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REVIEW ARTICLE

Measuring Participation for Children and Youth With Power Mobility Needs: A Systematic Review of Potential Health Measurement Tools

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Abstract

Objectives: To identify and critically appraise potential participation measurement tools for children aged 18 months to 17 years with power mobility (PM) needs.

Data Sources: Searches in 9 electronic databases identified peer-reviewed publications in English to January 2015, along with hand-searching included bibliographies.

Study Selection: The Preferred Reporting Items for Systematic reviews and Meta-Analyses statement was followed with inclusion criteria set a priori. Keywords and subject headings included participation and measurement terms with descriptors of young people who are potential PM candidates. Publications describing measurement properties of English-language tools were included if the items included ≥85% content related to participation and described at least 2 participation dimensions.

Data Extraction: Two reviewers reached consensus after independently screening titles and abstracts, identifying full-text articles meeting criteria, extracting data, and conducting quality ratings. Tool descriptions, clinical utility, and measurement properties were extracted. Study quality and measurement properties were evaluated using the COnsensus-based Standards for the selection of health Measurement INstruments checklist and the McMaster Outcome Measures Rating Form.

Data Synthesis: Of 1330 titles identified, 138 peer-reviewed publications met study inclusion criteria. Fifty tools were identified, of which 20 met inclusion criteria. Evidence supporting reliability and validity varied considerably. Two tools had responsiveness evidence, an important measurement property when evaluating change. Quality ratings were strongest for internal consistency and content validity. Ratings were downgraded because of small sample sizes and a limited description of missing data or study conditions.

Conclusions: While potential tools emerged (Assessment of Preschool Children's Participation, Preferences for Activities of Children, Child and Adolescent Scale of Participation, Child Engagement in Daily Life, Canadian Occupational Performance Measure, Questionnaire of Young People's Participation), none were judged best suited for use with children having PM needs. Further empirical studies with this population are needed before recommending use for PM applications.

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Improving participation in everyday life is a common goal and one of the most meaningful rehabilitation outcomes for children and youth with physical disabilities and for their families.[1,2] In this article, for ease of reading, "children" will be used in reference to children and youth aged 18 months to 17 years

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(inclusive) who may benefit from power mobility (PM) interventions, including assessment, prescription, provision, training, and monitoring use of powered devices such as wheelchairs, ride-on toy cars, standers, or scooters. For those with mobility limitations, PM devices are often recommended as one of several options to facilitate independent mobility.[3,4] Independent mobility enables children to move about their environment, providing foundational experiences for cognitive and psychosocial development.[5] Frequently, the expectation is that by enabling independent mobility, participation in everyday life will improve. However, there is limited empirical pediatric research evidence supporting the effectiveness of PM for increasing participation.[5-7] Determining suitable measurement tools is a necessary step toward quantifying the differences that PM makes on children's participation in everyday life.

The *International Classification of Functioning, Disability and Health* (ICF)[8] and the ICF Child and Youth version[9] serve as a conceptual framework, whereby health is influenced by the interaction between the individual's health condition, personal factors, body structures and functions, activity, participation, and surrounding environmental factors.[8,9] The ICF[8(p12),9] defines activity as "execution of a task" and participation as "involvement in life situations." Disability may be experienced as impairments in body structure or functioning, activity limitations, or participation restrictions.[8,9]

Participation in everyday life situations such as learning, contributing to family life, or playing with friends is crucial to children's healthy development[10] and influences self-confidence, satisfaction, competence, functional abilities, and social skills.[11,12] Ultimately, participation in these life situations promotes well-being, growth, and independence.[1,13] PM devices, considered an environmental factor,[8,9] aim to minimize restrictions and improve participation.

Evidence suggests that children with physical disabilities participate in less diverse, more indoor, home-based, and less physically active life situations compared with typically developing peers or those with other types of disabilities.[14,15] Moreover, differences in age, sex and ability levels influence children's engagement, intensity, and enjoyment, as well as the support needed.[13,16] However, research regarding participation in childhood life situations specifically for those using PM is limited.[5-7] Given the importance of understanding the nature, variability, and consequences of participation,[17] continued investigation is warranted.[4,18] This lack of knowledge about children's participation while using PM is further compounded by studies that use measurement tools with unknown or limited reliability and validity. Selection of tools should be guided by evidence of the tools' reliability and validity for the population under investigation in order to have confidence in the interpretation of findings.[19] The shortage of measurement tools validated with children using PM is one reason research has not progressed further.[7,18]

List of abbreviations:

COPM	**Canadian Occupational Performance Measure**
COSMIN	**COnsensus-based Standards for the selection of health Measurement INstruments**
ICF	***International Classification of Functioning, Disability, and Health***
OMRF	**McMaster Outcome Measures Rating Form**
PM	**power mobility**

Within the last decade, reviews have synthesized information about tools developed to measure participation,[1,11,20,21] with some targeting specific populations.[22-26] Given that children using PM have a variety of diagnoses with limited numbers within a single diagnostic group, the relevance of these reviews' findings are debatable and suggests a need to measure participation based on functional ability rather than by diagnoses alone.[15] Furthermore, many reviews[11,20-22,24-26] explore tools for both activity and participation, making it difficult to separate tools that measure participation only. While there is a body of evidence that supports the influence of PM on activity-level outcomes, the real need is to demonstrate the impact of PM on participation.[5,7] Debate over how to define participation and differentiate it from activity within the ICF framework makes measuring this construct more complex.[2,8,9,11] Additionally, reviews operationalize participation differently, making it harder to compare results.

Choosing a suitable tool to measure participation is challenging, given the number of measurement tools available, the different dimensions of participation that are evaluated by these tools,[2,11] and the unique needs of children who may benefit from PM. The purpose of this systematic review[27] was to identify and critically appraise participation measurement tools appropriate for use in children younger than 18 years with potential PM needs, and to advance our understanding of what tools might be suitable for describing their participation. Our primary clinical question was, "For children under 18 years of age with mobility limitations who may benefit from PM interventions, what measurement tools are used to assess participation in everyday life situations?" Secondary questions included, "Are the reported measurement properties adequate for measuring participation in children with PM needs?" and "What aspects of participation do these tools address?"

Methods

The National Center for the Dissemination of Disability Research comprehensive guidelines[27] along with the Preferred Reporting Items for Systematic reviews and Meta-Analyses statement[28] were used to structure this systematic review. A review protocol is available from the authors.

Search strategy

An electronic database search conducted by 2 reviewers (D.A.F., A.A.) identified primary peer-reviewed studies and systematic reviews published from database inception to January 2015. Nine databases included CINAHL, EBM Reviews (eg, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Health Technology Assessment), EMBASE, ERIC, Health and Psychosocial Instruments, MEDLINE (Ovid SP), OTseeker, Physiotherapy Evidence Database (PEDro), and PsycINFO.

A multipurpose keyword search strategy included word stem descriptors of children with mobility limitations, participation, and measurement tools. Keywords were also mapped to relevant database subject headings. Supplemental table S1 (available online only at http://www.archives-pmr.org/) provides a listing of keywords and search terms for each database, while supplemental appendix S2 (available online only at http://www.archives-pmr.org/) gives a sample search strategy.