

SEXUAL HEALTH IN RHEUMATIC AND MUSCULOSKELETAL DISEASES: A CRITICAL NARRATIVE REVIEW FROM MEASUREMENT TO CARE

**SAÚDE SEXUAL NAS DOENÇAS REUMÁTICAS E MUSCULOESQUELÉTICAS:
UMA REVISÃO NARRATIVA CRÍTICA DA MENSURAÇÃO AO CUIDADO**

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ABSTRACT

This review critically examines how sexual health and its psychosocial impact have been conceptualized, measured, and incorporated into care for people with rheumatic and musculoskeletal diseases. It adopts a critical narrative approach across rheumatic conditions, guided by a structured search for relevant guidelines, consensus statements, systematic reviews, meta-analyses, and qualitative studies. The literature consistently identifies a high frequency of sexual difficulties associated with pain, fatigue, stiffness, functional limitations, genital dryness, vasculopathy, altered body image, psychological distress, medication effects, and relationship strain. However, pooled prevalence estimates are heterogeneous, and the evidence is characterized by predominantly cross-sectional designs, limited assessment of clinically relevant distress, and instruments focused on genital performance, binary gender categories, and recent sexual activity. Contemporary rheumatology guidelines address contraception, fertility, pregnancy, lactation, and medication safety in detail, but do not constitute comprehensive sexual health guidelines. Pleasure, autonomy, identity, communication, violence, discrimination, and sexual justice remain peripheral. The review identifies sexuality as a legitimate health and social participation outcome, rather than merely an adjunct to reproduction or a marker of erectile or vaginal function. Further research should prioritize co-developed multidimensional measures, longitudinal cohorts, pragmatic trials, implementation research, and samples that capture intersecting social identities and inequalities.

Keywords: Rheumatology; Sexuality; Psychosocial impact; Quality of life; Sexual justice.

RESUMO

Este trabalho visa analisar criticamente como a saúde sexual e seu impacto psicossocial têm sido conceituados, mensurados e incorporados ao cuidado de pessoas com doenças reumáticas e musculoesqueléticas. Para isso, foi conduzida uma revisão crítica de escopo pan-reumático, orientada por uma busca estruturada por diretrizes, consensos, revisões sistemáticas, metanálises e estudos qualitativos relevantes. A literatura converge quanto à elevada frequência de dificuldades sexuais, associadas à dor, fadiga, rigidez, limitação funcional, secura genital, vasculopatia, alterações da imagem corporal, sofrimento psíquico, efeitos farmacológicos e tensões relacionais. Entretanto, as prevalências agregadas apresentam heterogeneidade, predomínio de estudos transversais, baixa avaliação do sofrimento clinicamente relevante e instrumentos centrados no desempenho genital, no binarismo de gênero e na atividade sexual recente. Diretrizes reumatológicas contemporâneas tratam em detalhes de contracepção, fertilidade, gestação, lactação e segurança medicamentosa, mas não equivalem a diretrizes de saúde sexual integral. Prazer, autonomia, identidade, comunicação, violência, discriminação e justiça sexual permanecem periféricos. De modo geral, constatou-se que a sexualidade é um desfecho legítimo de saúde e de participação social, não um apêndice reprodutivo nem um simples marcador de função erétil ou vaginal. Nesse aspecto, estudos voltados à medidas multidimensionais cocriadas, coortes longitudinais, ensaios pragmáticos, pesquisa de implementação e amostras interseccionais são necessários.

Palavras-chave: Reumatologia; Sexualidade; Impacto psicossocial; Qualidade de vida; Justiça sexual.

1. INTRODUCTION

Advances in treating inflammatory rheumatic diseases have expanded opportunities to control disease activity, preserve function, and prevent structural damage, particularly through early treatment strategies and treat-to-target follow-up (Grigor *et al.*, 2004; Schneider; Burmester, 2019). Despite this progress, limitations and care needs persist that are not fully captured by indicators of inflammatory activity. Pain, fatigue, stiffness, changes in body image, and emotional and relational effects can compromise important aspects of life even when treatment response is satisfactory (Scott *et al.*, 2018). In this context, sexuality is an important dimension of well-being and social participation. Understanding it requires consideration of both clinical manifestations and the experiences, relationships, and priorities of people with rheumatic and musculoskeletal diseases.

Existing evidence syntheses have shown that sexual difficulties are common in these populations and are associated with physical, psychological, and interpersonal factors. Restoux *et al.* (2020) identified effects of inflammatory arthritis on sexual function and intimate relationships, including experiences related to pain, fatigue, reduced desire, and fluctuations in disease activity. In women with systemic autoimmune rheumatic diseases, Minopoulou *et al.* (2023) synthesized 68 studies involving 5,457 participants and estimated a pooled sexual dysfunction prevalence of 63%, with substantial between-study heterogeneity ($I^2 = 94\%$). These findings establish the clinical relevance of the problem while also showing the limits of interpreting a pooled estimate as a uniform representation of experiences that vary by disease, population, context, and measurement criteria.

The field has also broadened its conceptual frameworks. Mitchell *et al.* (2021) proposed an interconnected framework comprising sexual health, pleasure, well-being, and justice as four pillars for public health research and practice. Giardulli *et al.* (2025) incorporated this framework into a scoping review protocol focused on rheumatic and musculoskeletal diseases. Preliminary findings presented by the group at the 2026 EULAR Congress also indicated imbalances across the domains studied and limitations in measuring and representing diversity, although their publication as a conference abstract warrants cautious interpretation (Giardulli *et al.*, 2026). These contributions provide a basis for examining sexuality beyond indicators of functional performance and inform this review's conceptual framing.

An interpretive and translational challenge nevertheless remains: how can instrument scores be related to people's perceived needs and to decisions about care? A low sexual function score alone does not establish the importance attributed to a difficulty, the associated distress, the desire for change, or the circumstances in which sexual activity occurs. Likewise, an association between symptoms and sexual function neither establishes its causal direction nor demonstrates which intervention would produce meaningful benefits. Interpretation requires distinguishing related but noninterchangeable concepts, including sexual function, satisfaction, distress, and well-being, and examining how measurement choices influence problem identification, outcome selection, and the evaluation of care.

This challenge also concerns the relationship between evidence and care organization. Recommendations addressing reproductive issues must be examined in light of their scope and their capacity to

meet different sexuality-related needs. This analysis explores how knowledge of clinical manifestations, subjective experiences, and assessment instruments can inform an approach that encompasses comfort, intimacy, autonomy, communication, and access to care. Differences in gender, sexual orientation, age, functional status, and sociocultural context are therefore relevant to both interpreting findings and defining the populations to which conclusions can be applied.

