Chapter 6

A systematic review of instruments assessing participation: challenges in defining participation

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Abstract

Objective

To evaluate: (1) whether instruments which intend to measure participation actually do and (2) how frequently specific aspects and domains of participation are addressed.

Data sources

A systematic search was performed in PubMed.

Study selection

Included were patient-reported instruments that primarily aim to measure participation.

Data extraction

The full-text instruments were extracted from the articles or obtained from the authors. Two reviewers independently rated each item of the included instruments as measuring participation (yes, no, or undetermined). For each item, the specific aspect and domain of participation were categorized.

Data synthesis

Included were 103 instruments (2445 items). Of the included items, 619 items concerned participation and 217 concerned undetermined items. In total, 68 instruments contained at least 1 (sub)scale with 50% or more participation or undetermined items. The participation items referred to the participation aspects: participation problems (53%), participation accomplishment (31%), and satisfaction with participation (9%). The domains of the participation items concerned: work/study (27%), social life (27%), general participation (19%), and home (11%). The undetermined items mainly referred to domains about leisure (43%), transport (26%), and shopping (12%).

Conclusions

According to our working definition of participation, most instruments that aim to measure participation do so only to a limited extent. These instruments mainly assess aspects of participation problems and participation accomplishment. The domains of participation covered by these instruments primarily include work/study, social life, general participation, home, leisure, transport, and shopping.

Introduction

In healthcare and in research, there is an increased focus on the assessment of a person's participation. Functioning and health are increasingly conceptualized as including involvement in life situations and including personal and environmental factors instead of just including the disease.[1] Several definitions of participation are available and new participation measures have been developed. These participation measures seem to include a wide range of participation items, domains, and aspects. It is not clear if these instruments measure participation in a valid way. In order to measure participation in a valid way, it is important to have a clear definition of the construct of participation. However, consensus on a criterion standard for defining and measuring participation is lacking.[2]

The International Classification of Functioning, Disability and Health (ICF) defines participation as an individual's involvement in life situations in relation to health conditions, body functions and structure, activities, and contextual factors.[3] Activity is defined as the execution of a task or action by an individual.[3] Although there are 2 definitions for activity and participation they are treated as 1 category in the ICF, which makes it difficult to clearly operationalize these different concepts in measurements.[4-6]

Several other definitions of participation have been provided. For example, Wood[7] called participation "handicap," referring to a disadvantage, which limits or prevents the fulfilment of a role that is normal for an individual. Nagi[8] called participation "disability," referring to a limitation in performing socially defined roles.[9] Cardol et al.[10] described perceived participation as a complex concept in which many factors are involved, and that rehabilitation treatment should address physical, social, emotional, and environmental aspects to make a contribution to meaningful participation. Jette et al.[6] suggested that participation involves more complex behaviors that can be accomplished using a variety of tasks or component actions, rather than activities that reflect relatively simple physical tasks. Perenboom and Chorus[11] defined participation as "the involvement in life situations, which includes being autonomous to some extent or being able to control your own life, even if one is not actually doing things themselves. This means that not only the actual performance should be the key indicator, but also the fulfilment of personal goals and societal roles."[11(p578)] Another operationalization of participation can be found in Wilkie et al.[12] They combined several factors and considered items as participation only if they obtained information relating to an action, task, or life situation that occurs in relation to contextual factors.[12] Levasseur

et al.[13] defined social participation as the accomplishment level and satisfaction with participation in social roles. In the different definitions of participation, some key elements can be identified: the importance of the context or environment; the meaning of community; client-centeredness; determinants other than the health condition; and interdependence and social networks rather than independence.[14]

Several instruments have been developed that intend to measure participation. These instruments vary widely in the operationalization of participation.[15] For example, some instruments contain typical participation items addressing role issues like "My chances of fulfilling my role at home as I would like are . . . very good-very poor" (Impact on Participation and Autonomy [IPA])[16,17] or "I spend most of my days occupied in a work activity that is necessary or important to me" (Reintegration to Normal Living Index [RNL]).[18] However, instruments may also contain nontypical participation items that are focusing on the impact of body function on functional activities, such as "How much time did you spend on your health condition or its consequences" (World Health Organization Disability Assessment Schedule II [WHO-DASII])[19] or "Worked for short periods of time or taken frequent rests because of your health . . . All the time–none of the time" (Functional Status Questionnaire [FSQ]).[20]

Different domains of participation can be distinguished in instruments that intend to measure participation. Some instruments mainly focus on one specific domain of participation like work, social involvement, or leisure, whereas other instruments combine several domains of participation. Some authors[11,15,21,22] use the ICF subdomain Activity and Participation to categorize participation items. For example, chapters d3 to d9 in the activities and participation component of the ICF are one of the suggested options for operationalizing participation.[15] Other authors argue that of the 9 ICF domains, the first 3 domains (d1, learning and applying knowledge; d2, general tasks and demands; and d3, communication) focus on activities and not on participation and that 2 ICF domains (d4, mobility and d5, self-care) contain a mixture of activities and participation.[12] The 4 other ICF domains (d6, domestic life; d7, interpersonal interactions and relationships; d8, major life areas [eg, work]; and d9, community social and civic life) deem to measure participation.[12]

Another distinguishing factor is the different aspects of participation. The literature often refers to 2 aspects to assess participation: objective and subjective participation. An example of objective participation is society-perceived participation, which is based on a social standard (societal perspective). An example of subjective participation is person-perceived participation,[23] also called

handicap, which is based on an individual's life experiences and preferences (individual's perspective).[24] Levasseur et al.[13] also described 2 aspects: an objective aspect, participation accomplishment (eg, difficulty with and assistance used to carry out roles), and a subjective aspect, satisfaction with participation (eg, satisfaction with the accomplishment of social roles).[9,13]

The present review evaluates: (1) to what extent instruments that intend to measure participation actually do so according to our working definition of participation (based on the key elements and general ideas in literature); and (2) how frequently specific aspects and domains of participation are addressed by these instruments. Problems and potential solutions related to the operationalization of participation are discussed.

