

ORIGINAL RESEARCH

Developing an Item Bank to Measure Economic Quality of Life for Individuals With Disabilities



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Abstract

Objective: To develop and evaluate the psychometric properties of an item set measuring economic quality of life (QOL) for use by individuals with disabilities.

Design: Survey.

Setting: Community settings.

Participants: Individuals with disabilities completed individual interviews (n=64), participated in focus groups (n=172), and completed cognitive interviews (n=15). Inclusion criteria included the following: traumatic brain injury, spinal cord injury, or stroke; age ≥ 18 years; and ability to read and speak English. We calibrated the items with 305 former rehabilitation inpatients.

Interventions: None.

Main Outcome Measure: Economic QOL.

Results: Confirmatory factor analysis showed acceptable fit indices (comparative fit index=.939, root mean square error of approximation=.089) for the 37 items. However, 3 items demonstrated local item dependence. Dropping 9 items improved fit and obviated local dependence. Rasch analysis of the remaining 28 items yielded a person reliability of .92, suggesting that these items discriminate about 4 economic QOL levels.

Conclusions: We developed a 28-item bank that measures economic aspects of QOL. Preliminary confirmatory factor analysis and Rasch analysis results support the psychometric properties of this new measure. It fills a gap in health-related QOL measurement by describing the economic barriers and facilitators of community participation. Future development will make the item bank available as a computer adaptive test.

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Early definitions of quality of life (QOL) emphasized an individual's or country's standard of living, wealth, comfort, and material goods.¹ Quantifiable units were earnings, type of automobile one drove, and size of one's house. During the 1928 presidential campaign, the Republican National Committee promised Americans that a vote for Herbert Hoover was a vote for

"a car in every garage and a chicken in every pot," implying that prosperity was the way to measure QOL.² Dwight Eisenhower's 1960 Commission on National Goals and Lyndon B. Johnson's Great Society programs began to emphasize the social aspects of QOL,²⁻⁴ and new definitions of QOL came to reflect subjective qualities that reflected lifestyle, happiness, and well-being.^{5,6} Subsequently, health-related quality of life (HRQOL) was defined as subjective evaluations of status or capacity that reflect a health condition. In adopting the World Health Organizations' conceptual structure of health, measurement strategies to evaluate HRQOL focused on physical, emotional, and social well-being.⁷ Because of this shift, the influence of economic issues and subjective material resources on HRQOL has been minimized, and

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Table 1 Economic QOL measures identified by literature review

Measure	No. Potential Item Stems Identified	Weaknesses	No. Items in Final Item Bank
Measures/items identified through environmental factors literature review			
Measure of the Quality of the Environment ⁴⁹	17	• Checklist format	0
Child and Adolescent Scale of Environment ⁵⁰	5	• Items either inconsistent with domain definition or overly specific	0
Craig Hospital Inventory of Environmental Factors ⁵¹	1	• Focus on barriers only	0
Supports Intensity Scale ⁵²	2	• Checklist format	0
Guernsey Community Participation and Leisure Assessment ⁵³	1	• Vague or overly specific items	0
Assessment of Living Skills and Resources ⁵⁴	1	• Checklist format	0
Untitled survey of personal, social, and environmental influence ⁵⁵	1	• Inconsistent with domain definition	0
Interpersonal Support Evaluation List ⁵⁶	2	• Overly broad/general	0
Untitled list of emergent themes ⁵⁷	4	• Too specific	0
Systematic Pedestrian and Cycling Environmental Scan ⁵⁸	1	• More an assessment of social support than economic QOL	0
Untitled list of environmental factors ⁵⁹	4	• Too specific	0
Untitled measure of environmental factors ⁶⁰	1	• Items are vague, irrelevant, or overly specific	0
		• Developed for individuals with intellectual disabilities only	0
		• Not considered reliable	
		• Requires further development	
Measures/items identified through targeted economic QOL literature review			
General Social Survey ²⁶	1	• Solely addresses satisfaction component	0
European Organization for Research and Treatment of Cancer QLQ-C30 ²⁹	1	• Only 1 item addresses economic QOL	0
The Wisconsin Quality of Life Index ⁶¹	6	• Only 1 item addresses economic QOL	0
Family Quality of Life Survey-2006 ⁶²	13	• Not targeted to those with physical or cognitive disabilities	0
		• Not targeted to those with physical or cognitive disabilities	0
		• Does not take into account financial barriers related to disability	0

little has been published about perceived economic resources and their influence on HRQOL.

The economic burden of disability requires us to question why perceived economic factors are not conceptualized as part of HRQOL. Reduced household income is associated with lower levels of life satisfaction in older adults who have retired; loss of income after retirement is related to lower life satisfaction rather than to the loss of a role as worker.⁸ Perceived financial hardship is negatively related to HRQOL in a number of populations, including patients with advanced cancer,⁹ breast cancer,¹⁰⁻¹²

human immunodeficiency virus,¹³ end-stage kidney disease,¹⁴ amyotrophic lateral sclerosis,¹⁵ Parkinson's disease,¹⁶ and schizophrenia.¹⁷ Although there is substantial support for a relation between economic factors and HRQOL, there is a paucity of research focusing on patient-reported economic factors.

This dearth of research on economic QOL is striking given the costs of disability. For example, first-year costs after traumatic spinal cord injury (SCI) range from \$218,504 to \$741,425 in the first year depending on the injury level and severity, with the highest estimates for high tetraplegia; for subsequent years, cost estimates range from \$15,313 to \$132,807 inclusive of health care, medications, supplies, durable medical equipment, and personal assistance.¹⁸ For traumatic brain injury (TBI), medical costs alone are \$4906 higher than costs for individuals of the same age, sex, calendar year, and severity of nonhead injuries; persons with TBI incur costs that are on average \$22,838 more than persons without TBI.¹⁹ For stroke, first-year cost estimates are \$41,856 inclusive of ambulance, hospital stays, physician services, rehabilitation therapies, assistive devices, and home health care; annual follow-up costs are estimated at \$64,800, including medication, informal care, and nursing home care.²⁰ Unexpected health events are especially likely to translate into ongoing financial loss.²¹ Compounding the cost of disability is the inability to return to one's

List of abbreviations:

CFA	confirmatory factor analysis
CFI	comparative fit index
HRQOL	health-related quality of life
QOL	quality of life
RMSEA	root mean square error of approximation
SCI	spinal cord injury
SCI-QOL	Spinal Cord Injury Quality of Life Measurement System
TBI	traumatic brain injury
TBI-QOL	Traumatic Brain Injury Quality of Life Measurement System

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