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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.

Keywords

Economics; Outcome assessment (health care); Psychometrics; Quality of life; Rehabilitation

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 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 previous occupation or employment status; 11.9% of individuals with disabilities compared with 6.3% of the nondisabled population are unemployed.²² Chronic unemployment or underemployment and associated income loss are significant barriers to HRQOL and participation.

Economic barriers to health treatment, accessible housing, transportation, and assistive technology are critical to HRQOL. Economic barriers limit access to health care, resulting in increased morbidity and mortality. Individuals with disabilities often need home modifications that require structural renovations at substantial cost. The economic burden is compounded by insufficient resources to afford transportation for work or leisure. The economic components of HRQOL are important facilitators and barriers to community participation. Economic restrictions can have a profound impact on an individual's economic QOL. Subjective appraisals of the adequacy of resources to live life the way one wants include necessities (eg, food, shelter), health and personal care resources, and discretionary expenses (eg, Internet) and social activities (eg, concerts, sporting events). Individuals who experience inadequate economic resources, despite objective indicators to the contrary, can experience economic hardship, which in turn, has a deleterious effect on QOL.

Despite the paucity of literature, there is evidence that economic factors are perceived to be important contributors to HRQOL in persons with SCI.^{23–25} Individuals with higher net worth report smaller declines in well-being after the onset of disability than those with lower net worth; however, these effects diminish with time—those with lower net worth recover some well-being.²⁶ Disability is associated negatively with satisfaction with income, social life, and leisure time.²⁷ Although these findings highlight the importance of economic QOL, the measures that have been used to assess this construct are limited.

Commonly used measures of HRQOL usually omit economic-specific items; when they are included, they tend to be limited and generic. For example, the General Social Survey²⁸ and European Organization for Research and Treatment of Cancer Core Quality of Life questionnaire (EORTC QLQ-C30)²⁹ contain only 1 economic item, and it is not designed for individuals with disabilities. Instruments with more complete coverage of economic concerns include the Wisconsin Quality of Life Index³⁰ and the Family Quality of Life Survey-2006.³¹ These instruments were developed using classical test theory and have deficiencies in internal consistency and reliability. Though objective measures of financial status help us understand an individual's potential for economic self-sufficiency, objective information does not correlate highly with self-reported HRQOL.²¹ Large-scale, population-based data collection assessments of objective financial status (eg, health and retirement study)²¹ do not lend themselves to use in clinical or research settings. These measures do not reflect the financial needs of individuals with disability. For example, an individual with complete tetraplegia may have different financial needs than an individual with an uncomplicated mild TBI (eg, a person with tetraplegia could require specialized attendant care, expensive adaptive equipment, home modifications). An objective measure of economic characteristics would not reflect a person's ability to afford assistive devices or rehabilitation services. Common expenditures are often more costly for individuals with

disabilities. For example, a power wheelchair user's needs are not met by the cheapest car on the lot, given their need for custom vehicle modifications. It is important to distinguish income and wealth; some people with high incomes spend much of their income and are in significant debt, whereas others live within their means despite lower incomes. Income is only modestly related to subjective well-being³²; if an individual perceives an economic barrier to participation in life activities, this perception defines a barrier to participation. Though items measuring the ability to "live life the way I want" do not provide the same information as objective indicators, they address the construct of economic QOL. A new measure of economic QOL containing this type of subjective items is necessary to improve assessment of HRQOL in individuals with disabilities.

