



USABILITY OF WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE IN CHRONIC TRAUMATIC BRAIN INJURY

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Objectives: To investigate functioning measured with the 12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0) in patients with mild, moderate and severe traumatic brain injury, and to compare patients' experiences with assessments made by their significant others and by consultant neurologists.

Methods: A total of 112 consecutive patients with traumatic brain injury (29 mild, 43 moderate, 40 severe) and their significant others completed a 12-item WHODAS 2.0 survey. A neurologist assessed functioning with the International Classification of Functioning, Disability and Health minimal generic set.

Results: The total patient and proxy WHODAS 2.0 sum score was rated as severe, and impairments in household tasks, learning, community life, emotional functions, concentrating, dealing with strangers, maintaining friendships, and working ability as around moderate in all 3 severity groups. In standing, walking, washing, and dressing oneself the reported impairments increased from mild in mild traumatic brain injury to moderate in severe traumatic brain injury. A neurologist rated the overall functioning, working ability, and motor activities most impaired in severe traumatic brain injury, while there were no between-group differences in energy and drive functions and emotional functions.

Conclusion: Patients with chronic traumatic brain injury perceive a diversity of significant difficulties in activities and participation irrespective of the severity of the injury. We recommend assessing disability in traumatic brain injury with the short and understandable WHODAS 2.0 scale, when planning client-oriented services.

Key words: activities and participation; disability; functioning; ICF; severity; chronic traumatic brain injury; WHODAS.

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Traumatic brain injury (TBI) is one of the leading causes of disability and death worldwide (1–3). TBI affects people of all ages and often results in

MAIN MESSAGE

Functioning of patients with traumatic brain injury was assessed with two simple questionnaires: the 12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0) and the 7-item International Classification of Functioning, Disability and Health minimal generic set. Patients and their significant others rated the overall disability as severe, with difficulties in household tasks, learning, emotions, participation, relationships, and working ability. Even after mild traumatic brain injury patients may report remarkable cognitive and emotional difficulties. In more severe injury, physical motor functions are also often impaired. We recommend assessing disability in traumatic brain injury with the WHODAS 2.0 scale when planning client-oriented services.

permanent disability. When patients with different injuries are evaluated, TBIs cause the most severe health issues (4) and long-lasting consequences for both physical and mental health (5, 6) irrespective of the severity of injury (7). Even mild TBI (miTBI) may cause a diversity of problems in cognitive and emotional functions, energy and drive, and in carrying out daily routines and work (8–20).

Numerous instruments have been used in evaluating the severity and outcome of TBI, in assessing patient's problems and needs, and in monitoring treatment effects. From the clinician's point of view, a barrier to efficient assessment is the vast number of instruments available (21). To unify the assessment of functioning around the world and to permit comparisons between different health conditions, the World Health Organization (WHO) has developed the International Classification of Functioning, Disability and Health (ICF) framework (22) and ICF-based assessment instruments. One of these instruments, the 12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0) (23–25) is a generic tool measuring activities and participation in 12 different domains. As participation has been associated more strongly with quality of life than other impairments (26–28), and as many problems after TBI have also been linked with activities and participation (29), participation ability is an important target of rehabilitation that aims to improve quality of life after TBI.

As far as we know, this is the first study to investigate functioning measured with the WHODAS 2.0 in patients with miTBI, moderate (moTBI) and severe (sTBI). This study aims to clarify the usability of the WHODAS 2.0 as an assessment tool for the consequences of TBI.

PATIENTS AND METHODS

Between December 2015 and December 2016, the 12-item WHODAS 2.0 was posted to 220 consecutive attendees of patients with recent over 3 months or past TBI (diagnosis according to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) criteria) and their significant others 2 weeks before their appointment at a specialist outpatient clinic of a university hospital. The outpatient clinic both evaluates recently injured patients and takes care of patients with past injuries with ongoing problems and rehabilitative needs. A total of 116 patients responded, of whom 4 were excluded. Exclusion criteria were: patients under 18 years of age at the time of injury; those with a current major medical or psychotic condition or another neurological diagnosis, including spinal cord injury; and those with inability to understand, co-operate and answer. A total of 112 patients fulfilled the inclusion criteria and participated in the study. In some cases the questionnaire was completed at the outpatient clinic to avoid missing data. Of the 112 significant others, 60 (53.6%) were spouses, 19 parents, 11 children, 9 siblings, 1 other relative, 4 close friends, and 8 trained caregivers.

