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Comparing Disability between Traumatic Brain Injury and Spinal Cord Injury using the 12-item WHODAS 2.0 and the WHO Minimal Generic Dataset Covering Functioning and Health

Research article

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Short title: Disability in Brain and Spinal Cord Injuries

Abstract

OBJECTIVE: To compare disability between two patient groups using short validated tools based on International Classification of Functioning, Disability and Health (ICF).

DESIGN: Cross-sectional study.

SETTING: University hospital specialist outpatient clinic.

SUBJECTS: 94 patients with traumatic brain injury and 59 with spinal cord injury.

MAIN MEASURES: Disability evaluated using self-reported and proxy 12-item WHODAS 2.0 (World Health Organization Disability Assessment Schedule), and physician-rated WHO minimal generic dataset covering functioning and health.

RESULTS: The two measures used showed severe but very different disabilities in these patient groups. Disability was assessed worse by physicians in the spinal cord injury population (sum 15.8 vs 12.7, $p=0.0001$), whereas disability assessed by the patients did not differ significantly between the two groups (sum 18.4 vs 21.2). Further analysis revealed that in patients with “high disability” (the minimal generic dataset score ≥ 15), self-reported functioning was more severely impaired in the traumatic brain injury group compared to the spinal cord injury group (29.7 vs 21.4, $p<0.0001$), with no difference between these two diagnostic groups in patients with “low disability” (the minimal generic dataset below 15). Patients with traumatic brain injury perceived more difficulties in cognition, getting along and participation, patients with spinal cord injury in mobility and self-care.

CONCLUSION: Both generic measures were able to detect severe disability but also to detect differences between two patient populations with different underlying diagnoses.

Key words: disability; spinal cord injury; traumatic brain injury; WHODAS; WHO minimal generic dataset covering functioning and health

Introduction

There are numerous instruments for evaluating the severity and outcomes of either traumatic brain injury¹⁻⁴ or spinal cord injury⁵⁻⁷. In traumatic brain injury, the most widely used diagnosis-specific tool is the Glasgow Outcome Scale (GOS)⁸. The later extended modification of this scale has been found to correlate with another disease-specific measure, the Functional Status Measure⁴ in patients with traumatic brain injury. In spinal cord injury, on the other hand, two outcome measures: the disease-specific Spinal Cord Independence Measure (SCIM III)⁶ and the generic Functional Independence Measure (FIM) have been shown to correlate with each other.

Even if separate health-condition-specific instruments may be useful in the follow-up of one patient or one group of patients^{9,10}, they do not enable comparing patients with different diagnoses behind their disabilities. To unify the assessment of functioning around the world, and to enable comparisons between different diseases, the World Health Organization (WHO) has developed and validated ICF-based¹¹ generic assessment tools for these purposes. The shortest and the simplest of these generic instruments are the 12-item WHODAS 2.0¹², and the seven-item WHO minimal generic dataset covering functioning and health¹³. As far as we know, there are no studies using these tools to compare functioning between two different neurological diagnoses.

In this study, we wanted to evaluate whether short global measures could detect differences in the pattern of disability in patients whose disability arises from quite different causes. It is not known whether decisions on allocating rehabilitative resources between different diagnosis groups could be based on simple functioning measures, or whether these measures allow clinical or economic comparisons between people with different causes of their disability. To find possible relevant differences between two disabled patient groups, we wanted to compare the use of these measures in two patient populations with a central nervous system injury but forming a strong contrast: one

group with mostly severe motor loss but preserved cognition, and another group with mostly cognitive and emotional problems but preserved mobility.

The objective of this study was to compare disability in patients with spinal cord injury and traumatic brain injury using both WHODAS 2.0 and the WHO minimal generic dataset. We also wanted to determine to what extent different evaluators (patient, proxy and physician) using the same measures gave similar scores.

