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Sexual Health, Pleasure, Justice, and Well-Being in People With Rheumatic and Musculoskeletal Diseases: A Scoping Review Protocol

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ABSTRACT

Introduction: Sexual health, pleasure, justice (equity in sexual rights and experiences), and well-being are crucial determinants of health and life quality, yet often overlooked in the rheumatic and musculoskeletal diseases (RMD) field. However, this topic has received more attention recently, and there is a need to map the current literature to inform the direction of future studies. Hence, this protocol outlines a scoping review to systematically map existing evidence on sexual health in people with RMD, exploring key themes and identifying evidence gaps across multiple dimensions, including sexual well-being, justice and pleasure.

Method and Analysis: This scoping review will follow the methodological guidance of the Joanna Briggs Institute and be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews. The search strategy will involve PubMed, Embase, Cochrane Central, CINAHL, PsychInfo, LGBTQIA+ Source, Web of Science, and the grey literature. Identified articles will be reviewed based on the eligibility criteria. The results will be narratively synthesised and aligned with the framework proposed by Mitchel et al. (2021), identifying four pillars of comprehensive public health for sexuality: ‘Sexual Health’, ‘Sexual Pleasure’, ‘Sexual Justice’, and ‘Sexual Well-Being’.

Dissemination: The scoping review will synthesise the scientific literature published on sexual health, pleasure, justice and well-being in people with RMD. This review will provide an understanding of how sexual health is addressed in the literature to inform future research and clinical practices. The findings will be disseminated as research publications, including peer-reviewed article(s), conference abstract(s)/presentation(s), and plain language summaries.

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1 | Introduction

Sexual health, pleasure, justice and well-being are crucial determinants of health and quality of life (Dorner et al. 2018; Mitchell et al. 2021). Sexual health involves prevention of sexually transmitted infections, fertility regulation and sexual function (World Health Organisation 2010). Sexual pleasure is satisfaction influenced by personal factors and interpersonal dynamics (Braeken and Castellanos-Usigli 2018). Sexual justice emphasises equitable, person-centred sexual experiences and access to restorative justice (Starrs et al. 2018). Sexual well-being addresses inequities in gender and sexual identity, promoting safety and self-esteem (Muise et al. 2010). Despite their relevance, these aspects of public health are often impacted among people with long-term conditions such as rheumatic and musculoskeletal diseases (RMD) (McInnes 2003; Radhakrishna, Kayidhi and Ravindran 2024). In people with RMD, factors such as pain, fatigue, low levels of physical activity, joint stiffness and use of certain medications can impact different aspects of sex and intimacy (Dorner et al. 2018; Helland et al. 2011; Tristano 2014).

Despite the importance of sex and intimacy in RMD, this aspect of health is often overlooked by healthcare professionals during routine health visits (Schmalzing et al. 2020), with research in this field only recently gaining attention. A growing body of evidence across various disciplines, including rheumatology, psychology, and sexual health, often focuses on dysfunctions and impairments in reproductive health, such as low levels of sexual desire and arousal, low vaginal lubrication, infertility, reproductive hormones alterations, pain during intercourse, and erectile dysfunction (Boussaid et al. 2022; Carrillo-Izquierdo et al. 2018; Cetin, Buyuk and Ayan 2020; Dorner et al. 2018; Minopoulou et al. 2023; L. F. Perez-Garcia et al. 2020; Wolgemuth et al. 2021; Yan et al. 2024; Zhang et al. 2018; Zhao et al. 2018). As such, these studies often lack a holistic view encompassing emotional, social, and psychological dimensions of sexual health, namely sexual well-being, justice and pleasure (Van Doornum, Ackerman and Briggs 2019). Only one study described the overall impact of inflammatory arthritis on sexual health in men in the Netherlands (Luis Fernando Perez-Garcia et al. 2021). Moreover, existing studies on sexual health in RMD have been conducted on different RMD populations, measuring sexual health in an inconsistent manner lacking validation and standardisation (Restoux et al. 2020).

Given the varied methods and outcomes of current research in this area, understanding sexual health in people with RMD remains unclear. A scoping review is well-suited to systematically explore and map the breadth of evidence, identify key themes and highlight existing evidence gaps across multiple domains of sexual health among people with RMD. This approach will help identify which domains are under-researched and how current assessment methods may lack validation in RMD populations. The review will ultimately provide an understanding of how sexual health is addressed in the literature to inform future research and clinical practices.

1.1 | Rationale for Conducting a Scoping Review

The impact of RMD on sexual health and how the impact is assessed in practice will be examined from an interdisciplinary

point of view (Schmalzing et al. 2020; Van Doornum, Ackerman, and Briggs 2019). A scoping review will be conducted to systematically map available literature on this topic, providing an overview of current knowledge and highlighting areas where further research is needed (Munn et al. 2022). The framework proposed by Mitchel KR et al. that identifies four pillars of comprehensive public health for sexuality will be adopted (Mitchell et al. 2021). All four pillars can be hindered by RMD.

