WHO), sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality [1]. This means that sexual health has to be seen from a holistic perspective, including physical, psychological, and social aspects of well-being. To receive such a well-being also requires a positive and respectful approach to sexuality and sexual relationships.

The International Classification of Functioning, Disability and Health (ICF) [2] includes sexual health in two different areas: sexual functions and intimate relationships. The ICF core sets for patients with Rheumatoid Arthritis (RA) acknowledge both areas as important since the patients can be affected by the disease [3].

About 36-70% of all RA-patients experience reduced sexual health, and their perceived problems are directly or indirectly caused by their disease [4-8]. A majority of the patients with RA are women. However, there are differences concerning sexual health for men and women, especially during sexual activities. Women report more joint difficulties than men [9].

Sexual health difficulties due to RA can include decreased sexual arousal, decreased sexual desire, and decreased satisfaction. Different problems can cause sexual health difficulties for women with RA. It can be fatigue, pain, limited physical ability, negative body image, and depression [4,5,7,8,10-12]. Limited physical ability can affect different areas of sexual activities, for example, restricted hand mobility limits the possibility of caressing the partner [7], and restricted mobility in larger joints limits possible sexual intercourse positions [5,7,12]. According to Kraaimaat et al, there is a correlation between decreased mobility, depression, and

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decreased sexual health [8]. Negative body image can be connected to the amount of morning stiffness [10].

Research concerning women with RA and their sexual health has mainly focused on describing the problems, with few comments on how to improve the women's sexual health.

The mentioned solutions include increased and improved communication between health staff and patients [11] and physiotherapy. The recommendations of physiotherapy are based on pain relief treatment and joint mobility treatment with the aim to reduce pain and improve daily functional capacity as a prerequisite for engaging in sexual activities [4,8,13].

Mobility treatment, pain reduction, and physical activities are often included in physiotherapy for patients with RA. The habits of physical activity can affect sexual health, since increased physical capacity can increase the prevalence of sexual intimacy [14]. Physiotherapy treatment has been shown to increase mobility, self-esteem, and physical daily activities, and to reduce pain for patients with RA [15,16]. This could indirectly influence sexual health for this group. Concerning direct treatment of sexual health, there has been a study of cognitive-behavioural physiotherapy in order to enhance sexual function for women with chronic pain [17], which showed positive results.

## **Aim**

The aim of the study was to explore sexual health in relation to physiotherapy in women living with RA.

## **Method**

### **Method and data collection**

An explorative qualitative interview study with a phenomenological approach was performed. The purpose was to uncover women's experiences of sexual health when living with RA and their experiences of physiotherapy in this context. To facilitate the interviews an interview guide was used [18] that focused on experiences of sexual health when living with RA. The interview guide consisted of the following themes: marital status, duration of RA, medication, age at onset of disease, changes in the disease during the last three months, definition of sexual health, importance, experiences of sexual health over the life span and in different situations in life, relations between RA and sexual health/sexual activity/intimate relationships, suggestions for improvement of sexual health, experiences of physical and psychological functions, body image, main problems when living with RA, experiences of physiotherapy interventions, believed effect of physiotherapy, experienced emotions and usefulness of physiotherapy when living with RA. Three pilot interviews were performed before the start of the study. These

were used to verify the interview guide and were not included in the study.

The informants were informed of the study by leaflets and by their local physiotherapist at the hospitals. The leaflets contained information about the study and who to contact if they wished to participate. Interested participants contacted the first author by mail or phone, and then they received additional information about the study. Before each interview all the participants received both oral and written information about the project, and confirmed their participation in the project in writing with informed consent. The project has been approved by the regional ethical committee in Linköping, Sweden. The project number is M48-09.

The individual interviews were conducted by the first author at the local hospitals. Each recorded interview lasted between 25-54 minutes, depending on the amount of information given by the informant. The interviews were transcribed verbatim. The transcribed version of the interview was sent to the participants to allow them to correct misinterpretations by the interviewer. None of the informants made any corrections of their interview material.

### **Data analysis**

The analysis was performed according to Giorgi [19,20]. Phenomenology was chosen since it aims to show the phenomena from the experiences and the views of the person being studied, and it is a recommended methodology for use in physiotherapy research [21,22].

Validation and reliability in phenomenology, according to Giorgi, is obtained when the described phenomena are captured by the intuited essence, and this description can be used consistently [23]. The analysis of the material according to Giorgi consists of the following steps [19,20]:

1. Reading through the material to get a general sense of the whole statement.
2. Re-reading of the material to discriminate meaning units from a holistic perspective and to focus on the experience of sexual health when living with RA.
3. Going through the meaning units and expressing deepened insight contained in them more directly.
4. Synthesizing of the transformed meaning units into a consistent statement regarding the subjects' experience.

In addition to the interviews, the informants filled in the Health Assessment Questionnaire (HAQ DI) [24] in order to ensure variability of the functional ability of the informants. The original HAQ included a question about sexual health, but the HAQ DI has excluded this question. The HAQ DI is an instrument intended to

measure the informants' level of functional ability in daily activities. The HAQ DI is regularly used in rheumatology research and has been used in studies concerning sexual health and RA [5,12,25].

### Informants

Criteria for inclusion in the study were women with a diagnosed RA for at least two years, who had experience of physiotherapy, living in the county of Jönköping in Sweden. The informants should be permanent residents of the region where the study was conducted.

The 10 informants were between 42 and 66 years old, median age - 59.5 years old. A majority of the informants lived in stable, long-lasting relationships. The number of diagnosed years with RA differed between 2-31 years, median 9 years, for the informants. Some of the informants had experienced several years of joint pain before they were diagnosed. Four informants used biological medications, five had other Disease Modifying Anti-Rheumatic Drugs (DMARDs), and one informant had chosen not to have any DMARDs at all. Biological medication is treatment designed to stimulate or restore the ability of the body's immune system to fight infection and disease. This brief description of medications is to show variability among the informants concerning level of medication. The HAQ-levels of the informants varied between 0-2.13 (0 is the minimum and 3 is the maximum score possible), which indicates a great variety in daily functional ability. The work ability differed between the informants, from sickness pension to full-time employment, but most of them worked part-time. Four of the informants also had other diseases (high blood pressure, chronic obstructive lung disease and depression).

All of the informants had earlier experiences of physiotherapy treatment, to improve physical function. All of them had experience of hydrotherapy. Some of the informants had only experience from group exercises, and others had experienced both group exercises and individual physiotherapy. Group exercises included both hydrotherapy and land-based activities. The experienced individual physiotherapy consisted of: massage, acupuncture, exercise programs, stretch exercises, transcutaneous electrical nerve stimulation, and coaching towards physical activity.

### Results

The main theme that emerged in the material was that the body and the total life situation affected sexual health. Three categories were included in the theme: 1) sexual health - physical and psychological dimensions, 2) Impacts of RA and 3) Possibilities to increase sexual health - does physiotherapy make a difference?

### Sexual health - physical and psychological dimensions

Sexual health was experienced and described by the informants as containing both a physical and a psychological dimension. The physical dimension was experienced as touch, caressing, showing love and tenderness as well as sexual intercourse. The psychological dimension of sexual health was experienced as being there for another person, psychological closeness, feeling loved, and caring for someone. Some of the informants defined limits for their own sexual health, for example, explaining that sexual intercourse no longer was included in their sexual health. The informants experienced the importance of sexual intercourse differently. Sexual health was not experienced to be limited to sexual intercourse.

*"Sexual health for me is not sexual intercourse. It's more like physical closeness."*

Some informants had no sexual desire and were negative to sexual activities. A negative attitude towards sexual activities and loss of sexual desire affected their relationships in a negative way. The informants that described an acceptance of this by their partners or an increased acceptance over time also described less strain on their relationship. Others experienced sexual health as very important, and considered sexual intercourse as a joyful experience. All mentioned closeness and caring as important aspects of a relationship. *"Attraction, yes. That you are... That tenderness is mutual and that you... That you're now together with each other."*

The informants mentioned different emotional experiences related to their definitions of sexual health. Pleasure, happiness, joy and the opportunity to release emotions were experienced, but also increased pain and psychological pressure. Feeling attractive and being attracted to the opposite sex were also included in sexual health, as well as feelings of unattractiveness.

*"You're happier simply because you've got someone."*

Sexual health was also experienced as a close sexual companionship, doing things that felt good for each other, and having pleasurable sexual experiences with the partner. To achieve sexual health, understanding and communication between the partners were vital, as well as honesty with each other, and willingness to participate in the sexual relationship. Sexual health and the importance of sexual health were experienced to have changed in different phases of life.

*"Yes. I don't put too much weight in it. It was more important when I was younger. One does revalue things. I wouldn't have responded like this 10 years ago."*

### Impacts of RA

The informants experienced that RA could have physical, psychological, emotional, and relational impacts on

them. Most informants experienced negative impacts of RA, both directly and indirectly, on their sexual health.

Physical impacts of RA were experienced to be similar for the informants such as pain, fatigue, stiffness, and swollen joints, with varying severity. Some of the informants also experienced decreased physical ability, deformed joints, and reduced muscle strength, which could lead to decreased ability to walk and to perform daily activities. There was a large variety of direct negative impact on sexual health: deformed hip joints which made sexual intercourse impossible, pain (before, during and after sexual activities), hip mobility problems during intercourse, decreased mobility in sexual activities in caresses, decreased sexual arousal and desire, pain when being touched, pain when caressing the partner, decreased sexual satisfaction, and fewer possible positions for sexual intercourse. Caresses could lead to increased pain, and in those cases further sexual activities were often avoided.

*"And then, it hurts so much when someone touches me that I feel, no, you mustn't touch me."*

*"I've lost my sexual desire."*

*"Sex simply doesn't work. I can barely walk sometimes."*

Some of the informants had gone through or planned to go through joint surgery.

Body image was experienced to be affected for some of the informants, and the most common negative impact was increased weight due to medication and inability to be physically active. RA was experienced to influence the whole life situation.

Psychological impacts of RA were experienced but differed within the group. A positive impact was increased psychological strength, which was achieved by having to handle the physical impacts of RA. Negative impacts were problems due to sleeping difficulties, anxiety, worry, frustration, fear of being abandoned by their partner, feeling old, and being angry. The negative emotions affected the sexual life of the informants, for example, worrying about increased pain during sexual activities led to avoidance of sexual activities, and feeling old was connected to feelings of being unattractive.

*"...but I get so damned mad for I can't manage anything without feeling pain as a result of it."*

*"For I have felt I'm not good enough. In different ways, not just sexually."*

The relational impacts of RA were experienced within the field of sexuality, as for example different sexual needs. Other relational impacts of RA concerned reduced capacity to perform daily activities. The informants described experiences both from present and earlier relationships. One informant experienced an improved relationship with her partner after the RA diagnosis.

*"Well, it's a little like this - what I can do and what I can't do. The discussion pops up now and then on what we want to do. He wants to do it, but I can't and that's a pity, I think."*

*"I couldn't manage anything. I couldn't even manage intimacy because I couldn't bear being touched."*

#### **Possibilities to increase sexual health - does physiotherapy make a difference?**

Reflections about possibilities to improve sexual health were a new field for the informants. Most of them had not reflected on their sexual health or thought it possible to improve it. Some informants were satisfied with their sexual life. However, in the interview situations, possibilities to increase sexual health were explored. The informants described that if their pain and fatigue could be decreased, and if their sexual desire could be increased, they believed that their sexual health would be improved.

*"If I hadn't had pain, it would have worked better. Take away tiredness."*

Some of the informants had experienced direct positive effect of physiotherapy on their sexual health, and some had not reflected on this topic before the interviews. Several of the informants described perceived effects of physiotherapy for rheumatic patients in general, and not only from their personal experiences.

Direct experienced effects of physiotherapy concerning sexual health included increased physical activity levels, knowledge of their own physical capacities, and increased fantasy. Increased knowledge of physical abilities and increased physical capacity could make sexual activities easier since the informants felt that they had enough physical strength to manage specific intercourse positions. Physical activities during physiotherapy were described as a way to get a widened range of positions that could be used in sexual activities. Touch and increased ability to accept being touched were mentioned by some informants as important for sexual health. Several physiotherapy interventions include touching and passive joint mobility stretching. Increased joint movement was given as a suggestion for more possible positions for sexual intercourse. Increased relaxation was mentioned as an effect of physiotherapy that improved sexual health.

*"I think it has helped me to be more agile."*

*"Because you get softer in your body. You get energy as well. You get a burst of energy."*

The positive emotions following a physiotherapy session were experienced to have given an increased attention for the partner and more energy to the relationship. Increased self-esteem and a positive body image were experienced to have improved the feeling of sexual attractiveness.

*"Yes, I think so. In any case, to maintain agility and strength and to feel satisfied. You're in fact exercising and you feel satisfied with your body."*

Some of the informants believed physiotherapy to be more important concerning sexual health for patients with severely decreased mobility and low range of joint movement. Exercise programs that decreased pain were also believed to improve sexual health, since several of the informants mentioned pain as an important factor that could decrease sexual health.

Informants experienced both positive and negative effects of physiotherapy, and all of the informants still had a positive opinion of physiotherapy, and had experienced emotions of contentment and joy regarding treatment sessions. All informants expressed a flow of positive emotions during and after physiotherapy, such as joy, feeling appreciated and cared for. These emotions increased the experienced positive effects of physiotherapy.

The informants described their physiotherapists as a coach, a provider of information concerning the body and the disease, someone who gave them feedback and back-up in their daily activities. The physiotherapist was considered by the informants to have an important role in rheumatological care.

*"It's also that you get... how you should do and feedback and I ask like this: 'What should I do if I want to have muscles there? If I want help with the right exercises.'"*

According to the informants, sexual health could also be improved by imagination, fantasies, and planning of sexual activities that consisted of: spending time together on holidays, creating a more intimate atmosphere with your partner, finding time for more foreplay and using stimuli for love, such as music.

