

ORIGINAL RESEARCH

Environmental Factors Item Development for Persons With Stroke, Traumatic Brain Injury, and Spinal Cord Injury



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Abstract

Objectives: To describe methods used in operationalizing environmental factors; to describe the results of a research project to develop measures of environmental factors that affect participation; and to define an initial item set of facilitators and barriers to participation after stroke, traumatic brain injury, and spinal cord injury.

Design: Instrument development included an extensive literature review, item classification and selection, item writing, and cognitive testing following the approach of the Patient-Reported Outcomes Measurement Information System.

Setting: Community.

Participants: Content area and outcome measurement experts (n=10) contributed to instrument development; individuals (n=200) with the target conditions participated in focus groups and in cognitive testing (n=15).

Interventions: None.

Main Outcome Measures: Environmental factor items were categorized in 6 domains: assistive technology; built and natural environment; social environment; services, systems, and policies; access to information and technology; and economic quality of life.

Results: We binned 2273 items across the 6 domains, winnowed this pool to 291 items for cognitive testing, and recommended 274 items for pilot data collection.

Conclusions: Five of the 6 domains correspond closely to the *International Classification of Functioning, Disability and Health* taxonomy of environmental factors; the sixth domain, economic quality of life, reflects an important construct that reflects financial resources that affect participation. Testing with a new and larger sample is underway to evaluate reliability, validity, and sensitivity.

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The General Assembly of the United Nations' has identified participation as a primary and highly valued goal of rehabilitation, health care, and social services for people with disabilities.¹ People with disabilities and their advocates emphasize that the physical, social, political, and economic aspects of the environment are important influences on health and participation.² The World Health Organization's *International Classification of Functioning, Disability and Health* (ICF)³ has become the de facto taxonomy by which to describe the precursors and consequences of disability. The ICF identifies environmental factors into the following 5 categories: products and technology; natural environment; support and relations; attitudes; and services, systems, and policies. In spite of its ascendancy, the ICF has been criticized for failing to provide a model of the disablement/enableness process.⁴ The ICF provides no less than 3 different coding conventions for its 5 environmental factor chapters, leaving instrument developers with considerable latitude in how to operationalize environmental factors.

Many measures of the physical and social environment lack a strong theoretical foundation^{5,6} and fail to clarify the dynamic interaction between participation and environment.⁷ Mallinson and Hammel⁸ emphasize the need for a transactional measurement approach that describes activity and participation in the context of the environment, including physical, social, and attitudinal supports; barriers to task and role performance; and social and community participation.

In spite of these conceptual and measurement challenges, the last decade has seen increased interest in the development of measures of the environment, and there are several high-quality reviews of these instruments in the rehabilitation literature.^{5,9} For example, Whiteneck,⁵ Noreau,⁹ and colleagues describe methodologic challenges in operationalizing environmental factors. There is, however, no consensus on which instruments are best for describing participation-environment interactions. Empirical evidence of the impact of the environment on participation is inconsistent.^{9,10}

Many contemporary measures of the environment use the classical test theory and combine multiple aspects of the environment into a single scale or report descriptive, item-level information only; these issues are reviewed in the first article of this special issue.¹¹ Given that participation occurs across multifaceted environments, instrument development must strike a balance between measurement precision and respondent burden.⁵ Rather than try to capture the environment in its entirety (which would be very difficult to do), we should focus on assessing aspects of the environment that either are amenable to change or are expected to affect specific outcomes in targeted communities. Although it remains unclear what the most appropriate measurement models are for assessing environmental factors and their impact on participation, it is evident that we need additional research and approaches to refine the construct of environmental facilitators and barriers to participation.

List of abbreviations:

AT	assistive technology
ICF	<i>International Classification of Functioning, Disability and Health</i>
PROMIS	Patient-Reported Outcomes Measurement Information System
SCI	spinal cord injury
TBI	traumatic brain injury

Contemporary psychometric methods and the application of item response theory provide a viable approach to measurement of environmental factors. In this study, we sought to apply a fresh approach to the measurement of environmental factors using the mixed-methods instrument development process championed by the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative.¹² We sought to focus on environmental factors that people with disabilities perceive as facilitating participation or acting as barriers. We purposely focused on the subjective experiences of environmental factors, which are best captured by self-report, rather than objective environmental descriptions. These issues are summarized in the second article of this special issue.¹³ Therefore, the objectives of this article are (1) to describe the methods used to operationalize environmental factors; (2) to describe the results of a research project to develop measures of environmental factors that affect participation; and (3) to describe an initial item set of facilitators and barriers to participation. The goal of the larger project of which this study is a component is to develop, test, and evaluate measures of environmental factors and their influence on participation for persons with stroke, traumatic brain injury (TBI), and spinal cord injury (SCI). A validated set of environmental factor instruments will allow us to determine to what extent they influence social health and participation.

Methods

We used a mixed-methods approach to constructing and evaluating items. The major tasks, which are subsequently described, entailed concept elicitation, item classification and creation, and item refinement. These tasks and procedures follow the standards established by the PROMIS Network.¹² A domain chair and cochair oversaw the development of each item set. We obtained institutional review board approval for this project prior to the start of this project.

Phase I: Concept elicitation, qualitative focus group analysis, and conceptual modeling

As part of our ongoing research on participation, we had access to verbatim transcripts from 38 focus groups involving >200 people with diverse disabilities across different sites and regions.¹⁴⁻¹⁶ The samples included people with stroke, TBI, SCI, and other disabilities. We analyzed these data to create participation and quality of life assessments (eg, community participation indicators, SCI quality of life/TBI quality of life measurement systems).¹⁶⁻¹⁸ In the focus groups, participants stressed the importance of environmental factors influencing participation; the depth and detail of environmental factor information allowed us to reanalyze the data for the current project. We used a grounded theory approach and constant comparative approach to coding and interpreting.¹⁹ This analysis yielded rich environmental factor themes, detailed examples, and relevant quotes to highlight specific factors across the groups. We categorized the feedback in 8 distinct environmental factor domains identified as important by people with disabilities. The second column of [table 1](#) lists the domains. Some of these domains directly correspond to ICF typology shown in column 1 (eg, systems, services); others focus on specific components of ICF environmental factor chapters (eg, transportation, assistive technology [AT]), and one represents an issue that is an infrequent focus of research, economic quality of

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