- ‘Sexual Health’ encompasses fertility regulation, sexually transmitted infection prevention and management, sexual violence prevention, and sexual functions such as desire and arousal, as defined by the World Health Organisation (World Health Organisation 2010);
- ‘Sexual Pleasure’ addresses the diverse and psychological satisfaction of the sexual experience, including person-related factors (e.g., the nature and timing of sexual activities, orgasm occurrence and contraceptive use) and event-related factors (e.g., interpersonal dynamics, communication, negotiation, and trust) (Braeken and Castellanos-Usigli 2018);
- ‘Sexual Justice’ addresses social, cultural, and legal supports for equitable person-centred sexual and reproductive experiences, promoting equal access to restorative justice (Starrs et al. 2018).
- ‘Sexual Well-being’ addresses inequities related to sexuality and sexual behaviour, particularly those driven by gender and sexual identity (e.g., sexual safety, security, self-esteem, self-determination and comfort with one’s sexuality) (Muise et al. 2010).

1.2 | Aim & Objectives

This scoping review aims to systematically map what is known about sexual health, pleasure, justice and well-being in people with RMD. Our specific objectives are as follows.

1. Map the breadth of evidence available on sexual health, pleasure, justice and well-being in people with RMD.
2. Identify how sexual health, pleasure, justice and well-being were assessed in people with RMD, examining the validity of the methods/tools adopted and the sexual health-related domains assessed.
3. Synthesise the identified evidence and identify any knowledge gaps on the topic.

The results will inform future scientific inquiry and quality improvement across health and care settings related to sexual health, pleasure, justice and well-being in people with RMD.

2 | Material and Methods

This scoping review will adhere to the methodological guidance for scoping reviews of the Joanna Briggs Institute (JBI) (Peters, Marnie et al. 2020; Peters, Godfrey et al. 2020). The reporting will follow the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al. 2018).

2.1 | Research Team

The research team includes experts in qualitative and quantitative research, evidence synthesis, and sexual health, as well as two patient research partners with RMD (AL, SRS). See, Supporting Information S1: Table S1, for the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) Checklist Short Form (Staniszewska et al. 2017).

2.2 | Review Question(s)

The following scoping review aims to answer the following research question: 'What is known about sexual health, pleasure, justice and well-being in people with RMD?'

2.3 | Eligibility Criteria

Articles will be considered eligible for inclusion if they meet the Population, Concept and Context (PCC) framework criteria proposed by the JBI (Table 1; Peters, Godfrey et al. 2020).

2.4 | Search Strategy and Information Sources

The search strategy will be implemented in multiple medical literature databases: PubMed, Embase, Cochrane Central, CINAHL, PsychInfo, LGBTQIA+ Source and Web of Science (Supporting Information S2–Table S2 and S3). The strategy will be modified for use in the other databases. These databases were selected because of their relevance to health research and their ability to track citations. All medical literature databases will be searched from the date of inception. A grey literature search will also follow the Canadian Agency for Drugs and Technologies in Health (CADTH) tool for searching health-related databases (Ottawa and CADTH 2022). The CADTH tool makes the grey literature searching process transparent and systematic (Saleh A, Ratajeski M, & Bertolet M, 2014). If required, the authors will be contacted for further information or missing data. Any changes will be highlighted in the scoping review output. The International Prospective Register of Systematic Reviews database (PROSPERO) was consulted to check for ongoing reviews on this topic. No systematic reviews were found on this topic. Citations will be managed using Mendeley Reference Manager (Version 2.126.0, Elsevier and Mendeley Ltd.).

2.5 | Article Selection

All entries will be uploaded to Covidence (Veritas Health Innovation, Melbourne, Australia) where exact duplicates will be automatically removed. Each identified article will be reviewed by two blinded reviewers. A title and abstract review will be conducted by the same two reviewers, followed by full-text screening, as Covidence uploads the full-text directly on

TABLE 1 | Criteria for inclusion and exclusion following the Population, Concept and Context framework.

Population:

Inclusion:

- Adults (≥ 18 years old) of any gender and sex assigned at birth with a diagnosis (clinical or self-reported) of RMD;
- Specific types of RMD aligned to those included within RheumaMap from the European alliance of associations for rheumatology (EULAR) (Francis Berenbaum et al. 2019);
- Comorbidities, such as neurological, psychiatric, neoplastic, and endocrine condition, but their presence will be highlighted.

Concept:

Inclusion:

- Sexual health, pleasure, justice and well-being in people with RMD as referred to in the framework of Mitchell et al. (Mitchell et al. 2021);
- All types of articles reporting primary studies, both qualitative and quantitative (observational or experimental) with no restrictions on time, geographical location, setting and language;
- Surveys, questionnaires, standardised tools or scales that assess sexual health, pleasure, justice and/or well-being (even one domain will suffice for inclusion);

Exclusion:

- Reviews, editorials, commentaries, expert opinions, letters to editors, book review chapters, conference abstracts or study protocols, however, their references will be checked for eligible studies;
- Articles focusing only on organic or biological aspects of genitalia, without assessing sexual functions or their impact on sexual health, pleasure, justice and well-being—if an article reports an increase in genital hormones or genital inflammation in people with RMD without assessing its impact on sexual dimensions, it will be excluded.

