

# Sexual Health and Intimate Relationships in Rheumatoid Arthritis

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## 1. Introduction

The aim of this chapter is to describe how rheumatoid arthritis (RA) can affect sexual health and intimate relationships negatively and to explore some possible ways to improve sexual health for persons with RA. To introduce the subject the chapter will begin with a short introduction to the term sexual health and how chronic illness can affect sexual health. Thereafter follows a description of how RA affects sexual health and intimate relationships, current research in this field by the authors, suggestions on how to improve sexual health and intimate relationships for persons with RA, and finally new research in the area and conclusions.

## 2. Background

According to World Health Organization (WHO) (World Health Organization 2006) sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality. Sexual health incorporates a positive and respectful approach to sexuality and sexual relationships, and includes the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. To have a good sexual health is not only absence of sexual diseases, but is connected to self-esteem, intimate relationships and general quality of life. Sexuality has a multidimensional nature consisting of biologic, affective, cognitive and motivational parts. During the lifespan, sexuality is an integrated part of life. A good sexual health is to many people an important factor in order to achieve a desired quality of life, but the essence of what is good sexual health differs between individuals. A description of what a good sexual health is can also differ during the lifespan for the same person due to life circumstances. According to a recent study one of the two main predictors of global life satisfaction is satisfaction with sexual life (Tasiemski, Angiaszwili-Biedna, and Wilski 2009). A person's sexual health affects their intimate relationship. A poor sexual health can also affect the person's view of the possibilities of finding a partner to share an intimate relationship with.

Chronic illness affects the patient physically, psychologically, socially and in their relationship with their partner. The impact of a chronic disease on sexual health can be due to indirect factors influencing sexual function such as altering self-image, fatigue, pain and dependency (Basson and Schultz 2007). Sexual health is one of the domains that can be

affected by chronic illness, such as RA. Effects of chronic conditions on sexual health is often under diagnosed (Bitzer et al. 2007), which can prolong or worsen the difficulties. Sexual health is included in the International Classification of Functioning, Disability and Health (ICF) (*International Classification of Functioning, Disability and Health*. 2001) within two separate areas, sexual functions (body functions) and intimate relationships (activity and participation). The ICF core sets for rheumatoid arthritis (Stucki et al. 2004) acknowledge both areas as important since they can be affected by the disease. However, since sexual health is a complex and broad field there are other components of the ICF, such as pain, sleep, physical functions, psychological functions etc., that are of importance when exploring sexual health. The importance of sexual health is at the same level for persons with a chronic disease as for healthy persons (Kedde et al. 2010) Therefore sexual health must be acknowledged by health care professionals. This is especially important since people with decreased sexual pleasure due to physical impairment can experience a decreased overall wellbeing which can be very distressing (Hull 2008).

The prevalence of RA is approximately 0.5-1% and the disease affects the life of the persons with RA in many different areas during life. There is a gender division for RA, with more women than men getting the disease (Englund et al. 2010). RA is characterised by joint swelling, joint tenderness and destruction of synovial joints (Aletaha et al. 2010). It is a chronic inflammatory disease and common symptoms are pain, fatigue, limited function, and decrease in physical capacity. The criteria for RA were revised in 2010 in order to increase focus on earlier stages of the disease (Aletaha et al. 2010). The most important treatment outcomes for persons with RA are reduction of pain, disability, fatigue and improved general wellness (Carr et al. 2003). All of these outcomes are connected to sexual health. The commonality of sexual health problems for persons with RA makes it assumable that sexual health is addressed routinely by health professionals within rheumatology and in patient reported outcome measurements. However, neither standard patient reported outcome measurements nor communication about sexual health is common within the field of rheumatology. Commonly used patient reported outcome measurements for RA such as Stanford Health Assessment Questionnaire (HAQ) (Fries et al. 1980) and Arthritis Impact Measurement Scales 2 (AIMS2) (Meenan et al. 1992) do not include questions about sexual health and intimate relationships. In the revised version of the HAQ, the Multi-Dimensional Health Assessment Questionnaire (MD-HAQ) one simple question about effect on sexuality by the disease is included (Pincus, Sokka, and Kautiainen 2005). If the MD-HAQ was used more often it might enhance the communication about sexual health in the clinical situation. Unfortunately MD-HAQ is only available in a few languages which limits the use of the instrument both in research and clinical work.

Generic outcome measurements are often used for patients with RA, such as Short Form 36 (SF 36) (Ware and Sherbourne 1992) and the EQ5D (EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group 1990). These instruments are also lacking questions concerning sexual health. The lack of inclusion of sexual health and intimate relationships in the patient reported outcome measurements is a principal reason why the subject rarely is brought up in clinical meetings between persons with RA and health professionals. By using patient report outcome measures that include sexual health for patients with RA the communication about sexual health between health professionals and patients might be easier to start and perhaps increase.

