Outcome measures

42
OUTCOME MEASURES

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Introduction

Assessment of patient functioning is done for three main reasons: diagnosis, prognosis and evaluation (Tate, Goubec and Sigmundsdottir, 2013). In this chapter the focus is on outcome measurement in relation to intervention evaluation. Measuring the outcome of health care is 'a central component of determining therapeutic effectiveness and, therefore, the provision of evidence-based healthcare' (Van der Putten et al., 1999, pp. 480–484). Information regarding the outcome of neuropsychological rehabilitation is not only important for researchers, clinicians, managers and policy makers, but especially for the patients and their families. Neuropsychologists often conduct extensive testing during pre-treatment assessment, but in clinical practice it is less common to measure outcome systematically after treatment.

Clinicians and researchers wanting to measure outcomes of neuropsychological rehabilitation are faced with an overwhelming number of available instruments. Additionally, outcome of treatment can be measured on many different levels of human functioning. Currently, there is no international consensus on outcome measures in our field, neither in clinical practice nor in research.

This overview of currently available measures is to support clinicians and researchers in making informed choices. The instruments are presented and organised according to the framework of the International Classification of Functioning, Disability and Health (ICF; WHO, 2001). Special emphasis is placed on level of participation as an important goal of rehabilitation. In addition, criteria for choosing an outcome measure are presented, and finally some recent developments in outcome measurement are discussed.

What is a good measure?

There are many instruments available and it is difficult to know which measure to choose. The most frequently used measure is not necessarily the best measure. An example is the use of the Mini Mental State Examination (MMSE) for cognitive screening in stroke patients. Although it is the most widely used instrument, it has insufficient sensitivity to detect cognitive deficits in patients after stroke (van Heugten, Walton and Hentschel, 2015). This is not surprising since the MMSE was originally developed to assist in identifying people with dementia and is therefore sensitive to

memory deficits but not to other cognitive deficits commonly seen after stroke. From this example it becomes clear that instruments should be assessed in terms of their psychometric properties, both in general and in relation to the purpose for which the measure was designed.

Reliability and validity are two broad aspects which should be considered, but for outcome measures, responsiveness is also essential; the ability of the instrument to detect clinically relevant changes over time. Several authors have suggested assessment criteria for outcome measures. Terwee et al. (2007) suggested the following quality criteria for health status questionnaires: content validity; internal consistency; criterion validity; construct validity; reproducibility; agreement; responsiveness; floor and ceiling effects; and interpretability. Andresen (2000) proposed criteria for the assessment of disability outcomes: conceptual underpinning; availability of norms/standard values; measurement model taken into account; presence of item/measurement bias; low respondent and administrative burden; reliability; validity; responsiveness; availability of alternate/accessible forms and culture/language adaptations.

It is difficult to appraise all instruments thoroughly before using them, but often there are systematic reviews of outcome measures on specific domains available in which quality assessments have been done. For instance, Gregório et al. (2014) conducted a review on instruments assessing coping in patients with brain injury and Polinder et al. (2015) conducted a systematic review of measures for health related quality of life in traumatic brain injury (TBI). These papers support the reader in choosing an outcome measure.

Framework for outcome measurement in neuropsychological rehabilitation

Once the researcher or clinician has appraised the quality of potential instruments, there is still a large number of instruments to choose from. Systematic reviews or recommendations from expert groups may further support the choice of an outcome instrument. In addition to quality, widespread use and expert opinion can be considered in the selection process.

The ICF offers a useful framework to describe human functioning and can give guidance on what to measure. A good example in which instruments are categorised according to ICF domains is the systematic review of Tate et al. (2013) on assessment tools in TBI. This led to a set of 728 unique instruments that have been used in TBI research.