Accordingly, this critical narrative review analyzes concepts, evidence, instruments, and guidelines related to sexual health in rheumatic and musculoskeletal diseases, connecting frameworks developed in the general population with the specific features of these conditions. Its scope includes rheumatoid arthritis, systemic lupus erythematosus, systemic sclerosis, Sjögren disease, spondyloarthritis, fibromyalgia, and osteoarthritis, while recognizing distinctions among inflammatory, systemic autoimmune, degenerative, and chronic pain conditions.

The proposed contribution integrates five dimensions that are often examined separately: clinical and psychosocial mechanisms, people's experiences, measurement constructs and instruments, implications for care, and evidence gaps. This integration clarifies how measurement limitations affect clinical interpretation, which needs remain poorly represented by available outcomes, and which research designs would be appropriate to investigate them. The review thus offers a critical analysis connecting knowledge of the frequency of sexual difficulties with the definition of meaningful outcomes, the development of interventions, and a research and implementation agenda oriented toward well-being and equity.

2. METHODS

A structured critical narrative review of sexual health in rheumatic and musculoskeletal diseases was conducted. This approach suits integrating clinical evidence, psychosocial experiences, measurement assumptions, and normative documents in a field characterized by heterogeneous concepts, designs, and outcomes. The review aims to examine how sexuality, sexual function, and sexual well-being have been conceptualized, measured, and incorporated into care, considering convergences and tensions between identifying dysfunction and adopting a multidimensional perspective on sexual health. The methodological approach comprised a targeted literature search, purposive selection of sources relevant to the review objective, and descriptive critical appraisal, supplemented by retrospective curation of bibliographic exports and verification of the references used in the manuscript.

We searched Scopus, PubMed, and SciELO without publication-year restrictions, updated through September 2026, and structured the search around three areas: rheumatic and musculoskeletal diseases; sexual health, function, and well-being; and psychosocial impact, using the following the search strings: (rheumat* OR "rheumatoid arthritis" OR "systemic lupus erythematosus" OR "systemic sclerosis" OR "systemic scleroderma" OR sjogren* OR sjögren* OR spondyloarthrit* OR spondyloarthropath* OR "ankylosing spondylitis" OR "psoriatic arthritis" OR fibromyalgia OR osteoarthritis* OR "doenças reumáticas" OR "artrite reumatoide" OR "lúpus eritematoso sistêmico" OR "esclerose sistêmica" OR espondiloartrite* OR "artrite psoriásica" OR fibromialgia OR osteoartrose) AND (sexuality OR "sexual health" OR "sexual function*" OR "sexual dysfunction*" OR "sexual well-being" OR "sexual wellbeing" OR

"sexual well-being" OR "sexual satisfaction" OR "sexual pleasure" OR "sexual distress" OR "sexual justice" OR "sexual rights" OR "sexual activit*" OR "sexual quality of life" OR intimacy OR "intimate relationship*" OR dyspareunia OR "erectile dysfunction" OR "vaginal dryness" OR libido OR orgasm* OR FSFI OR IIEF OR Qualisex OR sexualidade OR "saúde sexual" OR "função sexual" OR "disfunção sexual" OR "bem-estar sexual" OR "satisfação sexual" OR "prazer sexual" OR "sofrimento sexual" OR "justiça sexual" OR intimidade OR dispareunia). The thematic description included English and Portuguese terms covering both clinical conditions and the functional, subjective, and relational dimensions of sexuality. The conceptual organization of terms was not considered equivalent to the history of the search expressions actually executed.

We also included official documents from the World Health Organization (WHO), the European Alliance of Associations for Rheumatology (EULAR), and the American College of Rheumatology (ACR), along with guidelines, consensus statements, and publications purposively selected for their conceptual, clinical, or methodological relevance. This complementary selection covered definitions of sexual health, sexual rights, clinical communication, instrument measurement properties, and reproductive health recommendations. We also retained references relevant to the evolution of treatment and outcomes in rheumatic diseases. We determined relevance by each source's contribution to the review's argument, regardless of whether it appeared in the exports from the three databases.

We prioritized normative documents, international consensus statements, systematic reviews, and meta-analyses, alongside empirical studies relevant to the topics discussed. We considered

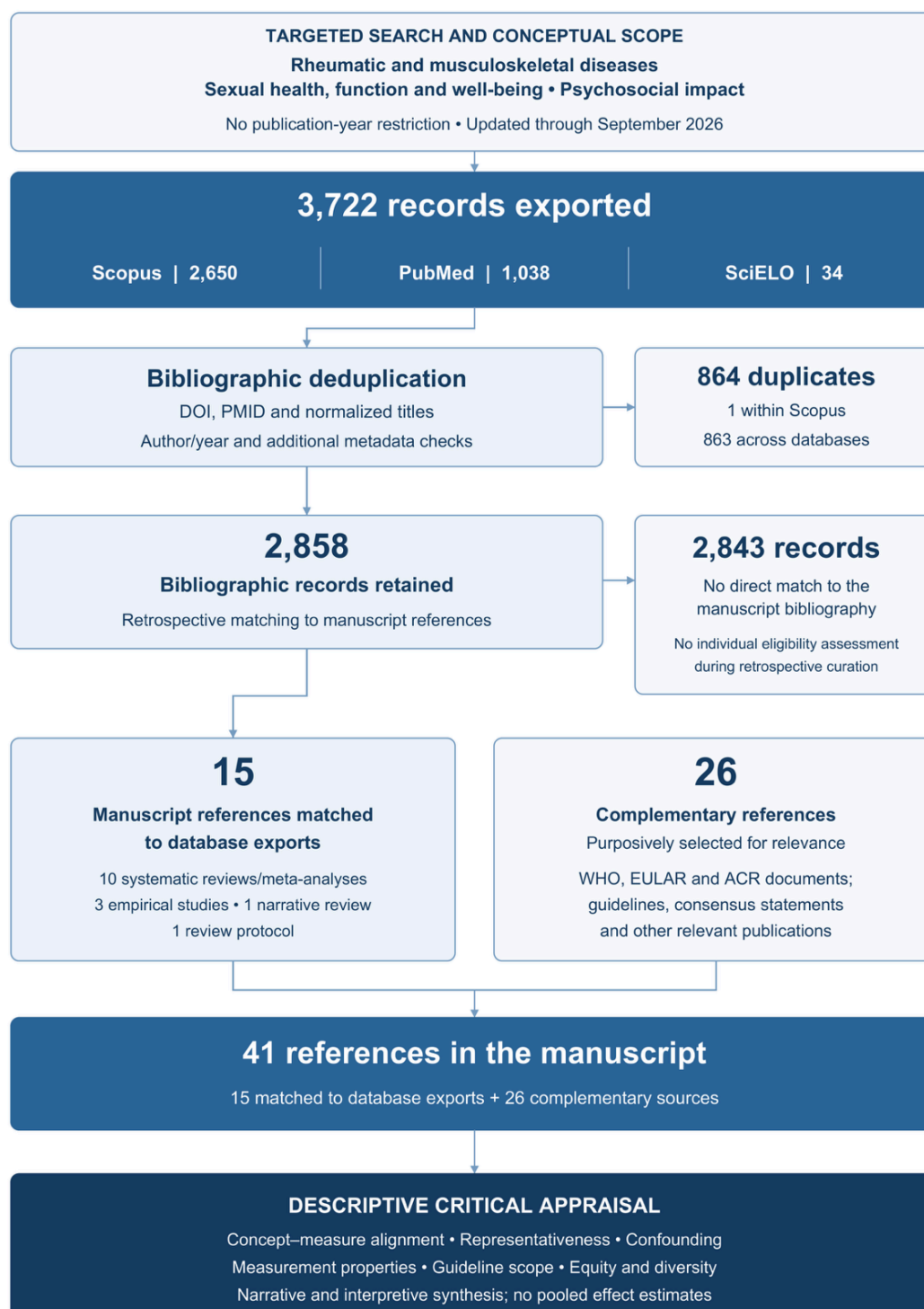
qualitative research for its contribution to understanding experiences of intimacy, adaptation, and care. Observational studies were used to discuss associations and the frequency of sexual difficulties, acknowledging their limitations for causal inference. Clinical syntheses prioritized publications from 2015 to 2026; foundational definitions and instrument development studies were retained regardless of publication date. The clinical scope included rheumatoid arthritis, systemic lupus erythematosus, systemic sclerosis, Sjögren disease, spondyloarthritis, fibromyalgia, and osteoarthritis, encompassing inflammatory, systemic autoimmune, degenerative, and chronic pain conditions.