Earlier research concerning communication about sexual health issues with persons with RA, indicates that this rarely appears in the meeting between the person with RA and health

professionals (Abdel-Nasser and Ali 2006; Akkas 2010; Josefsson and Gard 2010; Hill, Bird, and Thorpe 2003; Rkain et al. 2006). Possible reasons for this will be discussed further in this chapter. Persons with RA can also be unaware of the fact that their reduced sexual health can be due to RA and therefore patient information about sexual health and RA is important. Ways of informing patients are by using material that often is available from organizations for persons with RA, both on-line and/or by leaflets. There are also on-line help-lines for persons with RA, where questions about sexual health have been presented (Richter et al. 2011). It is possible that further use of such information including sexual health might assist the communication concerning sexual health between partners and perhaps also between persons with RA and health professionals.

### **3. How does RA affect sexual health and intimate relationships?**

Sexual health difficulties due to RA can include decreased sexual arousal, decreased sexual desire and decreased satisfaction (Abdel-Nasser and Ali 2006; Karlsson, Berglin, and Wallberg-Jonsson 2006). The reasons for reduced sexual health often include both psychological and physical components. These factors can be experienced in combination or separately and they might change during the course of the disease. Psychological responses to chronic illness can include feelings of loss of independence, disrupted self-image, depression and anxiety (Basson and Schultz 2007). The physical components can include pain, fatigue, reduced functional ability, reduced strength and mobility (Hill, Bird, and Thorpe 2003). Both the psychological and the physical factors interrupt and affect sexual health in several ways. Problems before sexual activities can be due to decreased sexual arousal and/or negative body image (Gutweniger et al. 1999). Decreased sexual desire is reported for 50-60% of patients with RA (Abdel-Nasser and Ali 2006). Sexual health difficulties during sexual activities can be pain and/or decreased mobility. After sexual activities, persons with RA can experience sexual health problems such as decreased satisfaction and increased pain. There can also be an altering of the sexual activities such as wanting to reach orgasm quickly, because prolonged sexual activity increases both pain and fatigue (Elst et al. 1984).

Intimate relationships can be affected negatively by RA and there has been some studies concerning the situation of the partner of a person with RA according to the persons with RA (Rkain et al. 2006; Matheson, Harcourt, and Hewlett 2010; Bermas et al. 2000). Factors that can influence the intimate relationship of a person living with a chronic illness are: if the partner reacts negatively to illness; fear of rejection from the partner; lack of information about sexual rehabilitation; and if there is a cultural belief that persons with illness should not be engaged in sexual activities (Basson and Schultz 2007; Clayton and Ramamurthy 2008). There is also research showing that RA has a negative impact on the sexual relationship according to spouses of individuals with RA (van Lankveld et al. 2004; Lapsley et al. 2002). Reasons for this can be psychological distress and the need for social support within the relationship.

There is some research concerning how various medical treatments affect sexual health, but it is far from complete. Therefore there is limited information concerning the effect of common medication for RA on sexual health. Corticosteroids are often used for persons with RA and they can cause weight gain and "moon face" (i.e. edematous appearance of the face), which can be perceived as ugly and unpleasant by the person taking the medication (Clayton and Ramamurthy 2008). Feelings of being unattractive affect sexual health

negatively. Another common medication for persons with RA are non steroidal anti-inflammatory drugs (NSAIDs). NSAIDs have a negative effect on sexual desire and sexual arousal (Clayton and Ramamurthy 2008). There is a lack of research concerning the effects of newer Disease Modifying Anti Rheumatic Drugs (DMARDs) on sexual health. However, older DMARDs, such as methotrexate and sulphasalazine, have a known negative effect on erection (van Berlo et al. 2007).

Negative impact on sexual health is common for persons with RA. Previous research has shown that sexual health is decreased for 36-70% of persons with RA (Areskoug-Josefsson and Oberg 2009). Studies have been performed in different cultural contexts, but the problems remain similar, e.g. decreased sexual satisfaction, pain during sexual activities and diminished sexual desire (Yoshino and Uchida 1981; Abdel-Nasser and Ali 2006; van Berlo et al. 2007; van Lankveld et al. 2004; Josefsson and Gard 2010). These problems affect individuals with RA in Europe, U.S.A., Asia and Africa (Yoshino and Uchida 1981; Abdel-Nasser and Ali 2006; van Berlo et al. 2007; Rkain et al. 2006; Hill, Bird, and Thorpe 2003). Persons with RA often experience a change in the importance of sexual health during the lifespan since the importance decreases with increased age (Helland, Dagfinrud, and Kvien 2008; Hill, Bird, and Thorpe 2003; Abdel-Nasser and Ali 2006; van Berlo et al. 2007).

Decreased satisfaction with sexual life has been shown to be persistent during the first two years of RA, which indicates that the problems remain even after control of disease activity has been achieved (Karlsson, Berglin, and Wallberg-Jonsson 2006). Karlsson et al also showed that persons living with RA for a longer period of time had worse sexual health. The reasons for a decrease in sexual health also include fatigue, pain, stiffness, limited physical capacity, joint mobility and depression (Kraaimaat et al. 1996; Yoshino and Uchida 1981; Helland, Dagfinrud, and Kvien 2008; le Gallez 1993). Several of the mentioned symptoms occur in combination which can further increase the difficulties. An example of this is decreased functional ability, reduced hip mobility and fatigue, which all have a negative effect on sexual health because they contribute to fatigue (Ibn Yacoub et al. 2011). The different symptoms due to RA that have a negative impact on sexual health will be described briefly.

