From the 2006 NIDRR SCI Measures Meeting Participation Following Traumatic Spinal Cord Injury: An Evidence-Based Review for Research

Report on the National Institute on Disability and Rehabilitation Research Spinal Cord Injury Measures Meeting

Quality of Life/Participation Committee:

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Abstract

Background/Objective: To report an evidence-based review of participation instruments that have been used in spinal cord injury (SCI) clinical practice and research.

Methods: Rehabilitation literature was searched for instruments used by at least 2 independent SCI researchers since 2000. Each instrument was reviewed by 2 committee members. One person reviewed the scale and documented the level of use and psychometric properties. The second committee member verified the values and made suggestions for changes.

Results: Three instruments met the review criteria: Craig Handicap Assessment and Reporting Technique (CHART), Assessment of Life Habits (LIFE-H), and the Impact on Participation and Autonomy (IPA). Each instrument incorporates different perspectives in the measurement of participation. The LIFE-H uses a qualitative approach, whereas the CHART adopts a quantitative approach; both are based on societal norms of participation. In contrast, the IPA integrates individual choice and control in defining participation. CHART is the most widely used instrument, although its development predates the development of the ICF. The IPA is a relatively new instrument, and its psychometric properties have only recently published.

Conclusions: Continuing research is needed to develop conceptually and psychometric valid measures of participation for use with people with SCI. Priorities include understanding the relationship between objective and subjective indicators of participation, describing the dimensions of participation, and identifying appropriate measurement models and psychometric approaches to evaluate the nonhierarchical character of participation. Researchers and clinicians should be aware of the strengths and limitations of existing measures to make informed decisions about appropriate instruments.

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Key Words: International classification of function; Disability; Participation; Outcome measures; Rehabilitation research; Spinal cord injuries; Quality of life; Measurement, instruments

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INTRODUCTION

The past 3 decades have seen substantial improvements in the medical, technologic, and pharmacologic management of spinal cord injury (SCI) (1). As a result, people with SCIs are living longer and achieving greater functional independence. With greater life expectancies, the focus of rehabilitation and intervention for people with SCI has shifted from medical management of the acute condition to issues that affect quality of life and community participation.

Participation is defined as “involvement in life situations” (2) and is a core concept in all major models of disability, including the World Health Organization’s (WHO) International Classification of Functioning, Health

and Disability (ICF) (2), the Institute of Medicine's Models of Disability (3), and the National Institute on Disability and Rehabilitation Research's Long-Range Plan (4). In the United States, participation is the hallmark of legislative and executive initiatives including the American with Disabilities Act (5) and the New Freedom Initiative (6). Furthermore, participation is related to a person's ability to be an active and contributing member of society and, as such, is a highly valued rehabilitation outcome for people with disabilities (including those with SCI), their care partners, and society at large (7).

The WHO has been at the forefront of conceptualizing the impact that injury and illness has on people's lives (8). In 1981, the WHO introduced the International Classification of Impairments, Disability, and Health (ICIDH) (9). This model traces a linear, unidirectional path from individual impairments (such as paralysis secondary to SCI) to "handicap" at the social level (such as the inability to fulfill life roles like worker, spouse, or parent). "Handicap" was understood as disadvantage in social and economic life that people with disabilities experience, either because of their impairments or the social stigma that their impairments elicit (10). The ICIDH was criticized on multiple fronts, including its use of pejorative language and its failure to account for the role that environmental factors (such as inaccessible environments or punitive employment policies) have on an individual's ability to assume desired, developmentally appropriate roles.

In 2001, the WHO substantially revised the ICIDH and replaced it with the ICF. This revision shifted the emphasis from "the consequence of impairment and disease" to the "components of health" (8). The concept of "handicap" was replaced with "participation," which is defined as "involvement in life situations." In addition to this shift in nomenclature from "handicap" to the more neutral and less pejorative term of "participation," the ICF also strives to reflect the dynamic interplay between impairments, activities, participation, health conditions, personal characteristics, and contextual factors. In particular, the ICF depicts participation as being influenced by environmental factors, personal characteristics, and impairments and activity limitations. Although the ICF conceptually distinguishes activities from participation in both its model of disability and its definitions, the ICF provides only 1 list of codes for activity and participation, leaving the user to decide whether all codes apply to both concepts or whether codes in some domains are activities, whereas codes in other domains reflect participation. This failure to distinguish activity from participation has been described as a step backward (7), and the Institute of Medicine has prioritized clarifying this conceptual ambiguity (3).

