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The *World Health Organization Disability Assessment Schedule 2* (WHODAS 2.0): remarks on the need to revise the WHODAS

World Health Organization Disability Assessment Schedule 2 (WHODAS 2.0): comentários sobre a necessidade de revisar a WHODAS

World Health Organization Disability Assessment Schedule 2 (WHODAS 2.0): observaciones sobre la necesidad de revisar WHODAS

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Abstract

Functioning and disability are concepts in increasing use in clinical settings and in public health. From the public health perspective, the use of functioning as a third health indicator could show more than the frequency of a disease and its death rates, offering information on how the population performs its activities and participation. Clinically, the functioning assessment can provide information for patient-centered health care and specific clinical interventions according to their functioning profile. WHODAS 2.0 is a generic tool to assess health and functioning according to the ICF functioning model. It is an alternative to assess functioning in a less time-consuming way, whereas the duration of the application is one of the main ICF critiques. This paper aims to present some of WHODAS 2.0 inconsistencies and weaknesses as well as strategies to cope with them. In this paper, we present some weaknesses related to the WHODAS layout; wording and scoring process. Some suggestions for strategies to correct these weaknesses are presented, as well.

International Classification of Functioning, Disability and Health; Needs Assessment; Health Status Indicators

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Introduction

Information on functioning and disability has become increasingly important to describe health and health-related states of people with any kind of health conditions. Functioning-related concepts, classifications and measurements play a central role in clinical practice, teaching and research [1]. In addition, functioning is considered a Clinical Outcome Assessment (COA), which means that it can be used as a clinical assessment to measure patient outcome in a clinical trial [2], as we can see in some papers already published [3,4,5,6,7]. As a COA, functioning has been used in several health fields, e.g. in the health care of people with schizophrenia [8]; migraine [9]; cancer [10]; arthrogryposis [11]; dyspnea [12]; stroke [13]; chronic musculoskeletal pain [14]; congenital heart disease [15]; and prior to hematopoietic stem cell transplantation [16].

In the public health field, the importance of functioning is growing gradually. There are discussions about its use as a third health indicator, in addition to mortality and morbidity. As a set, these 3 health indicators could offer more reliable information on the performance of health strategies in the health systems. Functioning could be used along with mortality and morbidity in prevention and promotion of health; as an indicator for rehabilitation; as an indicator for curative health services; and for palliative health care. In all the five fields cited, the morbidity and mortality without functioning fail to provide comprehensive information to the health management [17]. In a country with an equitable health system, knowing the population functioning profile may be more important than knowing the occurrence of diseases and their deaths in this population. Only with the functioning information can we know their true health care needs [17]. Strategies of functioning information collection in health surveys are also laid down in the literature [18]. Some tools as the *Model Disability Survey* – MDS [19] and the *World Health Organization Disability Assessment Schedule* – WHODAS can be used [20]. Reinforcing the functioning role in the public health field, the *11th International Classification of Disease* – ICD-11 (https://icd.who.int/browse11/l-m/en) came up with a new section, "V Supplementary section for functioning assessment" in order to "*…allow creating functioning profiles and overall functioning scores for the individuals, which are suitable to describe and quantify the level of functioning associated with health conditions. To guide functioning assessment, the section includes two International Classification of Functioning, Disability and Health (ICF)-ground instruments developed by World Health Organization (WHO): the WHO Disability Assessment Schedule (WHODAS 2.0 36-item version), and the Model Disability Survey (MDS). The section is complemented by a generic set of functioning categories with a high explanatory power derived from the ICF Annex 9*". The inclusion of functioning assessment in the ICD shows its weight in monitoring the burden of health events.

According to the WHO, functioning is defined as a "*generic term which includes body functions and structures, activities and participation. It indicates the positive aspects of the interaction between the individual (with a health condition) and its contextual factors (personal and environmental factors)*" (WHO. International Classification of Functioning, Disability and Health. v. 2. http://www.who.int/classifications/icf/en/), whilst disability is an umbrella term for impairments of the body functions, activity limitations or participation restrictions. These conceptualizations of functioning and disability are the fundamental basis of the (ICF), that conceives functioning as a multiple dimensional concept, accepting the biopsychosocial perspective as its framework [21].

In the past 15 years, the ICF has been assimilated and discussed by the user community in clinical or research settings and with its use some critiques have arisen. One of the ICF strengths, its comprehensiveness, is also a point of criticism [22]. To facilitate the use of the ICF and shorten its time-consuming application WHO started to develop and establish strategies to support the use and application of the ICF in a convenient and less time-consuming way. In line with this, ICF Core Sets [23], short lists of the ICF categories tailored to the specific needs of people with specific health conditions and ICF-based assessment tools such as the *World Health Organization Disability Assessment Schedule 2.0* (WHODAS 2.0) [24] have been developed.