Retrospective curation examined three CSV files containing 2,650 Scopus records, 1,038 PubMed records, and 34 SciELO records, for a total of 3,722 bibliographic occurrences. Each occurrence received a unique identifier that preserved its source database, file, and position within the export. We recorded file integrity identifiers and retained original metadata, enabling tracing of normalization and consolidation operations. Deduplication involved sequential comparison of DOIs, PMIDs, and normalized titles, including translated variants available in the records, together with publication year and first author. Normalization addressed differences in case, diacritics, punctuation, and character encoding. Matches with discordant identifiers underwent additional checks of authorship, journal, volume, issue, and pagination. We preserved the provenance of each occurrence, identified discrepancies, and decision rationales. Translations, editorial versions with distinct identifiers, preprints, and related publications were not automatically treated as duplicates; the remaining bibliographic units therefore do not necessarily represent independent studies. Figure 1 presents the retrospective curation pathway for the sources used in this critical narrative review.

We consolidated 864 duplicate occurrences: one within Scopus and 863 resulting from overlap across databases. This left 2,858 bibliographic units. We obtained abstracts from the database exports and linked them to corresponding occurrences in the other databases.

The manuscript bibliography examined during retrospective curation comprised 41 references. Cross-matching against the consolidated dataset identified 15 sources in the exports. The remaining 26 references represented complementary purposive selections of institutional documents, guidelines, and publications relevant to the topic's conceptual foundations, as reported by the authors. The review retained these sources in its documentary corpus and recorded their provenance separately.

Figure 1 — Retrospective curation of bibliographic records for the critical narrative review.



Retrospective bibliographic curation; not an exhaustive systematic study-selection process.

Source: Prepared by the authors (2026). Counts refer to the 41-reference bibliography examined during retrospective curation, before adding references during manuscript revision.

The 41 references examined during retrospective curation were organized in a traceability matrix documenting bibliographic identification, database matches, document type, role in the synthesis, and unresolved documentation issues. The 15 sources identified in the exports comprised 10 clinical systematic reviews or

meta-analyses, three empirical studies, one narrative review, and one review protocol. The complete corpus also included institutional documents and a conference abstract. The protocol was distinguished from a results publication, and findings reported in the conference abstract were treated as preliminary.

The critical appraisal described in the manuscript considered alignment between concepts and measures, population representativeness, temporality, control of confounding, heterogeneity of findings, potential sample overlap, and the inclusion of historically underrepresented groups. Instrument analysis examined correspondence between the domains assessed and the breadth of sexual health, including cultural applicability and assumptions about anatomy, gender, partnerships, and sexual activity.

We examined guidelines and institutional documents for their scope and relevance to caring for people with rheumatic diseases. Recommendations on contraception, fertility, pregnancy, lactation, and medication safety were distinguished from guidance addressing comprehensive sexual health. Interpretation connected clinical and functional components with pleasure, intimacy, autonomy, communication, rights, and sexual justice to identify convergences, limitations, and gaps in translating evidence into care.

The corresponding author performed curation, which involved neither independent duplicate human verification nor formal application of risk-of-bias assessment tools. Its scope was limited to organizing records and reconstructing the bibliography used in a traceable manner. The synthesis was narrative and interpretive, without pooled effect estimates or claims of exhaustive coverage.

3. RESULTS AND DISCUSSION

3.1. Sexuality And Sexual Health In The General Population

3.1.1. Sexuality as a Dimension Of Life

In its working definition, WHO describes sexuality as a central aspect of being human throughout life, encompassing sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. People may experience or express it through thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles, and relationships. Biological, psychological, social, economic, political, cultural, legal, historical, religious, and spiritual factors shape it (World Health Organization, 2006). This definition counters two common reductions: sexuality is neither limited to intercourse nor exhausted by anatomy or reproduction.

Sexuality also has a temporal dimension. It changes with age, illness, treatment, loss, new partnerships, gender transitions, menopause, parenthood, and changes in functional capacity. Sexual activity is not a prerequisite for sexuality; abstinence may be a legitimate choice, a temporary circumstance, or an unwanted consequence. The same frequency of sexual practices may mean satisfaction for one person and distress for another. Population norms should therefore not turn difference into pathology.

3.1.2. Sexual Health as Well-Being And a Right

WHO defines sexual health as physical, emotional, mental, and social well-being related to sexuality, rather than merely the absence of disease, dysfunction, or infirmity. It requires a positive and respectful approach, opportunities for pleasurable and safe experiences, and

freedom from coercion, discrimination, and violence; it depends on the respect, protection, and fulfillment of sexual rights (World Health Organization, 2006). The operational framework reinforces a holistic approach that considers a life-course perspective, diverse needs, human rights, and social and structural influences at multiple levels (World Health Organization, 2017).