Pain is the major reason why persons with RA seek medical care, and pain is strongly associated with functional status, anxiety, depression (Sokka 2005) and quality of life (Garip, Eser, and Bodur 2010). The experiences and the intensity of pain can differ during different stages of the disease, but for many persons with RA chronic pain is an everyday problem. Chronic pain can in itself lead to decrease of sexual health, and sexual activities can increase pain (Ruehlman, Karoly, and Taylor 2008). Thereby persons with high levels of pain might avoid sexual activities in order to lessen the risk of exacerbating their pain. The avoidance of sexual activities can be shown as less amount of sexual activities, or shortening the sexual activity time wise, as well as a complete avoidance of engagement in sexual activities.

Concerning joint mobility, whilst it is mainly hip mobility that is problematic for women with RA during sexual intercourse (Abdel-Nasser and Ali 2006), involvement of other joints can also affect a person's sexual life. For example, inflammatory joints in the hands and limited hand function can reduce the ability to caress one's partner. Pain in the hands can lead to avoidance of holding hands, which can limit the romantic side of an intimate relationship. The enjoyment of being caressed can also be reduced due to pain when being touched (Josefsson and Gard 2010). Hugging can also be difficult if there is inflammation or decreased joint mobility in the shoulders. Those limitations are rarely discussed when discussing sexual health, but it is important to acknowledge that a good sexual health includes more than sexual intercourse.

Many persons with RA consider morning stiffness to be problematic and the level of morning stiffness is correlated with pain and physical capacity (Khan et al. 2009). Morning stiffness in itself can be problematic for intimate relationships if a person prefers to engage in sexual activities in the morning when fatigue can be less troublesome.

A major consequence of RA is limited physical capacity, which is connected to a number of symptoms including pain, limited mobility, stiffness and fatigue. Another reason for limited physical capacity among persons with RA might be the attitude towards physical activities for persons with RA. Until a few decades ago persons with RA were recommended not to engage in physical activities (Reinseth et al. 2010), and this inactivity decreased their physical capacity even further.

Having to cope with a chronic disease, and its' consequences, can cause low mood, anxiety and depression. All of these symptoms can be present for persons with RA and can affect their sexual health negatively. Depression is often associated with increased fatigue, pain and anxiety (Gettings 2010). Persons with RA can experience reduced psychological wellbeing, even if they are not suffering from depression, due to the effects of RA on their daily life.

Fatigue has been shown to affect quality of life as well as psychosocial aspects of life for persons with RA. Fatigue interferes with a person's ability to perform daily activities of life and this symptom is present in 40-80% of persons with RA (Ibn Yacoub et al. 2011). Among persons with RA, many of them believe that reduction of fatigue should be a major treatment aim (Pollard, Choy, and Scott 2005). There is a link between disease activity and fatigue, showing that persons in remissions have reduced feelings of fatigue according to their score on fatigue scales (Ibn Yacoub et al. 2011). However, the effect of the biologics on fatigue induced by RA is small (Chauffier et al. 2011), indicating that the problem of fatigue remains despite the development of this new class of drugs.

Many persons with RA also have secondary Sjögren's syndrome (Coll et al. 1987), a chronic disease that can decrease a person's sexual health both indirectly and directly. Indirect effects can be connected with increased fatigue (Ibn Yacoub et al. 2011). Direct negative effects on sexual health are due to Sjögren's syndromes effects on exocrine glands, which leads to vaginal and mouth dryness. Thus persons with Sjögren's syndrome can feel discomfort when kissing and can also experience problems with painful intercourse (Tristano 2009). This, of course, affects sexual health negatively. In a majority of the research about RA and sexual health, the prevalence of Sjögrens syndrome in the investigated group is not reported, which must be seen as a limitation of these studies.

#### **4. Current research**

In order to explore women's experiences of sexual health when living with RA and their experiences of physiotherapy in this context, a research plan of four studies was prepared. Two of the completed studies are discussed in this chapter.

The first study was a qualitative interview study. The study consisted of interviews with ten women with RA on their views of how their sexual health was affected by RA and how their sexual health could be improved (Josefsson and Gard 2010). The subjects ("informants") varied in age (42-66 years old), illness duration (2-31 years) and HAQ levels (0-2.13). The material from the interviews was analysed with a phenomenological approach according to Giorgi (Giorgi 1985; Giorgi 2000). This model of analyses contains the following steps:

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.

The following themes emerged from the analysis of the material: Sexual health - physical and psychological dimensions; and, Impacts of RA and Possibilities to increase sexual health - does physiotherapy make a difference?

The informants' view of sexual health showed individual views but all the informants believed sexual health to be complex and composed of several different physical and psychological factors. Described factors, such as, caresses, feelings of closeness and attractiveness, and affectionate attitudes towards the partner, as well as sexual activities and sexual intercourse were included in their view of sexual health. This broad perception of sexual health by the informants is in line with the definition of sexual health by WHO (Defining sexual health. Report of a technical consultation on sexual health, 28-31 January 2002, Geneva 2006).

