Archives of Physical Medicine and Rehabilitation
journal homepage: www.archives-pmr.org
Archives of Physical Medicine and Rehabilitation 2016;■:■■■-■■■

ORIGINAL RESEARCH

An Item Bank to Measure Systems, Services, and Policies: Environmental Factors Affecting People With Disabilities

Jin-Shei Lai, PhD, OTR/L,[a] Joy Hammel, PhD, OTR,[b] Sara Jerousek, BS,[c]
Arielle Goldsmith, MS,[c] Ana Miskovic, BA,[c] Carolyn Baum, PhD, OTR,[d]
Alex W. Wong, PhD, DPhil,[d] Jessica Dashner, OTD, OTR,[d] Allen W. Heinemann, PhD[c,e]

From the [a]Department of Medical Social Sciences and Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL; [b]Department of Occupational Therapy, University of Illinois, Chicago, Chicago, IL; [c]Center for Rehabilitation Outcomes Research, Rehabilitation Institute of Chicago, Chicago, IL; [d]Program in Occupational Therapy, Washington University, St Louis, MO; and [e]Department of Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine, Chicago, IL.

Abstract

Objectives: To develop a measure of perceived systems, services, and policies facilitators (see Chapter 5 of the *International Classification of Functioning, Disability and Health*) for people with neurologic disabilities and to evaluate the effect of perceived systems, services, and policies facilitators on health-related quality of life.

Design: Qualitative approaches to develop and refine items. Confirmatory factor analysis including 1-factor confirmatory factor analysis and bifactor analysis to evaluate unidimensionality of items. Rasch analysis to identify misfitting items. Correlational and analysis of variance methods to evaluate construct validity.

Setting: Community-dwelling individuals participated in telephone interviews or traveled to the academic medical centers where this research took place.

Participants: Participants (N=571) had a diagnosis of spinal cord injury, stroke, or traumatic brain injury. They were 18 years or older and English speaking.

Interventions: Not applicable.

Main Outcome Measures: An item bank to evaluate environmental access and support levels of services, systems, and policies for people with disabilities.

Results: We identified a *general factor* defined as "access and support levels of the services, systems, and policies at the level of community living" and 3 *local factors* defined as "health services," "community living," and "community resources." The systems, services, and policies measure correlated moderately with participation measures: Community Participation Indicators (CPI) – Involvement, CPI – Control over Participation, Quality of Life in Neurological Disorders – Ability to Participate, Quality of Life in Neurological Disorders – Satisfaction with Role Participation, Patient-Reported Outcomes Measurement Information System (PROMIS) Ability to Participate, PROMIS Satisfaction with Role Participation, and PROMIS Isolation.

Conclusions: The measure of systems, services, and policies facilitators contains items pertaining to health services, community living, and community resources. Investigators and clinicians can measure perceptions of systems, services, and policies resources reliably with the items described here. Moderate relations between systems, services, and policies facilitators and PROMIS and CPI variables provide support for the measurement and theory of environmental effects on social functioning related to participation.

Archives of Physical Medicine and Rehabilitation 2016;■:■■■-■■■

Supported by the National Institute on Disability, Independent Living, and Rehabilitation Research through a Rehabilitation Research and Training Center on Improving Measurement of Medical Rehabilitation Outcomes grant (grant no. H133B090024).

Disclosures: none.

0003-9993/16/$36 - see front matter © 2016 by the American Congress of Rehabilitation Medicine
http://dx.doi.org/10.1016/j.apmr.2016.06.010

Individuals with neurologic disabilities, such as a spinal cord injury (SCI), traumatic brain injury (TBI), and stroke, are likely to experience long-term functional issues that affect participation many years after rehabilitation, suggesting that long-term disabilities should be considered as chronic conditions.[1-6] People with long-term disabilities have identified repeatedly that environmental facilitators and barriers affect their participation in home, communities, employment, and society, pointing to environmental barriers as "disabling."[7-9]