Previous research has consistently shown that people with SCI experience barriers to participation across many major life domains. Decreased employment opportunities (11,12), limited social support and family role

functioning (13,14), limited access to recreational and leisure activities (15), and a lack of accessible transportation (16–18) have been identified as barriers to participation for people with SCI. Dijkers' meta-analysis of quality of life for people with SCI identified participation as a key component and contributor to quality of life (19). Participation is more closely related to quality of life than either level of impairment or functional performance (19). Therefore, participation outcomes are significant both in their own right and in their relationship to overall life satisfaction and quality of life of people with SCI.

Given the importance of participation to people with disabilities, disability policy, rehabilitation research, and clinical practice, it is imperative that clinicians and researchers have access to outcome measures that accurately measure participation in ways that are both conceptually and psychometrically sound. Thus, the purpose of this study was to conduct an evidence-based review of SCI literature to identify appropriate participation outcome measures for use in research and practice.

METHODS

As part of a National Institute on Disability and Rehabilitation Research (NIDRR)-sponsored review of outcome measures in SCI research, international experts in outcome measurement and SCI were assembled and divided into workgroup committees based on their area of clinical expertise to conduct a comprehensive review of the SCI rehabilitation research literature. Using an evaluation scheme developed by Johnston and Graves, outcome measures were systematically reviewed, and their validity in SCI was graded using a 4-star system (20). The star ratings were as follows: • = no formal validity/reliability published, * = questionable or insufficient validity, ** = minimal validity, *** = content and metric reliability and validity shown, and **** = extensively validated and widely used. This paper reports the findings of the participation workgroup. Major research databases, including PubMed, PsychINFO, and CINAHL, were searched for research studies that had participation as a key outcome using the search terms "spinal cord injury and participation," "spinal cord injury and community integration," and "spinal cord injury and handicap" (the WHO term used to define involvement at a societal level before the adoption of the ICF). Three inclusion criteria were required for an instrument to be included as part of this study: (a) related to or used with people with SCI, (b) cited in the literature within the period 2000 through 2007, and (c) used by at least 2 researchers or research groups during this time period. Once instruments were deemed eligible for inclusion, a comprehensive review of the research literature was conducted to evaluate each instrument's conceptual foundations and psychometric properties using a formal set of assessment criteria (Table 1). Two individuals reviewed each instrument. Preliminary findings were presented at a preconference of the 2006 American Spinal Injury Association meeting that

was sponsored by the NIDRR. In preparation for publication, the literature review was repeated for 2005 to 2007, and relevant information is included in this manuscript.

RESULTS

Although there are a number of published measures of participation, only 3 met the inclusion criteria for review in this study: the Craig Handicap Assessment and Reporting Technique (CHART), the Assessment of Life Habits (LIFE-H), and the Impact on Participation and Autonomy (IPA). Other instruments were excluded because they lack widespread application beyond the developers' team or evidence of application or validation on people with SCI. For example, participation and community integration are extensively studied in people with traumatic brain injuries, and a number of instruments have been developed for this population (eg, the Participation Objective, Participation Subjective) (21). Table 1 summarizes the psychometric, clinometric, and conceptual properties of these 3 participation instruments.

Craig Handicap Assessment and Reporting Technique

The CHART was developed by Whiteneck et al (22) for people with SCI and is the most widely used participation instrument in rehabilitation research). The CHART is based on the ICIDH, the precursor to the ICF, and was developed to provide a simple, objective measure of the degree to which impairments and disabilities result in handicaps after initial rehabilitation. The CHART contains 32 items across the 6 WHO domains of handicap including physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. The validity and reliability of the CHART have been well established among both cross-disability and SCI samples. The CHART has been evaluated using both item response theory (IRT) and the Rasch model. The CHART has a ceiling effect for high functioning people with SCI, particularly those with ASIA motor scores >50, and the distributions of the subscales and total scores are skewed.