An important aspect to achieving sexual health was an increased communication between partners and knowledge about the impacts of RA concerning sexual health. Written information, shared with the partner, could be used as a basis to discuss their own mutual sexual life. Long-lasting relationships were experienced to increase the possibilities of having an open communication concerning sexual health between partners. The partner's own health also affected the sexual health for the informants, and a healthy spouse increased the possibilities of having good sexual health.

## Discussion

As this is an explorative first study of experiences of sexual health in relation to physiotherapy, we used a qualitative design with a phenomenological approach to cover the lived experiences of sexual health when living with RA. Phenomenological approach with analysis according to Giorgi, has been used in earlier

physiotherapy research concerning musculoskeletal disorders [26] and in other studies in rheumatology. One of the interviews was short time-wise, which could indicate that the researched phenomena were not fully explored [18], and it is possible that the informant was not willing to share her views of the researched phenomena due to the sensitivity of the topic. A follow-up interview with this informant might have given additional data. The phenomenological research approach indicates that a small sample size is sufficient to explore the researched phenomena [27] and to ensure that the collected data can be fully explored. There has been discussion concerning the truthfulness of face-to-face interviews in sexuality research [28], but as the first exploratory study of experiences of women's sexual health when living with RA and their experiences of physiotherapy in this context, phenomenology was chosen as the most appropriate method for the study.

The informants were informed that the interviewer was a physiotherapist, which might have influenced the believed effects of physiotherapy in a positive way. It is also possible that the knowledge of the interviewer, concerning physiotherapy for RA, increased the ability to deepen the interviews. Counter effects of medicines were not brought up in the interviews since they are not considered relevant from a physiotherapy perspective, even if those effects might affect sexual health. The revealed information in this area is limited to what the informants included in the perspective of sexual health. The emerged themes are specific to the informants and the context, but generalisation could be possible to other individuals in similar contexts.

Changes in health can lead to reducing the importance of sex in life [29], and results showed that multidimensional factors, due to RA, influenced sexual health for the informants.

The results showed that decreased mobility and muscle strength could have a negative impact on sexual health due to difficulty in finding comfortable positions during sexual activities, or limiting the amount of possible sexual intercourse positions. Those findings coincide with findings in other research [4,8,9,11,12,30]. Inability to be as physically active as the informants wanted to be was mentioned as a reason for reduced sexual health. This could be important knowledge in clinical practice since physiotherapy often is directed towards increasing physical activity. Body image did not seem to be a major issue for the informants, even though some of them were visually marked by RA. The reasons for this could be a field for future research.

Emotional experiences due to RA were anger, frustration, and fear of being abandoned by the partner. Fear of being left by the partner can depend on decreased sexual activities [31]. Those emotions can affect sexual

health in a negative way, and might need to be addressed more often when talking about sexual health for patients with RA.

The informants mentioned not only pain in connection to sexual intercourse, but also pain when being touched/caressed, and this needs to be considered since caresses are still important in a relationship, when the importance of sexual intercourse is lowered. Pain when being caressed has not been focused on in other studies.

Changes during life and age can affect sexual desire [32], and age also has an effect on the importance of sexual ability for patients with RA [11], which implies that the interviews might have differed concerning importance of sexual health and sexual activities, if the informants had been younger. The age of the informants indicates that several of them should have experienced menopause, but none of them mentioned this in the interviews. This is interesting since menopause and hormonal changes can affect both RA [33,34] and sexual health [35].

Decreased sexual satisfaction was mentioned by some of the informants. This has been brought up in other studies, but the conclusions differ [9,12,36,37]. According to van Lankveld et al, sexual satisfaction is lower among patients with RA and their partners [36] compared to healthy individuals. This was unrelated to pain and level of functional ability. Majerovitz and Revenson [37] disagree with those results, and indicate that greater functional disability is related to lower sexual satisfaction, especially for women. Van Berlo's findings show no differences in sexual satisfaction between patients with RA and controls [9].

Decreased sexual health is common for women with RA, and their sexual health problems remain after two years of RA, despite medication [38]. This shows the importance of finding ways to improve sexual health for women with RA. The most common areas mentioned for improvement by the informants were decrease of pain and fatigue, as well as increase of sexual arousal. Reflections on how to improve sexual health were quite new to the informants, and it is possible that other problems related to RA were more prioritized. Practical suggestions on how to improve sexual health included better communication between partners, better information about consequences of RA on sexual health, and physiotherapy.

Physiotherapy can affect sexual health positively in different areas according to the informants. According to Hill et al [11] most of the sexual health problems due to RA are related to symptoms which could explain why the informants thought or had experienced that physiotherapy could improve sexual health. Physiotherapy is often directed towards improving activities of daily living, and sexual relations should be included in this

context [39]. Physiotherapy in general has changed towards becoming more of an active treatment, including coaching towards increased physical activities [40]. Increased activity levels can increase perceived health status and reduce fatigue for patients with RA [41,42], and were mentioned as giving direct positive effect on sexual health by the informants, which is also stated by Monga et al. [43]. Those results coincide with results of older healthy women, where physical fitness and high levels of sexual activity were related [14]. Physiotherapy interventions based on exercise therapy can also reduce fatigue [42], which then indirectly can increase sexual health according to the informants. Pain was decreased by physiotherapy, and since pain is one of the dominating factors that decrease sexual health, physiotherapy must be highlighted as an important way to improve sexual health for patients with RA. Increased muscle relaxation was mentioned as a positive effect of physiotherapy by the informants, but progressive muscle relaxation interventions on quality of life for patients with RA have not been shown to have long-term effect [44]. Physiotherapy was considered to increase the amount of possible sexual intercourse positions by increasing joint mobility, increased muscle strength, and the patients' knowledge of their own physical abilities. Muscle strength exercise is common treatment for patients with RA [45], and is usually supervised by a physiotherapist. Knowledge of one's own physical ability was connected to positive self-esteem and a more positive view of the body, and increased feeling of sexual attractiveness, all of which can influence sexual health. Positive emotional reactions during physiotherapy were mentioned by the informants, and those emotions can increase the effect of physiotherapy [46]. There were also positive emotional reactions after physiotherapy, which the informants noted as positive for their relationship with their partner. Some of the informants believed that physiotherapy gave a greater effect on sexual health for patients with more severe physical limitations. As authors we believe that physiotherapy has an important role in improving sexual health for women with RA. The study has deepened the knowledge of experiences of sexual health for women with RA.

The awareness of physiotherapists concerning the possibilities of affecting sexual health directly/indirectly for women with RA is a field for future research, as well as whether/how women with RA want physiotherapists to address with them the issue of sexual health in relation with physiotherapy. There is a need for further research concerning whether physiotherapy treatment directed at improving sexual health for women with RA can get positive results, or whether effect of physiotherapy on sexual health only can be seen as an indirect co-effect of physiotherapy interventions in general. There also is a

need for research concerning which physiotherapy interventions are most effective to use in order to improve sexual health, in order to evaluate direct effect of physiotherapy on sexual health.

## Conclusion

- Sexual health was affected by RA in different ways for the informants.
- Possibilities to improve sexual health were improved partner communication and physiotherapy.
- Physiotherapy can play an active role in improving sexual health for patients with RA.

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## Authors' contributions

The planning of the study, data analysis, results, and discussion were performed by both authors. KAJ performed the data collection and drafted the section on results and discussion. Both authors read and approved the final manuscript.

## Competing interests

The authors declare that they have no competing interests.

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# Paper II



## RESEARCH ARTICLE

# Sexual Health in Patients with Rheumatoid Arthritis: Experiences, Needs and Communication with Health Care Professionals

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### Abstract

Pain, fatigue and decreased joint mobility caused by rheumatoid arthritis (RA) often decrease sexual health in RA patients. Regular physiotherapy interventions in patients with RA are often aimed at improving those factors. The aim of the present study was to explore the experiences and views of patients concerning the impact of RA on their sexual health, the possible impact of physiotherapy interventions, and communication in clinical situations. A self-administered questionnaire was sent to patients with RA at two rehabilitation clinics in Sweden. The questionnaire included questions concerning the impact of RA on intimate relationships and sexual function, as well as experiences of physiotherapy and sexual health communication with health professionals. The questionnaire was answered by 63 patients. The majority of the patients thought that pain, stiffness, fatigue and physical capacity were related to sexual health. Communication between health professionals and patients about sexual health was less common, even if the desire for communication about sexual health was higher in this study than in other studies. The authors concluded that physiotherapists need to be aware that pain, fatigue, decreased joint mobility and physical capacity can affect sexual health and that physiotherapy can make a difference in sexual health in patients with RA. The impact of RA on sexual health is rarely discussed by health professionals and RA patients, and needs greater attention. Copyright © 2012 John Wiley & Sons, Ltd.

### Keywords

Rehabilitation; physiotherapy; sexual health; rheumatoid arthritis

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### Introduction

Sexual health should be viewed in a holistic perspective that includes physical, psychological and social aspects of well-being. This perspective was confirmed by a qualitative study of female patients with rheumatoid arthritis (RA), who expressed that sexual health should be considered a broad subject with physical, emotional, psychological

and relational factors (Josefsson et al., 2010). Sexual health is included in the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) in two different areas: sexual functions and intimate relationships. Both areas can be affected by RA, which is why they are incorporated into the ICF core sets for patients with RA (Stucki et al., 2004).

A large number of patients with RA (36–70%) experience a negative impact on sexual health, where the reduction in sexual health and the perceived problems in this area are directly or indirectly caused by the disease (Abdel-Nasser and Ali, 2006; Baldursson and Brattstrom, 1979; Kraaimaat et al., 1996; Pouchot et al., 2007; Yoshino and Uchida, 1981). The problems can be physical, relational, emotional and/or psychological and are associated with personal and social factors (Akkas et al., 2010).

Physical factors that decrease sexual health in patients with RA are fatigue, pain, negative body image, decreased joint mobility and muscle strength, and inability to be sufficiently physically active (Abdel-Nasser and Ali, 2006; Areskoug-Josefsson and Oberg, 2009; Baldursson and Brattstrom, 1979; Bath et al., 1999; Elst et al., 1984; Gutweniger et al., 1999; Hill et al., 2003; Josefsson and Gard, 2010; Kraaimaat et al., 1996; Rkain et al., 2006; van Berlo et al., 2007). Pain in RA can be both variable and unpredictable (Pouchot et al., 2007) and can affect patients with RA in many different areas of life. Pain can reduce sexual desire (Abdel-Nasser and Ali, 2006). Fear of increased pain in association with sexual activity can lead to an avoidance of sexual activity and/or trying to reach orgasm as quickly as possible and thereby reduce the risk of increased pain (Elst et al., 1984). The level of fatigue can be high, even when RA is well controlled with medication (Repping-Wuts et al., 2008). The impact of fatigue on negative emotions and the consequences in life can be associated with gender, with women experiencing more problems with fatigue than men (Nikolaus et al., 2010). Research on mobility limitations in association with sexual health has dealt mainly with mobility in the lower extremities. Limitations in hip/knee mobility have shown diverse results, depending on whether the mobility limitations have affected sexual health (Elst et al., 1984; Rkain et al., 2006; Yoshino and Uchida, 1981). Depression and negative emotions, such as feeling old and unattractive, are examples of psychological and emotional factors that can be caused by RA which may affect sexual health negatively (Abdel-Nasser and Ali, 2006; Baldursson and Brattstrom, 1979; Josefsson and Gard, 2010; Kraaimaat et al., 1996; Lempp et al. 2006). The relational impact of RA includes the psychosocial burden that may be experienced by the partner (Matheson et al., 2010).

Sexual health problems often include decreased sexual arousal, decreased sexual satisfaction and decreased sexual activity. Studies have shown gender differences in how RA affects sexual arousal and sexual satisfaction. Women with RA have a greater decrease in sexual satisfaction than men after the onset of disease (Akkas et al., 2010) and the majority of them have reduced sexual arousal (Abdel-Nasser and Ali, 2006). Satisfaction with sexual health is an important predictor of global life satisfaction in patients with RA (Tasiemski et al., 2009), and low sexual well-being indicates lower overall happiness (Laumann et al., 2006). The association between sexual satisfaction and global life satisfaction indicates the importance of promoting sexual health, especially since increased general well-being is prioritized by patients with RA (Ahlmén et al., 2005).

Improvement of sexual health in persons with RA is important, since a negative impact on sexual health is common in this group of patients and it is known that these problems remain after two years of RA, in spite of medication (Karlsson et al., 2006). The most frequently mentioned solutions for improving sexual health in patients with RA include more and better communication between health staff and patients (Hill et al., 2003) and physiotherapy interventions (Areskoug-Josefsson and Oberg, 2009; Kraaimaat et al., 1996; Yoshino and Uchida, 1981). Unfortunately, communication between health staff and patients concerning sexual health is limited (Abdel-Nasser and Ali, 2006; Akkas et al., 2010; Hill et al., 2003; Majerovitz and Revenson, 1994; Rkain et al., 2006) and rehabilitation staff engage less often in talks with patients about sexual health compared with other health professionals, in spite of equal training and an equal level of discomfort in discussing sexual health issues (Haboubi and Lincoln, 2003).

Physiotherapy interventions for patients with RA often include mobility treatment, pain reduction and physical activities. Physiotherapy can reduce pain and increase mobility, self-esteem, mood and physical daily activities in patients with RA (Josefsson and Gard, 2010; Kavuncu and Evcik, 2004; Lineker et al., 2001), which can indirectly influence sexual health in these patients. The habit of performing regular physical activity can affect sexual health, since greater physical capacity can increase the prevalence of sexual intimacy and psychological well-being (Bortz and Wallace, 1999; Josefsson and Gard,

2010). In regard to direct physiotherapy treatment for improving sexual health, a study of cognitive behavioural therapy was performed in a multi-professional pain rehabilitation programme, which showed promising results (Breton et al., 2008).

Using a self-administered questionnaire sent to patients with RA, the aim of the present study was further to explore patients' experiences of and views on the impact of RA on sexual health, and the experiences and needs of physiotherapy; to explore experiences of communication between patients with RA and health professionals concerning sexual health; and to analyse the internal consistency of the questionnaire.

