INPLASY PROTOCOL

To cite: Fisette-Paulhus et al. Patient-reported outcomes measures for assessment of sexual functioning and sexual well-being in women with physical disabilities: A scoping review. Inplasy protocol 202280033. doi: 10.37766/inplasy2022.8.0033

Received: 09 August 2022

Published: 09 August 2022

Corresponding author:
Mélanie Morin

melanie.m.morin@usherbrooke.ca

Author Affiliation:
Faculty of Medicine and Health Sciences, Université de Sherbrooke.

Support: **No disclosure.**

Review Stage at time of this submission: **Preliminary searches.**

Conflicts of interest:
None declared.

Patient-reported outcomes measures for assessment of sexual functioning and sexual well-being in women with physical disabilities: A scoping review

Fisette-Paulhus, I[1]; Gagnon, C[2]; Labbé, C[3]; Morin, M[4].

Review question / Objective: **What is the current evidence on patient-reported outcomes measures (PROMs) to assess sexual functioning and sexual well-being in women with physical disabilities? The main objective of this scoping review is to identify, synthesize, and critically evaluate the available evidence on validated PROMs used to assess sexual functioning and sexual well-being in women with physical disabilities. Specifically, we aim to discuss the construct assessed with those PROMs and evaluate their psychometric properties.**
Eligibility criteria: **This scoping review will use PCC (Participant, Concept, Context) [19] as a framework. Participants: Studies that included women (teenagers and adults) with physical disabilities will be appraised. Concept: Literature that evaluates the use of PROMs to assess sexual functioning and sexual well-being in women with physical disabilities. Context: This study will consider any publication without limitations regarding the year published.**

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 09 August 2022 and was last updated on 10 August 2022 (registration number INPLASY202280033).

INTRODUCTION

Review question / Objective: **What is the current evidence on patient-reported outcomes measures (PROMs) to assess sexual functioning and sexual well-being in women with physical disabilities? The main objective of this scoping review is to identify, synthesize, and critically evaluate the available evidence on validated PROMs used to assess sexual functioning and sexual well-being in women with physical disabilities. Specifically, we aim to discuss the construct assessed with those PROMs and evaluate their psychometric properties.**

Rationale: **To our knowledge, published reviews up to now have mainly focused on**

PROMs used to assess sexual dysfunction in the general population [1, 2] or in a disease-specific population (neurologic disorders [3], cancer [4, 5], etc.), but no available review has gathered evidence on the use of those PROMs in women with physical disabilities. Studies have shown that persons with disabilities engage in sexual interaction significantly less [6, 7] and have multiple factors that can directly or indirectly affect their sexual function and well-being (e.g. biological, psychological or sociocultural) [8, 9]. People with physical disabilities, including women, can suffer from spasticity, less or no sensation or incontinence, which affect their sexual functioning and well-being [8]. In addition, disabled women often have specific sexual issues of their own, like pelvic floor disorder, lubrification and dyspareunia [9, 10]. As most reviews focused only on sexual dysfunction, it is essential to analyze and compare the construct of each PROM to assess the direct and indirect factors that can affect sexual function and sexual well-being. Thus, it is important to assess sexuality in its globality, especially in women, in order to provide appropriate support and care. This scoping review will allow clinicians to choose the best tool to assess sexual function and sexual well-being in women with physical disabilities and to manage sexual limitations affecting this population.

Condition being studied: Based on the International Classification of Functioning, Disability and Health (ICF), a disability refers to any impairment, activity limitation and participation restriction [11]. According to the United Nation, persons with disabilities are a group of people living with long-term physical, mental or sensory impairment that can have an impact on participation [12]. Populations within this group (e.g. people with spinal cord injuries, amputation, musculoskeletal disorders, etc.) are experiencing physical limitations resulting from various causes, including congenital diseases and injuries. Those conditions can seriously affect multiple aspects of daily living, including sexual function and well-being [8]. However, people with physical disabilities are often too embarrassed to ask questions about sexual difficulties [6] and health professionals often neglected addressing the subject because they are uncomfortable discussing sexuality or don't have the resource or time [13-15]. Validated patient-reported outcomes measures (PROM) assessing sexual function and well-being are interesting tools to start the discussion and provide specific information about this subject [16]. Thus, it is necessary to conduct a scoping review to identify validated and adapted PROMs assessing sexual function and sexual well-being in women with physical disabilities.

