

QUALITY OF LIFE

Let's talk about sex, rheumatology!

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Standfirst

New research reports that men with inflammatory arthritis experience effects on sexual health beyond erectile dysfunction, affecting their emotional, mental, and social health. Training to empower health professionals to have conversations about sex could improve support for people with rheumatic diseases.

Refers to Fernando Perez-Garcia, L. et al. It is not just about sex: viewpoints of men with inflammatory arthritis on the overall impact of the disease on their sexual health. RMD Open 7, e001821 (2021).

Main text

The World Health Organisation states that sexuality is “*a central aspect of being human throughout life, which encompasses sex, gender identities and role, sexual orientation, eroticism, pleasure, intimacy and reproduction*”¹ However, the focus on sexual health in the rheumatology literature has largely been limited to function, specifically fertility issues in women, and erectile dysfunction in men. Perez-Garcia and colleagues² have used Q-methodology to explore the impact of inflammatory arthritis on sexual health in 30 men with rheumatoid arthritis or polyarticular juvenile idiopathic arthritis. The results provide important insights into their experiences.

Q-methodology combines qualitative and quantitative techniques to identify groups of people with similar opinions. Participants sort statements of opinion according to how much they agree with each statement across a grid representing a normal distribution. The participants are then grouped according to their views. In the study conducted by Perez-Garcia et al.², three viewpoints were identified: “Arthritis negatively affects my sexual health”, “I am keeping up appearances” and “I am satisfied with my sexual health”. Consistent with reported prevalence of sexual problems in inflammatory arthritis, 43% of the participants populated the “I am satisfied with my sexual health” viewpoint, reporting limited impact on sexual health. Q-methodology aims to gather opinions, and is not powered for epidemiological claims; nevertheless, it is notable that those satisfied with their sexual health reported lower disease activity than those in the other two groups.

In the new study, participants forming the first two viewpoints all reported experiencing an impact on their sex lives due to inflammatory arthritis, but they differed in their specific experiences². Men in both groups reported physical symptoms (such as pain) having a negative impact, causing sex to become less spontaneous or less frequent. However, those who formed the “Arthritis negatively affects my sexual health” viewpoint experienced a broader impact on their sexual health, including erectile dysfunction and relationship issues such as feeling guilty towards their partners, and not feeling fully understood. Men who formed the “I am keeping up appearances” viewpoint, described a negative impact on self-esteem due to inflammatory arthritis, with physical differences (such as swollen joints) and inability to demonstrate physical prowess (both in general and during sex) affecting their feelings of attractiveness.

In a systematic review (published in 2020) of the impact of inflammatory arthritis on intimate relationships and sexual function³, among 55 eligible studies, only five were qualitative, and of these only one focused solely on men. This found men with systemic lupus erythematosus reported struggling to fulfil expected obligations as sexual partners, leading to feelings of guilt and emasculation. These findings are consistent with those reported by Perez-Garcia et al.² Similarly, my own qualitative findings in men with systemic sclerosis⁴ indicate they worry about the impact of systemic sclerosis on intimacy and on their sexual partner’s satisfaction. Women with inflammatory arthritis describe feeling pressure to maintain a normal sex life, to protect their relationships³. These findings suggest either a real or perceived pressure on both men and women to subscribe to traditional gender roles in relation to sex, with the potential for psychological impact if inflammatory arthritis prevents these roles being fulfilled.

Perez-Garcia et al. found that men in their study indicated they experience an impact of inflammatory arthritis on masculinity, translating to lack of confidence with sex². Some men reported hiding symptoms from their partners and trying to keep up appearances, which is consistent with the idea that men try to behave according to traditional masculine ideals and can subscribe to a learnt ‘boy code’ of hiding feelings of vulnerability⁵. Research in patients with rheumatoid arthritis has identified the need for clinicians to explicitly ask men about psychosocial and emotional issues⁶, which should be extended to include asking about issues related to sex. An indirect approach can often be effective, such as asking about how partners are coping, as opposed to direct questioning about feelings of masculinity.

Evidence suggests that providing information to men with long term conditions offers reassurance and increases feelings of control⁷. However, Perez-Garcia et al. found that men reported difficulties accessing information related to sex, finding online information inadequate and healthcare professionals too busy to address this issue. A study conducted

in Denmark found 93.5% of women and 85.5% of men with rheumatoid arthritis had not discussed sexual issues with health professionals in the preceding 5 years⁸. This may be a result of social taboos relating to sex causing health professionals to feel uncomfortable raising the topic. Multidisciplinary health professionals in rheumatic diseases report that they seldom discuss sexual health with patients, despite considering it important⁹. However, those professionals who had received relevant training in sexual health reported feeling more comfortable and raising it as an issue more frequently than staff without such training⁹. Providing training to empower health professionals to discuss sexual-health issues with patients should therefore be a key consideration.

Until recently, the majority of research on the psychosocial impact of inflammatory arthritis has either addressed differences between the sexes or focused solely on women⁶. Perez-Garcia et al. therefore make an important contribution to understanding an overlooked aspect of men's experiences of such conditions. However, it is worth noting that experiences of sex and intimacy also remain under-researched in women with inflammatory arthritis³. Further research is needed to understand the support needs and preferences for sexual-health, and how these differ between men and women.

For sexuality in general, it is worth noting that the majority of rheumatology research is conducted through a broadly heterosexual lens. In this context it is important to highlight that patients from LGBTQ+ communities experience considerable health inequalities due to individual or institutional heteronormativity, as well as discrimination or victimization¹⁰. Future research in rheumatology should address whether the support needs of people from LGBTQ+ communities are appropriately served, not only in relation to sexual health, but also more broadly.

Sex is an important aspect of quality of life, but it is still widely considered a taboo topic. Although discussing sex in relation to reproduction is generally considered appropriate, social barriers remain in discussing sex in relation to eroticism, pleasure, and intimacy. However, appetite seems to be growing for more open discussion of sex and intimacy among healthcare professionals, as illustrated by the inclusion of a session entitled "Myths and taboos around relationships: strategies for a sexy life" at the 2021 EULAR European Congress of Rheumatology. Further research is needed to explore how healthcare professionals can support people with rheumatic diseases to have healthy sex lives.

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