Sexual health in rheumatic diseases: an unmet need in patient-centered care

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Patient-centered care has become a central pillar in modern rheumatology. Beyond controlling inflammation and preventing organ damage, clinicians are increasingly encouraged to address the outcomes that matter most to patients, including physical function, emotional well-being, social participation, happiness and quality of life[1-3]. Sexual health is an integral component of this holistic approach. The World Health Organization defines sexual health as a state of physical, emotional, mental, and social well-being in relation to sexuality, rather than merely the absence of disease or dysfunction. Sexuality is therefore much more than sexual activity or physiological function, encompassing intimacy, relationships, body image, self-esteem, identity, and overall well-being[4]. Nevertheless, discussions surrounding sexual health remain uncommon in routine rheumatology practice, and this domain continues to be underrepresented in both clinical care and research[5, 6].

This neglect is particularly concerning given the substantial burden that rheumatic diseases can impose on sexual health. Chronic pain, fatigue, stiffness, reduced mobility, and physical disability may directly interfere with sexual activity. In addition, visible manifestations of disease, such as skin involvement, joint deformities, weight changes, or physical limitations, impact body image and self-confidence. Psychological factors, including anxiety, depression, fear of pain, fear of failure, concerns about satisfying one's partner, feelings of guilt, frustration, and concerns about attractiveness, may further contribute to difficulties in intimacy and sexual relationships. The specific challenges may vary across diseases, ranging from pain and restricted axial mobility in spondyloarthritis, to vaginal dryness in Sjögren's disease, body image concerns in systemic sclerosis, or joint damage in rheumatoid arthritis. Together, these factors illustrate how rheumatic diseases may affect multiple dimensions of sexual health[5, 7].

Several barriers contribute to the limited discussion of sexual health in routine clinical practice. Healthcare professionals often report lack of time, insufficient training, uncertainty regarding how to address sexual concerns, or fear of causing discomfort. Patients, in turn, may hesitate to raise the subject due to embarrassment, cultural factors, or the belief that sexuality is not an appropriate topic to discuss during a medical consultation. As a result, both parties may assume that the other is unwilling to engage in the conversation, creating a cycle of mutual silence[8, 9].

Beyond the barriers to discussing sexuality, challenges also arise in its assessment. Most instruments currently used today were originally developed to assess sexual dysfunction, focusing predominantly on physiological domains such as sexual interest, sexual arousal (that encompasses erectile dysfunction in men and lubrication in women), orgasm dysfunction and sexual pain (such as vaginism and dyspareunia)[10, 11]. While these aspects are important, they

may not fully reflect the broader concept of sexual health. Sexual dysfunction and sexual health are related but distinct concepts. Focusing exclusively on physiological function risks overlooking important relational, emotional, identity-related, and adaptive dimensions of sexual well-being. This distinction is more than a semantic exercise. What clinicians and researchers choose to measure ultimately shapes what they recognize as important. If assessment is limited to physiological function, substantial aspects of the patient experience may remain invisible. A patient may report preserved sexual function while experiencing significant difficulties related to intimacy, body image, or emotional connection. Conversely, impaired sexual function does not necessarily equate to poor sexual well-being if individuals and couples have successfully adapted to the challenges imposed by the disease.

A further conceptual challenge concerns the historical predominance of male-centered perspectives in sexual health research, particularly erectile function, resulting in a landscape of instruments that often reflects a male-centered and physiologically oriented view of sexuality[12]. Female sexual health, despite being profoundly affected in conditions such as Sjögren's disease and systemic sclerosis, remains comparatively underexplored[12, 13]. This imbalance may have influenced not only the topics investigated but also the priorities embedded in existing instruments, potentially limiting their relevance across different patient populations.

Future research should therefore move beyond the simple question of whether sexual dysfunction is present. Instead, it should seek to determine what aspects of sexuality are most relevant to patients and whether these are adequately represented in existing assessment tools. Figure 1 illustrates this conceptual shift from the assessment of sexual dysfunction towards a broader and more patient-centered understanding of sexual health. This discussion also raises a fundamental question for future instrument development: should sexual health in rheumatic diseases be assessed through a single framework applicable to all individuals, or should assessment strategies be adapted to better capture the diverse biological, psychological, relational, and sociocultural experiences that shape sexuality across different patient populations? Addressing these questions will require not only methodological rigor but also meaningful patient involvement to ensure that future instruments reflect lived experience rather than solely clinical assumptions.