## Methods

### Study group

Patients with RA from two different rehabilitation clinics in the middle of Sweden during 2008–2009 were invited to participate in the study. The inclusion criteria were having a diagnosis of RA, being registered for physiotherapy treatment at one of two rehabilitation clinics in the middle of Sweden and being aged >18 years.

### Questionnaire and procedure

The data were collected by a self-administered, written questionnaire which was sent to participants by post. The questionnaire included closed and semi-closed questions (see Appendix 1). The mailing also included an addressed envelope, in which the questionnaire was to be returned to the researcher. Each participant was given a code; non-responders were sent a new questionnaire three weeks after the first one had been sent out.

The questionnaire was developed from the results of an earlier explorative, qualitative study (Josefsson and Gard, 2010) and valid questionnaires used in this research area. Questions 5, 21–22 and 28–33 were

based on those in the questionnaire constructed by Hill et al. (2003). Question 13, 16 and 19 were based on questions from 15D (Sintonen, 2001), a questionnaire developed by Fugl-Meyer and Sjögren Fugl-Meyer (1999), and another questionnaire constructed by Majerovitz and Revenson (1994). As the questionnaire was developed from a mixture of sources, its internal consistency needed to be tested across all items.

### Analysis

A statistical correlation analysis was performed using Spearman's rank correlation. It was necessary to use a non-parametric test owing to the relatively small sample size and because ordinal variables were used. SPSS version 17.0 was used in the analyses. Chronbach's alpha was used to analyse internal consistency for all items on the ordinal level in the questionnaire. Explorative factor analysis was performed using principal component analysis (rotated method) on the 10 items in the questionnaire. A scree plot was also carried out to confirm the results.

Question 20 was divided into two separate questions before the analysis. The first part was a dichotomized question, asking whether or not the respondent was in a relationship; the second part, which was included in the factor analysis, covered the other four optional answers to the question, 'I think my relationship feels good and works'.

### Ethics

The project was approved by the regional ethics committee in Linköping, Reg. No. M222-09. All participants gave their informed consent to participate in the study.

### Results

In total, the study group consisted of 150 patients (28 men and 122 women). The response rate was 42% (63 patients) (Table 1). The average age of the

**Table 1.** Descriptive data of study participants

	Age average (range)	Living with a partner	Having a healthy partner	Other chronic diseases	Disease duration Average (range)
Women, <i>n</i> = 51	56 years (19–77)	78%	64%	46%	15 years (2–50)
Men, <i>n</i> = 12	61 years (38–76)	92%	75%	25%	10 years (1–20)

Chronbach's alpha for internal consistency was 0.74. If item 21 was deleted, Chronbach's alpha increased to 0.85.

responders was 57 years (the average age of non-responders was 58 years). Some patients did not answer all questions; these patients gave reasons in writing for not answering specific questions – for example, concerning being single and having chosen not to be sexually active.

Explorative factor analysis was performed using principal component analysis (rotated method; varimax rotation, Eigen value >1). Items with high factor loadings defined each dimension. The results showed that the items in the questionnaire belonged to three meaningful factors: sexual well-being, body image and relationship (Table 2). In Table 2, all loadings among the items are shown. To be a clinically meaningful item in one of these factors, we considered that each item must have a loading over 0.50, in accordance with Hair and Anderson (1998). To be clinically meaningful, each item was also referred to the factor in which it had the highest loading. Therefore, in accordance with these principles, the factor 'sexual well-being' contained five items; the factor 'body image' contained two items and the factor 'relationship' contained two items. These factors will be used in future studies.

### Experiences of and views on the impact of RA on sexual health and the experiences and needs of physiotherapy

Patients experienced a large variety of symptoms and combinations of symptoms that were caused by their RA, but pain and fatigue were the most common (81% experienced pain and 78% fatigue). Other

symptoms were morning stiffness, feeling depressed, swollen joints and sleeping disturbances. The duration of the symptoms varied, from being constant to having symptoms at specific times during the day or having days without any symptoms at all. Most patients agreed/strongly agreed that there were strong associations between pain, stiffness, fatigue, physical capacity, positive experiences/feelings and sexual health.

The majority (87%) of patients had had experiences of physiotherapy and considered it to have been a positive experience. Forty-two per cent of patients had had both individual and group physiotherapy.

Twenty-nine per cent of respondents experienced a negative or very negative body image. Their view of their bodies changed after their RA diagnosis – 38% in a negative way and 14% in a positive way. Currently having a negative body image was significantly correlated with having had an increased negative body image and decreased sexual desire since the onset of the disease, as well as with low sexual desire, low sexual well-being and a feeling that the disease had had a negative effect on their ability to function sexually (Table 3). In Table 3, the Spearman correlation coefficient has been adjusted for the effects of age and disease duration.

Sexual well-being was described by 37% of respondents as good or very good, and 37% said that RA had negative effects on their sexual health. The symptoms that affected their sexual health varied, but pain, fatigue and decreased joint mobility were most common. A reduction in sexual desire due to RA was reported by 62% and a continuing experience of lack of/decreased sexual desire by 54%. Generally

**Table 2.** Explorative factor analysis using principal component analysis (rotated method) on the 10 items in the questionnaire

	Sexual well-being	Body image	Relationship	Communalities
Body image	0.194	0.883	-0.177	0.849
Change in body image owing to RA	0.166	0.804	0.218	0.722
Sexual well-being	0.629	0.409	0.369	0.699
Sexual satisfaction	0.608	0.600	0.216	0.776
Impact of RA on sexual satisfaction	0.764	0.412	0.047	0.755
Satisfaction after sexual activities	0.712	0.159	0.431	0.718
Impact on sexual satisfaction	0.858	0.056	0.021	0.740
Experience of relationship	-0.004	0.004	0.919	0.844
Impact of RA on relationship	-0.223	-0.077	-0.844	0.769
Importance of sexuality	0.828	0.172	0.025	0.715
Total eigenvalue sum	4.840	1.667	1.080	
% of variance	48.399	16.672	10.800	
Cumulative %	48.399	65.071	75.871	

**Table 3.** Spearman's rank correlation test for body image and need for advice/information concerning sexual health, adjusted for the effects of age and disease duration. The two-tailed significance levels presented below are the correlation coefficients

Question	Need for information (Q1)	Body image (Q2)
Q1. Due to my disease I have felt a need for information and advice for my sexual life ( <i>n</i> = 53)		-0.41*
Q2. When I see myself in a mirror I feel... ( <i>n</i> = 50)	-0.41*	
Q3. Since I got RA, my attitude towards my body has changed ( <i>n</i> = 51)	-0.48**	0.59**
Q4. My disease has affected my ability to function sexually ( <i>n</i> = 51)	-0.33**	0.36**
Q5. I would describe my sexual wellbeing as... ( <i>n</i> = 49)	-0.36	0.53**
Q6. I think my sexual desire... ( <i>n</i> = 50)	-0.32	0.50**
Q7. If I compare my sexual desire today with before the start of my rheumatoid disease, it is... ( <i>n</i> = 50)	-0.47*	0.52**

\**p* < 0.05.\*\**p* < 0.01.

decreased sexual satisfaction due to RA was reported by 43% and weak or no sexual satisfaction after sexual activity was described by 19%.

Twenty-five per cent of patients experienced a negative impact on their relationship with their partner. Some patients answered this question even if they were not currently in a relationship and some added that they had answered the question using an earlier relationship as a model. Sexuality was rated by 56% of patients as important or very important. The majority of patients agreed/strongly agreed that there were strong associations between pain, stiffness, fatigue, physical capacity, positive experiences/feelings and sexual health.

### Communication between patients with RA and health professionals

The majority (75%) of patients had not discussed sexual health or the eventual effects of RA on sexual health when they were diagnosed with RA. Only one patient reported that sexual health was sometimes discussed with their rheumatological team, and none of the patients discussed sexual health often or regularly with them.

Concerning the way in which the subject of sexual health should be broached, patients had different preferences and the question allowed multiple choices in the response. Some of the patients (14%) did not want any information concerning sexual health and RA from health professionals, others (43%) wanted to bring up the subject themselves when necessary and 17% wanted medical staff to address the subject. Twenty-seven per cent preferred written information

about sexual health in the waiting room and 29% wanted to have such information available on the internet.

There was a greater need for advice and information about sexual health in four groups: 1) patients with a negative body image; 2) patients with a poorer body image since the onset of the disease; 3) patients with decreased sexual desire since the onset of the disease and 4) patients with a reduced ability to function sexually due to the disease (Table 3).

Patients wanted to talk to different health professionals about sexual health; some wanted to talk to their rheumatologist (32%), and others to their nurse (6%), occupational therapist (5%), physiotherapist (11%) or counsellor (11%). Multiple choices were given in this question. The majority preferred to talk to their partner and 27% to a close friend. Ten per cent preferred not to talk about sexual problems, even if they experienced them. Only one patient asked for assistance from health care professionals about sexual problems, in spite of the fact that 19% of the patients reported that they had a need for information and advice about their sexual life.

Some patients had written additional comments in the questionnaire. Several expressed a wish that the topic had been brought up when they were younger, or earlier in the development of the disease. There were also comments indicating that sexual health had never been broached by their rheumatological team. Further comments concerned the importance of the spouse being given information about RA and how it could affect sexual health. One patient was negative about being given the questionnaire, since she felt that it was insulting to be asked about sexual issues as a patient with RA.

## Discussion

The authors had performed an earlier interview study with women with RA concerning the physical and psychological effects of RA on sexual health. The qualitative results of that study were then used as the basis for developing the questionnaire used in the present study (Josefsson and Gard, 2010). In the present study, the original topics were further studied in a larger group of patients. The validity of the questionnaire was enhanced by using knowledge gained in the previous qualitative study (Josefsson and Gard, 2010) and by using relevant questions from earlier studies in the field (Fugl-Meyer and Sjögren Fugl-Meyer, 1999; Hill et al., 2003; Majerovitz and Revenson, 1994). A face validity check was also done on a group of RA patients before this study.

There is an increasing trend towards less participation in questionnaire surveys (Henderson et al., 2010). One way to increase participation is to offer a reward for participation (Henderson et al., 2010); this was not done in the present study. The response rate in the present study was fairly low, but other studies using questionnaires concerning sexual issues have shown even lower response rates, perhaps owing to the sensitivity of the subject (Akkas et al., 2010; Laumann et al., 2006; van Berlo et al., 2007). In a study of sexuality among Swedes, the lowest response rates were observed in older women (Fugl-Meyer and Sjögren Fugl-Meyer, 1999). Female gender and old age have also been shown to be factors that reduce response rates in questions about sexuality in other studies of the impact of rheumatological disease on sexual health (Healey et al., 2009; Helland et al., 2008; van Berlo et al., 2007). The lack of any reward in the present study, the sensitivity of the subject and the fact that the majority of the study participants were elderly women could have been reasons for the low participation in the study.

The prevalence of RA in Sweden is 0.77% (Neovius et al., 2010) and the gender division is 72.8% women and 27.2% men (Englund et al., 2010). The representation of women with RA in the present study was higher than that in Sweden overall, which may have had an effect on the results, since women with RA report more joint difficulties than their male counterparts (van Berlo et al., 2007). Because of the small group of men included in the study, no conclusions on gender differences were investigated in the present study.

The concept of physiotherapy was only described in terms of whether the respondents had had an experience of individual and/or group physiotherapy. The aim of the study was not to draw any conclusions from respondents' specific physiotherapy interventions but to ascertain their level of experience of physiotherapy and their perception of its effect.

### Experiences of and views on the impact of RA on sexual health and the experiences and needs of physiotherapy

The results of the present study showed different impacts of RA on sexual health, such as physical, psychological and emotional impacts, which all affected patients' intimate relationships. The negative impacts of RA on sexual health are worse when physical disability is more severe (Abdel-Nasser and Ali, 2006; Majerovitz and Revenson, 1994). No measure of disease severity was included in the questionnaire, which was a limitation of the study. In the present study, 56% of participants rated sexual health as important or very important. In other studies that have tried to measure the importance of sexual ability, 56–80% of participants rated sexual ability as very important (Akkas et al., 2010; Hill et al., 2003). It is possible that the non-responders rated sexual health as being of lesser importance, and therefore avoided answering the questionnaire. However, since the results were similar to those from other research, we believe them to be valid.

The frequency of patients describing a decrease in sexual health and in the level of sexual activity due to RA was comparable with that found in studies in other countries (Abdel-Nasser and Ali, 2006; Baldursson and Brattstrom, 1979; Helland et al., 2008; Kraaimaat et al., 1996; Pouchot et al., 2007; Yoshino and Uchida, 1981). A study that measured the impact of culture on how RA affects intimacy and sexual relationships, in which cultural personalities were defined by standards other than ethnic origin, showed that different cultural personalities experienced a similar negative impact of RA on intimacy (Devins et al., 2009), which might be a reason for this similarity.

The sexuality of both the partner and the patient has been shown to be affected by RA (Majerovitz and Revenson, 1994) and the level of strain on the partnership caused by RA was similar in the present

study to that found in other studies (Hill et al., 2003; Yoshino and Uchida, 1981). One study concerning identity in the partnership of patients with RA showed that tension over sexual intimacy can be caused by RA (Lempp et al., 2006). The strain on the relationship can be a result of several symptoms of RA, such as pain, fatigue and negative emotions.

The intrusiveness of fatigue caused by RA in daily life has been acknowledged in other studies (Hewlett et al., 2005; Repping-Wuts et al., 2008), and fatigue was considered by several respondents to be an important reason for poorer sexual health. For example, fatigue can be described as mental or physical, as well as having or not having an underlying reason (Nikolaus et al., 2010). In the present study, there was no distinction between different forms of fatigue, which might have been a limitation. RA patients sometimes believe that fatigue is a part of the disease that they need to handle themselves (Hewlett et al., 2005; Repping-Wuts et al., 2008). To change this view, it is important to understand the secondary effects of fatigue and that different health care professionals working with RA patients must take an active part in decreasing fatigue by using tools relevant to their profession. For physiotherapists, this would mean promoting and coaching the patient towards physical exercise, since fatigue has been shown to be affected by physical exercise interventions (Lineker et al., 2001; Neill et al., 2006).