In this paper, we will provide some explanatory remarks on the latter one, the WHODAS 2.0. WHODAS 2.0 is a generic tool designed to assess functioning according to the ICF framework by using the following six functioning domains in people aged 18 years and over: cognition, mobility, self-care, getting along, life activities and participation. It consists of 36 questions in its long version: Cognition (6 questions); Mobility (5 questions); Self-care (4 items); Getting along (5 items); Life

activities (8 questions); and Participation (8 items). Besides this 36-item version WHO also provides versions containing 12 questions and a hybrid version (12+24), in which questions can vary from a minimal of 5 to a maximal of 36. The application mode ranges from an interview version or self-administered version to a proxy version. For each version of the instrument there is a standardized version according to the format of the respondent (interview, self-administered and proxy). In all versions, functioning is being assessed by a general score ranging from 0 (no disability) to 100 (full disability), with the 36 item-versions allowing also scores for domains [25].

Since its publication in 2010, the WHODAS has been translated into several languages, always dependent on WHO's approval. There are translations into more than 47 languages and dialects [26] such as Hebrew [27]; Chinese [28]; Polish [29]; Japanese [30]; Norwegian [31]; and Portuguese [25]; just to name a few. Translations and cross-cultural adaptations have been welcomed by WHO as the WHODAS is intended to be one of the favorite tools to measure health and disability across cultures in a standardized way [32]. Besides that, a tool aiming to assess functioning in a standardized, less time-consuming and straightforward way could facilitate the assessment and more specifically the identification of needs in health care; matching treatments and interventions; measuring clinical and research outcomes and effectiveness; setting clinical priorities; and allocating resources [32].

With WHO's endorsement, WHODAS 2.0 has had its use spread gradually and quickly throughout the world in clinical and research settings [26]. As a result of this, the literature has shown some examples of its use as in the assessment of functioning in aged population in Poland [33]; in the check for the association between disability and common mental disorders [20]; in the research of the symptoms of depression and anxiety [34]; in the description of the gap in activities and participation between people with and without disabilities [35]; in the analysis of the participation of colorectal cancer survivors [36]; relating educational level and disability in people with dementia [37]; in the investigation of disability in people with HIV [38]; among others. Several papers with clinical approach can also be found. Reports of researches on evaluating mental functions in individuals with Huntington disease [39]; on assessing disability in men referred for treatment with work-related primary mental health care problems [40]; on researching the effect of a community-based rehabilitation intervention for people with schizophrenia [41]; on investigating disability in patients undergoing neurosurgical procedures [42]; on the knee posture during gait and global functioning post-stroke [43]; could be examples.

WHO mentions the following advantages for the use of WHODAS:
(1) Direct link to the ICF, as it was developed following the ICF framework. WHODAS is not a list of codes derived from ICF, as ICF Core Sets are; it is a questionnaire that covers domains as defined in the ICF framework and classification.
(2) Cross-cultural comparability – WHODAS was developed and tested to be used around the world, ensuring its cross-cultural comparability;
(3) Availability of sound psychometric properties – validity and reliability were extensively tested and approved in validation studies.
(4) Ease of use – the self-administered WHODAS version application can last 5 minutes and the interview application, 20 minutes, a relative short time for data collection;
(5) Broad range of availability – WHODAS is available in more than 30 languages, all free to use around the world [24].

It has also been said that WHODAS can be considered a patient-reported outcome measure (PROM) with direct application in multidisciplinary services like community rehabilitation services [44]. Doubtless, the features presented above are strengths that would already favor the tool but WHODAS has yet another even more interesting feature. By using its domains and total scores it is possible to consider functioning as a quantifiable concept, ranging from 0 (no disability) to 100 (full disability), both for domain scores and for total score. The WHODAS scores will also provide the opportunity to compare and analyze functioning and disability in (clinical) population and subpopulations.

However, there are possible weaknesses or even inconsistencies that can only be seen in the practical application of the WHODAS. In Brazil, we have been working with WHODAS since 2015 and our experience is threefold: firstly, by becoming familiar with WHODAS conceptualization and content from reading the relevant literature; secondly, by translating the user's manual to Portuguese and by adapting it for the Brazilian specific needs; and thirdly, by applying the WHODAS in a broad range

for clinical and research settings in Brazil. In doing so, some inconsistencies have become evident in the process of translating, adapting and applying WHODAS to our research and clinical practice.

This paper aims to highlight these inconsistencies and to point out a set of proposals to cope with them from the Brazilian perspective. By presenting weaknesses of WHODAS and discussing how to cope with them, this paper (1) will contribute to its appropriate use in the health care process, benefiting professionals and researchers in the field of health and rehabilitation in Brazil and other countries in which WHODAS has been used, and (2) will provide a set of information to be considered in the case of preparing a revised version of the WHODAS and its manual.