In summary, economic factors are neglected in HRQOL measures designed for disability populations. The available measures are limited in scope and do not consider financial barriers related to disability or the costs of health care and personal assistance. It would be difficult to obtain a reliable measure of economic QOL using few items. Therefore, the goal of this project was to develop a patient-reported measure of economic and financial QOL that is relevant to individuals with disabilities. The new measure is designed to complement contemporary patient-reported measures, including a family of measures focused on environmental factors³³ (eg, contextual factors, which may positively or negatively affect an individual's ability to function)³⁴ and the Spinal Cord Injury Quality of Life Measurement System (SCI-QOL)³⁵ and Traumatic Brain Injury Quality of Life Measurement System (TBI-QOL).³⁶

Methods

Literature review

We completed a review of environmental factor instruments and identified 40 potential items related to economic QOL. However, none of these items were included in the item pool due to the weaknesses listed in Table 1. Then, we conducted a comprehensive literature review of patient-reported outcome measures using the following search terms: *economic satisfaction*, *financial satisfaction*, *economic well-being*, and *financial well-being*. We identified 21 items for inclusion in the economic QOL item pool (table 1).

Individual interviews

We conducted semistructured interviews with individuals with SCI (n=44) and TBI (n=20) focused on HRQOL. We contacted participants through hospital inpatient and outpatient referrals. Interviews typically lasted 2 hours; participants received a \$20 honorarium. We based interview questions on the literature review; the interview consisted of open-ended questions about the general nature of HRQOL after injury. Interviewers recorded responses verbatim and organized them by content area. Participant-generated issues indicated important areas for further investigation in the focus groups subsequently described.

Focus groups

We conducted focus groups as part of the SCI-QOL³⁵ and TBI-QOL³⁶ projects during which economic concerns and their relation to HRQOL emerged. The SCI-QOL data

included transcripts of 12 groups of 65 individuals and 4 clinician focus groups of 42 individuals.^{35,37} The TBI-QOL data included transcripts of 7 groups with former patients (n=33), TBI clinicians (2 groups, n=15), and caregivers (4 groups, n=17).^{35,36} Qualitative analysis of the transcripts³⁸ allowed us to identify themes and domains, from which we wrote 31 additional items.

Reanalyses of focus group data for economic QOL

We pooled and integrated the qualitative data from the studies previously described with a new set of 20 focus groups that included >200 participants with diverse disabilities, age, race/ ethnicity, and socioeconomic status.³⁹ We transferred focus group transcripts to ATLAS.ti version 5.0 software^a and reanalyzed them for environmental constructs. We used an iterative, constant comparative method to analyze and interpret the transcripts.^{40–44} We generated 32 additional economic QOL items from focus group data. In total, the preliminary item pool consisted of 84 economic QOL items.

Item development and refinement

Coinvestigators completed a qualitative review of these items to improve clarity and conciseness, confirm the construct representativeness, and reduce redundancy. Five items were vague, 13 were overly specific, 16 were inconsistent with the domain definition, and 13 were redundant. We retained 37 items after removing the vague, overly specific, inconsistent, and 20 of the redundant items.

Next, we sought to ensure the content validity of the item pool using Willis' methods.^{33,37} We conducted cognitive interviews with individuals with SCI, TBI, and stroke by asking them to answer each item, describe their thought processes in answering each item, and describe the meaning of each item. A minimum of 5 individuals reviewed each item. We revised the items based on this feedback. We assessed the reading level of the items using the Lexile Framework^b and rewrote items above a fifth grade reading level. The resulting item pool contained 37 items ranging from a first through fifth grade reading level.

Calibration study participants and data collection procedures

We recruited participants from a registry of former patients of a Midwestern rehabilitation center. The calibration sample included 305 participants with TBI (n=100), stroke (n=100), and traumatic SCI (n=105). The institutional review board at the affiliated university reviewed and approved this study (approval no. STU00018893). Inclusion criteria were age 18 years; ability to read and understand English at a fourth grade level; and traumatic SCI, TBI, or stroke. Participants answered items during in-person (n=203) or telephone (n=102) interviews.

Data analysis

We evaluated unidimensionality of the 37-item pool using confirmatory factor analysis (CFA) with the following criteria: comparative fit index (CFI) >0.9,⁴⁵ root mean square error

^aATLAS.ti software, ATLAS.ti Scientific Software Development GmbH.