The results of the present study showed that pain was perceived as a factor that commonly reduces sexual health. Pain reduction is a prioritized outcome for RA and has been shown to affect several aspects of life, including sexual health (Josefsson and Gard, 2010). Pain affects sexual health in many ways, as it can reduce sexual desire, sexual satisfaction and the amount of sexual activity (Abdel-Nasser and Ali, 2006). A reduction in pain can thus lead to better sexual health. Pain reduction is an important part of physiotherapy interventions for patients with RA. The interventions include, for example, transcutaneous electrical neural stimulation (TENS), hydrotherapy, thermotherapy and physical exercise (Kavuncu and Evcik, 2004; Lineker et al., 2001).

Morning stiffness can be reduced by physiotherapy (Lineker et al., 2001). The majority of the study group thought that decreased stiffness was related to an improvement in sexual health, and this is an

indication that physiotherapy to reduce stiffness might improve sexual health in RA patients. A high degree of morning stiffness not only negatively affects sexual satisfaction, but is also related to a more negative body image (Abdel-Nasser and Ali, 2006; Gutweniger et al., 1999). It may be of interest to investigate further the positive impact of RA on body image experienced by some of the participants, since earlier studies showed only a negative impact in this regard (Gutweniger et al., 1999; Lempp et al., 2006; Jorge et al., 2010), and body image is directly correlated with function, self-esteem and quality of life (Jorge et al., 2010). We recommend that the patient's experiences of his/her body image should be explored during the physiotherapy examination. Another factor that shows the importance of this issue is the relationship between poor body image and decreased sexual health that was observed in the present study. It is possible that participants' experience of physiotherapy affected the answers, since physiotherapy interventions can be directed towards body awareness and functional capacity, which can affect individuals' views of their bodies.

Most of the patients believed that there were associations between decreased fatigue, decreased pain, decreased stiffness, increased physical capacity and sexual health. These connections should be further explored in physiotherapy research in the field of sexual health. Physiotherapy for patients with RA is often based on pain reductive and mobility treatment, as well as physical exercise. We believe that it is important to acknowledge sexual health in physiotherapy examinations. We consider it important that physiotherapists inform their patients about the associations between pain, physical capacity, fatigue, physical activity and sexual health. Physical activity levels are related to quality of life, and decreased physical activity is related to a lower quality of life in women with RA (Chang et al., 2009). Aerobic capacity training and muscle strength training are recommended as routine practice in patients with RA (Hurkmans et al., 2009). Sexual satisfaction has been shown to improve with increased physical fitness in men, but this has not yet been shown in women (Akkas et al., 2010; Pujols et al., 2009). Gender differences need to be further explored in connection with RA and sexual satisfaction, since the results of earlier studies have been diverse. One study reported no gender differences

concerning sexual satisfaction in patients with RA (van Berlo et al., 2007), while other studies reported that women's sexual satisfaction decreases more than men's after the onset of disease (Bortz and Wallace, 1999), and women with longstanding RA report lower sexual satisfaction than their healthy counterparts (Karlsson et al., 2006).

### Communication between patients with RA and health professionals

Even if the participants in the present study were more willing to address sexual problems than in the study by Hill et al. (2003), almost none of the present participants had actually done so. The person with whom patients most wanted to talk about sexual matters was their partner, and among health professionals was their rheumatologist. In the study by Hill et al. (2003), the nurse was also described as a high-priority person to talk to, but this was not the case among the respondents in the present study. Comparing Hill's study with ours, the different professions of the researchers and the possible variety in the clinical working models might have explained the differences in the results. The quality of the communication between health care professionals and patients has been shown to be associated with treatment satisfaction (Ahlmén et al., 2005). Therefore, health care professionals should not avoid broaching subjects that can be important to the patient, and should find the most appropriate way to enable each patient to communicate about the consequences of the disease and the treatment possibilities. In order to use the full potential of physiotherapy interventions in patients with RA, it is important that physiotherapists have adequate training in communication about sexual health and knowledge about the associations between sexual health and physiotherapy interventions.

### Conclusion

Physiotherapists need to be aware that pain, fatigue, decreased joint mobility and physical capacity can affect sexual health in patients with RA.

Health professionals and patients with RA do not discuss sexual health. It is important to have a strategy concerning how to broach the subject of sexual health in meetings between the patient with

RA and the health professional, to enable the best possible care to be given.

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## Appendix 1

### Questionnaire concerning sexual health in persons with RA and their experiences of physiotherapy

Sexual health is defined from a both physical and psychological perspective and may include close relationships with tenderness, touch and/or intimate sexual companionship. To have good sexual health is a part of being well, physically and psychologically.

*Below is a number of questions; fill in and cross the answers that apply to you.*

1. My age is \_\_\_\_\_ Years. I am  male  female
2. I am
  - Single
  - Living with someone
  - Married
  - Divorced
  - Widow/ widower
3. My partner
  - is healthy
  - suffering from \_\_\_\_\_
  - I don't have a steady partner
4. Disease debut
  - I felt the first symptoms (year) \_\_\_\_\_
  - I got diagnosed with RA (year) \_\_\_\_\_
5. I often feel the following due to my disease (*you may choose several alternatives*)
  - Pain
  - Swollen joints
  - Instability in joints
  - Stiffness
  - Fatigue
  - Sleeping difficulties
  - Other \_\_\_\_\_
6. Duration of the symptoms
  - Constant
  - Mainly in the mornings
  - Mainly during the day
  - Mainly in the evenings
  - Mainly at night
  - I have no symptoms one or several days in a row

Other \_\_\_\_\_

7. Except for RA, I also suffer from the following chronic symptoms

\_\_\_\_\_

8. I have experience of (*you may choose several alternatives*)

- Group physiotherapy  
 Individual physiotherapy  
 I have no experience of physiotherapy

*Below are two statements about physiotherapy. Please, cross the alternatives that are in line with your views and experiences.*

9. Physiotherapy makes me (*you may choose several alternatives*)

- Happy  
 Positive  
 Depressed  
 Tired  
 Strong  
 Other \_\_\_\_\_

10. I believe that physiotherapy is important for my (*you may choose several alternatives*)

- Physical capacity  
 Well-being  
 Self-confidence  
 Strength  
 Other \_\_\_\_\_

*Below are several statements about sexual health. Please, cross the alternatives that are in line with your views and experiences.*

11. When I see myself in a mirror I feel

- Very pleased  
 Quite pleased  
 Pleased  
 Quite displeased  
 Very displeased

Comment \_\_\_\_\_

12. Since I got RA, my attitude towards my body has changed

- Yes, I like my body better now  
 Yes I like my body less now  
 No, my opinion of my body has not changed

Comment \_\_\_\_\_

13. My disease has affected my possibilities to function sexually

- Yes, in a positive way  
 Yes, in a negative way  
 No, not at all  
 Doubtful

Comment \_\_\_\_\_

14. My sexual health is affected negatively by (*you may choose several alternatives*)

- Pain  
 Swollen joints  
 Instability in joints  
 Decreased motion  
 Decreased physical capacity  
 Stiffness

- Fatigue
- Sleeping difficulties
- Other \_\_\_\_\_

15. I would describe my sexual well-being as

- Very good
- Good
- Less good
- Unsatisfactory
- Very unsatisfactory
- Comment \_\_\_\_\_

16. I think my sexual desire is

- Normal
- Too strong or too often
- Too weak or too rare
- I have no sexual desire
- Comment \_\_\_\_\_

17. If I compare my sexual desire today with before the start of rheumatoid disease, it is

- Much more
- Some more
- Unchanged
- Less
- Much less
- Comment \_\_\_\_\_

18. After sexual activity I feel

- A strong satisfaction
- A quite strong satisfaction
- A weak satisfaction
- No satisfaction at all
- Comment \_\_\_\_\_

19. If I compare my sexual satisfaction today with before the start of my rheumatoid disease, it is

- Much better
- A little bit better
- Unchanged
- A little bit worse
- Much worse
- Comment \_\_\_\_\_

20. I think my relationship feels good and works

- Very well
- Quite well
- Ok
- Bad
- Very bad
- I don't have a relationship at present
- Comment \_\_\_\_\_

21. I experience that RA has affected my relationship with my partner

- Very much
- Quite a lot
- Quite little
- Very little
- Not at all

Comment \_\_\_\_\_

22. To me, in my life, sexuality is

- Very important  
 Quite important  
 Quite unimportant  
 Not important at all

Comment \_\_\_\_\_

23. I believe that there is a strong connection between decreased pain and improved sexual health

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

24. I believe that there is a strong association between decreased stiffness and improved sexual health

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

25. I think that there is a strong association between decreased fatigue and improved sexual health

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

26. I think that there is a strong association between improved physical capacity and improved sexual health

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

27. I think that there is a strong association between positive feelings and experiences and sexual health

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

*Below are some statements about health professionals and sexual health. Please cross the alternatives that are in line with your views and experiences.*

28. When I got RA the rheumatologist/rheumatological team discussed with me how my sexual health could be affected by the disease

- Totally agree  
 Agree partly  
 Don't agree at all

Comment \_\_\_\_\_

29. In my contacts with health care professionals (within rheumatology) we discuss sexual health

- Every time  
 Often  
 Rarely  
 Almost never  
 Never  
 When there is a need to discuss it

Comment \_\_\_\_\_

30. In my contacts with health care professionals (within rheumatology) I would like sexual health to be brought

up in the following way (*you may choose several alternatives*)

- I bring it up when there is need for it
- Health professionals bring up the subject
- The opportunity to discuss it by e-mail
- Written information in the waiting room
- Information on the internet
- I don't want sexual health to be brought up at all

Other \_\_\_\_\_

31. If I had/have sexual problems I would talk to (*you may choose several alternatives*)

- My partner
- Close friend
- Doctor
- Nurse
- Occupational therapist
- Physiotherapist
- Counsellor
- Other health professional
- I wouldn't talk about it

Other \_\_\_\_\_

32. I have, due to my disease, felt a need for information and advice for my sexual life

- Yes, a major need
- Yes, a certain need
- No
- Doubtful, don't know

33. I have asked for advice from health care professionals for sexual health problems

- Yes
- No

# Paper III



RESEARCH ARTICLE

Open Access

# Swedish version of the multi dimensional health assessment questionnaire – translation and psychometric evaluation

Kristina Areskoug Josefsson<sup>1,2\*</sup>, Charlotte Ekdahl<sup>1</sup>, Ulf Jakobsson<sup>3</sup> and Gunvor Gard<sup>1</sup>

## Abstract

**Background:** Health assessment measurements for patients with Rheumatoid arthritis (RA) have to be meaningful, valid and relevant. A commonly used questionnaire for patients with RA is the Stanford Health Assessment Questionnaire Disability Index (HAQ), which has been available in Swedish since 1988. The HAQ has been revised and improved several times and the latest version is the Multi Dimensional Health Assessment Questionnaire (MDHAQ). The aim of this study was to translate the MDHAQ to Swedish conditions and to test the validity and reliability of this version for persons with RA.

**Methods:** Translation and adaption of the MDHAQ were performed according to guidelines by Guillemin et al. The translated version was tested for face validity and test-retest in a group of 30 patients with RA. Content validity, criterion validity and internal consistency were tested in a larger study group of 83 patients with RA. Reliability was tested with test-retest and Cronbach's alpha for internal consistency. Two aspects of validity were explored: content and criterion validity. Content validity was tested with a content validity index. Criterion validity was tested with concurrent validity by exploring the correlation between the MDHAQ-S and the AIMS2-SF. Floor and ceiling effects were explored.

**Results:** Test-retest with intra-class correlation coefficient (ICC) gave a coefficient of 0.85 for physical function and 0.79 for psychological properties. Reliability test with Cronbach's alpha gave an alpha of 0.65 for the psychological dimension and an alpha of 0.88 for the physical dimension of the MDHAQ-S.

The average sum of the content validity index for each item was of the MDHAQ-S was 0.94. The MDHAQ-S had mainly a moderate correlation with the AIMS2-SF, except for the social dimension of the AIMS2-SF, which had a very low correlation with the MDHAQ-S.

**Conclusions:** The MDHAQ-S was considered to be reliable and valid, but further research is needed concerning sensitivity to change.

**Keywords:** Health assessment, Rheumatoid arthritis, Rehabilitation

## Background

In order to cover aspects of importance to the patients with Rheumatoid Arthritis (RA), the most appropriate outcome measurement for clinical practice must be chosen in the clinical situation. The outcome measurements have to be meaningful, valid and relevant. For patients with RA, questionnaires often are included in standard outcome

measurements. Due to the symptoms of RA, physical ability should be measured and a commonly used questionnaire for patients with RA is the Stanford Health Assessment Questionnaire Disability Index (HAQ), which has been available in Swedish since 1988 [1,2]. The HAQ has been used to measure physical function and it has been revised several times. The latest version, the Multi Dimensional Health Assessment Questionnaire (MDHAQ), has a broader perspective and better coverage of the domains in the International Classification of Functioning, Disability and Health (ICF) [3,4], but is not yet available in

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Swedish. The HAQ mainly concerns the activity domain, which gives a narrower perspective than the MDHAQ [5]. As an example, the MDHAQ has questions concerning fatigue and anxiety, and questions with limited relevance in the HAQ are omitted in the MDHAQ [1,6,7]. The importance of physical activity has increased for patients with RA, and this valuable item is included in the MDHAQ. These differences between the HAQ and the MDHAQ are of major importance, and it is therefore necessary to follow the development of improved health assessment and make the MDHAQ available in different contexts, in order to be able to assess the impact of RA. The MDHAQ has a short completion time compared to other tests, and the data collected are clinically useful [8]. The choice to translate and psychometrically test the MDHAQ under Swedish conditions is due to the increased scope of the MDHAQ and its usefulness in clinical practice in comparison with other outcome measurements [9]. The reliability of the original MDHAQ has earlier been tested with test-retest for the first ten items with kappa statistics, giving scores between 0.65 and 0.81 [7], and the translated versions having scores between 0.60 and 0.93 [10,11]. The criterion and construct validity of the MDHAQ has been investigated in earlier studies translating the instrument, with good results [10,11]. The criterion validity of the activities of daily living questions included in the MDHAQ, that derive from the original HAQ, has been tested under Swedish conditions showing that the correlation between the patient's evaluation of the activity and the therapist's measure of that activity was 0.91 with a significance of  $p < 0.0001$  [1]. The floor and ceiling effects of the MDHAQ have been reported to be acceptable (i.e. below the recommended cut-off point of 15%) [12,13]. The correlation between the items of the MDHAQ and pain (visual analogue scale), fatigue (visual analogue scale), advanced activities of daily living, anxiety and depression of the Arthritis Impact Measurement Scale (AIMS) showed a range of the Spearman's rank correlation coefficient between 0.50 and 0.75 [7]. The MDHAQ has been proven suitable for other rheumatic diseases than RA as well, which makes the instrument very useful and provides further reason to have the MDHAQ available in a Swedish version [14]. The MDHAQ [6] is to the best of our knowledge not used in Sweden, since it has not been tested under Swedish conditions and/or translated into Swedish.