*"Sexual health is close companionship, to be there for each other. Sexual health is also touching each other in a loving way."*

The informants also included feelings that arise in sexual situations and intimate relationships into their description of sexual health.

*"Sexual health is being together and caring for someone. Sexual health gives happiness and joy."*

Some of the informants described their views of what sexual health is and at the same time how it was affected by RA. Sexual health was limited for some of the informants, for example, parts of what they described as sexual health was accepted (e.g. closeness) and other parts were rejected (e.g. sexual intercourse).

They also believed that their view of sexual health and its importance changed during the lifespan. This could be due to other changes in life and to age.

*"You do revalue things. I wouldn't have answered the same way 10 years ago as I do now."*

An example of specific sexual problems mentioned by the informants was the difficulties that can come after having joint surgery.

*"But then it was my first hip replacement, well... It was so hard to come back after that, because I was so afraid that something would happen. I was so lucky, so I had both hips done at the same time."*

The results of this study show that the informant's sexual health was negatively affected by RA due to pain, fatigue, decreased joint mobility and anxiety. Experienced negative emotions due to RA included anger, frustration, and fear of being abandoned by the partner. Fear of being left by the partner might be considered as a threat and cause anxiety, which can further decrease sexual health.

*"And then it's like this, if somebody touches me, it hurts."*

The informants also linked RA to decreased sexual arousal and sexual satisfaction.

*"The arousal is gone and then you know that it is going to hurt when you try (to have intercourse). It first feels good, but then you know it is going to hurt and you think, should I tell, should I not? And afterwards it will hurt even more."*

*"The sexual satisfaction is not like before. Definitely not. I don't know what has happened."*

The problems with sexual health due to RA also affected the informants' intimate relationship with their partner. Some of the informants thought that their relationships had changed, but that they had a mutual understanding with their partner about how RA had

affected their sexual life. While others felt that their relationships suffered due to the sexual health problems. That sexual health should be free of coercion is stated by WHO and was not thought by the authors to be an issue for this group of informants, but still there were mentions of feelings of pressure to have sexual intercourse and also a direct mention that physical force should not be involved in sexual activities and that sexual activities should be voluntary. Perhaps coercion within intimate relationships for women with RA is more common than for other women and this is a field for future research.

*"I'm tired. And then it is all of the medication that lowers the sexual arousal so much. I have talked to my husband about it. That it is like, nothing. And still, I feel sorry for my husband... you have to do it just so he won't get hysterical. Yes, it has changed."*

A majority of the informants had experienced several of those problems. The informants thought that improving sexual health could be done by removing or decreasing the mentioned problems.

*"Take away the tiredness!"*

*"If I didn't have the pain."*

Suggestions on how this could be done were improved partner communication and physiotherapy.

*"So I think it is up to each person, but I'm sure that a lot of people would want someone to talk to. Except the partner, that you might not dare to talk with. Or you might think is embarrassing. If you have a conversation with someone about your sexual life, perhaps it is easier to come home and talk to your partner after that."*

Physiotherapy was considered to improve sexual health via pain reductive treatment, and exercise interventions by improving physical function, joint mobility, and fatigue. Physiotherapy for persons with RA is often directed towards increasing the level of physical activity and it is important that physiotherapists appreciate that, according to patient's feedback, this can also be used to improve sexual health.

*"Physiotherapy is good to be able to keep mobile and strong and to give feelings of satisfaction. By physical exercise you feel pleased with your body. Otherwise you lose your desire..."*

Experiences of positive feelings during physiotherapy and how those positive emotions can be of importance and enhance the effects of the physiotherapy interventions have been investigated (Gard 2000) but needs further exploration before being adopted for routine clinical use.

The results of the study lead to the conclusion, that physiotherapy can play an active role in improving sexual health for patients with RA according to the informants.

To further increase knowledge of the impact of RA on sexual health and how physiotherapy could affect it, a larger, second study was performed to complement the interview study (Josefsson & Gard, in print). This study was based on a new questionnaire, which was derived from the themes in the interview study and from earlier studies in the field (Josefsson and Gard 2010; Hill, Bird, and Thorpe 2003). Both men and women were included in this study so that possible gender differences could be explored. The results of this study show that a large majority of the patients agreed that there were strong connections between sexual health and pain, stiffness, fatigue, and physical function. Body image was affected by RA, but the study showed that the person's body image could be positively as well as negatively influenced after the diagnosis of RA. Most other studies have only shown a negative influence on body image of RA (Gutweniger et al. 1999). Although one study showed that body image did not affect sexual relationships for persons with RA (le Gallez 1993). The differences concerning the effect on body image by RA indicates that further

research should be performed to increase knowledge of the phenomena. The sexuality of both the partner and the patient was affected by RA and the level of strain on the partnership caused by RA was similar in this study to results found in other studies, where for example 35% experienced that RA had to put a strain on their partnership in the study by Hill et al (Hill, Bird, and Thorpe 2003; Matheson, Harcourt, and Hewlett 2010). This study also concluded that health professionals and their RA patients did not communicate about sexual health, which supports previous research in this field (Ryan and Wylie 2005; Hill, Bird, and Thorpe 2003). This result stresses the importance of having a strategy in order to improve communication concerning how to bring up sexual health in meetings between patients and health professionals. Additionally, health professionals need to be trained in dealing with sexual issues and communication about sexual health (Ryan and Wylie 2005) and they need to be aware of how they can assist patients in improving their sexual health. Physiotherapists also need to be aware that, in order to give best possible care, they should recognize that pain, fatigue, decreased joint mobility and impaired physical capacity can affect the sexual health of RA patients.