METHODS

Search strategy: A scoping review will be conducted in order to have an overall understanding of how sexual function and sexual well-being are assessed in women with physical disabilities in the current literature [17]. This scoping review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) [18] methodology. Search strategies using subject headings, keywords and word truncation were developed to locate published studies in PubMed (MedLine), CINAHL (EBSCO) and Embase (Ovid) databases. Articles found in databases (PubMed, CINAHL, Embase) will be imported into the reference management software EndNote. Duplicate articles will be removed. Then, two reviewers will individually scan the retrieved articles' titles and abstracts and select the relevant studies that meet the eligibility criteria. After that, those articles will be selected based on full article and evaluated again for eligibility. The agreement between authors concerning the eligibility of articles will be measured with a Cohen Kappa. Any disagreement will lead to a discussion between the two reviewers, and if necessary, a third reviewer will be involved to obtain a consensus.

Participant or population: Studies that include women with physical disabilities will be appraised. Studies on children or

persons without physical disabilities will be excluded.

Intervention: Any type of intervention that aimed to improve sexual function or sexual well-being will be included to investigate responsiveness or sensitivity to changes in the PROM. As this review aimed at evaluating the psychometric properties of the PROMs, the studies included are not limited to interventional studies.

Comparator: Not applicable.

Study designs to be included: This scoping review will include a variety of designs, such as PROM development, evaluation, and validation studies. Reviews will be excluded.

Eligibility criteria: This scoping review will use PCC (Participant, Concept, Context) [19] as a framework. Participants: Studies that included women (teenagers and adults) with physical disabilities will be appraised. Concept: Literature that evaluates the use of PROMs to assess sexual functioning and sexual well-being in women with physical disabilities. Context: This study will consider any publication without limitations regarding the year published.

Information sources: PubMed (Medline), CINAHL (EBSCO) and Embase (Ovid) will be used. References list and reviews will be explored, and additional studies may be included if they meet eligibility criteria.

Main outcome(s): 1) PROMs that are specifically developed for women with physical disabilities (condition-specific) and used to assess one or many domains related to sexual functioning and well-being (e.g. sexual dysfunction, impact of physical limitations on sexual function, etc.); 2) PROMs that are developed for the general population (generic) but used among women with physical disabilities will be appraised; 3) PROMs in which sexual functioning or sexual well-being is assessed as subscale (i.e. a sub-scale that can be used/scored separately) among women with physical disabilities. The construct assessed of each PROMs will be reported in a summarized table to facilitate qualitative analysis. Articles will be excluded if they include PROMs that have not been validated or use PROMs that evaluate sexual orientation, sexual identity, or the level of knowledge/education on sexuality.

Additional outcome(s): The use of validated PROMs assessing sexual functioning or sexual well-being in women with physical disabilities will be summarized and analyzed in terms of frequency of use by types of disability (neurologic, neuromuscular, musculoskeletal, cardiovascular, etc).

Data management: All studies emerging from the search strategy will be exported into the EndNote software program. After the selection process is completed, data extraction will be carried out by two researchers. The data extraction tool has been developed for this study and data extraction will be performed with this tool. Information extracted will include (1) study characteristics; (2) participants characteristics; (3) PROM characteristics; (4) data pertaining to psychometric properties. Any disagreement will lead to a discussion, and if necessary, a third reviewer will be included to obtain consensus.

Quality assessment / Risk of bias analysis: The Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) Risk of Bias checklist for PROMs [20] will be used to evaluate the methodological quality of PROMs, including psychometric properties such as reliability, validity, and responsiveness.

Strategy of data synthesis: Tables will be used to agglomerate and present the data. A descriptive analysis will be completed. Each PROMs will be described in terms of characteristics, construct, psychometric properties, and study population. Based on the results, the PROMs will be compared, and subgroup analysis will be performed based on the study population.

Subgroup analysis: None planned.

Sensitivity analysis: Not applicable.

Language restriction: Articles in English or French will be considered.

Country(ies) involved: Canada.

Other relevant information: Not applicable.

Keywords: Sexual functioning; Sexual well-being; Disability; Patient-reported outcomes measures.

Dissemination plans: The scoping review once completed will be published in a peer-reviewed journal and the results will be presented at relevant scientific congresses.