Methods

Defining participation

Our definition of participation is based on definitions found in the literature.[7-9,11,12] We defined participation as performing roles in the domains of social functioning, family, home, financial, work/education, or in a general domain. First, activities were distinguished from participation by stating that participation requires a social context, involving not just an environmental factor, but mainly involving other people. For example, we considered visiting friends as participation, but moving around the home may not involve other people and was therefore not considered as participation. We also excluded self-care activities, even if it included other people, because there is no social context involved. Second, we decided that participation should include a combination of multiple activities; these activities should be related to a role. In the models of Wood[7] and Nagi,[8] performing social roles was an important factor in distinguishing participation from activities.[9] According to Whiteneck and Dijkers,[9] activities are tasks performed by individuals. Activities focus on functional performance of an individual that can be done alone, while participation is the social role performance as a member of society with or for others.[9] Activities tend to be simple and distinct, while participation tends to be more complex and will broadly encompass several activities.[9] For example, visiting friends contains multiple activities (transport, communication) and is related to a role (being a friend) and is thus considered participation. Going to the movies also contains multiple activities, but is not necessarily related to a role and was therefore not considered participation.

Despite the definition, there are items that do not clearly meet the defined aspects of participation. Items related to shopping, sexual life, leisure, transport, and religion were felt to be undetermined. While such items can be seen as related to a social context and contain multiple activities, it is unclear if these items are related to a specific role function. Another undetermined domain is perception. According to the ICF, perception seems to be a personal contextual factor.[3] It is unclear if perception items, such as: "Because of your problem, do you feel handicapped?" (Dizziness Handicap Inventory)[25] or "I feel like part of this community, like I belong here" (Community Integration Measure),[26] belong to participation. The undetermined items are included in this review and labelled as undetermined.

We considered related concepts, such as autonomy, quality of life (QOL) and well-being, as not being equal to participation. Because autonomy is based on an individual's own values, needs, and choices it is narrowly connected to perceived participation. Autonomy gives a personal dimension to participation.[16] Although we agree with Cardol et al.[10] that the concept of autonomy is crucial to the successful operationalization of participation, we have decided not to consider autonomy as equivalent to participation because it can also be seen as a prerequisite for participation,[10] like other concepts such as interdependence and self-awareness. In the literature, QOL instruments are also often considered as participation measures.[13] Although participation is regarded as an important component of overall health-related QOL,[27-29] measures of QOL include other aspects of health, which do not concern participation. However, subscales of QOL instruments that aimed to measure participation were included.

Furthermore, one can question whether concepts like performance, work productivity, work ability, and work limitations should be considered as participation. Although these concepts seem to be closely related to participation accomplishment, we have not defined them as participation because they give information about the ability or the intensity of work rather than about participation in which a social context and role is involved.

Search strategy

A systematic search was performed in PubMed (up to February 2009) to identify instruments that intend to measure participation in an adult population. Several key words were used: *participation*, *handicap*, *client-centered*, *role*, *social disability*, and *reintegration*. Variants and combinations of the key words were used. The complete search strategy can be found in Appendix 6.1.

Screening abstracts and articles

Abstracts were included if: (1) the instrument was generic or disease-specific and primarily aimed to measure participation, handicap, or role functioning according to the authors of the articles. (2) The instrument aimed to measure at least 1 of the 3 participation aspects: participation accomplishment, participation problem, or satisfaction with participation. The first aspect, participation accomplishment,[13] refers to the extent or degree of participation. For example, "How often did you get together with friends or relatives, such as going out together, visiting each other's homes, or talking on the phone?" (FSQ).[20] The second aspect, participation problem, includes the difficulty in accomplishing social roles, that is, a person's experience of a participation problem or the meaning of the personal burden of the problem. For example, "Does your health limit your work or leisure activities?" (London Handicap Scale).[30] In addition to these 2 participation aspects, a third aspect can be distinguished: satisfaction with participation.[13] This aspect refers to perceived participation, that is, a person's current perception of participation according to what the person wants or expects. It can be seen as the level of satisfaction with participation in relation to the current situation. For example, "I participate in social activities with family and friends as is necessary or desirable to me" (RNL).[18] (3) The instrument was a self-report questionnaire or an instrument that had to be filled out by a health professional together with a client. (4) There was information available on the measurement properties, because these properties are important for implementing measures and instruments in clinical practice and in research. (5) The article was written in the Dutch or English language.

Abstracts were excluded if: (1) the article was a review study (except reviews of participation measurements); (2) the instrument measured related concepts of participation, such as impairment, activity (limitation), disability, job satisfaction, selfefficacy, autonomy, QOL, well-being, participation as in taking part in treatment or research, individual capacity and performance (what and how much somebody can perform regardless of context, situation, or social environment), work productivity, work ability, and work limitations; (3) the instruments needed to be completed by proxies; (4) the instrument was developed for people younger than 18 years of age.

Of all selected abstracts, full-text articles were obtained and selected according to the same inclusion and exclusion criteria as listed for the abstracts. If the instruments were not available, the authors were contacted to send the original questionnaire.

Two reviewers independently selected and rated the abstracts, full-text articles, and the instruments' items. Consensus about the criteria was obtained before the assessment process started. Selections and ratings were compared with regard to agreement and disagreement. Differences were discussed until consensus was reached. Based on the original codings of the 2 reviewers, we calculated the interrater agreement and found a kappa of 0.82.

Classification of participation items

All items of the included instruments were classified as measuring participation: yes (so called white items), no (black items), or undetermined (gray items). The white and gray participation items were classified according to 2 dimensions.

The first dimension, participation domains, classified the items according to which domain of participation was assessed: a social life, family, home, financial participation, work/education, or a general participation domain. The general domain covered items about overall participation like "How much did these difficulties interfere with your life?" (WHO-DASII)[19] or "Ask the patient to mark the line below in order to obtain a score for handicap (1: I can perform a completely normal role in life – 5: I am completely prevented from holding a normal role in life by my illness)" (Cambridge Multiple Sclerosis Basic Score [CAMBS]).[31] The white items were classified in the following 6 domains: social life, family, home, financial participation, work/education, or a general participation domain. The gray items were classified in the following 6 domains of which it is unclear if they measure participation: shopping, sexual life, leisure, religion, transport, and perception.

The second dimension, participation aspects, described the 3 different aspects of participation: participation accomplishment, participation problem, or satisfaction with participation.

Classification of participation instruments

Finally, the selected instruments were classified according to the degree to which they measure participation according to our working definition and criteria. For each instrument, the percentage of participation items was calculated for each subscale. If an instrument does not have subscales, the percentage of participation items of the whole instrument was calculated. Instruments or subscales of instruments with at least 50% participation items were labeled as white participation instruments. Instruments that measured at least 50% participation items, including the undetermined items, were labeled as gray participation instruments.