^bLexile Framework, MetaMetrics.

of approximation (RMSEA) $<.08$,⁴⁶ and $R^2>0.3$.⁴⁷ We examined residual correlations (criterion: $r>.20$) to identify dependency of item pairs.⁴⁸ We used MPlus 6.1 software^{49, c} with the polychoric correlation matrix and weighted least squares with adjustments for mean and variance estimation, the appropriate method to evaluate ordered categorical data. With an eventual goal of conducting 2-parameter item response theory analyses after collection of a larger sample, for the current phase of the project we used a 1-parameter (Rasch) analysis as implemented in Winsteps software.^{50, d} We chose this model rather than a 2-parameter model because it does not require as large of a sample size to obtain stable item parameters (eg, 200 vs 500).⁵¹ Rasch analysis provides a quantitative item review to assess the quality and appropriateness of the items. We used fit statistics for each item reported as mean-square values (criterion: 0.6–1.4) to evaluate fit to the Rasch model. At the scale level, Rasch analysis estimates the extent to which the items distinguish distinct levels of economic QOL in the sample by reporting a separation index (criterion: separation >2). A separation index <1 indicates that the items are not able to distinguish >1 level of QOL, whereas a separation index of 2 indicates that 2 levels of QOL can be distinguished. A separation index >2 indicates that at least 3 levels can be distinguished.⁵² We used the Rasch analysis-based information function at the item and scale levels to describe precision along the economic QOL continuum.^{53–55} We converted the measure's information function to reliability in which reliability of .95 corresponds to an information function of 20.

Results

Participant demographic characteristics

Hammel et al³⁹ reported the demographic characteristics of the focus group sample. Demographic characteristics of the cognitive interview sample are shown in table 2. Of the 15 participants, 6 were diagnosed with SCI, 5 with TBI, and 4 with stroke. Mean age was 45.5 ± 11.8 years; 67% were men. Of the participants, 33% were white, 57% were black, and 13% were another race. Hispanic or Latino ethnicity was selected by 13%. Of the participants, 53% reported the ability to walk, 47% reported using a walking device some or all of the time, and 47% reported using a wheelchair some or all of the time.

Demographic characteristics of the calibration sample are shown in table 3. Mean age was 47.9 ± 14.6 years; 64% were men. Of the participants, 43% were white, 42% were black, 2% were >1 race, and 12% were another race. Hispanic or Latino ethnicity was selected by 12%. Of the participants, 76% reported the ability to walk, 49% reported using a walking device some or all of the time, and 33% reported using a wheelchair some or all of the time. In the TBI sample, TBI severity^{56,57} ranged from mild (8%), moderate (6%), to severe (71%); 9% of cases had unknown severity. There were 39% that sustained disability in motor vehicle collisions, 21% in falls, 20% through gunshot wounds or other acts of violence, and 19% through other causes. In the SCI sample, 51% were diagnosed with paraplegia, and 46% were diagnosed with tetraplegia; 29% sustained completed injuries, 63% had incomplete injuries, and 7% were of unknown severity. In the stroke sample, 41% sustained hemorrhagic stroke, 34% had ischemic stroke, and 23% had unknown etiologies.

^cMPlus 6.1 software, MPlus (StatModel).

^dWinsteps 2014, JM Linacre. Available at: Winsteps.com.

CFA findings

Initial CFA results showed acceptable fit indices (CFI=.939, RMSEA=.089) for the 37 items. However, 3 items had $R^2 < 0.3$, and 4 item pairs demonstrated local item dependency with residual correlations ranging from .24 to .37; an additional 22 pairs were flagged for potential dependency (residual correlations .15–.20). After dropping 9 items sequentially, we retained 28 items. The CFI was .951, RMSEA was .095, R^2 was < 0.3 for all items, and no residual correlations exceeded 0.2; however, 9 pairs had borderline dependency with correlations between .15 and .20. We retained these 28 items in the Rasch analysis.