Patients and Methods

Between December 2015 and October 2017, a 12-item patient and proxy WHODAS 2.0 questionnaire was mailed to all consecutive patients with traumatic brain injury or spinal cord injury before their appointment at the Rehabilitation and Brain Trauma outpatient clinic of a university hospital. The Ethics Committee of the University of Turku and Turku University Hospital approved the study (19.5.2015 ETMK:73/1802/2015). The ethical standards of the World Medical Association Helsinki Declaration of 1975, as revised in 1983, were followed. All patients aged 20 to 60 years with an informed consent (94 patients with traumatic brain injury, and 59 with spinal cord injury) and their significant others were recruited. Patients with a current major medical illness, psychotic condition, another neurological diagnosis, concomitant traumatic brain injury and spinal cord injury, age under 18 years at the time of the injury, and those without the ability to co-operate were excluded. In some cases the questionnaire was completed at the outpatient clinic to avoid missing data. Of the traumatic brain injury patients' and spinal cord injury patients' significant others, 53% vs 68% were spouses, 17% vs 10% were parents, 10% vs 10% were children, 9% vs 0% were siblings, 1% vs 2% were other relatives, 3% vs 5% were close friends, and 7% vs 5% were trained caregivers, respectively.

At the outpatient clinic, a neurologist (in the case of traumatic brain injury) or a specialist in Physical and Rehabilitation Medicine (in the case of spinal cord injury) filled in the seven item minimal generic dataset with added demographic factors (age, gender, accommodation, marital status, educational level, and working status). Medical information (date of injury, diagnosis (ICD 10), type and severity of injury, comorbidities ¹⁴) was gathered from the hospital records.

Mild traumatic brain injury was classified according to the American Congress of Rehabilitation Medicine criteria ¹⁵. Traumatic brain injury was considered moderate if the Glasgow coma scale score at admission was 9-13 or duration of posttraumatic amnesia 1-7 days, and severe if the

Glasgow coma scale score at admission was 8 or lower or duration of posttraumatic amnesia longer than one week.

The level and severity of spinal cord injury was classified according to the American Spinal Cord Injury Association Impairment Scale ¹⁶. The term tetraparesis was used to describe impairment or loss of motor and/or sensory function in the injury of the cervical segments and paraparesis when the lesion was more caudal.

The 12-item WHODAS 2.0 ^{12, 17} includes twelve items (see Table 3) assessing six different disability domains (cognition, mobility, self-care, getting along, life activities, and participation) during the previous 30 days. Each of these twelve items is rated according to a 5-point Likert-type scale, grading the difficulty experienced by a participant in performing a given activity. Each of the separate twelve 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 sum score of all these twelve sub-scores ranges 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 (<http://www.who.int/classifications/icf/whodasii/en/>).

The WHO minimal generic data set of functioning and health ¹³ consists of seven domains of functioning: energy and drive functions, emotional functions, sensation of pain, carrying out daily routine, walking, moving around, and remunerative employment. “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 WHODAS, the sum score ranging from 0 to 28, with lower scores indicating better functioning.

Statistical analysis

The differences between the two diagnostic groups were tested for numeric variables with T-test for independent samples and for categorical variables using Chi-Square test. The Spearman correlation coefficient was used to test the correlation between variables. The 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. Linear regression analysis was used to investigate the association between diagnostic group and WHODAS sum score, adjusted with significant background factors. In the comparison of subgroups with the generic dataset score ≥ 15 or < 15 , ordinal scale variables were tested with the non-parametric Wilcoxon two-sample test. Statistical analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC, USA). P-values below 0.05 (two-tailed) were considered statistically significant.

Results

The demographic factors and the severity levels of the injuries are described in **Table 1**. Of the 94 patients with traumatic brain injury, injury was moderate or severe in 67 patients. Of the 29 patients with spinal cord injury with tetraparesis, two had a motor complete, and 27 an incomplete tetraparesis. Of the 30 paraparetic patients, 12 had a motor complete, and 18 an incomplete paresis: 40 (68%) of those with spinal cord injury had reached walking ability with or without assistance.