In measuring the outcome of neuropsychological rehabilitation, not all domains of the ICF are relevant to neurological disorders. Moreover, the very large number of ICF categories is impractical to use in routine clinical practice, nor should all categories be measured in outcome research. The World Health Organization (WHO) stimulated the development of brief core sets for specific diagnostic categories because the domains of the ICF are numerous and may not all be relevant to certain diseases. In Table 42.1 the brief core sets for stroke and TBI are presented as they form the two most prevalent aetiologies in adult neuropsychological rehabilitation. As can be seen from the table, a total of 34 ICF categories are represented, but overlap is only found in seven domains: memory; attention; consciousness; walking; self-care/washing oneself/toileting/dressing/eating; immediate family; and health services, systems and politics. However, many categories that are important to consider in a rehabilitation context are not included on this list, such as those in the domain of participation.

We performed a systematic review of instruments used in the previous 20 years to measure the outcome of neuropsychological rehabilitation (van Heugten et al., 2016). For this purpose we selected outcome measures from randomised clinical trials (RCTs) that were described in meta-analyses and systematic reviews in our field. This led to the identification of a total of 347 instruments. These can be divided into two main categories: neuropsychological tests (n=195); and other measures (n=152). Since the number of neuropsychological tests seems almost infinite, with each country having its own preferences and many neuropsychologists their personal favourites, it is

Table 42.1 ICF brief core sets for stroke and traumatic brain injury (www.icf-sets.org)

ICF domain	*ICF Category*	*Traumatic brain injury*	*Stroke*
Body function	Higher-level cognitive functions	×	
	Emotional functions	×	
	Energy and drive functions	×	
	Control of voluntary movement functions	×	
	Memory functions	×	×
	Sensation of pain	×	
	Attention functions	×	×
	Orientation functions	×	×
	Consciousness functions		×
	Mental functions of language		×
	Muscle power functions		×
Body structure	Structure of brain	×	
	Structure of upper extremity		×
Activities and participation	Carrying out daily routine	×	
	Communicating with – receiving – spoken messages		×
	Speaking		×
	Conversation	×	
	Walking	×	×
	Complex interpersonal interactions	×	
	Acquiring, keeping and terminating a job	×	
	Self-care	×	
	Washing oneself		×
	Toileting		×
	Dressing		×
	Eating		×
	Recreation and leisure	×	
	Family relationships	×	
Environmental factors	Immediate family	×	×
	Health professionals		×
	Health services, systems and policies	×	×
	Products and technology for personal use in daily living	×	
	Friends	×	
	Social security services, systems and policies	×	
	Products and technology for personal indoor and outdoor mobility and transportation	×	

unlikely that consensus could be gained in this area, so merely summarising instruments which have been used in RCTs serves no purpose. Moreover, since the goal of neuropsychological rehabilitation is typically not to facilitate recovery of cognitive impairments per se, these instruments are not presented here.

In Table 42.2 an overview of the ICF categories is presented along with the number of instruments per category for all measures other than neuropsychological tests (van Heugten et al., 2016). The instruments categorised under mental functions are rating scales, such as the Everyday Memory Questionnaire. As can be seen from the table, the instruments covering more than one category or more than one domain, which can be considered multidimensional are the most frequently used.

Obviously, 152 measures are too many and only give an indication of what is currently used. In order to limit the number of instruments to a core set which can be used in future research investigating the outcome of neuropsychological rehabilitation, several steps can be taken. Instruments

Table 42.2 ICF categories that have been measured in RCTs evaluating the effectiveness of neuropsychological rehabilitation in patients with ABI

ICF domain	*ICF category*			*Number of instruments*
Body functions	Mental functions	Global	Temperament and personality	3
			Energy and drive	2
		Specific	Attention	3
			Memory	3
			Emotion	19
			Higher level cognitive	9
		Multi-category		15
	Neuromusculoskeletal and movement related			2
	Multi-domain			3
Activities and participation	General tasks and demands			3
	Communication			2
	Interpersonal interactions and relationships			1
	Major life areas			3
	Multi-domain			36
Multidimensional				27
Contextual	Environmental			2
	Personal			17
Domains not considered by ICF				27
Quality of life				11
Other	Caregiver functioning			2

can be selected on the basis of their quality and/or on the basis of frequent use. Those instruments recommended by experts can be chosen or consensus procedures can be undertaken.