The separation index from the Rasch analysis was 3.36; the associated person reliability was .92, suggesting that these items discriminate about 4 economic QOL levels. Figure 1 shows the map of the items and persons on a shared log-odds scale. Item 24 (I have had services cut because I could not pay my bills) is the easiest item with which to agree and indicates the lowest level of economic QOL, whereas item 33 (I have saved 6mo of living expenses) is the hardest item with which to agree and represents the highest level of economic QOL.

Figure 2 displays item characteristics. Measure reflects the item difficulty with relatively harder-to-endorse items at the top and easier-to-endorse items at the bottom. Item fit is reflected in the mean-square fit statistic. Values > 1.4 identify noisy items that are measuring something in addition to the underlying construct; values $< .60$ indicate the item contributes relatively little unique information. Three items had borderline to poor fit with the economic QOL construct: item 29 (“I have delayed getting dental care because I could not pay for it”; mean-square infit=1.4); item 25 (“I have a good credit rating”; mean-square infit=1.45); and item 33 (“I have saved 6mo of living expenses”; mean-square infit=1.69). Item 33 is the hardest item to endorse, indicating that only persons with very high economic QOL would strongly endorse this item. Items with extreme difficulty are vulnerable to poor fit.⁵⁸

Item information function of each economic QOL item is depicted in figure 3; each curve represents the amount of information that an item provides in an overall estimation of a persons’ economic QOL. Curves with the highest peaks provide the most information about economic QOL measures. Several items provide low information: item 10 (“I can afford to go out with my friends”) was the least informative item, and item 33 (“I have saved 6mo of living expenses”) was the most informative item to describe economic QOL at the mean of the sample.

Figure 4 shows how these information functions are expressed in terms of reliability. The information function of each of the 28 items was transformed to a reliability function yielding reliability $> .90$ between Rasch scaled scores -1.87 and 1.87 and reliability $> .95$ between Rasch scaled scores -1.125 and 1.125 . The average sample economic QOL measure was $.89 \pm 1.33$ logits; 61% had measures with reliability $> .95$, 19% between 0.9 and $.95$, and 20% with reliability < 0.9 . The items are more sensitive to respondents with economic QOL above the mean than those with economic QOL below the mean.

Discussion

Costs of health care, accessible housing, reduced employment opportunities, and other economic factors are cited consistently as important issues related to QOL by people with disabilities. Despite this need, economic factors that affect QOL after traumatic injury or stroke are an understudied area. This study used a comprehensive approach to develop a measurement tool to assess economic QOL in individuals with disabilities.

We developed item pools using a participatory action research,⁵⁹ approach and qualitative methods. This process began with a systematic literature review and continued with rigorous qualitative analyses of several sets of focus groups and individual interviews with persons with SCI, TBI, and stroke and clinicians who treat individuals with these disabilities. The item development procedures followed the guidelines developed by the Patient-Reported Outcomes Measurement Information System.⁶⁰ We developed the economic QOL items based on feedback and qualitative data from individuals with disabilities to ensure that the selected items were relevant. Our goal was to develop a scale with broad generalizability for health care; therefore, items targeting specific conditions were not included.

From these activities, we wrote an item pool of 37 items and administered them to a sample of individuals who sustained SCI, TBI, or stroke. Rasch analyses allowed us to describe item characteristics and identify items that do not fit the Rasch model and remove them from the item pool. We retained a final item pool of 28 items. The CFA fit statistics indicate that these items compose a unidimensional construct, which we interpret as reflecting economic QOL. Through an iterative process, we removed items that had high correlations with other items, therefore reducing the degree of local dependence. The analyses allowed us to identify the items with the best information functions, items which best estimate individuals' underlying economic QOL.