This definition shifts the focus of clinical care. Someone without a sexually transmitted infection, unintended pregnancy, or genital dysfunction may nevertheless experience fear, humiliation, violence, lack of autonomy, or dissatisfaction. Conversely, someone with functional limitations may develop satisfying forms of intimacy through communication, adaptations, and support. Sexual health is therefore a context-dependent capacity, emerging from the relationship among the body, subjective experience, partners, services, and social conditions.

Rights have concrete implications. Laws, policies, and institutional practices can expand or restrict access to information, privacy, recognition of identity, protection from violence, and nondiscriminatory care (World Health Organization, 2015a). The Guttmacher–Lancet Commission positioned sexual and reproductive health and rights as universal components of health, autonomy, and development, highlighting needs beyond family planning (Starrs *et al.*, 2018). For people with disabilities or chronic illnesses, this perspective challenges the ableist presumption of asexuality and the idea that sexuality is a luxury when more serious problems are present.

3.1.3. Sexual Function, Pleasure, Well-Being, And Justice

Sexual function describes processes such as interest, arousal, lubrication, erection, orgasm, ejaculation, comfort, and satisfaction. Sexual dysfunction is a more demanding clinical category: it should not be inferred automatically from a low score, because duration, context, desire for change, distress, and alternative explanations matter. The Fifth International Consultation on Sexual Medicine consensus updated definitions and classification of dysfunctions in 2026, reiterating the need for standardization in clinical practice and research (Trost *et al.*, 2026). In rheumatic diseases, this caution is crucial: a desired reduction in activity during a pain flare does not, by itself, constitute a disorder.

Sexual pleasure refers to a positive subjective experience and cannot be inferred from performance alone. Sexual well-being includes safety, respect, sexual self-esteem, resilience in relation to past experiences, self-determination, and comfort with one's sexuality. Sexual justice examines the social distribution of resources, recognition, and opportunities: who can receive care, have recognized relationships, decline practices, access adaptations, and be heard without stigma. Mitchell *et al.* (2021) propose four interdependent pillars, sexual health, pleasure, well-being, and justice, and argue that sexual well-being marks equity and a meaningful public health outcome.

Distinguishing these concepts prevents substituting one for the others. An intervention may improve erections without reducing shame, control pain without restoring trust, or preserve fertility without ensuring autonomy. It may increase the frequency of intercourse under partner pressure and thereby undermine justice and safety. Appropriate assessment must ask what matters to the person, rather than only what the researcher can measure.

3.2. Impact Of Rheumatic Diseases On Sexual Health

The relationship is multifactorial and potentially bidirectional, as Table 1 critically maps the mechanisms linking rheumatic diseases and sexual health.

Table 1 — Critical map of mechanisms and evidence gaps concerning the impact of rheumatic diseases on sexual health.

Domain	Plausible pathways	What the evidence supports	Main limitation
Inflammation and symptoms	Pain, fatigue, stiffness, sleep, mobility	Consistent association between greater symptom burden and poorer function	Insufficient assessment of temporality and confounding
Organ involvement	Dryness, vasculopathy, fibrosis, neuropathy	Strong mechanistic plausibility in Sjögren disease and systemic sclerosis	Small samples; mechanisms rarely measured together
Mental health	Depression, anxiety, trauma, self-image	Recurring, consistent correlations	Bidirectional causal pathways
Relationships	Communication, caregiving, fear of rejection, satisfaction	Qualitative studies show changes in intimacy	Limited dyadic analysis; partners underrepresented
Treatment	Disease control versus adverse effects	Plausible indirect benefit of symptom control	Confounding by indication; few trials with sexual outcomes

Social structures	Income, access, discrimination, gender, disability	Strong theoretical framework and reports of barriers	Sexual justice largely absent from rheumatology evidence
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Source: Prepared by the authors (2026).

At the biological level, pain, fatigue, stiffness, weakness, dyspnea, restricted joint movement, neuropathy, vasculopathy, fibrosis, genital dryness, and hormonal changes may compromise comfort, desire, and genital response. At the psychological level, depression, anxiety, catastrophizing, trauma, low self-esteem, fear of pain, and unpredictable flares may alter attention, arousal, and initiation. At the relational level, task redistribution, dependence, poor communication, financial strain, and a partner's transition into a caregiving role may change reciprocity. At the structural level, poverty, inaccessible environments, racism, anti-LGBT prejudice, ableism, specialist shortages, and lack of privacy in services reduce available options.

Medications can have both beneficial and adverse effects. By controlling inflammation and pain, they may support sexuality; by causing fatigue, mood changes, dryness, gonadal dysfunction, or changes in appearance, they may compromise it. Antidepressants, antihypertensives, opioids, and other medications for comorbidities are relevant confounders. Cross-sectional studies linking medication use to poorer function are often affected by confounding by indication: patients with more severe disease receive more treatment. Attributing causality to a drug requires evidence of temporality, dose–response relationships, deprescribing, or active-comparator analyses, not correlation alone.

The biopsychosocial model can also be applied superficially, as a list of factors without causal relationships. A more useful formulation distinguishes mediators, moderators, and contexts. Inflammatory activity may increase pain and fatigue, which affect sleep and mood, in turn reducing interest and increasing conflict; partner support may moderate this pathway, while gender norms may shape interpretations of dependence or perceived performance failure. Repeated measures and longitudinal models are needed to test these sequences.

3.2.1. Rheumatoid Arthritis

In rheumatoid arthritis, painful hands, morning stiffness, restricted hip and knee movement, fatigue, and fear of exacerbation may interfere with touch, positioning, initiation, and maintenance of sexual activity. The impact extends beyond mechanics: bodily changes, dependence, and the loss of valued roles affect identity and perceived desirability. An earlier meta-analysis identified an increased risk of sexual dysfunction in women and men with rheumatoid arthritis, but rated the certainty of evidence as low because of the small number of studies and heterogeneity (Zhao *et al.*, 2018). A recent systematic review and meta-analysis focused on women and reaffirmed a high prevalence and associations with clinical and psychosocial factors, but it did not resolve the limitations of cross-sectional designs and limited sample diversity (Huang *et al.*, 2024).

Whether disease activity causes dysfunction remains less resolved than it may appear. Composite indices may share components with predictors, including pain, global assessment, and disability, generating associations through measurement overlap. People with

depression may simultaneously report greater disease burden and poorer sexual experiences. Conversely, studies that indiscriminately adjust for pain or mood may remove genuine mediating effects. Prespecified causal diagrams would be more informative than exploratory regressions involving multiple factors.

Evidence on effective adaptations is also limited. Ergonomics, energy conservation, timing of activities, communication with partners, and physical therapy may be clinically plausible, but are rarely tested as reproducible intervention packages. The Brazilian study by Ferreira *et al.* (2013) made an important contribution by documenting this topic among women with different rheumatic diseases, while also illustrating a field dominated by cross-sectional studies of women. Brazil's future contribution depends on multicenter cohorts that incorporate race/color, geographic location, income, sexual diversity, and access to the Unified Health System (SUS).