Results

Screening abstracts and articles

The reviewers screened 4967 abstracts and 320 full-text articles including 222 instruments. Selected were 189 articles on 112 instruments that measured participation according to the authors of the included articles. The participation items were classified for 103 instruments because 9 instruments could not be retrieved. The selection process of abstracts and full-text articles is described in Figure 6.1.

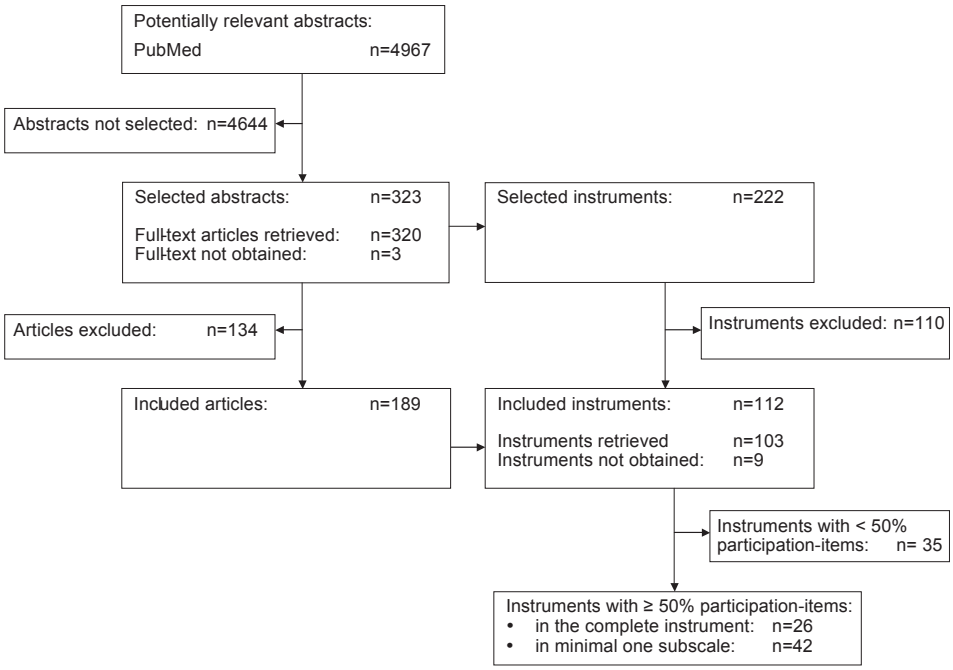

Figure 6.1 Inclusion of abstracts, articles and instruments

Classification of participation items

Number of participation items in the selected instruments

The 103 selected instruments contained 2445 items. Of the selected items 619 (25%) items were classified as measuring participation (white items), 1609 (66%) were classified as not measuring participation (black items), and 217 (9%) were classified as undetermined (gray items). In Table 6.1, the participation in society subdomain of the WHO-DASII is used to illustrate the white, gray, and black items.

D6.1 through D6.3 are white participation items and D6.8 is a gray participation item. The items D6.4 through D6.7 are not measuring participation because they refer to the impact of body functions on activities and feelings.

Table 6.1 Example of the WHO-DAS II – Subscale: Participation in society

Item description	Category	Participation grade
D6.1 How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	Social	White
D6.2 How much of a problem did you have because of barriers of hindrances in the world around you?	General	White
D6.3 How much of a problem did you have living with dignity because of the attitudes and actions of others?	Social	White
D6.4 How much time did you spend on your health condition, or its consequences?	NP	NP
D6.5 How much have you been emotionally affected by your health condition?	NP	NP
D6.6 How much has your health been a drain on the financial resources of you or your family?	NP	NP
D6.7 How much of a problem did your family have because of your health problems?	NP	NP
D6.8 How much of a problem did you have in doing things by yourself for relaxation or pleasure?	Leisure	Gray

Answer options: none, mild, moderate, severe, extreme/cannot do
Scale references can be found in Appendix 6.1
NP: not measuring participation

Classification of the items in participation domains

The 619 white participation items were classified in participation domains: 27% in the social life domain, 27% in work/study, 19% in general participation, 11% in home, 8% in family life, 6% in financial participation, and 2% in a combination of categories. The 217 gray items were classified into 6 domains: 43% in leisure activities, 26% in transportation/mobility, 12% in shopping, 7% in perception items, 7% in religion, and 6% in sexual items. Figure 6.2 illustrates the classification in participation domains.

Classification of the items in participation aspects

Of the 619 white participation items, 189 items (31%) referred to participation accomplishment, 329 items (53%) to a participation problem, 59 items (9%) to a satisfaction with participation problem, 24 items (4%) to a combination of participation accomplishment and problem, 12 items (2%) to a combination of participation accomplishment and satisfaction with participation problem, and 6

items (1%) could not be classified because of missing information in the articles and instruments. Of the 217 gray participation items, 57 items (26%) referred to participation accomplishment, 130 items (60%) to a participation problem, 18 items (8%) to a satisfaction with participation problem, 7 items (3%) to a combination of participation accomplishment and problem, and 5 items (2%) to a combination of participation accomplishment and satisfaction with participation problem.

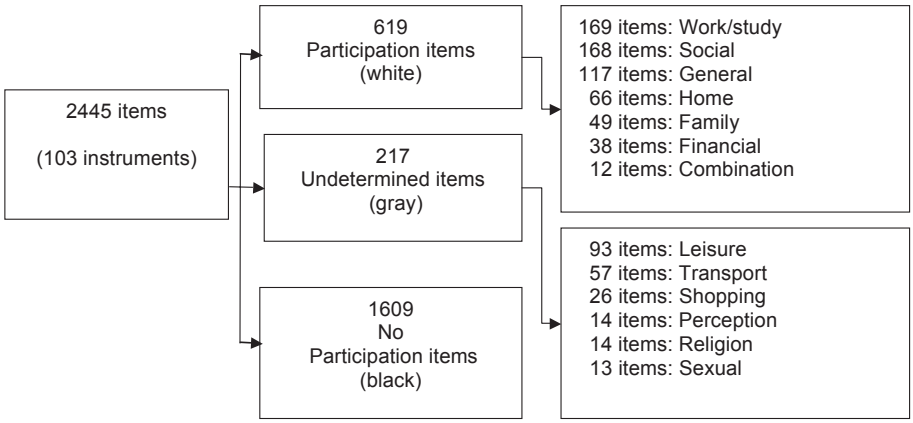

Figure 6.2 Classification of the items in the participation domains

Classification of participation instruments

Of the 103 selected instruments, 68 instruments contained 50% or more white and gray items in the whole instrument (1-scale instruments: 26 instruments) or in at least 1 subscale (multiscale instrument: 42 instruments). The 1-scale instruments enclosed 18 white and 8 gray instruments. The multiscale instruments enclosed 35 white and 7 gray instruments. Fifty-three instruments contained more than 50% white participation items and 15 instruments contained more than 50% white and gray participation items. The full list of instruments is presented in Table 6.2 (1-scale instruments) and Table 6.3 (multiscale instruments). Appendix 6.2 contains the abbreviations, names, and references of the 68 white and gray instruments.