Study limitations

The data collected here are sufficient for test development. However, there are limitations to the data set. First, we recruited a convenience sample that is less representative of the population of people with disabilities than is desirable. Cases were recruited at only 1 center and were not stratified to represent the population. Second, a sample of 305 is not sufficient to complete a 2-parameter item response theory analysis. When we recalibrate the items using a 2-parameter item response theory analysis, we will have a more representative sample (ie, evenly stratified by diagnosis and severity). Further, we were unable to evaluate the discriminability of each item, which is assumed to be equal by Rasch analysis but not by the 2-parameter model. A larger sample will allow us to estimate more stable calibration criteria and better estimates of economic QOL. Finally, the current study included 3 disability subgroups. Given the universal applicability of economic QOL, it is likely that these items would be appropriate for other disability subgroups and even a general health population.

Conclusions

Using participatory action research–based qualitative methods in conjunction with a contemporary psychometric approach, we developed a 28-item bank that measures economic aspects of QOL. Preliminary CFA and Rasch analysis results support the psychometric properties of this measure. It fills a gap in HRQOL measurement by describing the economic barriers and facilitators that affect community participation. This preliminary test of the item bank requires confirmation with a larger, more representative sample. The analyses presented here serve as a first step to ensure that the item bank contains a hierarchy of items across different levels of economic QOL and conforms to a 2-parameter item response theory model. Future work will examine convergent and discriminant validity of the measure. This measure will meet the standards used in the Patient-Reported Outcomes Measurement Information System network and supplement existing banks, providing state-of-the-art measurement of an important content area. The final economic QOL bank will complement emerging measurement systems (ie, SCI-QOL,³⁵ TBI-QOL³⁶) and other environmental factors scales³³ for use in rehabilitation research and practice.

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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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Fig 1.

Person and item map of 28 economic QOL items. Each # is 2, and each . is 1. Abbreviations: M, median; S, 1 standard deviation; T, 2 standard deviations.

Measure	Model SE	MnSq	Infit	r	Item
1.36	.06	1.69	.65	.33	I have saved 6mo of living expenses.
1.08	.06	1.20	.69	.4	I can afford to live where I want to.
1.02	.06	.94	.74	.3	I have enough income to live the life that I want.
.81	.07	.99	.71	.11	I can afford to travel.
.67	.06	1.16	.68	.32	I have access to extra money in the case of an emergency.
.61	.06	1.28	.64	.27	I can afford to go back to school.
.47	.06	1.16	.66	.28	I worry about paying my bills.
.42	.06	1.45	.59	.25	I have a good credit rating.
.35	.06	.74	.74	.2	I have enough income to meet my needs.
.28	.06	1.28	.59	.19	I have opportunities to make enough money to live in my community.
.15	.06	1.16	.61	.8	I can afford the personal care assistance that I need.
.07	.06	1.40	.56	.29	I have delayed getting dental care because I could not pay for it.
-.06	.07	.80	.70	.7	I can afford to participate in the social activities that I want to.
-.11	.06	1.02	.60	.22	I can afford cable television service.
-.15	.07	.98	.66	.1	I can afford to eat out when I want.
-.16	.07	.70	.70	.5	I can afford to pay my bills.
-.16	.06	.93	.61	.21	I can afford Internet service.
-.17	.07	.84	.68	.9	I can afford to participate in community events.
-.30	.07	.71	.68	.6	I can afford to live comfortably in my home.
-.33	.07	.68	.74	.10	I can afford to go out with my friends
-.38	.07	.95	.58	.12	I have enough income to pay my rent or mortgage.
-.48	.07	.84	.63	.20	I can afford to buy healthy food.
-.70	.07	1.28	.46	.16	I have delayed getting health care because I could not pay for it.
-.73	.07	1.00	.52	.15	I can afford air conditioning for my home.
-.80	.07	.68	.66	.23	I can afford to pay my bills on time.
-.89	.07	1.28	.44	.31	I have had to ask my friends for money.
-.93	.07	.77	.59	.18	I can afford to feed myself and my family.
-.94	.08	1.11	.47	.24	I have had services cut because I could not pay my bills.
.00	.07	1.04			
.63	.01	.26			

Fig 2.