Although the CHART has been criticized as a measure of participation because it was developed as a measure of the ICIDH concept of handicap rather than the ICF concept of participation (23,24), the CHART items have been shown to correspond well to the participation codes of the ICF (23). A more significant limitation of CHART is its focus on objective performance of normative life roles. Unlike some newer measures of participation, it does not assess respondents' subjective assessment or satisfaction with life roles or allow the personal preferences of the individual to be considered in the scoring.

The Assessment of Life Habits

The Assessment of Life Habits (LIFE-H) was developed by Fougereyrollas et al (25) to quantify social participation. It is

based on the Disability Creation Process Model (25) and defines participation as resulting from the interaction between personal and environmental factors. The LIFE-H operationalizes participation as life habits, defined as "those habits that ensure the survival and development of a person in society throughout life" (25). Habits are daily activities and social roles that are culturally defined according to age, sex, and sociocultural identity. The LIFE-H includes both habits related to survival and those engaged in by choice (26).

The LIFE-H consists of 240 items in 32 categories of life habits across 12 primary domains, including nutrition, fitness, personal care, communication, housing, mobility, responsibility, interpersonal relations, community, education, employment, and recreation. The LIFE-H's psychometric properties have been evaluated for people with SCI. It has been evaluated using IRT and the Rasch model; the measurement properties seem to be acceptable (27).

Although the LIFE-H has been used with SCI samples, there is a paucity of published research documenting the instruments use by researchers outside of Quebec and the developers' research group, indicating that the LIFE-H has not enjoyed widespread adoption by other rehabilitation researchers. The burden of administration of the long form may limit its adoption by rehabilitation clinicians and researchers. Although the LIFE-H strives to capture the dynamic interplay between the person and their environment that is central to current definitions of participation, the instrument's emphasis on action may bias scores against people with SCI whose impairments limit manipulation, mobility, and sensation (10).

Impact on Participation and Autonomy Questionnaire

The IPA was developed by Cardol et al (28) and is based on the definition of participation in the ICIDH-2 (an intermediate version between the ICIDH and the ICF) to measure participation and autonomy from an insider's perspective. Autonomy is included because the developers contend that decisional autonomy (the ability to exert choice and control over one's life) is a key determinant of participation. The IPA assesses participation restrictions using 32 items across 5 subdomains, including autonomy indoors, family role, autonomy outdoors, social relations, and paid work and education. An additional 9 items assess how problematic participation restrictions are for the individual.

The IPA has strong theoretical foundations related to both perceived participation and the concept of autonomy. The IPA is a relatively new instrument designed to assess perceived participation from the perspective of people with disabilities. It is used more extensively in Europe; there is no published work in North America. Through August 2007, 2 recent reports documented the IPA's psychometric properties in SCI samples (39,40). The instrument shows promise, but additional research is

Table 1. Comparison of Psychometric, Clinometric, and Conceptual Properties of Participation Measures