Remarks on inconsistencies and weaknesses of the WHODAS along with proposals to cope with them

Reflections on the WHODAS layout

It is known that the layout of a questionnaire can impact the way how it is "understood" and filled in as well as the quality of data and time of application [45] and as a consequence the results retrieved from the analysis of the questionnaire such as prevalence and risk estimations [46]. Therefore, it is essential to provide a questionnaire that is easy to apply and use in different populations.

The WHODAS manual states very clear recommendations for its application and scoring. Some instructions describe the application process and there are – for the interview version of the WHODAS – specific information about how to read the questions for the interviewee. An instruction is provided that the text in standard blue colored print should be read to the interviewee. It is well known that in many countries research funding issues are central and the budget is often limited. Printing colored texts implies higher costs for both, in research projects and in clinical use. To cope with this, we suggest the use of the standard print in bold; italic; capslock; or in grey color. So, the text would remain highlighted for the interviewers.

Furthermore, WHODAS uses two flashcards aiming *"to provide a visual cue or reminder for the respondent about important pieces of information to remember while answering questions"* [32]. However, the flashcards cannot be used when applying the WHODAS in blind or illiterate people. Therefore, we suggest the use of cards printed in Braille. So, they can be read by blind people if needed. For illiterate and blind people who do not read Braille, we propose that the interviewer read the flashcards whenever the interviewee asks for them. With these suggestions, we assure the participation of the groups of people who are blind and the illiterate. It should be said that the prevalence of people with blindness can reach 8% in the Sub-Saharan Africa; in Brazil this prevalence was 3.6% in 2013 [47]; and in 2010 the amount of people with blindness around the world could come to 32.4 million [48]. The illiterate population can also be significant in some countries, as well. Some African nations, for example, can have more than 50% of its population illiterate [49]. Considering these indicators, it can be seen that failing to adapt WHODAS for its use in these groups may represent the exclusion of large population groups from the WHODAS application process, compromising the quality and representativeness of the research and finally the health care.

Comments on the WHODAS wording

The wording of a tool has a central role since it will deliver the message which will impact the information collection. Therefore, efforts must be made to ensure a wording that is as clear as possible.

The questions D6.4; D6.5 and D6.6 have in their beginning a wording which implies incoherence with the pattern of WHODAS responses (none; mild; moderate; severe; extreme or cannot do) (Box 1). Thus, the question D6.4 begins with "How much time did you spend on…". Starting from this question, an answer related to time as "1 hour"; "12 hours"; "a day"; "a week"; or "a year" is expected. These alternatives are clearly different from those in WHODAS. Assuming the suggestions above were adopted, the heading of this question could be improved to "Manage the time you spent on your health condition or its consequences?".

Box 1

Questions of the participation domain that can be improved to be consistent with the response pattern of *World Health Organization Disability Assessment Schedule* (WHODAS).

In the past 30 days		None	Mild	Moderate	Severe	Extreme or cannot do
D6.4	How much time did you spend on your health condition or its consequences?	1	2	3	4	5
D6.5	How much have you been emotionally affected by your health condition?	1	2	3	4	5
D6.6	How much has your health been a drain on the financial resources of you or your family?	1	2	3	4	5

Questions D6.5 and D6.6 start both with "How much have…" (Box 2). This kind of question requires answers like "not at all", "much"; "little", among others.

The scientific literature on the validation of WHODAS shows worst confirmatory factor analysis (CFA) [50] and exploratory factor analysis (EFA) [51] results for the questions D6.4 to D6.6.

The remarks on the wording of the WHODAS are essential as the wording of a questionnaire tremendously impacts the results [52], consequences for the use of health services [53] and the prevalence of a health condition [54].

Remarks about WHODAS scoring process

The sum score of a questionnaire should be carefully executed according to the recommendations of the instrument developers. In the case of WHODAS, two different scores can be computed, a simple and a complex one. We would like to dwell on the latter, the complex one. The WHODAS manual explains that the complex score is based on the "Item-Response-Theory – IRT" and considering the SPSS syntax presented, it is noticed that some variables have different weights. It remains unclear why only some variables were weighted and others were not. An explanation about the analysis would be very welcome for a better understanding of the weighting process.

The steps to compute the complex score were summed up in the manual with the following wording: "Step 1 – summing of recoded item scores within each domain. Step 2 – summing of all six domain scores. Step 3 – converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability)". The domain scores are not clearly marked up by a heading. It could make the syntax more comprehensible and easily applicable.

There is a SPSS syntax available at page 59 of the manual, and we understand that some improvements can be made to this material. The questions D5.6; D5.7 and D5.8 cannot be found at the "Recode of polytomous items" section and there are at the end of this section the questions D5.8; D5.9; D5.10 and D5.11. The last four questions cited here are also in another syntax section. The issue lies on the fact that the questions D5.9 to D5.11 do not have the WHODAS pattern of answers. So, it seems that they should not be present in its syntax.