Item statistics in measure order. Measure indicates item difficulty in logits and the associated SE. Bold text indicates misfit (ie, values ≥ 1.4). Abbreviations: MnSq infit, mean-square in-weighted fit statistic; r , correlation between the item and measure.

Fig 3.
Information function of economic QOL items.

Fig 4.
Distribution of economic QOL scores across the measurement continuum defined by Rasch analysis.

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
		• Combines multiple aspects into single items ³⁰	
Supports Intensity Scale ⁵²	2	• Checklist format	0
		• Vague or overly specific items	
Guernsey Community Participation and Leisure Assessment ⁵³	1	• Checklist format	0
		• Inconsistent with domain definition	
Assessment of Living Skills and Resources ⁵⁴	1	• Overly broad/general	0
Untitled survey of personal, social, and environmental influence ⁵⁵	1	• Too specific	0
Interpersonal Support Evaluation List ⁵⁶	2	• More an assessment of social support than economic QOL	0
Untitled list of emergent themes ⁵⁷	4	• Too specific	0
Systematic Pedestrian and Cycling Environmental Scan ⁵⁸	1	• Items not representative of economic QOL construct	0
Untitled list of environmental factors ⁵⁹	4	• Items are vague, irrelevant, or overly specific	0
Untitled measure of environmental factors ⁶⁰	1	• 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
		• Only 1 item addresses economic QOL	
European Organization for Research and Treatment of Cancer QLQ-C30 ²⁹	1	• Only 1 item addresses economic QOL	0
		• Not targeted to those with physical or cognitive disabilities	
The Wisconsin Quality of Life Index ⁶¹	6	• Not targeted to those with physical or cognitive disabilities	0
Family Quality of Life Survey-2006 ⁶²	13	• Does not take into account financial barriers related to disability	0

Table 2

Demographic characteristics of cognitive interview sample

Variable	Total Sample (n=15)
Age (y)	45.5
Sex	
Male	10 (67)
Female	5 (33)
Ethnicity	
Hispanic	2 (13)
Non-Hispanic	13 (87)
Race	
White	5 (33)
Black	8 (57)
Other	2 (13)
Education	
Completed high school (diploma or General Educational Development)	3 (20)
Completed some college	12 (80)
Work status	
Employed for wages	2 (13)
Unemployed and looking for work	3 (20)
Unemployed and not looking for work	4 (27)
Retired because of disability	5 (33)
Retired not because of disability	1 (7)
Income level	
<\$20,000	10 (67)
\$20,000–\$49,999	1 (7)
\$50,000–\$99,999	2 (13)
\$100,000	1 (7)
Declined to respond	1 (7)
Able to walk some or all of the time	
Yes	8 (53)
No	7 (47)
Uses a walking device some or all of the time	
Yes	7 (47)
No	8 (53)
Uses a wheelchair some or all of the time	
Yes	7 (47)
No	8 (53)

NOTE. Values are n (%) or as otherwise indicated.

Table 3

Demographic characteristics of calibration sample

Variable	Total Sample (N=305)
Age (y)	47.9±14.6
Marital status	
Single	134 (44.0)
Married	92 (30.0)
Separated/divorced	61 (20.0)
Widowed	15 (5.0)
Living with partner	3 (1.0)
Sex	
Male	196 (64.0)
Female	109 (36.0)
Ethnicity	
Hispanic	35 (12.0)
Non-Hispanic	269 (88.0)
Declined to respond	1 (<1.0)
Race	
White	132 (43.0)
Black	129 (42.0)
Other	36 (12.0)
American Indian/Alaskan Native	1 (<1.0)
>1 race	5 (2.0)
Declined to respond	1 (<1.0)
Language	
English	293 (96.0)
Spanish	7 (2.0)
Other	4 (1.0)
Highest school level	
Some high school	32 (11.0)
Completed high school	64 (21.0)
Some college	108 (35.0)
Bachelor's degree	51 (17.0)
Some graduate school	12 (4.0)
Advanced degree (master's, doctorate, medical doctor)	38 (13.0)
High school diploma	
High school diploma	220 (72.0)
General Educational Development	47 (15.0)
Vocational high school	1 (0.3)
NA	35 (12.0)
Declined to respond	1 (0.3)
Current work status	