3.2.2. Systemic Lupus Erythematosus

In lupus, fatigue, pain, mucocutaneous manifestations, alopecia, photosensitivity, glucocorticoid-related weight changes, nephropathy, and prognostic uncertainty may converge to affect the body, mood, and relationships. Jin *et al.* (2021) found an association between lupus and a higher risk of sexual dysfunction, but the included literature was predominantly cross-sectional and heterogeneous. The finding is consistent with a substantial burden but does not establish a lupus-specific mechanism.

The field often conflates disease, treatment, and the social experience of appearance. A visible change may affect self-esteem in

settings shaped by racialized and gendered beauty standards; its impact is not purely dermatological. Measures of body image and stigma should be treated as potential mediators rather than peripheral covariates. Reproductive concerns, including fears of teratogenicity, high-risk pregnancy, or disease transmission, may also inhibit intimacy. However, the sexuality of people who do not wish to become pregnant should not be framed primarily in reproductive terms.

Studies involving men, transgender people, nonbinary people, and same-gender couples are scarce. The term female sexual function, as used in the sources, should be interpreted according to the sex or gender actually measured, avoiding automatic extrapolation to all women. Future research needs to record sex assigned at birth, gender identity, and relevant anatomy without treating these variables as mutually exclusive categories.

3.2.3. Systemic Sclerosis

Systemic sclerosis provides a clear example of the interaction among vasculopathy, fibrosis, skin changes, limited hand function, gastrointestinal symptoms, dyspnea, and self-image. Across 12 studies, Gao *et al.* (2021) found reported frequencies ranging from 76.9% to 81.4% for erectile dysfunction in men and from 46.7% to 86.6% for sexual difficulties in women. These ranges are not population prevalence estimates: only three studies included men, diagnostic criteria varied, samples were small, and participants were probably duplicated across two publications. The review itself considered the disease's independent effect controversial.

Nevertheless, specific mechanisms warrant investigation. Vasculopathy and fibrosis of the corpora cavernosa are plausible mechanisms in men; in women, dryness, pain, changes in genital blood flow, microstomia, contractures, reflux, Raynaud phenomenon, and body image concerns may coexist. The search for a single sexual biomarker should give way to multimodal models integrating vascular function, symptoms, distress, hormonal context, and relationships. Trials of hand rehabilitation or reflux control could include sexual outcomes as secondary endpoints, provided that they are selected with patients.

3.2.4. Sjögren Disease

In Sjögren disease, vulvovaginal dryness and dyspareunia have direct mechanistic plausibility, but reducing sexuality to lubrication reproduces the same narrow perspective criticized in this review. Fatigue, pain, mood, menopause, medications, communication, and partner responses also matter. The review by Hsu, Lee, and Koo (2024) and the meta-analysis by D'Andrea *et al.* (2025), both centered on the Female Sexual Function Index, support substantial impairment, but rely on overlapping primary studies, variable cutoffs, and assumptions about recent sexual activity.

A low score in a participant who has not been sexually active during the preceding four weeks may reflect pain, lack of a partner, choice, conflict, bereavement, or instrument design. If all these circumstances receive a score of zero, the instrument converts heterogeneous contexts into a single label. Research in Sjögren disease should combine assessments of function, distress, objective and perceived dryness, menopausal status, satisfaction, nonpenetrative practices, and preferences. Interventions involving

lubricants, moisturizers, local therapies, or pelvic floor physical therapy require individualized assessment and attention to safety; improvements in comfort should not be presented as guaranteeing relational well-being.

3.2.5. Spondyloarthritis And Psoriatic Arthritis

Axial spondyloarthritis often begins during periods of substantial relationship, educational, and occupational development. Axial pain, stiffness, fatigue, hip restrictions, uveitis, inflammatory bowel disease, and postural changes may limit sexual practices and spontaneity. The most recent systematic review and meta-analysis included 37 studies, with reported dysfunction prevalence ranging from 32% to 71%. Men had poorer scores in almost all International Index of Erectile Function domains except desire. Women had poorer overall Female Sexual Function Index scores and poorer arousal, pain, lubrication, and desire scores. However, only five studies exclusively involved women, and only four studies per instrument group could be pooled (Somer *et al.*, 2026).

These findings highlight both a clinical problem and a historical bias. For decades, spondyloarthritis was regarded as a male disease, and sexual research reinforced this framing by prioritizing erection. Even the recent meta-analysis identified uncertainty at the intersection with LGBTQIA+ communities. In psoriatic arthritis, skin and genital lesions, stigma, enthesal pain, and obesity may add distinct pathways, but disease-specific evidence is more limited and is often combined with evidence on psoriasis or spondyloarthritis. Studies should distinguish phenotypes, document genital involvement, and assess body image without attributing the entire effect to joint inflammation.

3.2.6. Fibromyalgia And Chronic Pain

In fibromyalgia, widespread pain, hypersensitivity, nonrestorative sleep, fatigue, cognitive difficulties, and emotional distress form a network particularly conducive to reduced pleasure and anticipation of pain. Ricoy-Cano *et al.* (2022) identified poorer sexual function in women with fibromyalgia, but the studies were mostly observational and relied on the Female Sexual Function Index. The 2025 review across systemic autoimmune rheumatic diseases included fibromyalgia as a related condition and reinforced the contribution of pain and psychological burden (Monisha *et al.*, 2025).

The risk of circularity is substantial in this context. Diagnostic criteria and measures of severity, depression, and sexual function share content related to fatigue, distress, and satisfaction. Psychotropic medications may mediate or confound associations. Furthermore, an account that psychologizes dysfunction may invalidate pain, whereas an exclusively nociceptive account may overlook trauma, violence, and relational context. Intensive repeated measurements, individual time series, and factorial trials could estimate how sleep, pain, expectations, affect, and medication vary before and after intimate experiences.

3.2.7. Osteoarthritis And Degenerative Conditions

Osteoarthritis is rarely central to the literature on sexuality, perhaps because aging and degenerative disease are inappropriately associated with asexuality. In a qualitative study of people with hip or knee osteoarthritis, pain and reduced mobility affected sexual health to varying degrees, while participants developed adaptations involving positions, pacing, and other strategies (Nilsing Strid;

Ekelius-Hamping, 2020). Qualitative evidence reveals that a frequency scale cannot capture how agency and creativity coexist with limitations.