#### **Aim**

The aim of the study was to test the reliability, face validity, content validity and criterion validity of a Swedish version of the MDHAQ.

#### **Method**

##### **Sample**

There were two groups of participants included in the study, each group was used for different tests; a reliability

test group and a validity test group. The participants in the study were diagnosed with RA and lived in the south of Sweden. The participants from a rehabilitation clinic were included consecutively into a smaller test group testing reliability of the MDHAQ-S. The participants from the rheumatology clinic were included consecutively in the larger test group, testing validity of the MDHAQ-S. Data were collected with questionnaires. The participants in both groups were included in the study consecutively. Written and informed consent for participating in the study was obtained from the participants. Persons who did not understand Swedish were excluded. Data of persons not willing to participate in the study were not collected. A registered physiotherapist or a registered nurse at the rehabilitation/rheumatological clinic assessed if the participant had sufficient knowledge of Swedish to be able to answer the questionnaires.

##### **Inclusion in reliability test group**

The reliability test group consisted of 30 persons with RA (diagnosed by a rheumatologist), aged  $\geq 18$  yrs, registered at a rehabilitation clinic in the south of Sweden. Test-retest was to be performed by this group.

##### **Inclusion in the validity test group**

The validity test group consisted of 100 persons with RA (diagnosed by a rheumatologist),  $\geq 18$  yrs, registered at a clinic for rheumatology in the south of Sweden.

##### **Instruments used**

The MDHAQ-S and Arthritis Impact Measurement Scale 2- Short Form (AIMS2-SF) were used in the study. The AIMS2-SF [15] was used to measure the concurrent validity of the MDHAQ-S. The age of the participants was not included in the questionnaires.

##### **MDHAQ-S**

The MDHAQ-S consists of the following parts: physical function, psychological status, pain, global health, fatigue, morning stiffness, and exercise habits, and includes Routine Assessment of Patient Index Data 3 (RAPID3) and Rheumatoid Arthritis Disease Activity Index (RADAI) self report joint count as well as a symptoms list and recent medical history [9,14]. The MDHAQ-S is estimated to be performed in five minutes. The first section, "physical function", of the MDHAQ-S (question1. a-j) includes ten activities of daily living scored 0-3 (0 = "without any difficulty", 1 = "with some difficulty", 2 = "with much difficulty", and 3 = "unable to do."). The sum of the answers is divided by three giving a score between 0 and 10. The questions concerning psychological status (question1.k-m) are scored 0 = "without any difficulty", 1.1 = "with some difficulty", 2.2 = "with much difficulty", and 3.3 = "unable to do." The sums are added to a total

sum of 0–9.9. The MDHAQ-S includes visual analogue scales with 21 circles measuring pain, global health and fatigue with a total score of 0–10 in 0.5 units. The review of symptoms (question 5) is a checklist of symptoms where the checked boxes are counted. Morning stiffness (question 6) is rated by yes or no and the amount of time in minutes. Change in status (question 7) is scored: 1 = Much better, 2 = Better, 3 = Same, 4 = Worse, 5 = Much worse. Exercise frequency (question 8) is scored 3 = 3 or more times a week, 2 = 1–2 times per week, 1 = 1–2 times per month, 0 = Do not exercise regularly, 9 = Cannot exercise due to disability/ handicap. The included RADAI consists of eight joints or joint groups scored 0, 1, 2 or 3. The RADAI scores are used in the RAPID3 (0–30 scale), which include four categories: High severity >12, Moderate severity = 6.1–12, Low severity = 3.1–6, and Remission <=3. The included RAPID3 and the RADAI have high reliability [16]. The RADAI is a valid instrument [17,18], and patient reported tender joint count has a moderate to marked correlation to assessment by health professionals [19].

The MDHAQ-S also includes questions about recent medical history, which are not scored.

#### **AIMS2-SF**

The AIMS2-SF is a self administered questionnaire with 26 items covering the ICF components activity limitations and participation restrictions [15] within five domains: physical function, symptoms, mood, social function and role function. Each item is answered using a five-point scale. Higher scores indicate higher level of impairment. The time to perform the AIMS2-SF is estimated to be ten minutes. The Arthritis Impact Measurement Scale (AIMS) was developed to assess outcome of healthcare for patients with RA [20] and has been further developed and shortened to the Arthritis Impact Measurement Scale 2-Short Form (AIMS2-SF) [15]. The AIMS measures the individual's functional, social, emotional and physical status. The AIMS-SF2 has been compared to the HAQ and been found to have better sensitivity to change than the HAQ [21]. This makes the AIMS2-SF a relevant instrument for use for comparison with MDHAQ-S, and the instrument is relevant in terms of its contents to persons with RA [1]. Both the HAQ and the AIMS 2 are valid and reliable instruments in Swedish [1,22]. The AIMS has also been used to test the validity of other outcome measurement tools for patients with RA [23].

#### **Translation and adaptation of the MDHAQ-S**

The adaption of the MDHAQ R808 [24] to a Swedish version (MDHAQ-S) was performed according to the guidelines by Guillemin et al. [25,26], which include the following steps:

1. Translation of the MDHAQ by two independent qualified translators.
2. Synthesize translations, which meant to compare the translated versions in order to achieve coherence in translations. This was performed by the authors.
3. Back-translation by two independent back-translators.
4. Committee review by a multi-professional committee. The committee was a rheumatologic team consisting of a rheumatologist, physiotherapist, counselor, occupational therapist, nurse and one of the researchers.
5. Thirty patients testing the questionnaire with an interviewer present. The interviewer can be used as an explanatory source if needed. The interviewer observes whether there are problems reading or responding to the questionnaire and asks about the ease of completion of the questionnaire. This step is revised from the original guidelines by Guillemin and follows the protocol by Hedin et al. [27].

#### **Reliability of the MDHAQ-S**

Reliability was tested with test-retest with a one-week interval. The test-retest was performed at a rehabilitation clinic in a county in the south of Sweden. Reliability was also assessed with Cronbach's alpha for internal consistency.

#### **Validity of the MDHAQ-S**

The floor and ceiling effects of the MDHAQ-S were measured in the validity test group. Floor effects were considered to be present if  $\geq 15\%$  scored an item as 0 (lowest possible score) and ceiling effects were considered to be present if  $\geq 15\%$  scored an item as 3 (highest possible score) on the MDHAQ-S. The content validity of the MDHAQ-S was tested by the reliability test group. The relevance of each question included was assessed with a content validity index, CVI, on a four-point scale (1- extremely relevant, 2 – quite relevant, 3 – slightly relevant and 4 – not relevant) [28]. The scale was dichotomized by putting extremely relevant/quite relevant (1 & 2) into one group and slightly relevant/not relevant (3 & 4) into one group. This test was performed when the original HAQ was adapted to Swedish [1], and comparisons of the relevance of questions existing in both the HAQ and the MDHAQ-S were made. The participants were asked to add additional important questions that they felt were lacking in the instrument.

Face validity was performed within a group of professional experts as well as by the participants by their rating of the relevance of the questions of the MDHAQ-S. The group of professional experts consisted of a rheumatologist, physiotherapist, counselor, occupational therapist, nurse and one of the researchers.

Criterion validity by measuring concurrent validity was tested by asking the respondents to complete the MDHAQ-S and the AIMS2-SF and testing the results for correlation. The MDHAQ-S was tested against the Arthritis Impact Measurement Scale 2- Short Form (AIMS2-SF) for correlation. The AIMS2-SF measures the individual's functional, social, emotional and physical status. The AIMS2-SF is a shorter and less time consuming version of the Arthritis Impact Measurement Scale -2 (AIMS2) with similar psychometric properties, convergent validity content validity, reliability and sensitivity to change [15,21,29]. The AIMS2-SF is easier for the patients to administer since it consists of fewer questions, 26 instead of 57. In order to achieve the best possible symptom agreement concerning arthritis pain between AIMS2 and AIMS2-SF, item 42 was replaced with item 38 in AIMS2-SF, which has been recommended in earlier studies [21,30]. The AIMS2-SF is a relevant instrument for use for comparison with MDHAQ-S due to the instrument's relevance of its contents to persons with RA and since the AIMS was used in the comparison with the HAQ when it was adapted to Swedish conditions [1]. The AIMS has also been used to test the validity of other outcome measurement tools for patients with RA [23], and both the AIMS and the AIMS 2 are valid and reliable instruments in Swedish [1,22].

#### Procedures

The reliability test group: The participants answered the questionnaire twice, once at the visit to the clinic and a second time one week after the visit. The participants answered the first questionnaire at a visit to the clinic with a physiotherapist present. The questionnaires were handed out and collected by the physiotherapist at the clinic.

The validity test group: The participants answered the questionnaires at a visit to the clinic. The questionnaires were handed out and collected by the nurse at the clinic.

#### Data analysis

The reliability of the Swedish version was assessed with Cronbach's alpha for internal consistency and test-retest for reproducibility with weighted kappa statistics and intra-class correlation. A high alpha, over 0.7, indicates that the items are adequately inter related [31]. The test-retest measure is used to estimate the reproducibility over time when no change is estimated to have taken place. The kappa values were considered to show excellent reliability if they were >0.75, fair to good reliability for values ranging between 0.4 and 0.75 and moderate to poor agreement for values <0.4 [32]. The floor and ceiling effects of the MDHAQ were analyzed. Content validity was tested with the content validity index (CVI). The items were considered to be relevant if the item-level CVI was >0.78 per item and the MDHAQ-S was considered to be relevant if the average

of the sum of the content validity index for each item was > 0.90 [28,33]. Concurrent validity was estimated by assessing the level of association between scores on the MDHAQ and the AIMS2-SF, with Spearman rank order correlation. Questions 5, 6 and 7 of the MDHAQ-S were not tested for correlation, since they were not considered by the authors to be relevant to be compared with AIMS2-SF. The correlations were measured comparing the total scores for each dimension of AIMS2-SF with total scores of the included dimensions of the MDHAQ-S.

The level of significance was set at  $p < 0.05$ . Data analyses were performed by SPSS 18.0 and VassarStats: website for statistical computation.

#### Ethics approval

The study was approved by the regional ethics committee in Linköping (d.no: 2011/142-31).

#### Results

The translation and adaption process of the MDHAQ led to the removal of two items as they were not applicable to Swedish context, "ethnic group" and "change of medical insurance" - part of question 10 ("Over the last 6 months you have had..."). Questions concerning ethnic group are unusual in Swedish health care questionnaires and was excluded according to the recommendation of the multi professional committee review, in step 3 of translational process. The other parts of the original MDHAQ were kept, and no additional items were included in the Swedish version. None of the participants in the reliability test group wanted to add or withdraw items to/from the MDHAQ-S and they considered the MDHAQ-S to be comprehensible and acceptable.

There were 100 patients who were invited to participate in the validity test group and 83 persons agreed to participate. There were 58 (70%) women and 19 men (23%) who participated. Six persons did not describe their gender. The results for each item with mean, standard deviation, range, response rate, floor effects and ceiling effects are presented in Table 1.

#### Reliability

The reliability test with Cronbach's alpha gave an alpha of 0.65 for the psychological dimension of the MDHAQ-S and an alpha of 0.88 for the physical dimension of the MDHAQ-S. Testing item total correlation showed that, if the item concerning sleep was removed from the psychological dimension, the Cronbach's alpha increased to 0.91. In the physical dimension of the MDHAQ-S, Cronbach's alpha remained stable when testing item total correlation for the items included (variance 0.86-0.87).

**Table 1 Characteristics for the MDHAQ-S items and scores**

Item/scale score	Mean (SD)	Range	Response rate%	Floor,% <sup>1</sup>	Ceiling,% <sup>2</sup>
1a. Dressing yourself, including tying shoelaces and doing buttons?	0.49 (0.59)	0-3	99%		
1b. Get in or out of bed?	0.28 (0.45)	0-3	99%		
1c. Lift a full cup or glass to your mouth?	0.29 (0.48)	0-3	99%		
1d. Walk outdoors on flat ground?	0.27 (0.52)	0-3	99%		
1e. Wash and dry your entire body?	0.39 (0.52)	0-3	99%		
1f. Bend down to pick up clothing from the floor?	0.48 (0.65)	0-3	99%		
1g. Turn regular faucets on and off	0.51 (0.74)	0-3	99%		
1h. Get in or out of a car, bus, train, or airplane?	0.46 (0.61)	0-3	98%		
1i. Walk 3 km?	0.90 (1.00)	0-3	98%		
1j. Participate in sports and games as you would like	1.35 (1.03)	0-3	94%		
Mean 10-item physical function score	1.76(1.56)	0-3	93%	14,5%	0%
1k. Get a good night's sleep?	1.05 (0.86)	0-3	96%		
1l. Deal with the feelings of anxiety or being nervous	0.42 (0.52)	0-3	94%		
1m. Deal with the feelings of depression or feeling blue?	0.46 (0.55)	0-3	95%		
Mean 3 item psychological score	1.96 (1.52)	0-3	93%	21,7%	0%
2. How much pain have you had because of your condition over the past week?	4.03 (2.31)	0-10	98%	6%	0%
3. Amount of pain in joints	13.12 (7.94)	0-54	99%	3,6%	0%
4. Considering all the ways in which illness and health conditions may affect you at this time, please indicate below how you are doing	3.69 (2.30)	0-10	98%	6%	0%
5. Amount of symptoms	10.05 (6.18)	0-60	99%	3,6%	0%
6. Morning stiffness, yes-no	1.32 (0.47)	1-2 (yes/no)	95%		
7. How do you feel today compared to one week ago?	2.59 (0.76)	1-5	98%	7,2%	1,2%
8. How often do you exercise aerobically?	1.36 (1.25)	0-4	93%	38,6%	21,7%
9. How much of a problem has unusual fatigue or tiredness been to you over the last week?	4.30 (2.79)	0-10	94%	8,4%	2,4%
10. Amount of other events	1.37 (1.32)	0-12	90%	28,9%	0%

<sup>1</sup>Worst possible value of the item or minimum total value of the scale. <sup>2</sup>Best possible value of the item or maximum total value of the scale.