Variable	Total Sample (N=305)
Employed for wages	51 (17.0)
Out of work <1y and looking for employment	10 (3.0)
Out of work <1y and not looking for employment	9 (3.0)
Out of work >1y and looking for employment	45 (15.0)
Out of work >1y and not looking for employment	50 (16.0)
Homemaker	4 (1.0)
Student	17 (6.0)
Retired because of disability	92 (30.0)
Retired not because of disability	24 (8.0)
Decline to respond	3 (1.0)
Total household income (per year)	
<\$20,000	136 (45.0)
\$20,000–\$49,999	62 (20.0)
\$50,000–\$99,999	41 (13.0)
\$100,000	28 (9.0)
Decline to respond	37 (12.0)
Living situation	
Home	291 (95.0)
Other	14 (5.0)
Walk some or all of the time	
Yes	233 (76.0)
No	67 (22.0)
Use a walking device some or all of the time	
Yes	149 (49.0)
No	151 (50.0)
Use a manual wheelchair some or all of the time	
Yes	100 (33.0)
No	200 (66.0)
Use a power wheelchair some or all of the time	
Yes	82 (27.0)
No	218 (72.0)
TBI-specific items	(n=100)
Age at injury (y)	32.8±14.6
Cause of injury	
Motor vehicle collisions	39 (39.0)
Fall	21 (21.0)
Other sport(s)	1 (1.0)
Gunshot wound/violence	20 (20.0)
Other	19 (19.0)
Diagnosis of TBI	
Mild	8 (8.0)
Moderate	6 (6.0)

Variable	Total Sample (N=305)
Severe	71 (71.0)
Unknown	9 (9.0)
Loss of consciousness	
Yes	86 (86.0)
No	13 (13.0)
SCI-specific items	(n=105)
Age at injury (y)	33.2±14.7
Cause of injury	
Motor vehicle collision	36 (34.0)
Fall	15 (14.0)
Diving	4 (4.0)
Other sport(s)	2 (2.0)
Gunshot wound/violence	31 (30.0)
Other	15 (14.0)
Diagnosis of SCI	
Paraplegia	53 (51.0)
Tetraplegia	48 (46.0)
ASIA classification	
Known: grade A (complete)	19 (18.0)
Known: grade B (incomplete)	11 (11.0)
Known: grade C (incomplete)	8 (8.0)
Known: grade D (incomplete)	8 (8.0)
Unknown (complete)	11 (11.0)
Unknown (incomplete)	38 (36.0)
Unknown/missing	7 (7.0)
Stroke-specific items	(n=100)
Experienced weakness	
Yes, left side only	50 (50.0)
Yes, right side only	40 (40.0)
Yes, both sides	1 (1.0)
No	8 (8.0)
Type of stroke	
Bleed (hemorrhage)	41 (41.0)
Infarct (blockage)	34 (34.0)
Unknown	23 (23.0)
Specific type of stroke	
Intracranial hemorrhage	14 (14.0)
Subarachnoid hemorrhage	5 (5.0)
Thrombosis	3 (3.0)
Embolism	8 (8.0)
Lacunar stroke	2 (2.0)
Unknown	57 (57.0)

Variable	Total Sample (N=305)
Location of stroke	
Superficial/cortical	1 (1.0)
Subcortical	5 (5.0)
Cerebellar	10 (10.0)
Brainstem	5 (5.0)
Combination	1 (1.0)
Other	2 (2.0)
Unknown	64 (64.0)

NOTE. Values are mean $\pm$ SD or n (%).

Abbreviations: ASIA, American Spinal Injury Association; NA, not applicable.