	CHART	IPA	LIFE-H
Construct and content			
Conceptual foundation	Based on the ICIDH concept of “handicap” (22)	Based on ICIDH-2 (28,37) to provide insider perspective on participation	Based on the Disability Creation Process Model (25)
Reason for development	To provide a simple, objective measure of the degree to which impairments and disabilities result in “handicaps” in the years after initial rehabilitation	Core belief that autonomy is a necessary precursor to participation	To assess the quality of social participation by documenting the way that people carry out daily life roles
Scope	Assesses the 6 ICIDH dimensions of “handicap”: (a) physical independence, (b) cognitive independence, (c) mobility, (d) occupation, (e) social integration, and (f) economic self-sufficiency	Assesses perceived participation in 5 domains: (a) autonomy indoors, (b) family roles, (c) autonomy outdoors, (d) social relations, (e) paid work and education	Assesses 12 categories of life habits: (a) nutrition, (b) fitness, (c) personal care, (d) communication, (e) housing, (f) mobility, (g) responsibilities, (h) interpersonal relationships, (i) community life, (j) education, (k) employment, and (l) recreation. Level of difficulty performing a life habit, type of assistance required, and level of satisfaction is rated for each item. Short form has 77 items and long form has 240 items
Format	Thirty-two items in the long form, 19 in the short form—objective questions related to nature and frequency of societal participation	Thirty-one items assess perceived participation, plus 8 items assess perceived problems across the 5 domains.	
Administration			
Mode	Interview either in person or by phone	Self-administration (by mail or in person)	Self-report assessment can be self-administered or in an interview
Disability adaptations	May be self-administered but some data may be lost	May be completed with assistance	Self-administration is not recommended for people with cognitive impairments
Time	May be completed by a proxy, evidence in support of the use of proxy data (29–31) Approximately 15 minutes	Approximately 20-minute average completion time (19.3 ± 4.7 minutes) (38)	May be completed by the patient, a significant other, or a health professional Approximately 30 to 60 minutes for the short form and 20 to 120 minutes for the long form depending on categories included
Languages	Short-form CHART-SF with 19 items can be used as a quick assessment (32) Developed in English Validated in Japanese (33) Translated into Spanish, Turkish, Mandarin, Italian, and Portuguese	Developed in Dutch English and Swedish versions developed through forward-back translation (38,39)	Developed in French and translated into English Translations into Spanish, German, Dutch, and Italian have been completed or discussed.
Reliability and responsiveness			
Item response theory—contemporary framework	Rasch analysis yielded a standardized information weighted-fit statistic with a mean of 0.0 and an SD of 1.5. Rasch analysis of each subscale indicated no item had a mean square infit > 1.2 and good person fit statistics (mean = 0.0, SD = 1.2) (22).	Rasch analysis with SCI sample of the perceived limitations in participation scale yielded a person separation reliability of 0.93 and item-separation reliability of 0.97; the perceived problem scale had a person separation reliability of 0.71 and item separation of 0.97 (40)	Rasch analysis compared LIFE-H results from a sample of 455 people with SCI with expert opinion. The measurement properties of the instrument are satisfactory (person reliability = 0.91 and agreement with expert opinion was high (item hierarchy $r = 0.89$ between experts and Rasch analysis) (27).

Table 1. Continued

	CHART	IPA	LIFE-H
Test–retest reliability	Test–retest reliability coefficient for a sample of persons with SCI over a 1-week period ranged from 0.80 to 0.95 for the subscales and 0.93 for the total score (22).	Scale 2 IPA-II may only be sensitive enough to detect people with and without perceived problems (40,57). Item hierarchy as expected. Test–retest coefficient from a cross-disability sample, including people with SCI over a 15-day period, ranged from 0.56 to 0.90; κ values for the problem-experience score ranged from 0.59 to 0.87. Although the level of test–retest reliability is adequate, values >0.80 are desirable (41).	The item-difficulty hierarchy obtained with SCI experts differed from the hierarchy obtained with TBI experts, suggesting that the construct varies across impairment groups (27). Test–retest reliability is satisfactory with ICC = 0.83 to 0.95 (25). Test–retest reliability was higher for daily activities subscores than social roles subscores (0.96 and 0.76, respectively).
Internal consistency—classical framework	With a sample of 6 different disability groups including SCI, Walker et al (34) reported an ICC of 0.93 for the total score. Total CHART correlation between participant and proxy was 0.83 for a sample of SCI participants (29).	After the elimination of 10 of the original 41 IPA items, Cronbach α for a 4 factor-analysis defined solution were social relationships (0.86), self-care and appearance (0.87), family role (0.84), and mobility (0.86) (42).	In a sample of adults and children with SCI, Fougereyrollas et al (25) reported a high level of internal consistency for the short and long forms of the Life-H (Cronbach $\alpha \geq 0.82$ and ≥ 0.90 , respectively). Both the long form and the short form show a high level of reliability in adult SCI samples (ICC = 0.89 and 0.83, respectively) (25). Individually, the 8 categories of life habits showed moderate to high reliability (ICC = 0.47 to 0.91) (25). Sensitivity needs to be evaluated.
Sensitivity to change	No evidence available regarding sensitivity to change	In a heterogeneous sample of 49 rehabilitation outpatients, responsiveness to improvements were substantial for family roles, autonomy outdoors, and work and education (SRM = 0.8, 1.2, and 1.3 respectively) and small for social relationships and autonomy indoors (SRM = 0.1 and 0.4, respectively) (43). Insufficient data to determine responsiveness to decline (44)	
Floor and ceiling effects	The scoring system sets a maximum subscale score of 100 for the level expected of the general population without disabilities. A substantial proportion of persons with disabilities perform societal roles at or above this level, resulting in a ceiling effect, particularly for individuals with lower level SCI (ASIA motor scores > 50).	Rasch analysis showed that 20% of people were either above or below the range of item calibration values, indicating a floor and ceiling effect (40).	The LIFE-H has a low ceiling in persons with SCI (14).