Table 6.2 Participation instruments (≥ 50% Participation-items): 1-scale*

Instrument	Total no. of items	Participation items (%)	Aspects of participation items (n)			Domains of white participation items (n)							Domains of gray participation items (n)					
			a	p	s	wo	so	ge	ho	fa	fi	co	le	tr	sh	pe	se	re
White																		
Activity Participation Questionnaire	2	100	2					2										
Disease Repercussion Profile	6	50		3			2				1							
Global Assessment of Functioning	1	100		1				1										
Keele Assessment of Participation	11	73			8	2	2		2	1	1							
Personal and Social Performance scale	1	100		1				1										
Profile of Occupational Engagement in people with Schizophrenia	9	56	4	1			2	3										
Australian Therapy Outcome Measure†	12	75		9		1	2	1	2					3				
Computerized Adaptive Testing -Osteoarthritis†	36	56	20		3	6	7			3		1						
Environmental Status Scale†	7	86	5	1		1	1	1	1		1			1				
Household and Leisure Time Activities Questionnaire†	11	73	8				2		2	1	1		1					1
Leisure Time Satisfaction†	6	83		5			4						1					
London Handicap Scale†	6	83		5		2	1				1			1				
Participation Scale†	18	61			11	1	6	1	1		1			1				
Role Activity Performance Scale†	12	67		8		2	1		1	3			1					
Role Functioning Scale†	4	100		4		1	1		1				1					
Strauss and Carpenter revised Outcome Criteria Scale†	9	78	2	5		2	2	2								1		
Sydney Psychosocial Reintegration Scale†	14	71		10		2	2	2		2			1	1				
Work and Social Adjustment Scale†	5	100	5			1	1	1					2					
Gray																		
Adapted Illness Intrusiveness Ratings Scale	13	77		10			1	2		1	1	1	2				1	1
Assessment of Life Habit	57	54	31 a+p			6	2	2	2	7	2	2	2	4	1		1	
Brief Cancer Impact Assessment	18	61		11		2	1		1	3	1		1				1	1
Community Integration Measure	10	50		5		1	1	1					1			1		
Hearing Handicap Inventory for the Elderly screening version	10	50		5			1	1					1			1		1
Rotterdam nine item handicap scale	9	78		7		1		1	1				2	2				
Social Functioning Scale	13	69	9					1	3		2			2		1		
Subjective Index of Physical and Social Outcome	10	60	3	3			3		1					1	1			

a: accomplishment; co: combination; fa: family; fi: financial; ge: general; ho: home; le: leisure; p: problem; pe: perception; re: religion; s: satisfaction with participation; se: sexual; sh:shopping; so:social functioning; tr: transport; wo:work/education.

*: Scale references can be found in Appendix 6.2.; †: White instruments containing white and gray participation items.

Table 6.3 Participation-Instruments (≥ 50 % white and gray participation-items): Multi-scale*

Instrument	Subscale	Total number of items	White items (%)	Gray items (%)	Aspects of participation items (n)			Domains of white participation items (n)							Domains of gray participation items (n)					
					a	p	s	wo	so	ge	ho	fa	fi	co	le	tr	sh	pe	se	re
American Heart Association Stroke Outcome Classification	Function	1	100			1				1										
Amputee Medical	Handicap-physical independence	1	100		1					1										
Rehabilitation Society	Handicap-mobility	1		100	1											1				
Australian Community	Adult learning	2	100		2			2												
Participation	Organized community activities	3	100		3				1	2										
Questionnaire	Voluntary sector activity	2	100		2			2												
	Political protest	2	100		2				2											
	Contact with extended family	2	50		1							1								
	Contact with friends	2	50		1				1											
	Social contact with workmates	2	50		1				1											
	Religious observance	2		50	1															1
Cambridge Multiple Sclerosis Basis Score	Handicap role in life	1	100			1				1										
Community Integration Questionnaire†	Integration to productive activities	4	75	25	4			3								1				
	Social integration	6	17	33	3			1							1		1			
Craig Handicap Assessment and Reporting Technique	Mobility scale	7	71	29	7			3			1			1	2					
F Quick - Disabilities of	Severity pain	2	100			2		1	1											
the Arm Shoulder and	Work module	4	75			3		3												
Hand	Sport module	4		75		3										3				
Functional Independence Measure	Psychosocial adjustment	1	100			1			1											
Functional Status Scale	Social / Role functioning	14	57		2	6		4	3			1								
Functioning Assessment	Occupational functioning	5	100			4	1	5												
Short test	Financial issues	2	100			2							1							
	Interpersonal relationship	6	67	17		5			3			1							1	
	Leisure time	2		100		2									2					
Health of the Nation Outcomes Scales	Social problems	4	75			3			1	2										

Table 6.3 Participation-Instruments (≥ 50 % white and gray participation-items): Multi-scale*