The reliability test group had 27 fully responded questionnaires which were used for the calculations. Test-retest was performed in two ways. The items for physical function item 1a- 1j were first summarized to one score and the items for psychological function were also summarized to one score. Test-retest with intra-class correlation coefficient (ICC) gave a coefficient of 0.85 for physical function and 0.79 for psychological properties, which showed a good reliability of the MDHAQ-S for the functional and the psychological properties.

The second analysis of test-retest was performed for all items in the MDHAQ-S separately. The kappa statistics of the items 1a-1 m showed a range between 0.35 and 0.82. The items with the highest scores were "Deal with feelings of depression or feeling blue?" (Kw = 0.82) and "Turn regular faucets on and off?" (Kw = 0.72), both showing excellent reliability. The items with the lowest scores were "walk three kilometers, if you wish" (Kw = 0.35), "Deal with feelings of anxiety or being nervous?" (Kw = 0.39) and these

two items show poor reliability. The other items in the first question have kappa values varying between 0.46 and 0.73, which is considered to be fair to good reliability.

Items 2-5 and 9-10 had an ICC of 0.75-0.86, which indicates very good reliability (items 5 and 10 concerning the amount of difficulties experienced). Items 6-8 were measured with kappa statistics and showed acceptable to very good results. Item 6 had a kappa of 0.51. This item also included a question concerning the duration of morning stiffness, which had an ICC of 0.28. Item 7, "How do you feel today compared to one week ago?", had a kappa of 0.41. Item 8, "How often do you exercise aerobically (sweating, increased heart rate, shortness of breath) for at least one-half hour (30 minutes)?", had a kappa of 0.95.

#### Validity

The floor and ceiling effects of the MDHAQ-S are below the cut-off point of 15% for the physical dimension, showing that RA has had a negative effect on their

physical capacity. The psychological dimension has a floor effect of 21.7% and a ceiling effect of 0%, which means that the participants has scored low effect of RA on their psychological function. There were floor and ceiling effects in question 8 concerning exercise habits and floor effects for question 10 (Table 1). Question 10 concerned changes in their medical history, such as having experienced a medical trauma, and in their social life, for example changed their medical status, during the last six months. The floor effect of this item shows that the participants had quite stable medical and social status.

The items were considered to be relevant if the content validity index was  $>0.78$ . Item 10 in the MDHAQ-S had an item-level CVI of 0.75. The range of the item-level CVI of the other items in the MDHAQ-S was 0.89-1.00, which indicates that those questions in the MDHAQ-S are highly relevant for persons with RA. The MDHAQ-S was considered to be relevant since the average of the sum of the content validity index for each item was 0.94.

None of the items in the MDHAQ-S and the AIMS2-SF had a very high correlation (Table 2). There were correlations for some of the items, with item 2 (pain) of the MDHAQ-S and the symptoms dimension of the AIMS2-SF having a high correlation ( $r = 0.77$ ). Item 8 (level of physical exercise) had a very low correlation with all items in the MDHAQ-S and the AIMS2-SF.

## Discussion

The results of this study indicate that the MDHAQ-S is a reliable and valid instrument that can be of use in rheumatologic clinical care among Swedish speaking patients with RA. The choice of forward-backward translation according to the guidelines of Guillemin et al. [25,26] can be discussed, since a comparison between forward-backward translation and dual-panel methodologies has shown differences [34]. The fifth step in the translational process was therefore changed, as recommended by Hedin et al. [27], in order to bring out the opinions of the patients for whom this test is intended to be used for in the future.

## Reliability

The size of the reliability test group was similar to the group size in the reliability test of the Finnish version of the MDHAQ [10]. In the Finnish version, only item 1a-m (for item description, see Table 1) was analyzed with test-retest and the scores were summarized with one score for physical function and one for psychological properties. The ICC in the Finnish study was 0.94 for physical function and 0.84 for psychological properties [10], which shows a better reliability than the results in our study. The Arabic version of the MDHAQ also had better ICC results, 0.99 for physical function and

0.65 for the psychological dimension [35]. However, they had only 48-96 hours between the test and the retest, compared to one week in this study, and there were some differences in the questions that were included, which might have affected the results. The Korean test-retest of the MDHAQ tested reliability item

by item [11], however. The results of the Korean version with kappa statistics ranged from 0.60-0.76 ( $p < 0.001$ ), which is considered good reliability, and the results in our study ranged from 0.39-0.82, which indicates a more varied reliability for the items in the first question concerning physical and psychological function in the MDHAQ-S. When using the recommended limits given by Kirkwood & Sterne [32], the MDHAQ-S shows varying results for reliability, but the majority of the items 1a-m have good reliability. The differences in the kappa statistics can be the reason why the ICC in our study was lower than in the Finnish study. The original MDHAQ had kappa scores of 0.65-0.81,  $p < 0.001$ , for the items in the first question concerning physical and psychological function [7], but there were differences in some of the items compared to the current MDHAQ. The MDHAQ-S is reliable, but the results show that the different translated versions of the MDHAQ vary in reliability in different contexts.

Cronbach's alpha of the original MDHAQ was 0.92 [6], which is higher than the scores of the translated versions. The Cronbach's alpha of the psychological dimension of the Korean version of the MDHAQ was 0.89, and the Cronbach's alpha for the physical function was 0.89 [11]. The results of our study are similar to that of the Finnish version, which had a Cronbach's alpha of 0.66 for the psychological function and 0.92 for the physical function [10]. In the Finnish version, the item correlation of the sleep question was clearly lower than the other psychological items [10], and this study shows the same result. Internal consistency for AIMS2-SF and MDHAQ was discussed as being indeterminate in a study by Oude Voshaar et al. (2011) since the Cronbach's alpha has been performed for the complete dimension of physical function, while it may be argued that it is more appropriate to divide this dimension further [12].

The floor effect of the psychological dimension of the MDHAQ-S is of interest for further research since an earlier study of the MDHAQ has shown no floor effect [12]. It is however unclear from that study whether all of the MDHAQ has been included or if only the first items in the physical and psychological dimension were included in the test. The Finnish version of the MDHAQ did not show a floor effect of the psychological dimension, and neither did the Korean version nor the original version of the MDHAQ [3,10,11]. The floor effects and ceiling effects for question 8 ("How often do you exercise aerobically (sweating, increased heart rate, shortness

**Table 2 Correlation between the MDHAQ-S and the AIMS2-SF**

	MD1 sum physical	MD 1Sum psychological	MD2	MD3 total sum	MD4	MD8	MD9	AIMS2 physical	AIMS2 symptoms	AIMS2 mood	AIMS2 social	AIMS2 role	AIMS2 total
MD1 Sum	-												
Physical													
MD1 Sum	<b>0.403</b>	-											
MD2	<b>0.617</b>	<b>0.357</b>	-										
MD3 Total sum	<b>0.549</b>	<b>0.419</b>	<b>0.487</b>	-									
MD4	<b>0.593</b>	<b>0.431</b>	<b>0.708</b>	<b>0.514</b>	-								
MD8	<b>-0.240</b>	-0.127	-0.128	-0.031	-0.204	-							
MD9	<b>0.370</b>	<b>0.534</b>	<b>0.471</b>	<b>0.431</b>	<b>0.468</b>	-0.075	-						
AIMS2-SF	<b>0.442</b>	0.106	<b>0.284</b>	0.179	0.210	-0.141	0.136	-					
Physical													
AIMS2-S	<b>0.646</b>	<b>0.355</b>	<b>0.767</b>	<b>0.578</b>	<b>0.582</b>	-0.064	0.384	0.269	-				
Symptoms													
AIMS2-SF	<b>0.252</b>	<b>0.565</b>	<b>0.297</b>	<b>0.427</b>	<b>0.416</b>	-0.072	0.445	0.055	<b>0.339</b>	-			
Mood													
AIMS2-SF	0.001	0.154	0.022	-0.023	0.148	-0.046	0.015	0.199	0.075	<b>0.392</b>	-		
Social													
AIMS2-SF	<b>0.435</b>	0.249	<b>0.413</b>	<b>0.330</b>	<b>0.436</b>	0.012	0.212	0.077	<b>0.339</b>	0.290	0.162	-	
Role													
AIMS2-SF	<b>0.528</b>	0.264	0.283	0.269	0.293	-0.177	0.206	<b>0.854</b>	<b>0.447</b>	<b>0.384</b>	<b>0.602</b>	<b>0.360</b>	-
Total													

Significant ( $p \leq 0.05$ ) correlations are in bold in the correlation matrix.

of breath) for at least one half hour (30 minutes?)” could imply that this question needs to be further explored. Due to the strong recommendations of physical exercise for persons with RA [36,37], a more specific instrument for physical exercise habits might be needed as a complement to the MDHAQ-S. Question 10 showed floor effects and, considering the type of question (changes in lifestyle, accidents etc. over the last 6 months), this is difficult to avoid. Overall, the floor and ceiling effects of the MDHAQ-S are acceptable, even if some items need further exploration.

#### Validity

The MDHAQ-S had very good content validity. Concurrent and criterion validity of the MDHAQ is good even if there are some questions that might need further development. The AIMS, the AIMS2 and the AIMS2-SF have been used in several other studies for comparison of patient reported outcome measurements [10,11,21,38]. The AIMS2-SF covers some of the items of the MDHAQ-S, but there are differences between the instruments in their coverage. In the Finnish version of the MDHAQ there was a high correlation between the physical dimension of AIMS2 and the physical component of the MDHAQ, but only a low correlation

was found in our study [10]. The other correlation coefficients showed similarities between our study and the Finnish study.

The social dimension of the AIMS2-SF showed a very low correlation with the items in the MDHAQ-S. This dimension might be considered difficult to use for comparison due to the changes that have taken place in people’s social life in Western countries, since it also had a low correlation in the Finnish study of MDHAQ [10]. Today’s social life does not demand physical capacities in the same way as before, since a great deal of social life is held over the internet or by phone. This must be considered in future studies.

Some of the patients in the reliability test group found it difficult to rate the relevance of the questions of the MDHAQ, since they thought that the relevance could differ during the years with the disease. The question about the amount of aerobic exercise (question 8) is difficult to compare with the other questions in the MDHAQ-S since there are so many things that influence exercise habits and all of those are not correlated to disease [39], which can be a reason for the floor and ceiling effects of this question. Motivation, time and other factors also play an important role. The importance of regular exercise for persons with RA is however a

strong reason why this question should still be included in the MDHAQ [40]. The question about exercise habits had excellent agreement in test-retest, but this could be due to the fact that it takes a long time to change exercise habits. The question should also probably be reformulated and include more steps in order to be sensitive to change. The validity of the MDHAQ is good, but further research to compare the MDHAQ-S with items of social life would be beneficial.

### Further research

There are several areas of interest for further research concerning the MDHAQ-S, such as the sensitivity to change of the MDHAQ, floor effects of the psychological dimension, correlation between items of social life and the MDHAQ-S and further development of the question concerning exercise habits. The MDHAQ-S should also be further investigated in different phases of RA, in order to find out whether the relevance of the MDHAQ-S is similar during the duration of the disease. In this study, the number of years with the disease and the medications were not described by the participants; they could therefore be in different phases of their disease.

Health literacy has been shown to have connections with lower physical function measured with the MDHAQ and it would be of interest to investigate this issue in a Swedish context [41]. Since several of the participants in the study have had RA for a long time, they have encountered this type of questionnaire earlier and may therefore have found the questionnaire easier to fill in than if they had been newly diagnosed and unfamiliar with this type of questionnaire. The level of education is included in the MDHAQ-S but, since it has no correlation with health literacy, it may be possible to remove this item from MDHAQ-S in the future [41].

### Conclusion

The MDHAQ-S has good reliability and validity and can be of use in clinical care for patients with RA, even if there are items that should be further developed to improve the MDHAQ-S. Further research is recommended concerning sensitivity to change.

### Abbreviations

AIMS: Arthritis Impact Measurement Scale; AIMS 2: Arthritis Impact Measurement Scale 2; AIMS2-SF: Arthritis Impact Measurement Scale 2- Short Form; CVI: Content validity index; HAQ: Stanford Health Assessment Questionnaire Disability Index; ICC: Intra-class correlation coefficient; ICF: International Classification of Functioning, Disability and Health; MDHAQ: Multi Dimensional Health Assessment Questionnaire; MDHAQ-S: Multi Dimensional Health Assessment Questionnaire, Swedish version; RAPID3: Routine Assessment of Patient Index Data 3; RADAI: Rheumatoid Arthritis Disease Activity Index.

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

The planning of the study was performed by KAJ, CE and GG. KAJ performed the data collection. The data analysis was performed by KAJ, GG, UJ. KAJ drafted the manuscript and all authors reviewed and approved the final manuscript.