## **5. How can sexual health be improved for persons with RA?**

There is very little evidence that the inflammatory process of RA influences the ability to engage in sexual activities, instead the problems appear to occur due to the symptoms of the disease, such as fatigue and pain. In order to investigate possible methods for improving sexual health in persons with RA, a literature review was performed by Areskoug-Josefsson & Oberg (2009). The review showed that research aiming to improve sexual health for patients with RA is scarce and only a few studies include specific recommendations. These recommendations were physiotherapy and improved communication. Communication concerning sexual health needed to be improved both between partners and between patient and health professionals. If patients with RA and health professionals communicate about sexual health, the health professionals get a broader view of how the disease affects the patient's life. Health professionals might think that persons with chronic diseases have more important subjects to discuss than their sexual health, but this must be the choice of the patient and not of the health professional. Health professionals could also inform the persons with RA that optimal treatment of the disease may reduce the sexual difficulties (Perdriger, Solano, and Gossec 2010). It is not always easy for persons with chronic illness to verbalise their sexual problems and it is important that health professionals acknowledge this and have skills in communication about sexual health (Kedde et al. 2010). Improved communication about sexual health often includes giving information such as how sexual health can be affected by RA, and how sexual health can be improved. Information, communication and physiotherapy should not be used as single interventions to improve sexual health, but in combination, in order to cover the full scope of the problem (Fig 1).

### **5.1 Treatment models**

All members of rehabilitation teams should be involved in discussing and working towards improving sexual health with RA patients (Haboubi and Lincoln 2003; Couldrick, Gaynor, and Cross 2010; Post et al. 2008). The studies performed by the authors show that physiotherapists are important for improving sexual health in RA patients, and the authors believe that each of the various team members should be involved to provide the best possible care for patients. All of the health care professionals that are involved in the care of



a person with RA, have different competencies that in different ways can improve sexual health for persons with RA, depending on the type of sexual health problem that the individual has. The treatment models that will be brought up in this chapter are the role of physiotherapy to improve sexual health and increased communication and information about sexual health issues.

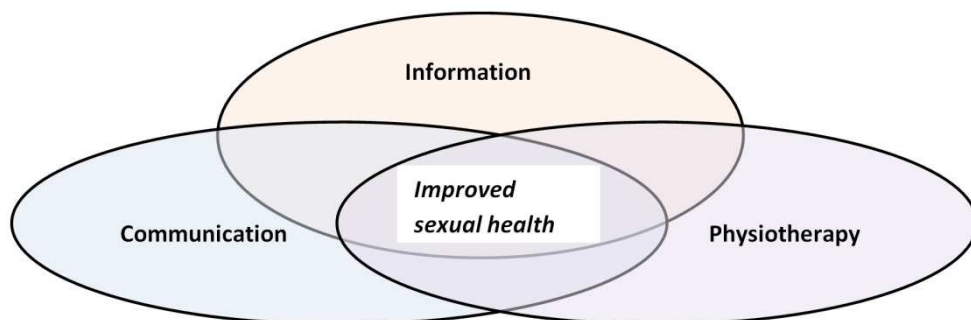


Fig. 1. Improvement of sexual health

### 5.1.1 The role of physiotherapy

In order to improve sexual health via physiotherapy the interventions must be individually assessed and the needs of the interventions can change during the disease. A person that has had RA for several years might have more joint difficulties and functional limitations, than a person with 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 (Hewlett et al. 2005). Physiotherapy for persons with RA often consist of mobility exercises, pain reductive treatment and physical activities. Those interventions are often combined and changed over time in order to have optimal effect. Included in physiotherapy interventions is information about joint protection and how to achieve a healthy life style. Due to lack of research there is limited evidence as to whether many physiotherapy interventions have a beneficial effect (Vliet Vlieland 2007). However, regular physical exercise and encouragement to increase physical activity have been proven to be effective in decreasing symptoms in persons with RA (Brodin et al. 2008). 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 (Cairns and McVeigh 2009; Cooney et al. 2011). For example, RA patients who exercise on a regular basis have less fatigue and disabilities compared to non-exercisers (Lee et al. 2006). Those positive effects of physical activities and regular exercise can enhance sexual health since the mentioned outcomes are affecting sexual health (Hill, Bird, and Thorpe 2003; Josefsson and Gard 2010). Physical activities can be coached directly by the physiotherapist in 2-3 sessions/week or by homebased programs where coaching is done by phone or by follow-up visits at the physiotherapy clinic (Brodin et al. 2008). Pain is a prioritized outcome for persons with RA and pain often affects sexual health negatively. Physiotherapy interventions aimed at pain reduction are common. The evidence of interventions such as TENS, acupuncture and massage is scarce due to few studies and

their poor methodological quality (Casimiro et al. 2002; Ying and While 2007; Cameron 2002). Despite the lack of evidence these interventions might be used and evaluated on the individual level with the aim to reduce pain. The interventions can also be aimed at improving sexual health; TENS could for example be used during sexual activities to reduce pain, but this also needs further research.