Mild TBI was classified according to the American Congress of Rehabilitation Medicine (30) and WHO (31) criteria, and TBI was considered moderate if the Glasgow Coma Scale (GCS) at admission was 9–13 or duration of post-traumatic amnesia (PTA) 1–7 days, and severe if GCS at admission was 8 or lower or duration of PTA longer than 1 week. All the patients had a history of a clear head trauma and a period of loss of consciousness or loss of memory or other transient neurological abnormality and GCS 15 or under. In addition, personal background information, including age, sex, accommodation, marital status, educational level, and working status was collected. Informed consent and information regarding the study were also included. Clinical information (date of diagnosis and comorbidities) was gathered from the hospital records, and the total number of comorbidities was counted (32). A neurologist at the outpatient clinic completed the 7-item ICF minimal generic set aiming at a simple and validated way to assess the level of functioning (33).

Both the WHODAS 2.0 and the generic set are ICF-based instruments, which ensure comparability across different health conditions and countries. The 12-item WHODAS 2.0 includes 12 items from different disability domains of the ICF activities and participation from the previous 30 days: learning and concentration, standing and walking, washing and dressing oneself, dealing with strangers and maintaining friendships, doing housework and working ability, emotional functions and engaging in community. Each of these 12 items is rated according to a 5-point Likert-type scale, which grades the difficulty experienced by the participant in performing a given activity. Each of the 12 items is scored from 0 to 4, where 0 means no (0–4%), 1 means mild (5–24%), 2 means moderate (25–49%), 3 means severe (50–95%), and 4 means extreme or complete (96–100%) difficulty in this specific activity. The total score of WHODAS 2.0 is the sum of the 12 sub-scores, ranging from 0 to 48, with lower scores indicating better functioning. Total

scores of 1–4 indicate mild disability, 5–9 moderate disability, and 10–48 severe disability (23, 34).

The minimal generic set consists of 7 domains of ICF: energy and drive functions, emotional functions, sensation of pain, carrying out daily routine, walking, moving around, and remunerative employment. Generic means that this assessment scale is applicable to all people despite their health conditions. Minimal means that the scale consists of the least number of domains of functioning that can be used to explain significant differences between people with health issues. The scoring system is similar to that of the WHODAS 2.0, the sum score ranging from 0 to 28, with lower scores indicating better functioning (33).

The study was approved by the ethics committee of the University and University Hospital (19.5.2015, 73/2015). The ethics standards of the World Medical Association Helsinki Declaration of 1975, revised in 1983, were followed.

Statistical analysis

Comparison between the 3 patient groups (miTBI, moTBI and sTBI) was carried out within categorical variables using a χ^2 test, or, in the case of too many small cell frequencies, Fisher's exact test. In numerical variables comparisons between 3 patient groups were carried out either by one-way analysis of variance (ANOVA), or, in skewed outcome variable (comorbidities) by the Kruskal–Wallis test. The Spearman correlation coefficient was used to test the correlation between variables. Correlations of 0–0.3 were considered weak, 0.31–0.50 moderate, 0.51–0.70 strong, and greater than 0.70 very strong. No adjustment was made for multiple comparisons, since in this small exploratory study the search for patterns is more important than formal statistical significance. Statistical analyses were performed using SAS 9.4 for Windows. *p*-values below 0.05 (2-tailed) were considered statistically significant.

RESULTS

Of the 112 patients who fulfilled the inclusion criteria and participated in the study, 29 had mild TBI, 43 moderate TBI and 40 severe TBI. There were no significant differences in demographic variables of these 3 severity classes (Table I).

The overall disability in these 3 severity levels of TBI was determined based on the minimal generic set sum score (0–28) assessed by a neurologist. In this assessment, the total score increased with the severity of TBI. In individual items, the same kind of increase with severity of TBI was found in the following items: remunerative employment, daily activities, walking, and moving around. The increase in impairment in remunerative employment was from moderate in miTBI to extreme in sTBI. There were no significant differences between the 3 patient groups in energy and drive functions, emotional functions, or sensation of pain, showing mild or moderate impairment (Table II).

The comparison of the responses to WHODAS 2.0 of the 3 patient groups, and, secondly, of their significant others are shown in Table III. The WHODAS 2.0 sum scores (severe impairment in each group) or the score

Table I. Demographic data of the 112 patients with mild ($n=29$), moderate ($n=43$) and severe ($n=40$) traumatic brain injury (TBI)