Joint replacement may improve mobility and reduce pain, but counseling about resuming sexual activity is often inconsistent. Preoperative and postoperative studies should assess not only time to resumption but also perceived safety, satisfaction, fear, counseling received, and diversity of practices. Age should not function as an implicit exclusion criterion. Multimorbidity, bereavement, menopause, vascular erectile dysfunction, and changes in partnerships need to be modeled rather than conflated with the effect of osteoarthritis.

3.3. Psychosocial Impact

3.3.1. Body, Identity, And Stigma

The body affected by rheumatic disease can become unpredictable: capable one day and exhausted the next, sometimes painfully affected in ways that are invisible and sometimes visibly altered by deformities, scars, alopecia, skin lesions, or weight changes. This unpredictability affects the sense of continuity of the self. Individuals may anticipate rejection before it occurs, avoid nudity, lighting, or new relationships, and interpret physical assistance as evidence of inadequacy. However, self-image is not solely an individual phenomenon; social standards of youth, productivity, thinness, ability, and gender shape it.

Internalized stigma may be mistaken for low desire. An exclusively functional question, such as whether someone can have intercourse, does not elicit shame, fear of disclosing a diagnosis, or difficulty

negotiating adaptations. Clinical care should avoid reinforcing the notion of a defective body. The goal is to expand choices consistent with values, boundaries, and consent, rather than restore a standardized sexual norm.

3.3.2. Mental Health And Bidirectional Causality

Depression and anxiety are repeatedly associated with poorer sexual function in rheumatic diseases. The relationship is bidirectional: distress reduces interest and arousal, while painful experiences or rejection worsen mood and self-esteem. Inflammation, sleep, poverty, and medication may affect both. Without temporal measurements, we cannot order these pathways. Clinical practice, however, need not wait for causal certainty to recognize distress and offer integrated care.

Depression screening should not replace a discussion of sexuality. A person may have a normal mood score yet experience genital pain, coercion, or loss of intimacy; another may prioritize depression treatment before any sexual intervention. Shared decision-making requires asking which problem matters and what change would be desirable. In research, prespecify mediation models and test competing hypotheses, with attention to post-exposure confounders.

3.3.3. Relationships, Caregiving, And Communication

Inflammatory arthritis may alter intimate relationships through pain, fatigue, changes in roles, dependence, and fear of causing harm. Restoux *et al.* (2020) showed that sexual function and relationships are intertwined, although the literature prioritizes individual outcomes. A partner's transition into a caregiving role may reduce

eroticism for some people and strengthen trust for others. Nonmonogamous relationships, being unpartnered, solo sexuality, and diverse relational networks remain largely overlooked.

Patients report wanting information but often wait for professionals to raise the topic; professionals, in turn, wait for patients to do so. A survey of rheumatology health professionals identified barriers including lack of time, training, resources, and comfort, despite widespread recognition of the topic's relevance (Helland *et al.*, 2013). An evidence synthesis on chronic illness identified similar factors, along with concerns about invading privacy and uncertainty about referral options (O'Connor *et al.*, 2019). The result is reciprocal deferral of responsibility that perpetuates silence.

3.3.4. Gender, Power, Violence, And Sexual Justice

Gender norms shape experiences. Men may interpret erectile dysfunction or dependence as a threat to masculinity; women may normalize pain, prioritize a partner's satisfaction, or be assessed solely in terms of availability for penetration. LGBTQIA+ people may face heteronormative questions, disregard for their practices, denial of care, and fear of disclosing their identities. Transgender people may have anatomies, hormone treatments, and sexual goals that binary instruments do not capture.

Illness and disability may increase financial or physical dependence, affecting the ability to decline practices and seek help. Asking about safety and coercion is part of care, but requires privacy, training, and access to protection. Increasing sexual frequency is never an appropriate outcome in the absence of consent and desire. Sexual

justice also requires evaluating benefits and risks in terms of power, access, and nondiscrimination.

3.3.5. Employment, Income, And Geographic Inequalities

Fatigue, work disability, and treatment costs affect privacy, housing, time, and resources for care. Long journeys to specialist services and a shortage of sexual health professionals deepen geographic inequalities. In Brazil, these barriers interact with race, gender, income, and the organization of SUS. National studies should go beyond replicating foreign scales to examine measurement invariance, language, acceptability, and feasible referral pathways in primary and specialized care.

3.4. International Guidelines: Scope Of Recommendations And Gaps In Sexual Health Care

The international documents examined contribute complementarily but differ in purpose, target audience, and the nature of their recommendations. WHO frameworks establish a broad understanding of sexual health, whereas rheumatology guidelines on reproductive health inform decisions about contraception, fertility, pregnancy, and medication safety. Professional competency documents, in turn, provide foundations for communication and biopsychosocial care. Distinguishing these functions is necessary to assess what each document recommends and which needs care still addresses insufficiently (Table 2).

Table 2 — Normative documents and frameworks related to sexual and reproductive health: contributions and limits of application to rheumatology.

Document	Nature and main contribution	Limitations and implications for sexual health
WHO, 2006 and 2017	Conceptual frameworks linking sexual health, well-being, rights, and social determinants.	Require translation into care procedures, professional responsibilities, and indicators relevant to rheumatology.
WHO, 2015 — brief sexuality-related communication	Recommendations for developing sexuality-related communication skills in primary care.	Application in rheumatology requires adaptation to the clinical context and evaluation of acceptability, feasibility, and outcomes.
ACR, 2020 — reproductive health	Guideline on contraception, fertility, assisted reproduction, pregnancy, lactation, hormone therapy, and medications.	Its scope does not provide an integrated pathway for assessing and managing the different components of sexual health.
EULAR — 2024 update, published in 2025	Recommendations on antirheumatic drugs in reproduction, pregnancy, lactation, and paternal exposure.	Medication compatibility is one dimension of care and does not replace assessment of sexual needs.
EULAR, 2020 — professional competencies	Framework for communication, person-centered care, and a biopsychosocial approach.	Provides professional foundations, but is not a specific protocol for sexual health assessment and management.
BSR, 2025 — Sjögren disease	Guideline that includes recommendations on vaginal dryness.	Addresses a specific clinical need; some guidance derives from indirect evidence and does not constitute multidimensional assessment of sexuality.

Source: Prepared by the authors (2026). The documents serve different purposes. The comparison examines their scope and potential connections without assuming equivalence among conceptual frameworks, professional competencies, and clinical guidelines.

The ACR guideline contains 12 good practice statements and 131 recommendations on reproductive health, including contraception, assisted reproduction, fertility preservation, pregnancy, lactation, hormone therapy, and medication use. Many recommendations are conditional, reflecting limitations in the available evidence and the need for shared decision-making (Sammartano *et al.*, 2020). The 2024 EULAR update, published in 2025, presents five overarching principles and 12 recommendations on antirheumatic drug use before and during pregnancy, during lactation, and in relation to paternal exposure (Rüegg *et al.*, 2025). These documents provide essential support for aligning disease control with reproductive planning.