The level of physical activity can affect sexual health, since increased physical activity can improve the amount of sexual intimacy (Bortz and Wallace 1999; Post et al. 2008). Introduction of physical activities as well as coaching towards increased physical activity is a basic, but important part, of physiotherapy. Physiotherapy for persons with RA has been shown to improve self-confidence, the amount of daily activities and reduce and depression (Kavuncu and Evcik 2004; Areskoug-Josefsson 2006; Neuberger et al. 2007). 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 (Josefsson and Gard 2010). All of which can affect sexual health in a positive way.

A higher amount of active leisure time activities decreases feelings of pain and fatigue, which can indirectly improve a person's sexual health (Reinseth et al. 2010). And, not surprisingly, a person's level of daily activities are positively correlated with sexual functioning (Monga et al. 1998), which implies the importance of encouraging persons with RA to adopt an active life in order to improve their sexual health. The level of physical fitness is also related to the level of sexual activities (Bortz and Wallace 1999), which is another indicator that it is important to involve physiotherapists and their expertise of coaching towards physical activity in rehabilitation for persons with RA. Physiotherapists regularly coach persons with RA towards being more physically active and to continue with physical activity after onset of the disease (Brodin et al. 2008), but the relation between sexual activity levels and physical activity levels shows that physical activity coaching should be done not only to improve physical fitness but also to improve sexual health.

Physiotherapy can also increase the choice of possible sexual intercourse positions by increasing joint mobility and muscle strength, and the patient's knowledge of their physical abilities. Different exercise positions that are involved in physiotherapy programs can inspire persons with RA to try new positions during sexual activities and encourage new sexual fantasies (Josefsson and Gard 2010). Examples of this could be exercises performed on all fours or exercises involving stabilization of pelvic region. Different coital positions put different levels of strain on joints and muscles. It is of value for physiotherapist to have a basic knowledge about this and to be able to answer questions of how joints and muscles are affected during sexual activities. Another key time for physiotherapists to work on and communicate about issues concerning sexual health is when patients have had joint surgery. Hip replacement surgery can of course affect positions during sexual activity. Similarly, shoulder surgery can affect hugging and caressing, as well as coital positions. Depending on the patient's preferences in their sexual life, their need for advice and their wish to communicate about sexual health differs, but the physiotherapist needs to be able to use their professional expertise concerning musculoskeletal issues, pain reduction and exercise interventions in order to provide the best care and information on sexual health matters.

## **6. Communication about sexual health**

Knowledge and openness about sexual health issues are important for rheumatology health professionals (Helland et al. 2011) and must be attained if good communication about sexual

health is to be established with RA patients. In order to do so the experiences and views of the persons with RA on how health professionals should communicate about sexual health need to be brought forward. When communicating about sexual issues the views of the persons with RA on possible ways to improve sexual health are important, since sexual health is a sensitive subject on which to communicate. The health professionals must be sensitive to how and if the person with RA wishes to discuss sexual health during clinical encounters. If knowledge and competence in communication about sexual health is lacking for health professionals, it is likely that sexual health will not be brought up, even if the person with RA wants to discuss it. The communication problems between health professionals and persons with chronic illness concerning sexual health have been brought forward in earlier research (McInnes 2003; Haboubi and Lincoln 2003). Health professionals within the field of rheumatology rarely have expertise in the field of sexual health, which can make them unsure of how it should be included in their professional role and if/how they should communicate about sexual health. However, it is important to find ways to communicate about sexual health, since ignoring these concerns may damage sexual health for persons with RA.

There are several possible reasons for the lack of discussion of sexual health by health professionals, such as: the sensitivity of the subject; the health professionals can be unsure on how to bring up the subject; being unsure of how they can support persons with RA having sexual health problems; and believing that somebody else in the health care team is responsible for discussing sexual health with patients (Couldrick, Gaynor, and Cross 2010; Stausmire 2004; Ryan and Wylie 2005; Bitzer et al. 2007). There can also be more practical reasons like lack of time or lack of privacy during the meeting between the patient and the health professional (Britto et al. 2000). One study (Haboubi and Lincoln 2003) examined the possible differences between different health care professionals concerning their ability to address sexual health with their patients. This study showed that all of the health professionals had similar reluctance in addressing the subject, but that physiotherapists and occupational therapists were the least likely to discuss sexual health with their patients (Haboubi and Lincoln 2003). The patients themselves might be unwilling to discuss sexual health, especially if they do not think that the health care professionals can offer any support (McInnes 2003; Bitzer et al. 2007). Additionally, they might believe that the onus is on the health professional to bring up the subject (Post et al. 2008). A way to show that sexual health is an accepted subject to discuss in clinical encounters is to have information leaflets about the subject in the waiting room.

