Social participation experiences of older adults with an early-onset physical disability: a systematic review protocol

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Abstract

Objective: The objective of this review is to assess and synthesize the available qualitative evidence on the experiences of social participation of older adults with an early-onset physical disability.

Introduction: Understanding the experiences of social participation among older adults with a physical disability acquired earlier in life can guide the development of interventions and policies. It will also help with fostering meaningful community participation and aid in improving the quality of their social participation.

Inclusion criteria: This review will consider primary studies that explore the experiences of social participation of older adults with an early-onset physical disability. The review will focus on qualitative data, including methods such as phenomenology, grounded theory, ethnography, action research, and feminist research. Studies in French or English will be considered for inclusion, and there will be no limitation on publication dates.

Methods: A keyword search strategy will be carried out in MEDLINE (Ovid), PsycINFO (Ovid), CINAHL (EBSCO), Web of Science, and The Cochrane Library. ProQuest Dissertations and Theses (ProQuest) will be searched for unpublished articles. Two independent reviewers will perform the screening and inclusion process, assess the quality of the evidence, and complete data extraction. The JBI approach to critical appraisal, study selection, data extraction, and data synthesis (meta-aggregation) will be used. The ConQual approach will be used to establish confidence in the synthesized findings.

Review registration number: PROSPERO CRD42022371027

Keywords: older adults; physically disabled; qualitative research; rehabilitation; social participation

Introduction

According to the World Health Organization, 15% of the world's population lives with a disability.[1] Due to medical and rehabilitation advances and improved social conditions, older adults with an early-onset physical disability are experiencing an increase in life expectancy.[2-4] An older adult with an early-onset physical disability is defined as a person with physical disability at birth, or acquired in childhood or young adulthood, who is aging.[3] The terminology *older adults with physical disabilities* is preferred in this article, as opposed to *physically disabled people*, to put the individual first, not their disability. In the United States alone, there is 12 to 15 million older adults with a disability that occurred prior to age 40.[5]

Molton and Yorkston[6] found that the life trajectories of older adults with an early-onset physical disability differ from the life trajectories of people who acquired a disability at a later age. As an example of this, older adults with a physical disability acquired earlier in life face additional medical problems, such as premature apparition of comorbidities or premature decline in health.[3,7] The intersection of aging and living with a physical disability also creates challenges for communities (eg, an increase in health costs, a need to adapt public policies).[2,4,8,9] Aging with an early-onset physical disability is also associated with reduced social participation.[6]

Social participation can be defined as "a person's involvement in activities providing interactions with others in community life and in important shared spaces, evolving according to available time and resources, and based on the societal context and what individuals want and is meaningful to them."[10(p.1)] For older adults, a fulfilling role in social participation is associated with lower risk of mortality,[10] greater self-esteem,[11] and a higher sense of control over one's life.[13,14] Satisfying social participation can also contribute to the preservation and development of physical,[15] cognitive,[16,17] and affective[15] capacities.

Several recent literature reviews have examined the social participation of older adults from different perspectives.[18-21] Ibrahim *et al.*[18] conducted a systematic review on the interventions supporting the social participation of community-dwelling older adults. A scoping study by Levasseur *et al.*[19] mentions the importance of proximity to resources, neighborhood safety, and social support networks as determinants of social participation of

older adults. Garmabi *et al.*[20] conducted a systematic review on the factors associated with the participation of community-dwelling older adults in leisure activities, and Townsend *et al.*[21] synthetized the barriers and facilitators for social participation of older adults.

However, even if social participation can have physical, cognitive, and affective benefits for older adults with an early-onset physical disability,[3,4,9] no review has focused on this population's experience of social participation. Knowledge about how social participation is experienced by this population remains sparse,[4,8] but primary studies on this topic have been published. For example, a recent qualitative study of the experience of social participation of older adults with the sequelae of traumatic brain injury suggests a list of facilitators (eg, feeling valued when doing an activity, having fun while doing the activity) and barriers (eg, doing activities with people with unequal levels of disability, negotiating winter conditions) to social participation.[7] Mars *et al.*[22] studied social participation in older adults with chronic physical illness. In their article, social participation was lived, described as a positive experience, and was structured around 4 domains (social contacts and social activities; work and informal support; cultural activities and public events; and politics and media). Rémillard *et al.*[23] conducted 60 semi-structured individual interviews with older adults with long-term mobility disabilities and found that this population is likely to experience barriers to social participation (eg, negative societal attitudes, limitation in transport accessibility and availability, financial limitation). In Raymond et al.,[24] social participation was described by participants (ie, older adults with early-onset spinal cord injury, hearing impairment, or cerebral palsy from birth) as both a vehicle for social inclusion and social exclusion.