Nevertheless, these recommendations do not encompass the full range of sexual needs of people with rheumatic and musculoskeletal diseases. Decisions about contraception or medication compatibility do not, by themselves, explain how to assess pain during sexual activity, changes in desire, difficulties with intimacy, dissatisfaction, body image-related distress, or discrimination-related barriers. As the WHO notes, connecting sexual and reproductive health requires preserving the specificity of both, rather than reducing the former to the objectives of the latter (World Health Organization, 2017). The issue is therefore a gap in integrating care agendas, while recognizing the intended scope of each guideline.

Specific recommendations also prevent this situation from being characterized as a complete absence of guidance. The British Society for Rheumatology (BSR) guideline for Sjögren disease, for example, addresses managing vaginal dryness. However, the document itself acknowledges the scarcity of population-specific treatment studies and the use of evidence from other contexts, particularly postmenopause. This example demonstrates both the feasibility of incorporating sexual needs into disease-specific care and the importance of making explicit the indirect evidence supporting some recommendations (Price *et al.*, 2025).

EULAR's generic competencies support this integration by emphasizing effective communication, participation, and understanding of the biopsychosocial impact of disease (Edelaar *et al.*, 2020). Translating these principles into care nevertheless requires defining when and how to address sexuality issues that the team can manage and which require referral. International mapping of sexual dysfunction guidelines also identified fragmented guidance, reinforcing the need for greater breadth and coordination (Gonsalves *et al.*, 2020). Among the documents examined in this review, no guideline spanning rheumatic diseases integrated a consent-based approach, multidimensional assessment, interventions, referral, and implementation indicators. This finding must be interpreted within the limits of a targeted search and narrative selection, without claiming to establish the absence of initiatives in other contexts.

WHO's brief sexuality-related communication approach provides a foundation for this discussion, although its use in rheumatology represents an adaptation that requires evaluation (World Health Organization, 2015b). As a care proposal developed in this review, the

discussion should occur privately, use accessible and inclusive language, explain its relevance, and offer the option to decline. Its usefulness depends on the capacity to respond to identified needs and provide information, follow-up, or referral. Implementation should therefore be evaluated not only by the number of people asked, but also by the approach's acceptability, access to care, and outcomes that patients themselves consider meaningful.

3.5. Measuring Sexual Health And Sexuality: Constructs, Validity, And Clinical Interpretation

Selecting an instrument requires explicitly defining what to assess. Sexual function, satisfaction, sexuality-related distress, and sexual well-being are related but noninterchangeable constructs. A measure may adequately assess one without representing the others. A methodological problem arises when a functional score is treated as equivalent to comprehensive sexual health or its classification is interpreted as a diagnosis without considering context, distress, and individual priorities. Table 3 compares instruments used in sexual assessment.

Table 3 — Characteristics and interpretive considerations of instruments used to assess sexuality.

Instrument	Main constructs and domains	Reference recall period ¹	Interpretive considerations
FSFI-19	Desire, arousal, lubrication, orgasm, satisfaction, and pain.	Previous four weeks.	Responses related to lack of activity may reduce scores across domains. Does not include a dedicated assessment of sexual distress.

IIEF-15	Erectile and orgasmic function, desire, intercourse satisfaction, and overall satisfaction.	Previous four weeks.	Distinguish total scores, domains, and purpose of use. No attempted sexual activity requires contextual interpretation.
IIEF-5/SHIM	Erectile function and intercourse satisfaction.	Previous six months in the original/usual formulation.	Not equivalent to the IIEF-15 or its six-item erectile function domain. Cutoffs should not be transferred between versions.
Qualisex	Impact of disease on sexual life, including physical, emotional, and relational aspects.	Previous three months in the original version.	Initially developed in rheumatoid arthritis. Use in other conditions requires consideration of adaptation and the properties demonstrated in each population.
PROMIS Sexual Function and Satisfaction, version 2.0	Modular measures of interest, function, discomfort, orgasm, and satisfaction, among other components.	Previous 30 days.	Domain selection depends on the question and experiences relevant to the person. Modularity does not justify creating an overall score without validation.

Source: Prepared by the authors based on instrument development and evaluation studies (2026).

The Female Sexual Function Index (FSFI) contains 19 items covering desire, arousal, lubrication, orgasm, satisfaction, and pain (Rosen *et*

al., 2000). The 15-item International Index of Erectile Function (IIEF-15) assesses erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction (Rosen *et al.*, 1997). Both therefore extend beyond genital performance alone. Their contribution to standardizing research is substantial; their limitations stem from the gap between the constructs measured and the breadth of conclusions sometimes attributed to them.

Distinguishing versions and domains are also essential. The IIEF-15, its six-item erectile function domain, and the IIEF-5/Sexual Health Inventory for Men (SHIM) are not equivalent measures. The IIEF-5 was developed as an abbreviated version to identify erectile dysfunction and classify its severity, with distinct content and interpretation (Rosen *et al.*, 1999). Referring generically to the IIEF without specifying the version compromises comparisons across studies, particularly when recall periods and cutoffs differ.

A recurring challenge is the absence of sexual activity. In the FSFI, certain responses related to inactivity can lower scores, so it is necessary to distinguish functional limitations, lack of opportunity, personal choice, and other circumstances. A similar problem arises when not attempting intercourse is interpreted as erectile incapacity. Inactivity, missing responses, refusal, and nonapplicable items represent different situations and should be recorded and handled according to the instrument's rules. Modifying scoring or excluding sexually inactive participants without justification may introduce further bias.

This distinction also affects prevalence estimates. A result below a given cutoff reflects an operational classification based on an instrument; it does not independently establish a clinical disorder.

Interpretation requires considering persistence, context, and distress, as appropriate to the condition under investigation. A review of FSFI measurement properties found variation in the quality of available evidence, reinforcing the need to select versions and interpret findings based on their psychometric support (Neijenhuijs *et al.*, 2019). In systemic autoimmune rheumatic diseases, the predominance of functional measures and the infrequent assessment of distress make it difficult to determine the extent to which observed differences reflect limitations, dissatisfaction, or a need for care (Minopoulou *et al.*, 2023).

Qualisex makes a particularly relevant contribution to rheumatology by assessing the impact of disease on sexual life. Its development involved patients and professionals, and its initial evaluation included 53 people with rheumatoid arthritis, with favorable validity and test-retest reliability findings. However, the sample size and composition limit the generalizability of these findings (Gossec *et al.*, 2012). Subsequent studies examined its adaptation and use in axial spondyloarthritis in Argentina and in women with fibromyalgia, extending investigation beyond the original diagnosis (Sommerfleck *et al.*, 2018; Gioia *et al.*, 2024). Appraise this evidence by population and property: internal consistency and cross-sectional associations, for example, do not independently demonstrate the ability to detect clinically meaningful changes over time.