Table 1. Continued

	CHART	IPA	LIFE-H
Dimensionality	CHART was designed to measure the 6 dimensions of handicap defined by the ICDH. No empirical evidence has been offered to support these 6 dimensions.	Rasch analysis of the Swedish version with a population of people with SCI showed the scale is made up of 2 unidimensional scales: perceived participation and perceived problems (40).	Multidimensionality was evident in a factor analysis of residuals, the first factor contrasted ADL with other items, the second factor contrasted work and study items with other items, and the third factor contrasted mobility items with other items (27).
Validity			
Criterion-oriented validity (concurrent)	<p>The CHART correlates moderately (0.50) with the Functional Independence Measure total score (30).</p> <p>FIM scores were negatively correlated with CHART scores (35).</p>	<p>IPA correlates negatively (-0.42 to -0.57) with the London Handicap Scale domains of mobility, physical independence, occupation, and social integration (40).</p> <p>IPA's autonomy outdoors correlates positively (0.29) with the Sickness Impact Profile's physical dimension (41).</p> <p>IPA's family role, autonomy indoors, and autonomy outdoors scores correlate moderately (0.49, -0.43, -0.51) with the SF-36's physical dimensions (41).</p>	<p>Correlations between grouped LIFE-H items and corresponding CHART dimensions ranged from negligible for social integration (0.14) to low for mobility (0.33) and occupation (0.36) to marked for physical independence (0.76) (45).</p> <p>The LIFE-H and Functional Autonomy Measurement System (Système de mesure de l'autonomie fonctionnelle, SMAF) were strongly correlated (0.70) and higher on the daily activity than the social role subscales (14).</p>
Discriminant validity	<p>Four CHART subscale scores differentiated individuals with SCI rated subjectively by clinicians as globally high or globally low on "handicap" and findings that CHART subscales differentiated people in different disability groups.</p> <p>CHART scores differentiated people with and without disabilities.</p>	<p>Correlations between LHS dimensions ranged from -0.01 to -0.29, showing the IPA's ability to differentiate its participation construct from related constructs (41).</p> <p>SIP68 and SF36 correlations were also small, as expected (41).</p>	<p>The LIFE-H distinguished people with SCI based on level and completeness of injury (14) and by living situation among older adults (45).</p>
Clinical use	<p>CHART has been used extensively with SCI and other disability samples. Its use to detect differences from short-term interventions has not been assessed.</p> <p>Systematic differences in CHART scores have been found in cross-sectional studies of persons aging with SCI.</p>	<p>The IPA's ability to describe client-identified problems in participation make it an attractive adjunct to rehabilitation and clinical practice by identifying client-centered priorities (44).</p> <p>Limited evidence of responsiveness to improvement suggests that change scores be interpreted with caution.</p>	<p>The LIFE-H can be used to elicit clients' satisfaction ratings for participation domains and facilitate goal setting in clinical practice (26).</p> <p>Clinical use, particularly in outpatient and community settings, is strong.</p>
Content validity	<p>CHART seems to have acceptable content validity based on its strong conceptual underpinnings, its ability to differentiate known groups with high and low handicap/participation, and its ability to differentiate among people with different types of impairments (or the general population).</p>	<p>The IPA is based on the participation definition contained in the ICDH-2, clinical experience of the multidisciplinary research group, and a small qualitative study with rehabilitation patients (28).</p>	<p>The LIFE-H's nomenclature underwent an extensive development process involving consultation with international experts including, researchers, service providers, and consumer representatives to assure that major aspects of social participation are addressed.</p>