The synthesis of this knowledge is important as it will contribute to the development of interventions and policies that foster meaningful and satisfying participation for older adults with early-onset physical disability. A preliminary search of PROSPERO, MEDLINE, The Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted in late October 2022, and no current or in-progress systematic reviews on the topic were identified.

This study will assess and synthesize the available qualitative evidence on the experiences of social participation of older adults with an early-onset physical disability.

Review questions

i) What is known about the experiences of social participation of older adults with an early-onset physical disability?
ii) What are the needs expressed by older adults with an early-onset physical disability with regards to social participation?
iii) What are the potential barriers and facilitators to social participation of older adults with an early-onset physical disability?

Inclusion criteria

Participants

This qualitative review will consider studies that include older adults (aged 55 and over) with an early-onset physical disability (those with a physical disability at birth, or acquired in childhood or in young adulthood).[3] Studies containing mixed ages will be considered provided 80% of the sample is older adults or demographic-specific information can be identified relevant to the inclusion criteria. In this review, participants' physical disabilities may result from a health condition present at birth (eg, spina bifida, cerebral palsy); a health condition (eg, multiple sclerosis); or a lesion (eg, brain injury, spinal cord injury) acquired in childhood or in young adulthood. The threshold of 55 years and over was chosen to align with age thresholds previously observed in studies[7] on older adults with an early-onset physical disability. This choice of age criterion also reflects that individuals with an early-onset physical disability are likely to experience premature aging.[25]

Although our research is rooted in the intersectionality between age and disability in relation to social participation, we recognize the importance of considering other social categorizations that may impact on the experience of social participation (eg, gender identity, sexual orientation, socioeconomic level, severity of disability, presence of comorbidity, ethnicity, race). Beyond the individual dimension, we also recognize the influence of systemic factors that can affect social participation (eg, attitudes towards people with disabilities, impeditive or difficult access to public services, free-of-cost social participation and/or health services). In this sense, we will provide a thorough description of the samples of the selected primary studies and, where possible, the results will be synthesized according to these factors.

Phenomena of interest

This review will consider studies that describe the experiences of social participation of older adults with an early-onset physical disability. In this study, the definition of social participation is taken from the study by Levasseur: "a person's involvement in activities providing interactions with others in community life and in important shared spaces, evolving according to available time and resources, and based on the societal context and what individuals want and is meaningful to them."[10(p.1)] This definition was chosen because it is based on an exhaustive inventory of definitions of social participation by older adults, accompanied by a content and a critical analysis of these definitions by content experts and knowledge users.

All occupations or activities carried out in a context that aligns with the definition by Levasseur et al. will be considered social participation. Thus, examples of social participation may include, but are not limited to, shopping for groceries with one's spouse at the market, going to a music show with friends, participating in supervised art therapy sessions at a day center, volunteering at a school, or participating in citizen consultations on neighborhood issues. There will be no limit to the level of social participation in terms of the inclusion criteria. It is important that all levels of social participation be considered to have the most comprehensive picture of experiences related to social participation possible.

Needs in relation to social participation are defined as "a gap between current and desired status"[26(p.2)] (eg, a need to engage in more activities with loved ones or a desire to participate in more work-related activities). Finally, barriers represent elements that hinder or limit social participation (eg, few opportunities for social participation in the environment, high cost of transport). Conversely, facilitators are those elements that enable and support social participation (eg, a built environment that adheres to universal access standards, a support network that offers accompaniment in the community).

Context

Experiencing social participation, in the context of this study, refers to the way in which an individual actualizes their social participation; that is, what they do, with whom they do it, the meaning given to their activities, the places they frequent, the resources they use in their environment to participate, their needs in terms of social participation, as well as the

elements perceived as having an influence on their social participation (ie, obstacles and facilitators).

The authors of this manuscript recognize the diversity and idiosyncrasies associated with experiences of disability and social participation. All studies that meet the objective of this review will be included regardless of the sociocultural context or country in which the studies were conducted. Given that the experience of social participation is idiosyncratic, this study will hopefully provide useful information on the diversity of these experiences, supporting the development for tailored interventions that embrace that diversity.

Types of studies

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Descriptive qualitative studies that describe the experiences of social participation of older adults with an early-onset physical disability will also be considered. Qualitative components of mixed-method studies will also be included if the qualitative results are reported separately. Quantitative studies, editorials, commentaries, letters, and conference abstracts will be excluded.

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.[27] This protocol is registered in PROSPERO (CRD42022371027).