	Mild TBI	Moderate TBI	Severe TBI
Age, years, median (range)	37.1 (20.8–71.6)	43.0 (21.6–73.4)	52.5 (18.2–77.5)
Years since diagnosis, median (range)	3.2 (0.5–29.4)	3.3 (0.7–21.3)	2.6 (0.3–25.4)
Education, years, median (range)	13 (9–20)	13 (6–20)	12 (6–25)
Comorbidities, median (range)	0 (0–4)	0 (0–2)	0 (0–2)
Present medication for depression/anxiety, n (%)	3 (10.3)/2 (6.9)	4 (9.3)/0	2 (5.0)/0
Sex, male, n (%)	10 (34.5)	21 (48.8)	25 (62.5)
Still working, n (%)	11 (37.9)	8 (18.6)	7 (17.5)
Cohabiting, n (%)	15 (51.7)	25 (58.1)	24 (60.0)
Institutionalized, n (%)	1 (3.4)	2 (4.6)	5 (12.5)
Injury characteristics, n			
Vehicle-related collision ($n=59$)			
Car	3	17	15
Motorcycle/snow scooter	0	3	2
Boat	0	1	0
Bicycle	4	6	5
Pedestrian	0	3	0
Fall			
Sports ($n=10$)			
Snowboard	0	0	1
Horseback riding	4	1	3
Ice hockey	1	0	0
Other slip or fall ($n=31$)			
Same level	4	8	8
>1.5 m	8	1	2
Blow to the head ($n=12$)			
Assault or violence	5	2	1
Other (work-related)	0	1	3

Table II. International Classification of Functioning, Disability and Health (ICF) minimal generic set scores in mild, moderate and severe traumatic brain injury (TBI) assessed by a neurologist

	Mild TBI Mean (SD)	Moderate TBI Mean (SD)	Severe TBI Mean (SD)	p -value
Generic set sum score	9.8 (5.4)	12.9 (6.1)	15.6 (4.2)	<0.001
Energy and drive functions	1.6 (1.0)	2.1 (1.1)	2.1 (1.0)	ns
Emotional functions	1.5 (1.2)	1.7 (1.1)	1.8 (1.0)	ns
Sensation of pain	1.3 (1.1)	1.6 (1.2)	1.4 (1.2)	ns
Daily activities	1.6 (1.0)	2.0 (1.0)	2.3 (0.7)	<0.01
Walking	0.6 (0.9)	0.9 (1.0)	1.8 (1.1)	<0.0001
Moving around	1.0 (1.1)	1.6 (1.5)	2.3 (1.1)	<0.001
Remunerative employment	2.3 (1.4)	3.0 (1.4)	3.9 (0.4)	<0.0001

SD: standard deviation; ns: not significant.

for working ability did not differ significantly between the patient groups even if the score tended to increase with increasing severity of TBI. When comparing the 12 domains separately, significant between-group differences were found in standing, walking, washing, and dressing oneself. No between-group differences were found in household tasks, learning, community life, emotional functions, concentrating, dealing with strangers, or maintaining friendships, where impairments were reported to be around moderate. The significant others rated these impairments similarly to the patients.

The correlations between the generic set sum score (assessed by a neurologist) and the WHODAS 2.0 sum

Table III. Functioning assessed with patient and proxy 12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0) in mild, moderate and severe traumatic brain injury (TBI)

	Patients ($n=112$)				Significant others ($n=112$)			
	Mild TBI Mean (SD)	Moderate TBI Mean (SD)	Severe TBI Mean (SD)	p -value	Mild TBI Mean (SD)	Moderate TBI Mean (SD)	Severe TBI Mean (SD)	p -value
Total score (0–48)	20.1 (13.8)	21.3 (10.4)	23.5 (12.2)	ns	19 (12.2)	20.2 (10.6)	25.0 (11.7)	ns
Standing (0–4)	1.4 (1.4)	1.9 (1.6)	2.3 (1.5)	<0.05	1.3 (1.4)	1.6 (1.5)	2.5 (1.6)	<0.005
Household tasks	2.0 (1.6)	2.0 (1.2)	2.3 (1.5)	ns	1.7 (1.6)	2.0 (1.2)	2.4 (1.3)	ns
Learning	1.7 (1.4)	1.8 (1.2)	1.9 (1.5)	ns	1.7 (1.4)	1.8 (1.2)	1.9 (1.5)	ns
Community life	2.4 (1.6)	2.3 (1.3)	2.0 (1.5)	ns	2.1 (1.3)	2.1 (1.4)	2.1 (1.4)	ns
Emotional functions	1.9 (1.1)	2.4 (1.2)	2.2 (1.2)	ns	2.1 (1.1)	2.3 (1.2)	2.3 (1.1)	ns
Concentrating	1.6 (1.3)	2.1 (1.4)	1.6 (1.6)	ns	1.3 (1.2)	1.7 (1.4)	1.8 (1.5)	ns
Walking	1.4 (1.5)	1.6 (1.6)	2.3 (1.6)	<0.05	1.2 (1.5)	1.6 (1.6)	2.4 (1.4)	<0.005
Washing oneself	1.0 (1.2)	0.6 (0.9)	1.6 (1.5)	<0.005	0.9 (1.1)	0.6 (0.9)	1.5 (1.4)	<0.05
Dressing oneself	0.8 (1.1)	0.6 (0.9)	1.3 (1.3)	<0.05	0.9 (1.1)	0.7 (1.0)	1.4 (1.4)	<0.05
Dealing with strangers	1.6 (1.3)	1.6 (1.1)	1.3 (1.4)	ns	1.7 (1.3)	1.6 (1.3)	1.7 (1.5)	ns
Maintaining friendships	1.7 (1.4)	1.9 (1.2)	1.6 (1.3)	ns	1.6 (1.2)	1.8 (1.2)	1.7 (1.4)	ns
Working ability	2.5 (1.5)	2.6 (1.4)	3.0 (1.4)	ns	2.4 (1.4)	2.7 (1.4)	3.0 (1.4)	ns