Recognition of these challenges has already prompted researchers to develop more specific instruments. Examples include QUALISEX, originally developed for rheumatoid arthritis, and QUALIPSOSEX, designed for patients with psoriatic arthritis[14, 15]. These initiatives represent important steps towards incorporating the specific ways in which rheumatic diseases may affect sexuality. However, their use remains limited, and important questions remain regarding their applicability across different rheumatic conditions and their ability to fully capture the

multidimensional nature of sexual health. Future instruments may need to combine broadly relevant aspects with sufficient flexibility to address disease-specific and individual patient experiences.

As rheumatology continues to embrace patient-centered care, sexual health can no longer remain a neglected domain. Integrating this dimension into routine practice does not necessarily require lengthy consultations or specialized expertise. Often, the first step is simply to normalize the topic and create a safe environment in which patients feel comfortable discussing concerns and fears related to intimacy, body image, desire, pain, relationships, or sexual well-being. In many cases, a simple invitation to discuss whether the disease has affected these aspects of life may be sufficient to open the conversation. When more complex needs arise, access to multidisciplinary support may be beneficial. Ultimately, sexual health is not merely about sexual function; it is about intimacy, identity, self-perception, relationships, and quality of life. The next step is therefore not only to recognize its importance, but to incorporate it systematically into clinical conversations, patient-reported outcome measures, professional training, and rheumatology research agendas.

Tables and Figures

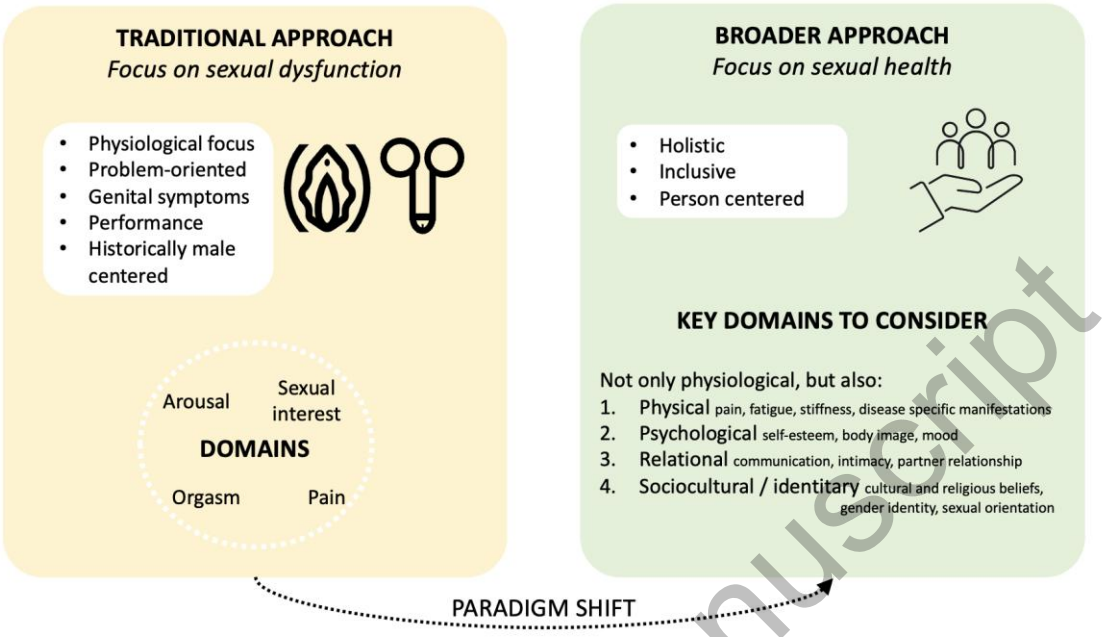

Figure 1. From sexual dysfunction to sexual health: a conceptual framework for assessment in rheumatic diseases. The figure illustrates the shift from a traditional approach focused primarily on sexual dysfunction and physiological domains towards a broader conceptualization of sexual health. This broader perspective incorporates physical, psychological, relational, sociocultural and identity-related dimensions that may influence sexual well-being in people with rheumatic diseases. The framework highlights the need for patient-centered assessment strategies and patient-reported outcome measures that capture aspects of sexuality that matter most to patients.

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