Instrument	Subscale	Total number of items	White items (%)	Gray items (%)	Aspects of participation items (n)			Domains of white participation items (n)							Domains of gray participation items (n)					
					a	p	s	wo	so	ge	ho	fa	fi	co	le	tr	sh	pe	se	re
Hearing Handicap Inventory for Adults†	Social/situational	12	33	25		4	3		3			1			2		1			
Hearing Handicap Questionnaire	Social restriction	5	80			4			1	3										
ICF Measure of Participation and Activities questionnaire	Domestic life	3	100			3			1		2									
	Interpersonal interaction and relationships	4	75	25		4			2					1					1	
	Major life areas	3	100			3		1					2							
	Community, social and civic life	4	50	50		4				2					1					1
Impact of Vision Impairment profile†	Social and consumer interaction	11	46	9	1	5			2	2			1				1			
	Leisure & employment	5	20	60		4		1							3					
Impact on Participation and Autonomy	Family role	8	75			5	1				4		2							
	Work& education	8	75			4	2	6												
	Social life and relationship	7	57			2	2		3	1										
	Autonomy outdoors	5	80	20		3	2		3	1					1					
Independent Living Skills Survey-self report	Leisure & community	12	8	58	8				1						6					1
Instrument for Home and Community participation	Home & community participation profile	20	50	40	18			3	2		3	1	1		4	1	1		1	1
Inventory of Functional Status-Dialysis	Social and community activities	5	100		5				5											
	Household activities	9	56	11	6						5						1			
Japanese Knee Osteoarthritis Measure	General activities	5	80	20	1	4				4					1					
Life Functioning Questionnaire	Duties at home (e.g. housework, paying bills, grocery, shopping, moving lawn, childcare tasks, car repairs)	4	50			2				1	1									
	Duties at work, school or activity center	4	50			2		2												
Living with Dysarthria	Role restriction	6	50				3	1	1			1								
Mayo-Portland Adaptability Inventory-4	Participation	9	56	22	7			2	1		1		1		1	1				
Multidimensional Scale of Independent Functioning	Global overall	1	100			1				1										
	Work	4	75		1	2		3												

Table 6.3 Participation-Instruments (≥ 50 % white and gray participation-items): Multi-scale*

Instrument	Subscale	Total number of items	White items (%)	Gray items (%)	Aspects of participation items (n)			Domains of white participation items (n)							Domains of gray participation items (n)					
					a	p	s	wo	so	ge	ho	fa	fi	co	le	tr	sh	pe	se	re
	Education	4	75		1	2		3												
	Residential	4	75		1	2					3									
New Handicap Scale	Social integration	1	100			1			1											
	Orientation awareness of surroundings	2	100			2				2										
	Occupation-work and leisure	1		100		1									1					
Oral Health Impact Profile	Handicap	6	50		3			1		1			1							
Participation Measure for Postacute Care	Role-functioning	5	80			4		4												
	Work	5	80			4		4												
	Education	5	80		1	2	1	3	1											
	Economic Life	4	50			2							2							
	Domestic Life	3	67	33		3					1	1					1			
	Interpersonal relationship	5	60	20	1	2	1		3									1		
	Community, social, civic	10	30	40	1	6			3						3					1
	Mobility	8		50		4										4				
Participation Objective	Major life areas	3	100				3	3												
Participation Subjective							a+s													
	Domestic life	8	38	13			4 a+s		1			1	1				1			
	Interpersonal interactions and relationships	8	63	13			6 a+s		4			1							1	
	Community, recreational and civic life	5		80			4 a+s								2		1			1
Perceived Impact of Problem Profile	Participation	5	100			1						1								
	Relationship	4	75			3			2			1								
Quality of Life Scale – Swedish version	Relations with others	5	100			5			2			3								
	Active participation	4	25	25		2		1							1					
Rating of Perceived Participation Questionnaire	Domestic life and caring	1	100				1				1									
	Education	1	100				1	1												
	Work & employment	1	100				1	1												
	Economic life	2	100				2						2							
	Mobility	4		75			3									3				
	Social relations	4	75	25			4		2			1							1	
	Social and civic life	2	50	50			2			1					1					

Table 6.3 Participation-Instruments (≥ 50 % white and gray participation-items): Multi-scale*

Instrument	Subscale	Total number of items	White items (%)	Gray items (%)	Aspects of participation items (n)			Domains of white participation items (n)							Domains of gray participation items (n)					
					a	p	s	wo	so	ge	ho	fa	fi	co	le	tr	sh	pe	se	re
Reintegration to Normal Living Index†	Daily functioning	8	38	38			6	1	1			1			2	1				
Short Form health survey -36	Role-physical	4	100		1	2	1			4										
	Role-emotional	3	100		1	1	1			3										
Social Role Participation Questionnaire	Time spent in roles	16	69	19	3	11		4	3	3		1			1	1		1		
	Performance in roles	16	75	19	1	3	11	4	3	3		2			1	1		1		
Stroke Impact Scale -64†	Participation	9	33	33		6		1	1					1	2					1
Subjective Handicap of Epilepsy scale	Social and personal	4	75			3			2			1								
	Self perception	5	60			3				3										
	Work and activity	16	69	19		14		7		3	1				2	1				
	Change	7	57	14		5		1	2	1					1					
Tinnitus Handicap / Support Scale	Disability / Handicap	9	67		2	4			1	4	1									
Vestibular disorder Activities Daily Living Scale†	Instrumental	7	43	29		5		1			2				1	1				
Voice Activity and Participation Profile	Effect on social communication	4	75			3			3											
	Effect on job	4	50			2		2												
Walking Ability Questionnaire†	Community	11	18	82	1	10			1	1					5	1	3			
World Health Organization - Disability Assessment Schedule II	Life activities	8	100			8		4			4									
	Overall	4	100		3	1				4										
	Getting along with people	5	80	20		5			4										1	
	Participation	8	38	13		4			2	1					1					
World Health Organization Quality Of Life – version for Older persons	Social Participation	4	75				3			3										

a: accomplishment; co: combination; fa: family; fi: financial; ge: general; ho: home; le: leisure; p: problem; pe: perception; re: religion; s: satisfaction with participation; se: sexual; sh:shopping; so:social functioning; tr: transport; wo:work/education; *: Scale references can be found in Appendix 6.2; †: Gray instruments

Discussion

Extent to which participation items and instruments measure participation

Based on a review of relevant literature, we used a definition of participation which was shared between the 2 raters and classified 25% of the items in our review as addressing participation, 66% as not addressing participation, and 9% of the items as undetermined items. According to our working definition of participation, only a few instruments (the Activity Participation Questionnaire [APaQ], the Global Assessment of Functioning [GAF], and the Personal and Social Performance [PSP] scale) consist entirely of participation items.[32] However, 2 of these instruments comprise a 1-item classification (PSP scale and GAF) and 1 instrument (APaQ) consists of just 2 items. Of the instruments with more items, the Keele Assessment of Participation (KAP) (73%) and the Profile of Occupational Engagement in people with Schizophrenia (56%) contain the most items measuring participation. Some other instruments have subscales that contain only participation items, like the Amputee Medical Rehabilitation Society physical independence, the CAMBS handicap/role in life, the Inventory of Functional Status (IFS) social community activities, and the Medical Outcomes Study Short-Form 36-Item Health Survey role-physical functioning subscale and role-emotional functioning subscale. It seems that instruments designed to capture societal consequences consistent with the participation concept in the ICF contained the greatest proportion of participation items.[12]

Most instruments also seemed to assess other constructs, including the activity level or even the body function level of the ICF.[11,21,33] Possibly, this is due to the fact that there is still no full consensus about the way participation should be defined.[4,9,11,12,22] This is not surprising considering that in the ICF classification, activity and participation are listed together and the user decides how to structure their relationship.[15] For example, Perenboom and Chorus[11] placed recreational activities in the participation category, while Jette et al.[6] placed these activities in a mobility activity domain and not on the hypothesized domain of social participation.