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## Paper IV



# Detecting decreased sexual health with MDHAQ-S

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## ABSTRACT

**There are instruments that measure sexual function or sexual health for persons with RA, but since sexual health is a sensitive issue, the hypothesis is that it would be easier to have a standard questionnaire that could indicate the need for communication about sexual health issues instead of an extra questionnaire with more detailed questions on sexual health. The aim of the study is to find out whether sexual health difficulties can be screened by factors included in the MDHAQ-S for persons with RA. This study explores the relation between factors included in the MDHAQ-S and the Sexual Health Questionnaire (QSH) using a mixed methods design combining quantitative and qualitative data. The MDHAQ-S covers sexual health issues, not only by using the question on sexual health, but also on other factors included in the questionnaire such as increased pain, fatigue, depression, anxiety, physical capacity, level of physical activity and body weight. To explore decreased sexual arousal, decreased sexual satisfaction and decreased sexual well-being, in-depth interviews must be held with persons with RA, either using a sexual health questionnaire or in a clinical interview.**

**Keywords:** Sexual Health; Rheumatoid Arthritis; Mixed Methods; Rehabilitation; Health Assessment

## 1. INTRODUCTION

Sexual health is connected to self-esteem, intimate relationships and general quality of life and is defined by the World Health Organization as a state of physical, mental and social well-being in relation to sexuality [1].

Good sexual health is an important factor in achieving a desired quality of life, even if the essence of good sexual health actually consists of differs between individuals. A description of what good sexual health is can also vary individually across the lifespan due to life circumstances. However, sexual life satisfaction is one of the two main predictors of global life satisfaction for persons with rheumatoid arthritis (RA) [2]. Being able to perform sexual activities is included in important life activities for persons with RA [3], and sexual health is often affected negatively by the disease [4-6]. A decrease in sexual health can be due to fatigue, pain, decreased physical capacity, negative body image and/or depression. Factors that might be of importance in detecting risk for decreased sexual health, for example pain, have been shown to have a significant correlation with sexual dysfunction in both men and women [7].

Communication about sexual health is an issue that should involve several health professions since multidisciplinary interventions are needed to improve sexual health [8]. Some health professionals hesitate to bring up the subject of sexual health with their patients, however, and sexual health issues are often not identified in patients with chronic diseases [9-11]. Since communication concerning sexual health is scarce among health professionals and patients with RA, it is important to find interview guide recommendations in clinical practice that are within the comfort zone for both patients and health professionals. Earlier research [12] shows that patients prefer health professionals to bring up the subject of sexual health with them. A recent study showed that patients with RA would not have brought up sexuality issues at all unless these issues were part of a questionnaire at a clinical visit [7]. Communicating about sensitive issues such as sexual health can be facilitated by the use of a questionnaire, in order to find indications of a need for information or support to the patient [13].

It would be of value to use standardized questions that

could detect a patient's perceived level of sexual health. Patient questionnaires are the most significant predictors of severe long-term outcomes in patients with RA [14]. There are instruments that measure sexual function or sexual health in persons with RA, but since sexual health is a sensitive issue, the hypothesis is that it would be easier if a standard questionnaire could indicate the need for communication about sexual health issues instead of using an extra questionnaire with more detailed sexual health questions. One of the most frequently used questionnaires for patients with RA is the Stanford Health Assessment Questionnaire (HAQ) [15,16], which does not include questions concerning sexual health [17]. The revised version, the Multi Dimensional Health Assessment Questionnaire (MDHAQ), has one question covering different symptoms of RA that includes a choice concerning an effect on sexual function [18]. The MDHAQ is regularly used both in research and in clinical care internationally and is available in a Swedish version, the MDHAQ-S [19]. The MDHAQ consists of the following parts: physical function, psychological status, pain, global health, fatigue, morning stiffness and exercise habits, and includes Routine Assessment of Patient Index Data 3 (RAPID3) and Rheumatoid Arthritis Disease Activity Index (RADAI) self report joint count [20] as well as a symptom list and recent medical history [18]. The items included in the MDHAQ can be related to sexual health. There are questionnaires concerning sexual health for persons with RA, and here we have used the Questionnaire of Sexual Health (QSH) together with the MDHAQ-S [21].

## 2. AIM

To find out whether sexual health difficulties can be screened by factors included in the MDHAQ-S for persons with RA.

### Research Goals

- To study the correlation between the factors included in the MDHAQ-S and the QSH.
- To identify predictors of sexual well-being in persons with RA.
- To describe the participants' reasoning concerning factors affecting their sexual health.

## 3. MATERIAL AND METHOD

The hypothesis is that standardized questions, such as those included in the MDHAQ-S, correlate with decreased sexual health. This study explores the relation between factors included in the MDHAQ-S and the Sexual Health Questionnaire (QSH) [21]. A mixed methods design combining quantitative and qualitative data was chosen to complement, deepen the understanding of and

support the findings of how different factors might affect sexual health [22,23]. The use of mixed methods research demands rigor to the quantitative and qualitative methods included [24]. The data were collected using two questionnaires, the MDHAQ-S and the QSH.

The QSH contains 21 questions: age, gender, civil status, partner's health status, body image, change in body image after onset of RA, effect of RA on sexual function, sexual well-being, sexual arousal, change in sexual arousal after onset of RA, sexual satisfaction, change in sexual satisfaction after onset of RA, status of relationship, effect of RA on relationship, importance of sexuality, connections between pain, fatigue, stiffness, physical capacity, positive feelings and experiences and sexual health, and how the respondent would like to be informed about sexual health for persons with RA. The questions in the QSH are written as claims with optional answers on Likert scales (3 - 5 options), except for the demographic questions and the question on information about sexual health, which had the following options: "I bring it up when there is need for it", "Health professionals bring up the subject", "Possibilities to contact by e-mail", "Written information in the waiting room", "Information on the internet", "I don't want sexual health to be brought up at all". The QSH includes the option of open answers to questions.

The internal consistency of the QSH, measured with Cronbach's alpha, was 0.74 [21]. The factor structure of the QSH, evaluated with principal component analysis (varimax rotation, Eigen value > 1), shows three meaningful factors: sexual well-being, body image and relationship [21]. The factor "sexual well-being" contains five items; the factor "body image" contains two items and the factor "relationship" contains two items. The QSH has also shown good face validity [21].

The questions concerning earlier experiences of physiotherapy and communication of sexual health with health care professionals have been removed in the revised version of the QSH in order to gain a more focused view of sexual health issues.

The MDHAQ [18,20] starts with "physical function" including ten activities of daily living scored 0 - 3 (0 = "without any difficulty", 1 = "with some difficulty", 2 = "with much difficulty" and 3 = "unable to do"). The sum of the answers is divided by three, giving a score between 0 and 10. The second section, with three questions concerning psychological status, has scores of 0 = "without any difficulty", 1.1 = "with some difficulty", 2.2 = "with much difficulty", and 3.3 = "unable to do". The sums are added to a total sum of 0 - 9.9. The MDHAQ-S includes visual analogue scales with 21 circles measuring pain, global health and fatigue with a total score of 0 - 10 in 0.5 units. The RADAI includes eight joints or joint groups scored 0, 1, 2 or 3. The RAPID3 scores (0 - 30

scale) include four categories: High severity > 12, Moderate severity = 6.1 - 12, Low severity = 3.1 - 6 and Remission ≤ 3. The review of symptoms is a checklist of symptoms where boxes that have been checked are counted. Morning stiffness is rated by yes or no and the amount of time in minutes. Change in status is scored: 1 = Much better, 2 = Better, 3 = Same, 4 = Worse, 5 = Much worse. Exercise frequency is scored 3 = 3 or more times a week, 2 = 1 - 2 times a week, 1 = 1 - 2 times a month, 0 = Do not exercise regularly, 9 = Cannot exercise due to disability/handicap. The MDHAQ-S also includes questions about recent medical history, which are not scored.

The reliability of the MDHAQ-S has been tested with Cronbach's alpha, intra-class correlation and kappa statistics and has shown good reliability [19]. The content validity of the MDHAQ-S was tested with a content validity index, giving a range of 0.75 - 1.00, with an average sum of 0.94 [19].

### 3.1. Study Group

#### 3.1.1. Quantitative Study Group

Swedish speaking persons with diagnosed RA above 18 years of age from a rehabilitation clinic in Sweden were invited to participate. The aim was to include 80 persons with RA in the study. It was a consecutive sample with a response rate of 67.5%, in total 54 participants. The participants' demographic data are shown in **Table 1**.

#### 3.1.2. Qualitative Study Group

Participants from an earlier study [21] that had the same inclusion criteria as for the quantitative study group were included, together with the quantitative study group, in the analysis of the open answers to the QSH (**Table 2**).

### 3.2. Data Collection

The questionnaires were given to patients who agreed to participate in the study, either at the clinic or sent home to the participant. The patients answered both questionnaires at the same time.

### 3.3. Data Analysis

#### 3.3.1. Quantitative Analysis

The collected data from the QSH and the MDHAQ-S were analyzed using descriptive statistics, frequencies and proportions, and were analyzed for correlation with Spearman's rank correlation for the items included as well as for the physical and psychological dimensions of the MDHAQ-S. Multiple regression analysis was performed to identify associated factors to sexual well-being.

**Table 1.** Demographic data of the quantitative study group.

	Age average (range)	Living with a partner
Women, <i>n</i> = 47	57 years (28 - 77)	33
Men, <i>n</i> = 7	64 years (51 - 72)	5

**Table 2.** Demographic data of the qualitative study group.

	Age average (range)	Living with a partner
Women, <i>n</i> = 98	56 years (19 - 77)	73
Men, <i>n</i> = 19	62 years (38 - 76)	16

The criterion variable was sexual well-being from the QSH, and the independent variables included from the MDHAQ-S were total score of physical function, total score of psychological function, pain, fatigue and general well-being. Descriptive statistics and independent sample test were used to describe the subgroup expressing decreased sexual health on the MDHAQ-S review of symptoms, as well as the subgroups with high levels of regular exercise and high Body Mass Index (BMI). The subgroup of those describing decreased sexual health was chosen since it is a direct question about sexual health, the exercise subgroup was chosen due to the known positive effects of a physically active lifestyle on sexual health and the subgroup of overweight (BMI ≥ 25) was chosen on the basis of the results from the open answers in the questionnaire.

#### 3.3.2. Qualitative Analysis

In the QSH, participants had the opportunity to describe their experiences in their own words as to whether and how RA had affected their sexual health. The open answers of the QSH were analyzed with content analysis [25]. Content analysis has been used in other studies that have analyzed open answers in questionnaires in combination with quantitative data analysis [26-28].

Each question was analyzed separately, and the content analysis consisted of the following procedure [25]:

- Reading and re-reading all answers to get a sense of the material.
- Sorting the material into meaning units.
- Coding meaning units.
- Comparing codes concerning similarities and differences.
- Differences between the two researchers concerning coding and categorisation were discussed from the view of the question and the completion of the answer.
- Categorizing codes and comparing similarities and differences.
- Differences between the two researchers concerning coding and categorisation were discussed from the view of the question and the completion of the an-

swer.

- Transforming the categories into a theme.

The researchers discussed the categories and themes together to gain consensus. The analysis of the open questions resulted in a theme with underlying categories.

### 3.4. Ethics Considerations

The study was approved by the regional ethics committee in Lund (d. no: 2012/14) and the answers were treated with confidentiality.

## 4. RESULTS

### 4.1. Quantitative Results

A healthy sexual life was rated as important or very important by 57% of the participants. Sexual problems were expressed in the MDHAQ-S, question 5, by 30% of the participants. A negative effect of RA on their sexual health was described in the QSH, question 6, by 52% of the participants. Sexual well-being was described as not very good or worse by 52% of the participants. Level of sexual arousal was described as too low or non-existent

by 65% of the participants, and 63% of the participants described that their sexual arousal had decreased after being diagnosed with RA. Sexual satisfaction after sexual activities was described to be weak or non-existent by 24% of the participants, and 43% of the participants described their sexual satisfaction as being lower after being diagnosed with RA.

#### 4.1.1. Correlation between Factors Included in the MDHAQ-S and the QSH

The MDHAQ-S was tested for correlation with QSH for the physical dimension, the psychological dimension, pain, general well-being, fatigue, exercise level and BMI (Table 3).