When disability was rated by a physician (**Table 2**), patients with spinal cord injury were rated more disabled than those with traumatic brain injury, especially in moving and walking, as expected. Both patient groups had a severe impairment in employment. In other functions, the mean scores reached mild to moderate impairment (**Table 2**).

When patients and their significant others rated functioning (WHODAS 2.0), the mean total disability score showed severe impairment in both conditions with no statistically significant difference ($p=0.2$) (**Table 3**). The scoring by significant others did not differ significantly from the scoring by patients. When comparing the twelve items of functioning separately, there was a clear difference between the two diagnostic groups on most items. Patients with traumatic brain injury experienced more problems than those with spinal cord injury in learning, concentrating, emotions, engaging in community, and dealing with people. Patients with spinal cord injury perceived more impairments in standing and walking.

The correlations between the minimal generic dataset sum score (assessed by a neurologist) and the WHODAS sum scores (patient and proxy) varied from moderate to very strong (in traumatic brain injury 0,69-0,73 and in spinal cord injury 0,50-0,55). The Cronbach's alpha values for reliability of the WHODAS patient sum was 0.88, the WHODAS significant other 0.89, and the minimal generic dataset sum 0.74.

In linear regression analysis, none of the background factors (age, gender, living at home, cohabiting, education, still working) explained the variation in the patient-rated WHODAS sum score; and of medical background factors (comorbidities, duration of disease, and the WHO minimal generic dataset sum score), only the effect of the physician-rated minimal generic dataset sum score was statistically significant. The further analysis with a dichotomic comparison of patients with high (≥ 15), and low disability (< 15) based on the physician-rated minimal generic dataset score (sum score over moderate level based on mean score per item >2 or ≤ 2), in the subgroup of “high disability” the patient-rated disability (WHODAS) was more severe in traumatic brain injury compared to spinal cord injury, with no difference between the two diagnostic groups in patients with physician-rated “low disability”. The assessment scores and distribution of the patients with the minimal generic dataset sum 15 or more, and below 15 classified by the injury type are demonstrated in **Table 4**.

Discussion

In this study we have shown the usability of generic ICF-based functioning tools (WHODAS 2.0 and the WHO minimal generic dataset) in comparing patients with traumatic brain injury and spinal cord injury. These short measures were thus able to characterize disability both in patients with remarkable motor loss, and in those with mostly cognitive and emotional problems. Despite the simplicity of these tools, the results indicate that adequate detail can be extracted for comparisons of particular sub-items of functioning when comparing different diagnostic groups.

The vast number of measurement tools has made comparing different studies and different patient populations challenging. Specific measurement tools have usually focused more on the symptoms and severity of the disease, rather than on functioning and quality of life, which are probably more important targets of rehabilitation, at least in the chronic phase of injuries and diseases⁷. As measuring different aspects of functioning in patients with disabling conditions has been considered to be critical, specific tools for these measurements have been developed. The most often used tools are based on ICF¹¹, or can at least be partly linked to ICF categories, in order to facilitate comparisons between instruments¹⁸⁻²¹. Instruments directly derived from the ICF such as ICF core sets are health-condition-specific and cannot be used to compare functioning in different diagnoses. Many functioning tools may also be too time-consuming (e.g. ICF Measure of Participation and Activities (IMPACT-S), Participation Scale (P-Scale), and Assessment of Life Habits (LIFE-H)) to help clinicians. The WHO has developed simple generic assessment tools to enable comparisons between different health conditions around the world. The 12-item WHODAS 2.0 has been found to be valid and reliable²²⁻²⁷. Our study is in line with previous studies showing strong correlation between WHODAS 2.0 and other measures of activity limitations²⁷, in our study with the WHO minimal generic dataset. As the 7-item minimal generic dataset is very brief, it has been suggested to be used as a starting point to address the comparability of data across studies and nations¹³.