Search strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE (Ovid) and CINAHL (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE (Ovid; see Appendix I). The search strategy was validated by a scientific librarian with expertise in the field of disability. The search strategy will be translated to meet the requirements of the respective search platforms. The reference list of all studies selected for

critical appraisal will be screened for additional studies. Studies published via MEDLINE (Ovid), PsycINFO (Ovid), CINAHL (EBSCO), Web of Science, and The Cochrane Library will be searched. ProQuest Dissertations and Theses (ProQuest) will be searched for unpublished articles. The search will include studies published in English or French, as our team consists of researchers proficient in both these languages. As imposing date restrictions can result in the exclusion of relevant studies conducted before a specific period, no restriction will be applied on the year of publication.

Study selection

Following the search, all identified citations will be collated and uploaded into Covidence (Veritas Health Innovation, Melbourne, Australia) and duplicates removed. Following a pilot test, titles and abstracts will be screened by 2 independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full, and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).[28]

The full text of selected citations will be assessed in detail against the inclusion criteria by 2 independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be reported in the final systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.[29]

Assessment of methodological quality

Eligible studies will be critically appraised by 2 independent reviewers for methodological quality using the standard JBI critical appraisal checklist for qualitative research.[27] Both reviewers will pilot test the confidence level of the evidence on an identical sample of 10% of the included articles.

Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be

resolved through discussion or with a third reviewer. The results of critical appraisal will be reported in narrative format and in a table.

All relevant studies, regardless of their methodological quality will undergo data extraction and synthesis. This will provide a comprehensive synthesis of the available evidence. Low-quality studies could potentially offer valuable insights into the studied phenomenon; however, readers will be provided with the level of evidence of all the primary studies included in this review. They will also be provided with the level of evidence of the syntheses that emerge from this review.

Data extraction

Data will be extracted from the included studies by 2 or more independent reviewers using JBI SUMARI's standardized data extraction tool.[28] The verbatim extracts will include specific details about the populations, context, culture, geographical location, study methods, and the phenomena of interest relevant to the review objective. Findings and their illustrations will be extracted and assigned a level of credibility. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta- aggregation approach.[30] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings based on similarity in meaning. These categories will then be subjected to a synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative format. Only unequivocal and credible findings will be included in the synthesis.

Assessing confidence in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a

Summary of Findings.[31] The Summary of Findings will include the major elements of the review and detail how the ConQual score was developed. Included in the Summary of Findings will be the title, population, phenomena of interest, and context for the specific review. Each synthesized finding from the review will then be presented along with the type of research informing it, score for dependability and credibility, and the overall ConQual score.

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Declarations

Université de Montréal is situated on land where, long before the arrival of the French, people of many Indigenous nations came together and interacted. We wish to acknowledge these nations, their descendants and the spirit of fraternity that presided over the signing in 1701 of the Great Peace of Montreal, a treaty that fostered peaceful relationships between France, its Indigenous allies, and the Haudenosaunee federation (pronunciation: O-di-no-sho-ni). The spirit of fraternity that inspired this treaty serves as a model for our own university community.

We recognize that the main campus of the *Université de Sherbrooke* is located on the unceded ancestral territory of the W8banaki Nation, the Ndakina.

Author contributions

ST and PS contributed to the writing of the original draft of the manuscript as well as the methodology. ST acquired the funding for the review and supervised the project. All authors contributed to the conceptualization of the project and to the review and editing of the manuscript.

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Appendix I: Search strategy

MEDLINE (Ovid)

Search conducted April 18, 2023

#	Query	Results retrieved
1	(Ageing or Aging or "grow* old*" or "older adult*" or elder* or "older person*").ti,ab.	613,349
2	Aging/	249,389
3	1 or 2	735,849
4	(Disabilit* or Disabled or Handicap* or "Physical limitation*" or impair* or incapacit*).ti,ab.	1,078,780
5	("multiple sclerosis" or "trauma* brain injur*" or "TBI" or "TBIs" or "brain trauma*" or "Acquired brain injur*" or "Head injur*" or "Spinal cord injur*" or "Spinal cord trauma*" or " traumatic encephalopath*" or Parapleg* or Tetrapleg* or Quadripleg*or Myelopath*).ti,ab.	221,856
6	Disabled Persons/ or exp Multiple Sclerosis/ or exp Brain injuries, Traumatic/ or Spinal Cord Injuries/ or Paraplegia/ or Quadriplegia/	196,808
7	4 or 5 or 6	1,304,762
8	((communit* or societ* or social or civic) adj3 (participat* or involv* or inclus* or integrat* or engag* or implicat* or interact* or activit* or citizenship)).ti,ab.	117,694
9	Social Participation/	3399
10	8 or 9	118,950
11	3 and 7 and 10	2154