Table 1. Continued

	CHART	IPA	LIFE-H
	The relationships between CHART and other domains of the disablement model, as well as injury and demographic characteristics, are as expected.	Construct validity is supported by 2 studies yielding a 4-factor solution accounted for 67% to 68% of the variance (28,40). The correlation between factors was low (0.25 to 0.52) (28). The factors were interpreted as indoor autonomy (43%), family role (11%), outdoor autonomy (7%), and social relations (6%) (41).	The instrument was refined with clinical evaluation and addition of items that were originally absent (26).
Applicability to persons with SCI	Two studies established the CHART as a reliable and valid instrument with SCI samples (22,36). CHART data on 1,998 cases in the NSCISC database provides the basis for norms by neurologic category (36).	Initial validation of the IPA included a limited number of people with SCI. Subsequent assessments of the IPA's psychometric properties have included greater numbers of people with SCI (40). There is insufficient evidence to categorize people based on their participation scores (44).	Validation studies of the LIFE-H have been conducted with more than 500 people with SCI. There are no published normative data. The clinical application and extent of psychometric evaluation of the LIFE-H suggests it is appropriate and applicable for people with SCI.
Major criticisms and drawbacks	Measures "handicap" and not participation The CHART total score is a misleading summary of "handicap;" use of subscale scores is recommended instead (36). Internal consistency with each dimension is weak because the items were developed as alternative methods for respondents to show absence of "handicap." Low ceiling	Floor and ceiling effects Insensitivity because of limited range and number of gaps Comparatively limited evaluation with SCI samples Promising instrument in need of further validation and refinement	Low ceiling Little empirical support for satisfaction scale Limited penetration in research and clinical practice Conceptual foundation (DCP) is not widely known
Overall rating	***Content and metric reliability shown The overall quantity and quality of the study results supporting the use of the CHART in measuring "handicap" in SCI is strong and has resulted in the CHART being the most frequently used measure of "handicap" and by extension participation in SCI research.	**Minimal validity for SCI population The IPA is a relative new instrument and evidence of its application to SCI samples is beginning to appear in the research literature.	***Content and metric reliability shown The LIFE-H has not been adopted widely as a clinical or research outcomes measure.

NSCISC, National Spinal Cord Injury Statistical Center database.

needed to document its use as a participation measure in general and for people with SCI in particular.

DIRECTIONS IN PARTICIPATION MEASUREMENT

Although outcome measurement and instrument development for participation is in its infancy, a number of promising instruments have been developed since the inception of this project, including the Participation Measure for Post-Acute Care (PM-PAC) (46), the Participation Survey/Mobility (PARTS/M) (47), and the PRO-PAR (24). The PM-PAC under development at Boston University is “an attempt to construct a fixed-length questionnaire that measures participation as conceptualized by the ICF” (46). The PARTS/M was developed at Washington University and is designed as a self-report survey that addresses participation in major life activities by people with mobility impairments. The authors state that the “components of participation included in this survey provide an approach to linking ICF classifications of health condition, environmental factors, and personal factors” (47). The PRO-PAR was developed through a multisite collaboration and was “constructed to complement assessments like the FIM instrument, with participation items designed to cover higher level, more complex life experiences included within the ICF domains of participation” (24).

Because the literature addresses the initial psychometric testing on these instruments and does not show their specific application to the SCI population, these instruments did not meet the eligibility criteria for inclusion in the formal evidence-based review process. These instruments do, however, represent the future of outcome measurement of participation and seek to address limitations of existing measures. Table 2 compares the conceptual and psychometric properties of these 3 instruments and their relative strengths and limitations.