Another relevant point is the analysis of the variables classified as "not applicable" – N/A. Some variables can be considered N/A if the respondent considers that the question does not apply to his/her situation, or that was not experienced by the respondent in the last 30 days. The main question is that the N/A variables are not "missing data", so, they should not be treated like this. It seems that the command "compute" (used in the syntax) will result in a blank score if at least one of the component variables of the operation is missing (IBM SPSS Statistics 20 Core System User's Guide IBM SPSS Statistics Options, 2011. https://www.csun.edu/sites/default/files/statistics20-core-system-guide-

Box 2

Questions of the participation domain that can be improved by changing its wording.

In the past 30 days		None	Mild	Moderate	Severe	Extreme or cannot do
D6.5	How much have you been emotionally affected by your health condition?	1	2	3	4	5
D6.6	How much has your health been a drain on the financial resources of you or your family?	1	2	3	4	5

64bit.pdf). So, if one or more variables are blank, the scores may not be calculated, losing the answered questions. The total score could not be calculated as well. A suggested excel file is offered online to compute the scores (https://drive.google.com/open?id=1CB47ZIriCErjakSzqul0AgSyBX3f9Qmj).

It should be stressed out that tool revisions have already been documented by the scientific literature aiming to make the tool more comprehensible [55]; socially adequate [56]; or in order to fit with modern diagnosis approaches [57]. So, the presented proposal is not uncommon in the scientific setting.

Conclusions

This paper provides remarks on weaknesses or inconsistencies of the WHODAS 2.0 that became evident in the translation, cross-cultural adaptation and in the daily use of the tool in the research and clinical settings in Brazil. The remarks are related to the WHODAS layout, wording and scoring process. Strategies such as layout updating, sentence reformulation, and scoring process suitability can work around these problems.

Although the remarks do not question the overall advantages in the usage of WHODAS, they should be taken into account when revising the WHODAS and its Manual as well as its syntax.

Contributors

S. Castro and C. M. Buchalla contributed in the conception, writing and final approval. C. F. Leite and M. Coenen contributed in ther design, writing and final approval.

Additional informations

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Resumo

A funcionalidade e a incapacidade são conceitos cada vez mais utilizados no contexto clínico e de saúde pública. Do ponto de vista da saúde pública, o uso da funcionalidade como terceiro indicador de saúde é capaz de refletir mais do que a frequência de uma determinada doença e as respectivas taxas de mortalidade, fornecendo informações sobre a maneira pela qual a população realiza suas atividades diárias e participação social. Clinicamente, a avaliação da funcionalidade pode subsidiar os cuidados de saúde centrados no paciente, além das intervenções clínicas específicas de acordo com o perfil de funcionalidade. WHODAS 2.0 é uma ferramenta genérica para avaliar a saúde e a funcionalidade de acordo com o modelo da CIF. É uma alternativa para avaliar a funcionalidade com menor dispêndio de tempo, uma vez que o tempo gasto na aplicação é uma das principais críticas do modelo da CIF. O artigo tem como objetivo abordar algumas das inconsistências e fraquezas do WHODAS 2.0, além de estratégias para enfrentá-las. O artigo, discute algumas fraquezas na formatação, redação e processo de pontuação do WHODAS, assim como, diversas estratégias para corrigí-las.

Classificação Internacional de Funcionalidade, Incapacidade e Saúde; Determinação de Necessidades de Cuidados de Saúde; Indicadores Básicos de Saúde

Resumen

Funcionamiento y discapacidad son conceptos cuyo uso está aumentando dentro del contexto clínico y de la salud pública. Desde la perspectiva de la salud pública, el uso del funcionamiento como un tercer indicador de salud podría mostrar más allá de la frecuencia de una enfermedad y sus efectos respecto a la mortalidad en la población, ofreciendo información sobre cómo desarrolla la población sus actividades y participación. Clínicamente, la evaluación del funcionamiento puede proporcionar información sobre la atención a la salud centrada en el paciente e intervenciones específicas clínicas, según su perfil de funcionamiento. WHODAS 2.0 es una herramienta genérica para evaluar la salud y su funcionamiento, respecto el modelo CIF. Se trata de una alternativa más breve para evaluar el funcionamiento, aunque la duración del formulario es una de las principales críticas el CIF. El objetivo de este trabajo es presentar algunas inconsistencias y debilidades del WHODAS 2.0, así como también estrategias para afrontarlas. En este artículo, presentamos algunas debilidades relacionadas con el formato del WHODAS; así como los procesos de redacción y puntuación. Asimismo, se presentan algunas sugerencias como estrategias para corregir estas debilidades.

Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud; Evaluación de Necesidades; Indicadores de Salud

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