Patient preferences regarding whom they wish to communicate with about sexual health differ. A common choice is the nurse or the rheumatologist, but the personality of the health professional, and the feeling as to whether the subject is "allowed" is more important than the profession (Areskoug & Gard, unpublished). Earlier research (Taylor and Davis 2006) shows that patients prefer the health professionals to bring up the subject of sexual health first. Health professionals might also have pre-conceived opinions that can make communication about sexual health more difficult. For example, health professionals are more reluctant to discuss sexual health with patients from ethnic minority groups, non-heterosexual patients and older age patients (Couldrick, Gaynor, and Cross 2010; Gott et al. 2004). Most RA patients are initially diagnosed with RA in later life, which might be a reason why sexual health is not generally discussed with this group of patients. Research into health professional students has shown that they have a high level of discomfort

concerning communication about sexual issues, which shows that it is not easier for younger or more recently educated health professionals to deal with this than it is for older, more established health professionals (Weerakoon et al. 2004).

There are gender differences showing that men have higher levels of sexual activity, interest in sex and better quality sex lives, and that those gender gaps increase with age (Lindau and Gavrilova 2010). However a recent study of patients with RA showed that male gender was associated with a larger negative impact on sexual activity (Helland, Dagfinrud, and Kvien 2008), which indicates that this field needs further exploration. There are of course several other factors influencing sexual health and the perspective of gender on sexual health is complex (Vanwesenbeeck 2009), but most individuals with RA are women and the subject of sexual health needs to be discussed with a gender perspective since there are differences concerning how RA affects the sexual health of women and men. As examples, women often experience that feelings of intimacy are more important than sexual arousal (Basson and Schultz 2007), and women often have more joint pain during sexual activities (van Berlo et al. 2007). One possible reason for the increased pain for women during sexual activities could be differences in strain on joints in intercourse positions, but the reasons for this need further investigation. There are also gender differences concerning sexual satisfaction, with females with RA having lower sexual satisfaction than men with RA (Majerovitz and Revenson 1994). For younger women with RA, pregnancy can be an issue that needs to be discussed, since pregnancy can cause a remission of symptoms but this positive effect relapses in 90% cases within 6 months post-partum (Gerosa et al. 2008; Ostensen 1999). It is necessary to have strategies of how to deal with both men's and women's sexual health within the rheumatological team and to acknowledge the gender differences. There are also differences in the use of coping strategies between men and women with chronic pain. Women are more prone to use coping strategies such as ignoring and self talk and traditional coping strategies does not seem to be relevant for men concerning chronic pain and sexual functioning (Ruehlman, Karoly, and Taylor 2008). Those gender differences should be taken into consideration when communicating about sexual health with persons with RA.

There might be sexual health problems that are more difficult to discuss than others, for example fear of being left by the partner or feeling forced to have sexual activities. Therefore it is important to have knowledge of one's limitations as a professional and to acknowledge when further expertise is needed in order to aid the person with RA.

### 6.1 Information

Information on the internet as well as patient-online-helplines can be of use. Several national organizations for persons with arthritis offer information about how intimate relationships and sexual life can be affected by RA. A recent investigation into a patient online helpline showed that 10% of the questions concerned sexual and reproductive issues (Richter et al. 2011). And for most RA patients a wide concept of sexual health, including social functioning and an emotional perspective, is more important than a more mechanical description of disease consequences on sexual health (Couldrick, Gaynor, and Cross 2010).

The following websites contains useful information about sexual health, intercourse positions and intimate relationships for persons living with RA. They are written in an informative and open manner and are a useful resource for RA patients and their partners.

<http://www.arthritiscare.org.uk/PublicationsandResources/Relationshipsemotions>

[http://www.cks.nhs.uk/patient\\_information\\_leaflet/arthritis\\_sexuality\\_arc](http://www.cks.nhs.uk/patient_information_leaflet/arthritis_sexuality_arc)

The website below contains information for persons who have had hip replacement surgery and gives information about recommended intercourse positions after hip replacement, as well as information about which positions should be avoided.

<http://www.ranawatorthopaedics.com/faq-hip.html>

## 6.2 Communication models

Studies of health professional's attitudes towards discussing sexual health with their patients often show that they feel uneasy and that they lack training in how to bring up sexual health issues with their patients (Couldrick, Gaynor, and Cross 2010). To be able to communicate about sexual health in a respectful and open way it is fundamental to have established a trusting relationship with the patient and to know one's own ability and limitations concerning issues of sexual health and intimate relationships. In order to ease and improve communication about sexual health, a communication model can be useful. In this section two different models will be introduced, the PLISSIT and the Recognition Model. Both models can be useful for health professionals working with persons with RA.

The **PLISSIT model** has been used when discussing sexual health with patients with various physical and mental diseases. The PLISSIT model provides a graded counseling approach that allows health professionals to deal with sexual issues at their own level of comfort and competence (Annon 1974). The model includes four steps:

**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 how RA affects sexual health and intimate relationships in the waiting room. A permission giving attitude can also be shown by using the following question: "It is common that persons with RA experience difficulties with their sexual health. Would you like some information about this?" or "Many persons with RA experience concerns on how RA affects their sexual life. Do you have any questions or concerns about this?" By asking if the person with RA wants information or has questions about sexual health issues, it gives the person with RA the possibility to decline to discuss the subject if they wish to do so. Therefore this might be a more relaxed way to start the conversation, than with direct questions, such as: "Has your disease affected your sexual life? In what way?"