Finally, the authors are part of a research team that is using a grounded theory approach to guide the development of a measure of participation for people with disabilities, especially those who are disenfranchised through the experience of disability and economic or social disadvantage. Eighteen focus groups ($n = 218$) were conducted with key rehabilitation stakeholders, including consumers, care partners, clinicians, payers, and policy makers. Their insider and outsider perspectives were used to develop a bank of items to measure participation. The community participation indicators (CPIs) include measures of objective performance, subjective evaluation, and participation values that shape and give meaning to participation (48). The instrument reflects stakeholders' feedback that participation is more than just the performance of a set of activities but is also an expression of core values and subjective appraisal of meaning and satisfaction. The CPI has been pilot tested in a population-based sample of 912 people with and without self-identified disabilities. The psychometric properties of the instrument are being evaluated with

specifically targeted subgroups of people with disability, including people with SCI.

DISCUSSION

Despite the recognition that participation is an important component of health, the development of instruments designed to capture the essence of participation has not reached fruition (7,24,47). There is no “gold standard” for measuring participation among people with disabilities, in general, nor among people with SCI, in particular. Furthermore, existing instruments may be inadequate to capture the dynamic interaction between the person and the environment inherent in the ICF definition of participation (10,23,49). Therefore, the onus for selecting appropriate measures of participation is placed on individual researchers and practitioners to consider carefully which instrument best meets their needs.

Each of the instruments reviewed incorporates different perspectives in the measurement of participation. For example, the LIFE-H uses a qualitative approach, whereas the CHART adopts a quantitative approach (26). The LIFE-H and the CHART are based on societal norms of participation, whereas the IPA integrates individual choice and control into the framing of participation. The IPA addresses the call for greater integration of the subjective experience of participation from the perspective of people with disabilities themselves (41,50).

Although the CHART is the most widely used and researched instrument, its development predates the development of the ICF. The CHART was designed to assess the domains of handicap in the ICIDH rather than the domains of participation in the ICF, but CHART items reflect many of the participation codes in the ICF. More importantly, the CHART predates the calls for including subjective appraisals and personal preferences of respondents in participation measurement. In this light, the CHART's focus on objective, norm-referenced performance is a limitation. The LIFE-H was designed to capture the dynamic interplay between individual's impairments and the environment that is central to contemporary definitions of participation. The review of Dijkers et al (10) of participation measures reported that the LIFE-H reflected the spirit of the WHO's conceptualization of participation; however, its theoretical grounding in the Disability Creation Process may serve as a barrier to its widespread adoption as the ICF gains ascendancy as the dominant model for participation. The IPA is a relatively new instrument, and published reports of its psychometric properties are only beginning to appear in the research literature.

Just as the 3 instruments included in this formal review span the continuum from objective (CHART) to subjective (IPA) assessments, the newer participation measurements also reflect these different perspectives. The PAR-PRO asks objective questions about the frequency of participation; the PM-PAC items ask for perceptions of difficulty of participation; and the PARTS/

Table 2. Comparison of New Measures of Participation

	PM-PAC (46)	PAR-PRO (24)	PARTS/M (47)
Purpose	Measures participation outcomes of rehabilitation services provided in outpatient or home-care settings	Measures home and community participation	Measures participation of people with mobility impairments
Conceptual basis	ICIDH-2	ICF	ICIDH-2
Developmental process	Items from legacy instruments based on expert opinion; items added to address ICHD-2 domains not in legacy instruments	Expert review of legacy instruments deemed relevant to ICF definitions	Items derived from qualitative studies of people with mobility impairments, their care-partners, and health care providers.
Administration mode	Self-report	Interview with patient or proxy	Patient self-report
Number of items	Fifty-one items across 9 domains	Twenty items rated at 3 time periods (admission, discharge, follow-up)	Twenty domains with 7 to 8 subquestions each
Rating scales	Multiple rating scales used to assess “how limited” participation is	Frequency of performance on a 5-point scale	Multiple rating scales per domain assess temporal, health-related, evaluative, and supportive participation components
Time (minutes)	Assessed in a 45- to 60-minute interview	Not indicated	25 to 40 minutes for web-based, 60 to 90 minutes for paper version
Reliability studies	Yes	Yes	Yes
Validity studies	Yes	Yes	Yes
Strengths	Covers ICF domains Comprehensive	Addressed major life domains Allows comparison to premorbid participation levels	Considerable consumer input Comprehensive
Limitations	Limitation focus may replicate negative conceptualization of earlier “handicap” measures Confirmatory factor analysis indicates that more complex model of participation is needed	Frequency counts only No subjective component	Length may be prohibitive in some settings Despite considerable input from consumers, the scope of the PARTS/M does not include many of their recommendations such as control, autonomy, desirability, needs
	“Don’t do this/not applicable” response option obscures individual preferences in participation Inherent limitations in short form fixed length assessments, including lack of low precision, potential ceiling and floor effects, and possible redundancies	Lack of specificity Potential floor effect	Limited to people with mobility impairments
		Validated on older sample	