There were significant correlations between the physical dimension of the MDHAQ-S and body image, decreased sexual arousal and decreased sexual health after onset of disease, as well as belief that a reduction of pain improved sexual health. The psychological dimension of the MDHAQ-S correlated significantly with body image, sexual well-being, worsened body image, decreased sexual arousal and decreased sexual satisfaction after onset of RA. A higher score on general pain showed a signifi-

**Table 3.** Correlation coefficients MDHAQ-S (significant correlations,  $p \leq 0.05$  are marked in bold).

	MDHAQ-S Physical dimension	MDHAQ-S Physical dimension	MDHAQ-S 2 (pain)	MDHAQ-S 4 (general well-being)	MDHAQ-S 8 (exercise level)	MDHAQ-S 9 (fatigue)	BMI
QSH4 (body image)	<b>-0.355</b>	<b>-0.317</b>	-0.231	-0.243	0.090	-0.093	-0.123
QSH5 (changed body image)	-0.140	<b>-0.373</b>	-0.127	-0.174	0.173	-0.245	0.037
QSH6 (decreased sexual function)	-0.116	-0.255	-0.046	-0.198	0.184	<b>-0.304</b>	0.159
QSH8 (sexual well-being)	-0.226	<b>-0.397</b>	<b>-0.382</b>	<b>-0.381</b>	0.156	-0.141	-0.180
QSH9 (sexual arousal)	-0.066	-0.246	<b>-0.402</b>	<b>-0.361</b>	0.039	-0.162	-0.167
QSH10 (changed sexual arousal)	<b>-0.284</b>	<b>-0.288</b>	<b>-0.399</b>	<b>-0.469</b>	0.218	-0.216	-0.016
QSH11 (sexual satisfaction)	-0.113	-0.023	-0.283	-0.093	0.108	0.105	-0.076
QSH12 (changed sexual satisfaction)	<b>-0.303</b>	<b>-0.305</b>	<b>-0.538</b>	<b>-0.455</b>	0.184	-0.155	0.060
QSH13 (satisfaction with relationship)	0.254	0.062	0.238	0.086	-0.104	-0.160	-0.072
QSH14 (effect on relationship)	0.201	0.134	-0.017	<b>0.332</b>	0.047	<b>0.300</b>	-0.247
QSH15 (importance of sexuality)	-0.046	0.073	-0.258	-0.020	0.029	0.118	-0.149
QSH16 (connection between pain and sexual health)	<b>0.337</b>	0.108	-0.074	0.067	-0.285	-0.085	0.016
QSH17 (connection between stiffness and sexual health)	0.210	0.187	0.111	0.191	<b>-0.311</b>	0.083	0.075
QSH18 (connection between fatigue and sexual health)	0.041	0.148	0.106	0.160	-0.184	0.085	0.058
QSH19 (connection between physical capacity and sexual health)	0.169	0.129	0.142	0.158	0.121	-0.052	<b>0.365</b>
QSH20 (connection between positive emotions/experiences and sexual health)	0.054	0.197	-0.096	-0.046	-0.124	0.005	0.085

cant correlation with lower sexual well-being, lower sexual arousal, decreased sexual arousal since onset of RA and decreased sexual satisfaction after onset of RA. A poorer score on general well-being correlated significantly with lower sexual well-being, lower sexual arousal, decreased sexual arousal, decreased sexual satisfaction and worsened relationship with the partner since onset of RA. A high level of fatigue correlated significantly with RA affecting the possibilities to function sexually and with a worsened relationship with the partner. Level of exercise correlated with the belief that decreased morning stiffness improves sexual health. BMI correlated with believing that improved physical capacity improves sexual health.

#### 4.1.2. Predictors of Sexual Well-Being for Persons with RA

The multiple regression analysis with sexual well-being as the criterion variable showed low Beta values for the items in the MDHAQ-S, indicating that the influence of the predictors on sexual well-being was low. There was however significance for the total score of the psychological dimension ( $p = 0.004$ ,  $B\text{-value} = -0.345$ ). The adjusted R square of 0.268 shows that our model accounts for 27% of the variance.

#### 4.1.3. Descriptive Statistics of Subgroups

The group describing negative effects on their sexual health in the MDHAQ-S did not differ according to age or BMI. There were significant effects in several issues on the QSH for this group, such as: decreased ability to function sexually ( $p = 0.04$ ), decreased sexual well-being ( $p = 0.03$ ), decreased sexual arousal ( $p = 0.01$ ), decreased sexual satisfaction after onset of RA ( $p = 0.02$ ) and negative effect on intimate relationship of RA ( $p = 0.03$ ).

Since several participants mentioned increased body weight due to RA in their open answers, and that this in turn affected their sexual health in a negative way, the group with a BMI representing overweight ( $>25$ ) was compared to the rest of the participants. The comparison showed a significant difference only for QSH, question 19: "I think there is a strong connection between improved physical capacity and improved sexual health" ( $p = 0.00$ ).

There is a strong belief in 46% of the participants that increased physical capacity increases sexual health, and an additional 37% of the participants partly agree. In the studied group, 22% of the participants exercise more than three times per week and 52% exercise one to two times per week according to the MDHAQ-S, question 8: "How often do you exercise aerobically for at least one half hour?" There were no significant differences between the group exercising regularly and the group not exercising regularly.

## 4.2. Qualitative Results

### Description of the Participants' Reasoning Concerning Factors Affecting Their Sexual Health

The open questions concerned experience of body image, sexual health, sexual relationship, sexual arousal, sexual satisfaction and eventual changes in those experiences due to RA. The open questions were analyzed according to the following key issues: "How has RA affected my experience of my body?" and "How has RA affected my sexual health?"

The categories included in "How has RA affected my experience of my body?" were physical changes (weight, appearance, physical function), changed experience of the body (changed body image, changed acceptance of the body, discontentment with the body) and effect of medication on the body. The body image was experienced to be less attractive after the diagnosis of RA. Increased body weight and feelings of being fat were mentioned by several participants as reasons for decreased sexual health and were experienced to be due to decreased physical ability owing to RA or to medical impacts. Loss of muscle and posture and developing a less attractive body shape were also considered to be effects of RA that had a negative effect on the participants' sexual health.

"Gained weight since the start of the disease and lost physical capacity and mobility".

"Have lost muscles, body shape and posture".

The participants also described negative feelings and aggression towards themselves and their body both in connection to sexual health and in general.

"Feels difficult not to be able to do as many things together as before, not only sexually".

Support for weight loss and increased exercise levels were considered an important strategy for improving sexual health.

"The last year's weight loss and exercise has given good effect".

Medication was described as both a way to improve and decrease sexual health. Some felt a direct improvement in being able to perform sexual activities, and others had experienced decreased sexual arousal due to medication.

"Before I had a diagnosis and medication I had a lot of pain and difficulties to move around in bed and everywhere. Now with medication, most things work".

"I have no sexual arousal since the start of medication with Humira".

The categories included in "How has RA affected my sexual health?" were changed physical functioning (pain, fatigue, changes in arousal, effects of age, decreased ability of intimacy) and effects on intimate relationships (acceptance within the relationship, worsening relation-

ship, improved relationship).

“A body that aches and hurts with a single touch. Muscular that feels like gravel. Tenderness and touch would be appreciated and needed, but sexual activity wouldn't work”.

There were descriptions of partial or complete loss of sexual arousal and decreased ability to reach orgasm, both in connection with pain and fatigue and as single symptoms stemming from RA.

The effect on the intimate relationship depended largely on the couples' strategies for coping with the symptoms of RA and an understanding partner.

Among the strategies, acceptance of the disease and the related symptoms was important, both for the person with RA and the partner.

“Despite all negative things I have a very understanding husband and it helps a lot”.

A strategy that was described by several participants was to exclude sexual activities from their life after the diagnosis, since sexual activities were considered difficult to perform. This strategy was described by several participants as unsatisfactory and also as troublesome in their relationship with their partner.

“Sex is a closed chapter of my life!”

“Would have needed help a lot earlier! Now it is unfortunately too late”.

“He is disappointed in me because I can't perform intercourse due to pain and ache. He has difficulties to understand that my body hurts so much when being touched. Now after two years he has stopped nagging, but it has been a great physical strain on us both”.

There were descriptions of wishes to regain a satisfactory love life with sexual activities or with new ways of sexual closeness and intimacy.

“Of course it would have been nice if it could work. Of course I miss it enormously”.

The theme that emerged from the categories in the qualitative analysis was *change*. Change was important in how the symptoms of RA were experienced in connection with sexual health and how these changes were coped with.

## 5. DISCUSSION

The question on sexual health in the MDHAQ-S that shows decreased sexual health in this study group (30%) is on a level with other studies concerning sexual health in patients with RA [4,5,21]. However, 52% of the participants describe their sexual well-being as being not very good/bad/very bad according to the QSH, indicating that the MDHAQ-S does not cover sexual health issues sufficiently. In comparison with the QSH, there are patients with decreased sexual arousal and decreased sexual satisfaction that are not detected by the question concerning sexual health in the MDHAQ-S. Sexual arousal

seems to be more difficult to retain compared to sexual satisfaction since sexual satisfaction is rated higher in this group than the amount of persons describing a negative effect on sexual satisfaction due to RA. Decreased sexual arousal has been considered to be an important factor in persons with RA in other studies [29-31].

High scores in the psychological factors of the MDHAQ-S can indicate decreased sexual health after onset of RA and ought therefore to be considered important when communicating with patients about psychological effects of RA. Anxiety, feelings of depression and sleeping difficulties have a negative effect on sexual health in persons with rheumatological diseases [32,33]. Poorer sexual health can also increase anxiety and feelings of depression [29].

VAS scores on the MDHAQ-S for general pain, general well-being and fatigue should be considered when estimating whether a person is in need of discussing his or her sexual health since the scores can indicate decreased sexual health.

In our results, a high level of fatigue correlated with a higher impact of RA on the relationship with the partner as well as with the ability to function sexually. Research results considering the impact of fatigue on sexual health show mainly that fatigue has a negative effect on sexual health [5,29,34,35], except in a study by Kobelt *et al.* that did not find significant support for fatigue influencing sexual health [36].

Pain has been shown in other studies to affect sexual health [6]. Our results showed that persons with higher VAS pain scores had lower sexual well-being and sexual arousal and that sexual arousal and sexual satisfaction had become worse since the onset of the disease. Those findings, together with earlier studies [33,35,37], give a clear indication that the issue of sexual health should be addressed when there is a high score for general pain on the VAS scale.

In a recent Swedish study, feeling lust was not a factor that promoted general health among persons with RA [38]. However, our study results showed that a lower general health score indicated lower sexual well-being, lower sexual arousal, a negative effect on the relationship with the partner and experienced decreased sexual arousal and sexual satisfaction since the onset of the disease. It is unknown whether the lower score of estimated general health indicates that poorer sexual health has given worse general health or vice versa. Good sexual health gives better general health, but low general health can also give low sexual health. Interest in sex and engaging in sexual activities decrease with poorer health [39].

The question of body weight is included in the MDHAQ-S, and weight gain can be an important issue in the experienced level of sexual health according to the

open answers in this study. We believe this to be a factor that is important to acknowledge when considering factors that affect sexual health in a negative way among persons with RA. The quantitative results did not show significant differences for participants with a high BMI concerning the level of sexual health, but a person might feel overweight at a lower BMI depending on the body weight before the onset of RA. The feeling of being overweight can also be due to changes in muscular mass or body disposition, which does not show in the BMI. However, a low body esteem and weight concerns can decrease sexual satisfaction for women [40]. A negative body image has a negative effect on sexual health in women with RA [6,35,37]. A poorer body image correlated significantly with the physical and psychological factors of the MDHAQ-S, thus indicating that high scores on the psychological and the physical factors of the MDHAQ-S are reasons to address sexual health issues with the patient.

Physical fitness can affect sexual health positively, since improved fitness levels increase the frequency of sexual intimacy [41]. This is also shown for persons with RA [36]. It is interesting to note that this is perceived to be true by a majority of the informants, indicating that physical activity can be considered a self-help strategy to improve sexual health.

The theme *change* that developed from the analysis of the open questions can be compared with the results of a qualitative study by Helland *et al.* ([29] where the disease was considered to be an interruption in life that demanded new strategies for sexual issues and within the relationship. Our study results show both strategies that have led to a maintained sexual relationship and strategies that have led to an end of sexual activities. This change can be ongoing during the course of the disease with changes in medication, family life and disease activity, and we therefore believe that sexual health ought to be addressed regularly in rheumatologic health care, and especially when such changes are known.

We believe that a questionnaire indicating eventual sexual health difficulties can be useful in easing the conversation concerning sexual health without losing respect for the person's integrity. It is important to acknowledge that some patients with chronic diseases hesitate to bring up problems with sexual health with health care professionals since they do not believe that they can get any help from them [42]. Every health care professional must thus be aware of what types of sexual health problems their interventions can be of use for and in which cases they must refer the patient to another specialist.

A questionnaire can be of aid in finding key issues that imply decreased sexual health for persons with RA, but it is also essential to acknowledge other signs such as negative body image, a decrease in daily activities and

changes in medication. When those factors are present, sexual health ought to be addressed, preferably by asking the patient if he/she would like information concerning how RA might affect sexual health or if he/she has any questions about this issue.

## Methodological Discussion

Mixed methods research can be used to explore how the themes identified in the qualitative data collection compare with the statistical results in the quantitative analysis and, in our study, we found the qualitative categories to be in line with the quantitative results. Mixed methods can be used with a focus on the methods included, with employing the other research method to strengthen the results of the main method or by using both methods to complement each other. In this study, we used the latter alternative since we believe the two methods to be complementary and to make the results more applicable in clinical encounters between health care professionals and patients with RA.

The response rate of 67.5% is good for research concerning sexual health, since questionnaires concerning sexual health often have lower response rates [31,43,44]. The response rate is also good considering that older women are more reluctant to answer questionnaires about sexual issues, and this is the main group in this study [5,31,45].

The QSH was used in this study owing to its validity and reliability in the Swedish context, as well as the inclusion of respondents that considered RA to be the cause of their sexual health difficulties. There are different questionnaires that are used to measure the impact of RA on sexual health. In the work of Palmer & Miedany [46], there are four questions concerning intimate relationships and sexual function. Those questions had a narrow perspective of sexual health, however, and did not include whether the patient with RA saw RA as the cause of their sexual dysfunction, or how their sexual health was affected by their experienced sexual dysfunction. Another questionnaire, Qualisex [47], focuses on the experience of sexual health over last three months, which might be misleading if the respondents have felt their decreased sexual health since the onset of the disease.

The Stanford Health Assessment Questionnaire (HAQ) includes the physical dimension of the MDHAQ-S, measuring functional ability in daily activities, visual analogue pain scale and visual analogue general health scale [17], which is not sufficient to detect decreased sexual health. Another often used questionnaire is the Arthritis Impact Measurement Scale 2-Short Form (AIMS2-SF) [48], which covers physical, psychological, emotional and social status but lacks a description of body image issues, changes in medication, exercise habits and description of experienced symptoms of RA. To

cover issues affecting sexual health, a health assessment questionnaire needs to have a broad scope that includes aspects of sexual health from a biopsychosocial perspective.

## 6. CONCLUSION

The MDHAQ-S covers sexual health issues, not only by using the question concerning sexual health but also by using other questions included in the questionnaire such as increased pain, fatigue, depression, anxiety, physical capacity, level of physical activity and body weight. To explore decreased sexual arousal, decreased sexual satisfaction and decreased sexual well-being, there is a need to make a deeper interview of persons with RA, either using a sexual health questionnaire or in a clinical interview. Improving communication about sexual health with respect for the person's integrity is essential, and further research into how this can be done is needed to improve sexual health in persons with RA.

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