An example in which frequency of use, quality of the instrument and expert opinion were all combined is the European consensus on outcome measures for psychosocial intervention research in dementia care (Moniz-Cook et al., 2008). A combined approach was carried out of web-based consultations, consensus meetings, a systematic literature review and a rigorous evaluation of utility, feasibility and psychometric properties. Twenty-two measures across nine domains were recommended to improve the comparability of intervention studies in Europe. Areas were identified where improved outcome measures for psychosocial intervention research studies are required.

In the field of spinal cord injury, basic data sets for specific domains of functioning were being developed with the purpose of including a minimal number of data elements, which together can be collected in routine clinical practice (Biering-Sørensen et al., 2012). Basic data sets are available for different domains, such as upper extremity functioning (Biering-Sørensen et al., 2014), pain (Widerström-Noga et al., 2016), quality of life (Charlifue et al., 2012) and activities and participation (Post et al., 2016a). These basic data sets are developed by committees of experts and reviewed by relevant organisations, such as international spinal cord associations and leading scientists in the field.

For the latter category, both performance and satisfaction ratings were considered and the data sets consist of items selected from two existing questionnaires (Spinal Cord Independence Measure III and the CHART; Post et al., 2016a).

Such procedures can also be undertaken to minimise the list of 152 instruments that have been used in research investigating the effectiveness of neuropsychological rehabilitation. A first step towards developing a core set of outcome measures for participation is given below.

Measuring participation after acquired brain injury

The British Society of Rehabilitation Medicine (BSRM) and Royal College of Physicians (RCP) in the United Kingdom define rehabilitation as 'a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function' and in terms of service provision this entails 'the use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society' (BSRM/RCP, 2003, p. 7). From this perspective, measuring the level of participation in society should at least be part of outcome measurement in any rehabilitation context.

In 2009 Noonan et al. published a review in which they identified instruments that assess participation as defined by the ICF. The following 11 instruments were selected: Impact on Participation and Autonomy (IPA); Keele Assessment of Participation (KAP); PAR-PRO; Participation Survey/Mobility (PARTS/M); Participation Measure-Post Acute Care (PM-PAC) and the computerised adaptive test version (PM-PAC-CAT); Perceived Impact of Problem Profile (PIPP); Participation Objective Participation Subjective (POPS); Participation Scale (P-Scale); Rating of Perceived Participation (ROPP); and World Health Organization Disability Assessment Schedule II (WHODAS II). At that time the WHODAS II had the best psychometric properties. Our review on outcome measures used in neuropsychological rehabilitation research in ABI patients found that none of these instruments have been used in published studies (van Heugten et al., 2016). This may suggest that mostly disease-specific participation outcome measures are used for patients with acquired brain injury.

Chung et al. (2014) compared the contents of participation outcome measures with the ICF core sets for TBI and reviewed the following instruments: Community Integration Questionnaire (CIQ); Craig Handicap Assessment and Reporting Technique (CHART); Mayo-Portland Adaptability Inventory-4 Participation Index (MPAI-4); Sydney Psychosocial Reintegration Scale Version-2 (SPRS-2); Participation Assessment with Recombined Tool-Objective (PART-O); Community Integration Measure (CIM); POPS; Community Integration Questionnaire-2 (CIQ-2); and Quality of Community Integration Questionnaire (QCIQ). Chung et al. concluded that the ICF core set could contribute to the development and selection of participation instruments. In our review on neuropsychological rehabilitation (van Heugten et al., 2016) the CIQ, CHART and QCIQ also emerged as the most common outcome measures for participation.

In her chapter on measuring outcome in TBI, Tate selected the following instruments to review as measures of participation (Tate, 2014): CIQ; CHART; Community Integration Measure (CIM); Functional Status Examination (FSE); Glasgow Outcome Scale (GOS); Impact on Participation and Autonomy (IPA); Mayo Portland Adaptability Inventory (MPAI); POPS; SPRS; Assessment of Life Habits (LIFE-H); ICF Measure of Participation and Activities (IMPACT-S); and WHODAS II. Overlap with the results of our review on neuropsychological rehabilitation was seen in the use of the CIQ, CHART and SPRS. Tate (2014) did not express preference for any of the reviewed participation measures.