As described in Lawton's environment competence press model,[10] as people age and during times of significant life changes such as those experienced after a disabling event, individuals increasingly rely on environmental resources they can access through family, friends, community networks, organizations, systems, and government to support their engagement and participation.[11,12] However, many of these environmental resources are not easily and equitably available to people with disabilities who need long-term services such as personal attendants, homemakers, and home modifications to help with basic and instrumental activities of daily living, for example, shopping, banking, and meal preparation.[13] People with disabilities often describe a lack of environmental and community supports and services to venture outside their homes and participate fully in society, such as accessible housing, transportation, childcare, and accommodations in the community and workplace. This is probably due to a lack of availability or lack of awareness of available resources.[14,15] Participation is restricted further if information about services is inaccessible or prepared in difficult to understand formats.[16] These environmental and community supports and services are often funded and regulated by national, state, and local systems and policies, with significant variations between states and systems, creating disparities in resource allocation and availability and across disability and aging groups, further resulting in substantial unmet needs.[17,18] Thus, services, systems, and policies represent a macro or societal level environmental effect on health and participation in the Social Determinants of Health framework widely used in public health and by the World Health Organization.[19] Access to affordable, reliable, and quality services that are coordinated across medical, health, home, and community-based providers and systems is essential to improve the likelihood of participating in one's community and realizing the health, quality of life, and well-being outcomes associated with participation.[13,20,21]

Little research has focused on the availability, accessibility, and effectiveness of environmental services, systems, and policies for people with long-term disabilities, nor the effects of service availability on participation and health in communities after rehabilitation.[21] When community services are available, quality and accessibility of services are inconsistent; thus, evaluating effectiveness of these services is challenging owing to a lack of commonality across services. Needed is a comprehensive environmental assessment tool that can assess access to, awareness of, and quality of supports and services across systems and policies, which can also take into account diversities across systems and policies, from the perspective of consumers. To address this need, we developed an item bank measuring access to and adequacy of services, systems, and policies as perceived by people living with long-term disabilities. Our target population was adults with TBI, SCI, and stroke living in their communities.

This article reports the psychometric properties of an item bank measuring access and support levels of services, systems, and policies at the level of community living and describes its potential applications across a continuum of settings from acute and inpatient rehabilitation to community-based services and programming, including developing primary care systems that follow people into their communities. An item bank is a set of items, defining a single construct and calibrated onto the same measurement continuum using item response theory models, including the Rasch measurement model.[22] This model allows comparison of scores from different informants at different times regardless of whether the same items are administered. We focused on developing an item response theory−calibrated item bank in this project because of its major advantage, in which respondents do not need to answer the entire item set. Item response theory−calibrated item banks allow the use of dynamic computerized adaptive testing and static short forms that enable precise estimation of a trait while minimizing response burden to informants[23-26] and tailored assessments that target individual's differences. These features are particularly important for individuals with disabilities because their functional status does not allow them to complete a lengthy and comprehensive survey, and levels of environmental resources and supports vary postrehabilitation.

List of abbreviations:

CFI	**comparative fit index**
CPI	**Community Participation Indicators**
DIF	**differential item functioning**
NeuroQoL	**Quality of Life in Neurological Disorders**
PROMIS	**Patient-Reported Outcomes Measurement Information System**
RMSEA	**root mean square error of approximation**
SCI	**spinal cord injury**
TBI	**traumatic brain injury**

Methods

Systems, services, and policies item pool development

This study was part of a research project to develop measures that affect participation and reflect the Environmental Factors codes represented in the *International Classification of Functioning, Disability and Health*,[27] as identified in Heinemann et al,[16] and to define an initial item set of facilitators and barriers to participation after stroke, TBI, and SCI. Details of the domain identification and item development were described in Heinemann[16] and are not repeated here. In brief, the initial systems, services, and policies item pool consisted of 411 items obtained from 3 sources: (1) focus groups composed of 201 people with SCI, TBI, and stroke across several states and across several federally funded research projects[14]; (2) results of a systematic literature review to identify relevant items from existing instruments (eg, Measure of Quality of the Environment,[28] Craig Hospital Inventory of Environmental Factors,[29] Home and Community Environment,[30] Facilitators and Barriers Survey/Mobility[31]); and (3) results of quantitative and qualitative research on long-term participation outcomes identified by people with long-term disabilities.[32,33] Two content experts reviewed these 411 items and recommended inclusion/exclusion of these items on the basis of content redundancy and appropriateness. The whole study team reviewed recommendations to