The debate in the literature about the definition and operationalization of participation and activities is important because participation is the outcome that may be most valued to people with disabilities, their family members, and society.[21] Consensus about the concept and assessment of participation is needed to identify or develop adequate instruments for measuring participation. We support the recommendation by Whiteneck and Dijkers[9] to divide the ICF into 2 distinct lists for activity and participation by focusing on social role performance. Activities focus

more on the individual level and participation at performance on the societal level.[9] This is also in agreement with the concepts introduced by Badley,[4] who distinguishes between acts, tasks, and societal involvement. According to Badley, societal involvement concerns "the individual as a player in socially or culturally recognized areas of human endeavor."[4(p 2339)] Examples of societal involvement include roles such as work and employment, leisure, parenting, and community, social, and civic life.[4]

In an attempt to operationalize the difference between activity and participation, we propose that the items that are related to social roles can be considered as important aspects of participation, while items that are related to daily activities on an individual level are aspects of activities and not of participation. To operationalize the concept participation, we therefore suggest that participation items require the performance of roles in a social context, involving not just an environmental factor, but mainly involving other people. Participation items also require a combination of multiple activities and these activities should be related to a role.

Participation domains

In this review, we found that instruments can focus on different domains of participation. For example, there are instruments that focus more on work (eg, Craig Handicap Assessment and Reporting Technique [CHART] mobility or the Participation Objective, Participation Subjective [POPS] major life areas), social aspects (e.g. FSQ social role functioning or the IFS Dialysis social and community activities), home aspects (e.g. IPA family role, or WHO-DASII), family aspects (e.g. Life Functioning Questionnaire leisure activities with family), or financial aspects (Independent Living Skills Survey, self-report version, money management).

The domains in this review correspond with the participation working definition used in this review. Therefore, the only domains included required a social context and a combination of multiple activities that are related to a role. These domains were extracted from relevant literature. Most items were found in the domains work/study, social life, general participation, and home. Some items concerned the domains family life and financial participation.

In our study, we did not consider items that corresponded with the 3 ICF domains that focused on activities (d1, learning and applying knowledge; d2, general tasks and demands; d3, communication)[12] as measuring participation. Of the 2 ICF domains that contained a mixture of activities and participation (d4, mobility;d5, self-care)[12] we did not consider items about self-care as participation because there is no social context involved. Whiteneck and Dijkers[9] classified

all items of the mobility domain as activities. In our study, the mobility domain (transport) items are considered undetermined items because it's questionable if mobility items are performed in an individual or in a social context and if it concerns a social role. Examples of transportation items in outcome measures are: "Can you use your transportation independently?" (CHART), "How often do you travel outside the home?" (Community Integration Questionnaire), and "Manage transportation needs" (Disabilities of the Arm, Shoulder and Hand [DASH]).

Although our undetermined domains: shopping, sexual life, leisure, and religion correspond with the 4 suggested ICF participation domains (d6, domestic life; d7, interpersonal interactions and relationships; d8, major life areas [eg, work]; and d9, community, social and civic life),[12] we still doubt if labeling them as participation is correct because one can question if these domains are necessarily connected to a role. For example, sexual life can be an activity in itself or it can, for example, be related to the social role of intimate partner. There are authors who consider the domestic life category of the ICF mainly as activities (an exception is d660, assisting others) because they focus on individual activities that may or may not involve other people.[9] The ninth category of the ICF (d9, community, social, and civic life) also includes leisure and religion. Some authors consider these items as participation because they can be seen as community-based roles that include engagement in leisure and in spirituality.[9] Because leisure and religion can also be performed on the individual level, with or without the involvement of others, we classified them as undetermined. Despite the differences between our domains and the ICF classification, we found that the used domains in this study were appropriate for operationalizing the concept participation according to the given working definition. Which domains of participation are useful to assess, depends on the purpose of measurement and the target population or situation. The choice for an instrument to measure participation should therefore at least be based on which participation domains one is interested in.

Participation aspects

The participation items in our review mostly referred to a participation problem (53%) and to participation accomplishment (31%). Only a few (9%) items referred to a satisfaction with participation problem. In 1999, Cardol et al.[34] stated that only a few measures tended to partially address the concept of person-perceived participation (participation based on an individual's life experiences and preferences). The authors concluded that the development of a generic person-perceived handicap questionnaire is essential for adequate assessment of needs,

outcome, and relevance of rehabilitation interventions from the individual's point of view.[34] When participation is evaluated from a societal point of view (participation based on a social standard), this can result in inadequate interventions and the possibility that the needs of the individual are not met or will be misinterpreted.[23,34] In our review, only 13 instruments that have 50% or more white or gray participation items, have 1 or more satisfaction with participation items (the KAP, Participation Scale, Functioning Assessment Short Test, Hearing Handicap Inventory for Adults, IPA, Living with Dysarthria, Participation Measure for Postacute Care, POPS, Rating of Perceived Participation Questionnaire, RNL, Medical Outcomes Study Short-Form 36-Item Health Survey, Social Role Participation Questionnaire (SRPQ), World Health Organization Quality Of Life for Older Persons).

From a patient-centered perspective, some people argue that only the satisfaction with participation items should be considered as participation.[17,35] Although this might be an attractive choice from the patient's perspective, one can argue that it is too closely related to satisfaction and may overemphasize the role of the patient in defining participation. In a qualitative research, participation was conceptualized as a cluster of values in which participation not only involves active engagement in life situations at the societal level, but also refers to the personal meaning and satisfaction resulting from that engagement.[13]

The participation problem aspect that we added to the 2 participation aspects as described by Whiteneck and Dijkers,[9] and Levasseur et al.[13] can be seen as a surplus because difficulty in accomplishing social roles is not described in the accomplishment aspect and not in the satisfaction with participation aspect.[13] The participation accomplishment aspect in our study is focused on performance (to what a person does in the actual environmental context)[36] and the participation problem aspect is focused on capacity (the ability to execute a task or action in a uniform environment).[36]

We argue that all 3 participation levels provide insight into a person's participation status. For example, information about participation accomplishment can be helpful to describe participation restrictions in epidemiologic studies and enables comparisons between groups or even societies.[37] Information about participation problems can be useful to know how well somebody has adapted and is able to function, while data about problems in satisfaction with participation allows health professionals to set goals and direct treatment plans, as not all restrictions or participation problems are deemed equally important by the respondent.[16,37] Depending on the issue of interest, one can choose an appropriate instrument that assesses the participation aspect(s) of interest.