The Evidence Based Review of Stroke Rehabilitation (EBRSR) funded by Canadian Partnership for Stroke Recovery (CPSR), a joint initiative of the Heart and Stroke Foundation and Canada's leading stroke research centres, published an overview of outcome measures for stroke rehabilitation

(Salter et al., 2013). The authors proposed the following outcome measures on the level of participation/handicap: Canadian Occupational Performance Measure (COPM); EuroQol Quality of Life Scale (EQ-5D); LIFE-H; London Handicap Scale (LHS); Medical Outcomes Study Short-Form 36 (SF-36); Nottingham Health Profile (NHP); Reintegration to Normal Living Index (RNLI); Stroke Adapted Sickness Impact Profile (SA-SIP-30); Stroke Impact Scale (SIS); and the Stroke Specific Quality of Life (SS-QOL). In our review on outcome measures used in neuropsychological rehabilitation research only the COPM and LHS were found to be used. From this list it becomes apparent that defining participation is not straightforward, as one could argue that measuring quality of life with the EQ-5D does not assess participation.

Taken together, the results of all the mentioned reviews, including our own on outcome measures in neuropsychological rehabilitation, the CIQ, CHART and SPRS seem to be good candidates for use as outcome measures in research because they have been used and recommended most frequently for use in patients with stroke or TBI and have good psychometric properties. In Table 42.3 some of the descriptive features of these instruments are summarised. Further information on the psychometric properties can be found in Tate (2014).

This chapter has not taken into account more recently developed measures. One example is the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P), which is a generic participation measure of both subjective (i.e. restrictions, satisfaction) and objective (i.e. frequency) participation in adults. The USER-P is a valid measure for participation in persons with physical disabilities (Post et al., 2012), is responsive in an outpatient rehabilitation setting (van der Zee et al., 2013) and had the greatest evidence of responsiveness compared to the IPA, IMPACT-S and the FAI (van der Zee et al., 2011). The USER-P has good reproducibility and is acceptable to patients (van der Zee et al., 2010). In a study with stroke patients, the USER-P showed that most participants experienced participation problems, despite relatively good physical recovery (van der Zee et al., 2013).

Table 42.3 Descriptive features of the CIQ, CHART and SPRS (see also Tate, 2014)

Instrument	*Number of items*	*Subscales/Item description*	*Administration time*	*Response form*	*Scoring*
Community Integration Questionnaire (CIQ)	15	Home integration Social integration Productive activities	<15 minutes	Open-ended response converts to 3-point Likert scale	0–29
Craig Handicap and Reporting Technique (CHART)	32	Physical independence Cognitive independence Mobility Occupational Social integration Economic self-sufficiency	~15 minutes	Open-ended response	0–100
Sydney Psychosocial Rating Scale (SPRS)	12	Occupational activity Interpersonal relationships Independent living skills	-	7-point Likert scale (no change to extreme change)	0–72 (high score=better)

Recent developments in outcome measurement

From both a research point of view and a health-care perspective, initiatives have been undertaken to standardise outcome measurement. The US National Institute of Health (NIH) stimulated the development of Common Data Elements (CDEs) in the field of neuroscience. The use of CDEs enables clinical investigators to systematically collect, analyse and share data across the research community. This improves research quality and the ability to transfer information between centres and allows for comparison and meta-analyses. In 2010 the first set of CDEs for TBI became available for hospital-based studies of acute TBI in adults; two years later a second version was launched (Hicks, 2013; Hicks et al., 2013). The second version of the TBI CDEs (v.2) was organised around four major study types: epidemiological research; studies on acute hospitalised patients; studies of rehabilitation for moderate/severe TBI; and mild TBI/concussion research.

The US National Institute of Neurological Disorders and Stroke (NINDS) encourages researchers to use NIH resources such as Patient Reported Outcome Measurement Information Systems (PROMIS). A PRO(M) is a Patient Reported Outcome (Measure) as used in clinical settings and clinical trials to assess responses directly from the patient. This means that the patient provided the information but the information itself is not necessarily of concern to the patients themselves. Patient Centred Outcomes (PCOs), on the other hand, cover issues of concern to the patient. Additionally, patient reported experience measures (PREMs) are also used, which focus on the patients' experiences and not on outcomes. PROMIS provide clinicians and researchers access to reliable, valid and flexible measures of health status from the patient's perspective. PROMIS measures are standardised, allowing for assessment of many different patient-reported outcome domains.