Language adaptation also requires contextualization. Brazilian studies have translated, adapted, and validated the FSFI and IIEF, but their findings do not automatically validate every version, disease, or use. For example, the Brazilian evaluation of the IIEF was conducted in a cardiopulmonary and metabolic rehabilitation setting, a context that should be considered before extrapolating its

findings to other rheumatic populations (Thiel *et al.*, 2008; Gonzáles *et al.*, 2013). No Brazilian Portuguese validation of Qualisex was documented in the sources consulted. This finding should be distinguished from the availability of versions in other languages or from studies that simply used the instrument.

PROMIS Sexual Function and Satisfaction offers a modular alternative, allowing measures to be selected based on the research question and the individual's experiences. Version 2.0 expanded its development contexts and included additional function and satisfaction domains, along with complementary item pools addressing activities, interfering factors, and sexuality-related bother. However, these items should not be automatically equated with a diagnostic distress scale (Weinfurt *et al.*, 2015). This flexibility does not eliminate the need to verify the authorized translation, cultural validity, and properties of each domain in the target population.

When sexual distress is a relevant outcome, its measurement should be explicit. For example, the Female Sexual Distress Scale–Revised (FSDS-R) has been adapted and evaluated in Brazilian Portuguese among women with and without complaints of vaginal laxity. This study is a useful reference but, by itself, does not demonstrate validity and responsiveness in people with rheumatic diseases or different gender identities (Pereira *et al.*, 2022). Combining function and distress measures may strengthen interpretation, provided that each instrument is appropriate for the population and that its scores remain conceptually distinct.

Based on these considerations, this review proposes a conceptual organization of assessment into three complementary components. The first addresses the person's priorities, the context of their sexual

experiences, and their willingness to discuss the topic. The second includes selected measures of function, satisfaction, disease impact, and distress, depending on the clinical or research question. The third addresses aspects poorly represented in usual instruments, including intimacy, self-image, autonomy, consent, communication, discrimination, and access to care, through open-ended questions or qualitative methods. This organization is a proposal by the authors; it is not a validated scale, a mandatory battery, or a clinical scoring and classification system.

Improving measurement requires participation by people with different diseases, ages, genders, sexual orientations, racial and ethnic backgrounds, and functional abilities. In addition to content validity, examine properties relevant to the measurement model and the instrument's purpose, including structure, reliability, measurement error, cross-cultural validity, invariance, and responsiveness. Longitudinal interpretation also requires distinguishing statistically significant change, change exceeding measurement error, and change patients consider important. COSMIN guidance provides a framework for these distinctions, although its conceptual use in this discussion does not constitute a formal COSMIN assessment of the sources included in this review (Prinsen *et al.*, 2018).

Inclusive measurement should retain necessary anatomical and clinical information while avoiding assumptions about identity, partnerships, practices, or goals based on that information. In research and interventions, this requires justifying the selected domains, specifying the versions used, and reporting how inactivity, nonapplicable items, and missing data were handled. Meaningful outcomes should align with agreed goals: greater comfort, less

distress, satisfaction, autonomy, or participation may matter even without increased sexual frequency or a change in a functional score.

3.6. Clinical And Public Health Implications

A feasible approach can be organized into six steps, consistently guided by consent: (i) legitimize the topic by explaining that pain, fatigue, medications, and disease may affect sexuality and that it can be discussed; (ii) ask about priorities by identifying whether there is a concern and whether the person wishes to address it; (iii) characterize the concern by distinguishing among desire, arousal, comfort, pain, orgasm, satisfaction, self-image, relationships, safety, and reproduction; (iv) identify modifiable factors, including disease activity, symptoms, comorbidities, medications, mental health, dryness, vasculopathy, mobility, and context; (v) agree on actions, including optimizing disease control, providing education and adaptations, safely reviewing medications, and involving partners only with permission; and (vi) refer and follow up through gynecology, urology, pelvic floor physical therapy, occupational therapy, psychology, sexology, social work, or protection services for violence, as needed.

This pathway is not a treatment guideline and does not justify interventions without individualized assessment. Genital pain, bleeding, lesions, suspected infection, new-onset erectile dysfunction, vascular symptoms, severe distress, or violence require appropriate evaluation. Medication review should weigh benefits, risks, and disease activity; discontinuing an antirheumatic drug to assess its sexual effects may be harmful. Current reproductive recommendations should be consulted when contraception,

pregnancy planning, paternal exposure, or lactation is relevant (Sammaritano *et al.*, 2020; Rüegg *et al.*, 2025).

At the service level, responsibility cannot rest solely with a professional who happens to feel particularly comfortable discussing sexuality. Confidentiality-preserving medical record fields, inclusive materials, simulation-based training, referral directories, protected time, and audits of the offer of care, rather than of intimate disclosures, are needed. The ethical indicator is not the number of people reporting sexual activity, but the number offered a respectful opportunity to discuss their concerns and to access care if they wish.

In public health, sexuality should be integrated into quality-of-life assessments, rehabilitation, health education, and disability policies. Surveillance systems and population surveys should include people with chronic illnesses and functional limitations. Communication should avoid prescriptive messages about returning to normal, while recognizing solo sexuality, nonpenetrative practices, asexuality, and the decision not to prioritize the topic.

4. CONCLUSIONS

The available evidence is sufficient to establish that sexual difficulties are common and clinically relevant in rheumatic and musculoskeletal diseases. It is insufficient to provide a universal prevalence estimate, confidently establish causality, or recommend a single treatment. Extreme heterogeneity, predominantly cross-sectional designs, the overrepresentation of cisgender women, limited assessment of distress, and the use of function-centered instruments constrain the strength of the conclusions.

ACR and EULAR reproductive guidelines represent essential advances but should not be treated as substitutes for comprehensive sexual health care. The WHO framework and the four pillars of sexual health, pleasure, well-being, and justice provide a more appropriate foundation. The next scientific advance requires more than administering the same questionnaire to another convenience sample: it calls for co-developing meaningful measures, testing mechanisms over time, evaluating pragmatic interventions, and implementing equitable care.

Bringing sexuality into rheumatology does not mean medicalizing every difference or requiring patients to disclose their intimate lives. It means recognizing sexuality as a legitimate dimension of health, offering informed choice, and responding when distress is present. The field's quality will be judged by its ability to expand autonomy and possibilities for living, including the choice not to prioritize sexuality, across diverse bodies and unequal social contexts.

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