Study limitations

The working definition of participation, the domains, and the participation aspects used in this study are the result of our interpretation of definitions in the literature. We have tried to distinguish the items, domains, instruments, and subscales that measure participation, but we recognize that other authors used different concepts and classifications; for example, authors who have chosen to use the ICF taxonomy. The used definitions and classifications are open for discussion.

In our study, we have tried to contribute to the process of reaching the necessary consensus about participation. We have suggested that participation should involve a combination of 3 key elements: social context, multiple activities, and role performance. Criticism on emphasizing the concept of social role to make a case for the social context of participation refers to leaving out important aspects of social inclusion (eg, interpersonal interaction or major life areas). Other persons can criticize the fact that we have left out certain items because they measure activity according to our working definition of participation, while other persons would have labeled this as participation. This criticism emphasizes the need for a consensus-based definition of the construct participation.

For adequate use of participation instruments in practice and in research, the instruments should have good measurement properties. We included only studies with information available on the measurement properties. Because we did not judge the quality of the instruments, the included instruments in our review do not necessarily endorse psychometric quality. Further reviews of the measurement properties of the participation instruments and scales are recommended. Recently Noonan et al.[15] paid attention to the measurement properties of 11 participation instruments. They concluded that the WHO-DASII has undergone the most psychometric testing, but that future research must continue to assess these instruments in persons with various health conditions to advance the conceptualization and measurement of participation.[15]

In this study, the gray and white participation scales were based on the information available in the articles and in the instruments. It is possible that other versions use different (sub)scales and are therefore not exactly the same as the (sub)scales we used.

Another limitation of this study can be the accuracy of the search. Because we only reviewed Dutch and English articles published in PubMed, we may have overlooked some important instruments. However, as mentioned in the introduction, the aim of this study was not to give a full review of all instruments that measure participation, but to systematically determine the extent in which participation instruments in literature indeed measure participation.

Conclusions

Our review shows that, according to our working definition of participation, most instruments that aim to measure participation do so only to a limited extent. Instruments differ in their content and operationalization of the concept participation. Most participation domains concerned the domains of work/study, social life, general participation, and home; fewer items concerned the domains family life and financial participation. Participation items mostly refer to participation problems and participation accomplishment and much less to satisfaction with participation.

For adequately assessing participation in the aimed populations or situations of interest, future research should focus on empirically assessing consensus about the operationalization of measuring participation, participation domains, and participation aspects.

Appendix

Appendix 6.1 Search strategy in Pubmed (10 February 2009)

Search	Query
#6	Search #5 NOT #4
#5	Search #1 AND #2 and #3
#4	Search infant[MeSH] OR child[MeSH] OR adolescent[MeSH] OR case reports[pt] OR congresses[pt] OR editorial[pt] OR clinical trial[pt] OR clinical trials[MeSH] OR (animal[mesh] NOT human[mesh]) OR pregnancy[MeSH] OR systematic[sb] OR "participation in treatment"[tiab] OR refusal to participate[MeSH]
#3	Search validation studies[pt] OR reproducibility of results [MeSH] OR psychometrics[MeSH] OR Health Status Indicators[MeSH] OR Outcome assessment [MeSH:NoExp] OR reproducibility[tiab] OR reproducible[tiab] OR reliability[tiab] OR reliable[tiab] OR "intraclass correlation"[tiab] OR "internal consistency"[tiab] OR valid[tiab] OR validity[tiab] OR responsive[tiab] OR responsiveness[tiab] OR factor analysis[tiab] OR factor analyses[tiab] OR factor structure[tiab] OR "sensitivity to change"[tiab] OR "clinimetric property"[tiab] OR "clinimetric properties"[tiab] OR "psychometric property"[tiab] OR "psychometric properties"[tiab] OR "measurement property"[tiab] OR "measurement properties"[tiab] OR "clinimetric analysis"[tiab] OR "clinimetric analyses"[tiab] OR "psychometric analysis"[tiab] OR "psychometric analyses"[tiab]
#2	Search participation[tiab] OR handicap[tiab] OR client-centered[tiab] OR client-centred[tiab] OR patient-centered[tiab] OR patient-centred[tiab] OR person-centered[tiab] OR person-centred[tiab] OR patient-perceived[tiab] OR person-perceived[tiab] OR "social disability"[tiab] OR "social impact"[tiab] OR "social consequences"[tiab] OR employment[MeSH] OR "work disability"[tiab] OR "work ability"[tiab] OR "work capacity"[tiab] OR "productivity"[tiab] OR "absenteeism"[tiab] OR reintegration[tiab] OR personal autonomy[MeSH] OR professional autonomy[MeSH] OR autonomy[tiab] OR patient-centered care[MeSH] OR self care[MeSH:NoExp] OR social adjustment[MeSH] OR leisure activities[MeSH:NoExp] OR social mobility[MeSH] OR choice behavior[MeSH:NoExp] OR "role functioning"[tiab] OR role[MeSH]
#1	Search instrument[tiab] OR measure[ti] OR interview[tiab] OR scale[tiab] OR diary[tiab] OR questionnaire[tiab] OR "clinical assessment tool"[tiab] OR questionnaires[MeSH] OR copm[tiab] OR "goal attainment scaling"[tiab] OR "life strengths interview"[tiab] OR (IPA[tiab] NOT "independent practice associations"[tiab])

MeSH :Medical Subject Heading; MeSH:NoExp: MeSH-No Explode; pt: Publication Type; ti:Title; tiab: Title/Abstract

Appendix 6.2 References Participation-Instruments (≥ 50 % white and gray participation-items)