When our results with high disability levels both in spinal cord injury and traumatic brain injury are compared to the previous register study on Taiwanese participants with disability benefits²⁸, the results are largely in line. Differences in study populations, however, prevent direct comparisons. Previously, however, domain-^{28,29} and gender-related²⁹ patterns of disability have been shown when using WHODAS in different diagnostic groups. Of other generic ICF-based tools¹⁹ the validated IMPACT-S²⁰ includes the same ICF domains as the 12-item WHODAS 2.0, but the higher number of items (33 vs 12 in WHODAS) and the simplified 3-level scoring may be a shortcoming. In the current study, assessments by a physician correlated well with patient- and proxy-rated functioning in both diagnostic groups, showing that both of these simple tools (WHODAS and the WHO minimal generic dataset) are practical. However, in the subgroup of more severely disabled patients, those with traumatic brain injury seemed to experience more difficulties than those with spinal cord injury. This can be influenced by the fact that the minimal generic dataset does not measure cognition in the same way as WHODAS. And obviously no absolute comparisons can be made as it is not really possible to give appropriate weight to how an individual will perceive his/her own severity. In single items of functioning, WHODAS was able to show clear differences between the two patient populations, one with more difficulties in mobility and self-care, and the other with more difficulties in cognition and participation, with highly restricted working ability in both diagnostic groups. Thus, WHODAS could be used as an easy tool to evaluate and compare service needs between individual patients and populations with different diagnoses.

There are some limitations to this study. A cross-sectional study design does not allow confirmation of any causal relationships of disability, i.e. whether they are based on the injury itself or its secondary consequences. The patient population was selected and limited in number, but adequate for the purposes of the study. As two different generic functioning scales (WHODAS and the WHO minimal generic dataset) were used, direct comparisons were not possible for all sub-items.

Even if WHODAS and the minimal generic dataset seemed to be adequate in the chronic phase as in our study, these results are not directly generalizable to the acute or subacute phase of these injuries³⁰. The retrospective evaluation of the initial severity of injuries was made as reliable as possible, by relying on all electronic medical records from the beginning of the injury. However, the aim of this study was not to describe the outcome of different severities of injuries. The patients with severely impaired cognitive abilities or memory were excluded, thus leaving out the most disabled patients. Patients and their significant others were not blinded to each other's evaluations; however, in the vast majority the responses were not identical.

In our study, both WHODAS 2.0 and the WHO minimal generic dataset appeared to be easy to use, and they were able to differentiate these two conditions both qualitatively and quantitatively. As the 12-item WHODAS proved to be simple enough for patients with traumatic brain injury and spinal cord injury, we recommend using these 12 items instead of the only seven item minimal generic dataset. These differences in activities and participation between the two conditions can be important, when focusing rehabilitation on the most challenging parts of daily living. In conclusion, these generic measures can detect disability arising from different causes, thus allowing some form of economic or clinical comparison between different populations and between people with different causes of their disability.

Clinical messages:

Both the 12-item WHO disability assessment scale and the seven-item WHO minimal generic dataset covering functioning and health can detect differences in the disabilities experienced by people with traumatic brain injury and spinal cord injury.

Both measures give similar data whether rated by the patient, a family member, or a physician.

Conflict of Interest Statement: The authors declare that there is no conflict of interest.