**LI- Limited Information:** Information can be given about how the RA affects sexual health and about treatments that can increase sexual health. This could be done by handing out information leaflets or by providing information verbally about how your specific professional expertise can be of assistance. 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 think is relevant.

**SS - Specific Suggestions:** This is a step with a problem solving approach. Suggestions might include: reading written material about sexuality and how it is affected by RA; taking pain medication before sexual activities; or advice on coital positions. 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.

This model also shows when the health professional needs to refer the patients to colleagues with more experience concerning sexual health, since the different steps clearly shows how far the discussion has reached. 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 is sufficient to improve their sexual health (McInnes 2003). There is an extension of the PLISSIT-model, the EX-PLISSIT which includes reflection to raise self-awareness to challenge assumptions and requires review of all interactions with patients (Taylor and Davis 2006).

The core of the **Recognition Model** is the recognition that disabled persons have sexual needs and desires (Couldrick, Gaynor, and Cross 2010). The Recognition Model identifies the existing skills among health professionals that can be used to promote and protect sexual health for persons with disabilities and is intended to be used by multi-professional teams. The step of recognition is important, especially if the health professionals' expertise is within disability, rather than sexual health. The Recognition model also aids in what is included in each professional role when it comes to addressing sexual health issues.

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. Sexual health issues should be employed with persons that express their sexuality in a different ways, not only with those persons that seem to be relevant, such as younger persons living in relationship with a partner of the opposite sex. Examples of persons expressing their sexuality in other ways can be persons who have chosen not to be sexually active or persons, persons having several partners or persons attracted to the same sex.

The following steps are described in the Recognition Model (Couldrick, Gaynor, and Cross 2010):

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 could be done for example 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.

1. 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.

2. Referral on, when necessary. This step demands that the team members have knowledge of wider resources that might be of use to the patient.

Psychosexual counseling by a sexologist can be an option when expert advice or intensive therapy is needed. Research concerning psychosexual counseling for persons with chronic physical illness is scarce, but the results of the available studies are promising (Kedde et al. 2010).

## 7. New research

The field of sexual health and intimate relationships is moving forward within rheumatology. Advances include self-strategies and cognitive behavioural therapy within physiotherapy as ways to improve sexual health (Helland et al. 2011; Breton, Miller, and Fisher 2008). The self-strategies showed great variety including postponing sexual activities during flares, ignoring restrictions, adapting positions, using alternative locations, using painkillers, initiating less strenuous sexual activities, engaging in sexual activities despite lack of desire and being creative during the sexual act. The efficacy of the strategies is not researched and further knowledge is needed in this field. The initial results from cognitive behavioural therapy to improve sexual health are promising (Breton, Miller, and Fisher 2008), but needs further investigation. Research on ways of coping with RA are also of interest in relation to sexual health, since the decrease in sexual health seems to be persistent during the disease.

## 8. Future research

Areas that need to be further researched within the field of sexual health and RA include:

- gender specific research; what are the differences between men and women in how RA affects sexual health? Which methods are most appropriate for improving sexual health in men with RA and in women with RA?
- the effects of disease modifying medication on sexual health
- the effects of physical activity and improved fitness on the sexual health of RA patients
- how to improve communication concerning sexual health between patients and health professionals
- which physiotherapy interventions are most effective for improving sexual health.

## 9. Conclusion

Sexual health and intimate relationships need further attention among health professionals, since many individuals with RA have decreased sexual health which can affect their intimate relationships negatively, and thereby decrease their general wellbeing and overall happiness. Each profession has a professional expertise that can assist RA patients in this field. Optimal treatment of RA can decrease sexual health problems for persons with RA,

since the difficulties are often connected with clinical disease activity. In order to give holistic care to persons with RA it is important to have a strategy within the rheumatological team on how to communicate and address problems concerning sexual health, and to acknowledge the need to protect, support and restore the sexual health of RA patients. To enhance the communication of sexual health there are useful communication models that are appropriate to rheumatological care.

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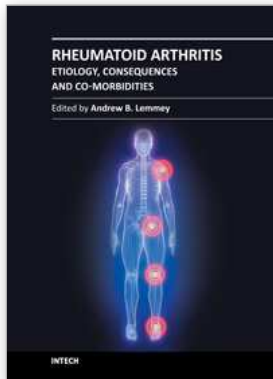


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## **Rheumatoid Arthritis - Etiology, Consequences and Co-Morbidities**

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The purpose of this book is to provide up-to-date, interesting, and thought-provoking perspectives on various aspects of research into current and potential treatments for rheumatoid arthritis (RA). This book features 16 chapters, with contributions from numerous countries (e.g. UK, USA, Japan, Sweden, Spain, Ireland, Poland, Norway), including chapters from internationally recognized leaders in rheumatology research. It is anticipated that Rheumatoid Arthritis - Etiology, Consequences and Co-Morbidities will provide both a useful reference and source of potential areas of investigation for research scientists working in the field of RA and other inflammatory arthropathies.

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