The Neuro-QOL measurement system is another tool from the NIH toolbox that provides a clinically relevant and psychometrically robust health-related quality of life (HRQL) assessment tool for both adults and children with common neurological disorders. The Neuro-QOL measurement system provides item banks and short forms that enable PRO measurement in neurological research (Gershon et al., 2012). Neuro-QOL is now available for different domains, such as positive affect and well-being (Salsman et al., 2013) and different aetiologies, such as epilepsy (Victorson et al., 2014), and is available in different languages, such as Spanish (Correia et al., 2015).

For spinal cord injury (SCI) specific measurement systems (i.e. SCI-QOL) and item banks have been developed and calibrated (Tulsky et al., 2015a, 2015b). For SCI many different basic data sets have been developed, such as sets for upper extremity function (Biering-Sørensen et al., 2014), activities and participation (Post et al., 2016a) and quality of life (Post el al., 2016b).

An international standard set of PCO measures after stroke was presented in 2016 by Salinas and colleagues. The standard set of measures was developed by an international expert panel representing patients, advocates and clinical specialists in stroke outcomes, stroke registers, global health, epidemiology and rehabilitation. PCOs proposed for assessment at 90 days were pain, mood, feeding, self-care, mobility, communication, cognitive functioning, social participation, ability to return to usual activities and health-related quality of life. The next stage for development is to evaluate the set in clinical practice.

A new perspective on outcome measurement: is health a state or an ability?

In 2011 a new definition of health was launched in the *British Medical Journal* (BMJ) (Huber et al., 2011). In the early thirties of the twentieth century, health was defined as the absence of disease. For the past 60 years the definition has been: a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Huber and colleagues argued that this definition has limitations and does not fit modern society anymore. They suggest redefining health as 'the ability to adapt and to self-manage' (p. 2). Since the publication of this new definition of health,

several developments have arisen. Huber and colleagues (2016) now propose a patient-centred operationalisation of the new, dynamic concept of health. They outlined six dimensions of positive health as: bodily functions; mental functions and perception; spiritual/existential dimension; quality of life; social and societal participation; and daily functioning.

Measuring outcome in line with this new perspective is a challenge and initial suggestions are offered. According to Huber et al. (2011), measuring health should be done by constructing health frames that take into account different operational needs (i.e. individual versus population, subjective versus objective). The existing methods for assessing functional status and measuring quality of life and sense of well-being offer a good starting point for measuring health from the newly proposed perspective. In addition, the notion of positive health is consistent with the long-held views of positive psychology. One of the first people to present the concept of positive psychology were Seligman and Csikszentmihalyi (2000). A review of positive psychology outcome measures was published in 2015 in which the following outcome domains were considered: self-efficacy; resilience; spirituality; life valuation; autonomy; sense of coherence; and resourcefulness (Stoner, Orrell and Spector, 2015). For each of these domains, instruments are suggested that have been used in chronic illness, TBI and older adults and may be suitable for use in dementia outcome research. The instruments that are recommended have been assessed in terms of quality using the criteria of Terwee et al. (2007). This new line of thinking may also stimulate developments in our own field of outcome measurement in neuropsychological rehabilitation.

Conclusions

In this chapter the importance of outcome measurement is emphasised and clinicians and researchers are offered guidelines on how to select a suitable outcome measure on the basis of different selection criteria. The overall quality of the instrument can be considered, including its psychometric properties. Additionally, the feasibility of the instrument for use in clinical practice or research can be taken into account and expert opinion or frequency of use can be an issue to consider in the selection process. For measuring the level of participation an overview of candidate instruments is provided and some instruments can be recommended. Finally, another perspective on outcome measurement is proposed in which the concepts of positive health and positive psychology are put forward.

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