Contributions of each author:

Author 1 - Isabelle Fisette-Paulhus - The author developed, prepared the protocol, and helped to elaborate the search strategy. She will participate in the study's selection, data extraction and assessment of the quality of PROMs. She will analyze, synthesize and report the results emerging from this study.
isabelle.fisette-paul.hus@usherbrooke.ca
Author 2 - Cynthia Gagnon - The author assisted in the conception and design of the study. She will supervise the selection, extraction and quality assessment. The author will contribute to the analysis and interpretation of the data. She will also participate in the redaction of the manuscript.
cynthia.gagnon4@usherbrooke.ca
Author 3 – Catherine Labbé – The author prepared the protocol and helped to elaborate the search strategy. She will participate in the study's selection based on inclusion criteria, data extraction and assessment of the quality of PROMs.
Catherine.Labbe2@USherbrooke.ca
Author 4 – Mélanie Morin - The author designed the project, supervised and prepared the protocol. She will supervise study selection, data extraction and quality assessment. The author will contribute to the analysis and interpretation of the data. She will also participate in the redaction of the manuscript. She will supervise the study.
melanie.m.morin@usherbrooke.ca

References: 1. Giraldi, A., et al., Questionnaires for assessment of female sexual dysfunction: a review and proposal for a standardized screener. J Sex Med, 2011. 8(10): p. 2681-706.
2. Daker-White, G., Reliable and valid self-report outcome measures in sexual (dys)function: a systematic review. Arch Sex Behav, 2002. 31(2): p. 197-209.
3. t Hoen, L.A., et al., A Quality Assessment of Patient-Reported Outcome Measures for Sexual Function in Neurologic Patients Using the Consensus-based Standards for the Selection of Health Measurement Instruments Checklist: A Systematic Review. Eur Urol Focus, 2017. 3(4-5): p. 444-456.
4. White, I.D., et al., Assessment of sexual difficulties associated with multi-modal treatment for cervical or endometrial cancer: A systematic review of measurement instruments. Gynecol Oncol, 2016. 143(3): p. 664-673.
5. Ratti, M.M., et al., Standardising the Assessment of Patient-reported Outcome Measures in Localised Prostate Cancer. A Systematic Review. Eur Urol Oncol, 2022. 5(2): p. 153-163.
6. Szasz, G., Sex and disability are not mutally exclusive. Evaluation and management. West J Med, 1991. 154(5): p. 560-3.
7. Ferreiro-Velasco, M.E., et al., Sexual issues in a sample of women with spinal cord injury. Spinal cord, 2005. 43(1): p. 51-5.
8. Nery-Hurwit, M.B., et al., Development of a Conceptual Framework of Sexual Well-being for Women with Physical Disability. Women's Health Issues, 2022. 32(4): p. 376-387.
9. Eisenberg, N.W., Andreski, SR. & Mona, L.R, Sexuality and Physical Disability: A Disability-Affirmative Approach to Assessment and Intervention Within Health Care. Curr Sex Health Rep 7, 19–29, 2015.
10. Nazari, F., et al., Sexual dysfunction in women with multiple sclerosis: prevalence and impact on quality of life. BMC Urology, 2020. 20(1): p. 15.
11. World Health Organisation, International

Classification of Functioning, Disability and Health (ICF). 2001.
12. United Nations, Convention on the Rights of Persons with Disability. 2006.
13. Summerville, P. and K. McKenna, Sexuality Education and Counselling for Individuals with a Spinal Cord Injury: Implications for Occupational Therapy. British Journal of Occupational Therapy, 1998. 61(6): p. 275-279.
14. Post, M., et al., Sexological Competence of Different Rehabilitation Disciplines and Effects of a Discipline-specific Sexological Training. Sexuality and Disability, 2008. 26: p. 3-14.
15. Areskoug-Josefsson, K., et al., Health Care Students' Attitudes Towards Working with Sexual Health in Their Professional Roles: Survey of Students at Nursing, Physiotherapy and Occupational Therapy Programmes. Sexuality and Disability, 2016. 34(3): p. 289-302.
16. Hatzichristou, D., et al., Diagnosing Sexual Dysfunction in Men and Women: Sexual History Taking and the Role of Symptom Scales and Questionnaires. J Sex Med, 2016. 13(8): p. 1166-82.
17. Peters, M.D.J., et al., Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth, 2020. 18(10): p. 2119-2126.
18. Tricco, A.C., et al., PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med, 2018. 169(7): p. 467-473.
19. Peters MDJ GC, M.P., Munn Z, Tricco AC, Khalil, H, Chapter 11: Scoping Reviews. In: Aromataris E MZ, ed. JBI Manual for Evidence Synthesis. JBI, 2020.
20. Conijn, A.P., et al., Assessing the quality of available patient reported outcome measures for intermittent claudication: a systematic review using the COSMIN checklist. Eur J Vasc Endovasc Surg, 2015. 49(3): p. 316-34.