SD: standard deviation; ns: not significant.

scores (patient and proxy) were strong to very strong (0.8 in miTBI, 0.7–0.8 in moTBI, and 0.6 in sTBI).

DISCUSSION

In this study, when functioning of patients with miTBI, moTBI, and sTBI was compared, the total level of impairment in functioning and working ability had a tendency to increase with increasing severity of TBI. When analysing specific activities, patients with sTBI compared with those with less severe TBI had more difficulties in standing and walking, and washing and dressing oneself. No significant between-group differences were found in household tasks, learning, community life, emotional functions, concentrating, dealing with strangers, or maintaining friendships, where impairment was rated as around moderate in all 3 patient groups.

This study is in line with previous studies showing a high proportion of residual complaints in patients with TBI, even in those with miTBI and even after years of injury (4–17). Based on our results, the functioning assessments by patients, significant others and treating neurologists were largely in line and thus probably also reliable. When functioning of patients with miTBI, moTBI and sTBI was compared, it seems clear that those with severe injury had more problems in activities requiring physical and motor functions. We regard the other finding of our study more important, all patient groups reporting problems in cognitive and emotional functions regardless of the severity of TBI. Even miTBI seems to cause clear, moderate mental problems and challenges in working ability. These findings could represent reduced cognitive functions even in miTBI, although cognition was not objectively assessed. Personal and environmental factors were not studied either, but could explain some of the perceived difficulties, as patients with milder TBI may face bigger challenges in everyday life and at work, as they are expected to perform better and need less assistance than patients with more severe TBI. Also, referral policies often differ between hospitals and health systems, which influences the nature of the patient population (35). It is also probable, that our participants, who were followed at a specialist university clinic, and especially after so many years since injury, are more at the severe end of miTBI with a complicated path of recovery (12, 27), but even so, the impairment in miTBI shown in our study warrants at least further studies on functioning of patients with miTBI. On the other hand, in previous studies the severity of miTBI has been found to have little long-term prognostic value (36).

Interestingly, patients irrespective of TBI severity rated emotional difficulties more severely impaired

than did clinicians. Clinicians, on the other hand, rated working ability more compromised than did patients with sTBI. It is possible that rating emotions is more difficult on the basis of outpatient visits than it is for the patients themselves and for their significant others. On the other hand, patients with TBI may lack insight, especially when evaluating more complex tasks, such as working ability.

Self-ratings as the 12-item WHODAS 2.0 in our study have been demonstrated to be useful and complementary outcome measures, both in healthy individuals and in patient populations (37, 38). In the light of our results, the 12-item WHODAS 2.0 could be recommendable in assessing the functioning of patients with TBI. As the severity of injury was not strictly correlated with impairments of activity and participation, measuring only injury-specific neurological findings, is probably not sufficient when targeting rehabilitative resources to improve the quality of life and participation of patients with TBI (26). Even if WHODAS 2.0 is a general functioning tool and not created for TBI, it seems to be a reliable and sensible tool for measuring difficulties perceived by patients with different severities of TBI.

This study has some limitations. The severity of the TBI was evaluated retrospectively, but with access to electronic medical records from the very beginning of the injury. Patients with severely impaired cognitive abilities or memory were excluded. Patients who initially had miTBI consist mainly of a fairly selected and restricted group with prolonged symptoms, not describing the average outcome from a miTBI. However, this study aimed to clarify the usability of the WHODAS 2.0 as an assessment tool for the consequences of TBI, and not at determining the outcome of TBI of varying severities. Although the number of patients was limited, it was adequate for the purposes of the study on the whole. The study was executed in 1 facility only, which may have an effect on the generalizability of the results. Two types of generic functioning tools were used (WHODAS and ICF generic set), making direct comparisons difficult. Both tools are, however, ICF-based and also have identical items.

In conclusion, this study indicates that assessing disability with the 12-item WHODAS 2.0 is reasonable, and could be used in planning client-oriented services for patients with TBI (13, 15, 27, 39, 40). In the chronic phase, patients with mild to severe TBI perceive a diversity of significant difficulties in activities and participations. Even in mild TBI cognitive and emotional consequences can be prominent and in more severe cases physical motor functions are also often impaired.

The authors have no conflicts of interest to declare.

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