M records both objective performance and subjective satisfaction. The issue of how best to incorporate the subjective and objective sides of participation into measurement will remain until a better conceptualization of participation emerges and empirical evidence of the relationship between these 2 components (along with their relationships to other concepts and measures) is available.

Another unresolved issue is the dimensionality of participation. Beyond the potential for an objective and a

subjective dimension, each instrument includes different domains of participation. The 6 CHART subscales reflect the domains of handicap in the ICIDH; the LIFE-H is based on the Disability Creation Process, the IPA claims the ICIDH-2 as its model, and most others cite the ICF as their conceptual base, but none has subscale structures matching the ICF domains. Comparability among participation measures is hampered by this lack of common domains. The conceptual blurring between activity and participation generated by the ICF adds to

the confusion. Clear conceptual distinctions between the concepts of activity and participation in the ICF are needed before the domains of participation can be articulated and empirically verified.

As our conceptual understanding of participation has evolved over the past 20 years, so has measurement theory and technology. Measurement experts have made great advances in instrument development through the application of contemporary psychometric methods. IRT, of which the Rasch model is 1 variation, is a family of mathematical models used to determine the characteristics of test questions and to estimate the trait level of people on the underlying dimension being measured (51,52). IRT presumes an item set is unidimensional (ie, that the items measured by an instrument represent a single latent trait [53]) and that that trait can be measured using a hierarchy of items arrayed from easiest to hardest (54). Although classical measurement theory dominated the 20th century and is the basis for most measures of health outcomes, these instruments are only able to provide a basic understanding of the instruments properties (53,54). Contemporary measurement theory, such as IRT and the Rasch model, offer more powerful psychometric analysis, greater precision, and flexibility and are rapidly becoming the methods by which instruments are developed and validated (55,56). However, developers of new participation measures struggle with the failure of participation items to form concise hierarchies, given the extent to which personal preferences determine in which areas of life people chose to participate. Consensus has not been reached about the use of modern psychometric methods to participation measurement.

RECOMMENDATIONS AND CONCLUSIONS

There is no gold standard for measuring participation among people with disabilities in general and people with SCI in particular. The CHART is the most widely used and researched instrument, but it is limited by ceiling effects, nonnormal distributions, the use of norm-referenced scoring not taking personal preference into consideration, and the absence of subjective assessments by respondents. Although other participation instruments address some of these issues, no tool has emerged as the consensus replacement for CHART to measure participation in SCI. The LIFE-H does a better job of capturing the dynamic interplay between individual impairments and the environment that is an integral part of contemporary definitions of participation. Although it has been tested and its use among people with SCI is documented, the LIFE-H has not been widely adopted in research or clinical practice. Although the IPA is conceptually sound, reports of its use as an outcome measure in SCI are only starting to be documented in the research literature. Several new participation measures show promise for their conceptual and psychometric

properties, but their applicability to SCI has not been established.

Ongoing efforts are needed to develop conceptually and psychometric valid measures of participation to be used with people with SCI. Particular priority should be placed on understanding the interplay between objective and subjective indicators of participation, determining the dimensionality of participation, and identifying the most appropriate measurement model and psychometric tools to fit the nonhierarchical character of participation. Until such time as these priorities are achieved and improved measurement of participation is available, researchers and clinicians must be aware of the strengths and limitations of existing measures to make informed decisions about which instruments to use.

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