Context:

- No specific restrictions to investigate studies from all geographical locations with participants regardless of specific social, cultural or sex/gender-based factors.

the platform. A pilot test, pre-formal screening for a random 10% of records retrieved, will be conducted as a calibration exercise to improve reliability across reviewers. Formal screening will start if the percentage interrater agreement is $> 90\%$. Otherwise, the inclusion and exclusion criteria will be further specified, and another pilot test will be performed. In case of conflict, a third author will be consulted. Reasons for the exclusion will be reported in the scoping review report. The final included studies will be mapped through the scoping review. A graphical representation of the studies' selection will be presented by adopting the PRISMA flow diagram (Page et al. 2021). The included studies will be uploaded to a secure OneDrive folder accessible to all authors. Study authors will be contacted if the full text articles cannot be retrieved.

2.6 | Data Extraction

Data will be charted based on the JBI Standardised Data Extraction Form (Peters, Marnie et al. 2020; Peters, Godfrey et al. 2020). The key data to be extracted include:

- Authors & year.
- Country of origin.
- Aims/purpose.
- Population and sample size.
- Theoretical framework.
- Study design.
- Data collection method (e.g., face-to-face, online and questionnaire).
- Intervention type, comparator and details of these (e.g. duration of the intervention, if applicable).
- Sexual domain(s): which domains of sexual health were assessed (e.g., Sexual health).
- Outcomes: which specific element of sexual health was investigated (e.g., erectile dysfunction), and the findings from papers.
- Methods of sexual assessment: which tool was adopted, and if it is validated.

3 | Conclusion

This form will be reviewed by all researchers involved and tested before implementation, following the same screening pilot test method. Researchers will independently extract the data. Given the iterative nature of data extraction, other data may be added to the proposed draft. The modifications will be reported in the forthcoming scoping review.

3.1 | Data Synthesis

The results will be narratively synthesised to classify the sexual domains and their measurement in people with RMD into overarching themes. The narrative synthesis by Popay et al. (Popay et al. 2006) will be followed to synthesise the findings across the included studies. The narrative analysis will not only summarise the results and characteristics of the included articles but will arrange study types into homogeneous sub-groups, report the data highlighting similarities and differences between studies, as well as discuss the data and strength of evidence based on the study design (Lucas et al. 2007). This process will adhere to the following steps: 1) developing a theoretical model; 2) developing a preliminary synthesis; 3) exploring relationships in the data; 4) assessing the robustness of the synthesis product (without adopting any specific tool) (Popay et al. 2006).

A descriptive summary of the findings will also be provided, enabling the authors to identify evidence gaps and suggest potential areas for future research. All the included studies will be reported and mapped to describe the search and the extracted

data and will be summarised in tables and figures. Since this process will be iterative, further categories might be added if appropriate.

3.2 | Methodological Quality Appraisal

No critical appraisal of the risk of bias will be performed in line with guidance on the scoping review (Peters, Marnie et al. 2020; Peters, Godfrey et al. 2020) as we intend to map the available evidence rather than provide clinical and synthesised answers to a question.

4 | Discussion

This scoping review will review the scientific literature published on sexual health, pleasure, justice and well-being in people with RMD. The main goals are to map the literature on this topic, identify the methodologies used to assess sexual health, pleasure, justice and well-being, and highlight any knowledge gap on the topic. The expected finding is that most studies will focus on biomedical assessment of sexual function, overlooking a more comprehensive definition of sexual health that includes sexual pleasure, justice and well-being as distinct biopsychosocial-cultural outcomes (Van Doornum, Ackerman, and Briggs 2019). This protocol is intended to help define and outline a transparent step-by-step process for conducting the review to minimise potential reporting biases. Deviations from the protocol, if necessary, will be noted in the full scoping review. The methodological framework currently recognised for conducting scoping reviews has been adopted to draft this protocol (Peters, Marnie et al. 2020; Peters, Godfrey et al. 2020; Tricco et al. 2018). The findings will be disseminated through peer-reviewed publication(s), conference abstract(s)/presentation(s), plain language summaries, and other potential enhanced publication content to ensure findings are accessible to the wider RMD community.

Author Contributions

The author takes full responsibility for this article.

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Ethics Statement

The authors have nothing to report.

Conflicts of Interest

Unrelated to this article, Simon R. Stones is an employee of Amica Scientific (a healthcare communications company that is funded by pharmaceutical companies), has received honoraria from Taylor & Francis, Sage, The Kennedy Trust, and the National Institute for Health and Care Research, is a trustee of RAIISE (a charitable incorporated organisation registered in England and Wales Number 1180704), is a member of the International Society for Medical Publication

Professionals Patient Engagement Task Force, and is the Chair-elect of the European Alliance of Associations for Rheumatology People with Arthritis/Rheumatism in Europe Committee.

Data Availability Statement

The data that supports the findings of this study are available in the supplementary material of this article.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.