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Table 1. Demographic data of the participants

Variables	Traumatic brain injury (n=94, mild=27, moderate=38, severe n=29)	Spinal cord injury (n=59, paraparesis= 30, tetraparesis n=29)
Age years (mean, SD)	41.4 (10.8)	43.5 (10.6)
Time since diagnosis, years (Q1/median/Q3)	1.1/ 2.9/ 7.4	1.4/ 4.8/ 10.2
Number of comorbidities (Q1/median/Q3)	0 / 0/ 0	0/ 0/ 1
Education, years (mean, SD)	13.4 (3.1)	12.6 (3.3)
Gender, female (n/%)	49 (52.1)	30 (50.9)
Still working (n/%)	22 (23.4)	13 (22.0)
Community living (n/%)	89 (94.7)	58 (98.3)
Cohabiting (n/%)	53 (56.3)	32 (54.2)

Table 2. Functioning (the WHO minimal generic dataset score) of the two diagnostic groups rated by a physician

Variable (mean, SD)	Traumatic brain injury (n = 94)	Spinal cord injury (n = 59)	p
Sum	12.7 (5.4)	15.8 (4.2)	0.0001
Energy and drive functions	1.9 (1.0)	1.1 (0.8)	<0.0001
Emotional functions	1.7 (1.0)	1.2 (0.8)	0.001
Sensation of pain	1.4 (1.2)	2.0 (1.8)	<0.01
Daily activities	1.9 (0.9)	1.8 (1.0)	0.4
Walking	1.0 (1.1)	2.7 (1.2)	<0.001
Moving around	1.5 (1.3)	3.5 (0.8)	<0.0001
Remunerative employment	3.1 (1.2)	3.5 (1.0)	0.05

Sum score 0-28, where 0 = optimal functioning. Each of seven items 0-4.

Table 3. Functioning (12-item WHODAS 2.0) of the two diagnostic groups rated by patients and their significant others

Variable	Patients		Significant others	
	Traumatic brain injury (n=94)	Spinal cord injury (n=59)	Traumatic brain injury (n=94)	Spinal cord injury (n=59)
	Sum (mean, SD)	21,2 (11,1)	18,4 (9,5)	21,3 (11,5)
Median (Mode):				
Standing	2 (0)	4 (4)	2 (0)	4 (4)
Household activities	2 (3)	2 (2)	2 (3)	2 (0)
Learning	2 (3)	0 (0)	2 (1)	0 (0)
Joining in community	3 (3)	1 (0)	2 (3)	1.5 (2)
Emotional functions	3 (3)	1 (1)	3 (3)	1 (1)
Concentrating	2 (0)	0 (0)	2 (0)	0.5 (0)
Walking	1 (0)	4 (4)	1 (0)	4 (4)
Washing	0 (0)	1 (0)	0 (0)	1 (0)
Dressing	0 (0)	1 (0)	1 (0)	1 (0)
Dealing with people	2 (0)	0 (0)	2 (0)	0 (0)
Maintaining friends	2 (3)	0 (0)	2 (2)	1 (0)
Work/study	3 (4)	3 (4)	3 (4)	2 (4)

WHODAS sum score 0-48, where 0 = optimal functioning. Each of twelve items 0-4.

Table 4. Proportion of patients with traumatic brain injury and spinal cord injury with the WHO minimal generic dataset score 15 or more and less than 15

Assessment scores and severity/level of the lesion n (%)	the minimal generic dataset \geq 15	the minimal generic dataset < 15	p
Traumatic brain injury: WHODAS sum mean (SD)			
the minimal generic dataset score (SD)	18.4 (1.9)	9.8 (8.7)	
WHODAS sum score (SD)	29.7 (7.7)*	16.8 (10.1)**	
mild injury	4 (13)	23 (37)	<0.01
moderate	12 (38)	26 (42)	
severe	16 (50)	13 (21)	
Spinal cord injury			
the minimal generic dataset score (SD)	18.4 (2.1)	11.7 (10.3)	
WHODAS sum score (SD)	21.4 (8.3)* p<0.0001	13.8 (9.5)** p=0.2	
<i>etiology:</i>			
traumatic	22 (61)	11 (48)	0.3
non-traumatic	14 (39)	12 (52)	
<i>level:</i>			
tetraparesis	17 (48)	12 (52)	0.4
paraparesis	19 (53)	11 (48)	
<i>walking ability</i>			
yes	20 (56)	20 (87)	0.01
no	16 (44)	3 (13)	