Abbreviation	Instrument Name	Reference
APAQ	Activity Participation Questionnaire	Li et al., 2009[38]
ACPQ	Australian Community Participation Questionnaire	Berry et al., 2007[39]
AHA-SOC	American Heart Association Stroke Outcome Classification	Lai and Duncan,1999[40] Kelly-Hayes et al., 1998[41]
AMRS	Amputee Medical Rehabilitation Society	Gardiner et al., 2002[42]
AusTOM	Australian Therapy Outcome Measure	Unsworth, 2008[43]
BCIA	Brief Cancer Impact Assessment	Alfano et al., 2006[44]
CAMBS	Cambridge Multiple Sclerosis Basis Score	Mumford and Compston, 1993[31]
CAT-OA	Computerized Adaptive Testing – osteoarthritis	Kosinski et al., 2006[45]
CHART	Craig Handicap Assessment and Reporting Technique	Segal and Schall, 1995[46]
CIM	Community Integration Measure	McColl et al., 2001[26]
CIQ	Community Integration Questionnaire	Kuipers et al., 2004[47] Willer et al., 1994[48]
DRP	Disease Repercussion Profile	Harwood et al., 1996[49] Carr and Thompson, 1994[23]
ESS	Environmental Status Scale	Stewart et al., 1995[50]
FAST	Functioning Assessment Short test	Rosa et al., 2007[51]
FIM	Functional Independence Measure	Desrosiers et al., 2003[52] Gurka et al., 1999[53]
F QuickDASH	F Quick - Disabilities of the Arm Shoulder and Hand	Fayad et al., 2008[54] Jester et al., 2005[55]
FSQ	Functional Status Scale	Jette et al., 1986[20]
GAF	Global Assessment of Functioning	Hilsenroth et al., 2000[56]
HHIA	Hearing Handicap Inventory for Adults	Newman et al., 1991[57]
HHIE-S	Hearing Handicap Inventory for the Elderly-screening version	López-Vázquez et al., 2002[58] Mulrow et al.,1990[59]
HHQ	Hearing Handicap Questionnaire	Gates et al., 2003[60]
HLTA	Household and Leisure Time Activities Questionnaire	Vidrine et al., 2004[61]
HONOS	Health of the Nation Outcomes Scales	Gigantesco et al., 2007[62]
IMPACT-S	ICF Measure of Participation and Activities questionnaire	Post et al., 2008[63]
IFS-dialysis	Inventory of Functional Status-Dialysis	Thomas-Hawkins, 2005[64]
ILLS-SR	Independent Living Skills Survey-self report	Wallace et al., 2000[65]
IPA	Impact on Participation and Autonomy	Cardol et al., 1999[17] Vazirinejad et al., 2003[66]
IVI	Impact of Vision Impairment profile	Hassell et al., 2000[67]
IRRS	Adapted Illness Intrusiveness Ratings Scale	Bettazzoni et al., 2008[68].
JKOM	Japanese Knee Osteoarthritis Measure	Akai et al., 2005[69]
KAP	Keele Assessment of Participation	Wilkie et al., 2005[32]
LFQ	Life Functioning Questionnaire	Altshuler et al., 2002[70]
LHS	London Handicap Scale	Harwood et al., 1994[30]
LIFE-H	Assessment of Life Habit Scale	Dumont et al., 2003[71]
LTS	Leisure Time Satisfaction	Stevens et al., 2004[72]
LWD	Living with Dysarthria	Hartelius et al., 2008[73]

Appendix 6.2 References Participation-Instruments (≥ 50 % white and gray participation-items)

Abbreviation	Instrument Name	Reference
MPAI-4	Mayo-Portland Adaptability Inventory-4	Malec et al., 2000[74]
MSIF	Multidimensional Scale of Independent Functioning	Jaeger et al., 2003[75] McGuigan and Hutchinson, 2004[76] Hobert et al., 2001[77]
NHS	New Handicap Scale	Rai et al., 1999[78]
OHIP	Oral Health Impact Profile	Awad et al., 2008[79]
P-Scale	Participation Scale	van Brakel et al., 2006[80]
PARPRO	Instrument for Home & Community participation	Ostir et al., 2006[81]
PIPP	Perceived Impact of Problem Profile	Pallant et al., 2006[82]
PM-PAC-CAT	Participation Measure for Post acute Care-Computerized Adaptive Test	Haley et al., 2008[83]
POES	Profile of Occupational Engagement in people with Schizophrenia	Bejerholm and Eklund, 2006[84]
POPS	Participation Objective, Participation Subjective	Brown et al., 2004[85]
PSP	Personal and Social Performance scale	Juckel et al., 2008[86]
QOL-S	Quality of Life Scale – Swedish version	Liedberg et al., 2005[87]
RAPS	Role Activity Performance Scale	Good-Ellis et al., 1987[88]
RFS	Role Functioning Scale	Goodman et al., 1993[89]
RNL	Reintegration to Normal Living Index	Daneski et al., 2003[18] Tooth et al., 2003[90]
Rotterdam nine item handicap scale	Rotterdam nine item handicap scale	Merkies et al., 2000[91]
ROPP	Rating of Perceived Participation Questionnaire	Sandström and Lundin-Olsson, 2007[92]
SCOCS-R	Strauss and Carpenter revised Outcome Criteria Scale	Poirier et al., 2004[93]
SFS	Social Functioning Scale	Birchwood et al., 1990[94] Vázquez Morejón and Jiménez Ga-Bóveda, 2000[95]
SPRS	Sydney Psychosocial Reintegration Scale	Kuipers et al., 2004[47]
SF-36	Short Form health survey -36	Jenkinson et al., 1994[96]
SHE	Subjective Handicap of Epilepsy scale	O'Donoghue et al., 1998[97]
SIPSO	Subjective Index of Physical and Social Outcome	Kersten et al., 2004[98]
SIS-64	Stroke Impact Scale -64	Duncan et al., 1999[99] Duncan et al., 2003[100]
SRPQ	Social Role Participation Questionnaire	Gignac et al., 2008[101]
TH/SS	Tinnitus Handicap / Support Scale	Erlandsson et al., 1992[102] Kuk et al., 1990[103]
VADL	Vestibular disorder Activities of Daily Living Scale	Cohen and Kimball, 2000[104]
VAPP	Voice Activity and Participation Profile	Ma and Yiu, 2001[105]
WAQ	Walking Ability Questionnaire	Perry et al., 1995[106]
WHO-DASII	World Health Organization-Disability Assessment Schedule II	Chisolm et al., 2005[19]
WHOQOL-OLD	World Health Organization Quality Of Life for Older persons	Halvorsrud et al., 2008[107] Fleck et al., 2006[108]
WSAS	Work and Social Adjustment Scale	Mundt et al., 2002[109]

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