WHODAS 2.0 in Community Rehabilitation

A Qualitative Exploration of Content and Construct Validity of a Generic Disability Measure

Stefan Tino Kulnik, Physiotherapy Department, Imperial College Healthcare NHS Trust, London, United Kingdom
Dimitra Nikoletou, Faculty of Health and Social Care Sciences, Kingston University and St. George's, University of London, United Kingdom

Introduction and Purpose

The 'World Health Organization Disability Assessment Schedule' (WHODAS 2.0)[1,2] is a generic, patient-reported outcome measure (PROM) based on the World Health Organization 'International Classification of Functioning, Disability and Health' (ICF).

In this study we explored the validity of WHODAS 2.0 as a routine PROM for community rehabilitation services in the United Kingdom (UK).

WHODAS 2.0 consists of 36 items, grouped in six domains: cognition, mobility, self-care, getting along with people, life activities (household and work/school), and participation in society[1,2]. Respondents rate the level of difficulty they experience with each item due to their health conditions and taking into account personal assistance and assistive devices available to them[2]. WHODAS 2.0 thereby incorporates social and environmental aspects of disability, portraying an inclusive as opposed to a strictly medical view of disability. This was considered relevant in the context of community rehabilitation, which can address social and environmental factors, for example through caregiver training or through the provision of aids.

Guidance on the validation of PROMs emphasizes the importance of qualitative evidence for a measure's content and construct validity in the particular context of measuring[3,4]. We found insufficient qualitative evidence for the validity of WHODAS 2.0 as a routine PROM in community rehabilitation in published literature. The purpose of this study was to generate such evidence.

Methods

The study was set in a community rehabilitation service (CRS) in London, UK. Hosted by the National Health Service (NHS), this CRS provides multi-disciplinary goal-oriented rehabilitation for adults with heterogeneous medical background. The service offers physiotherapy, occupational therapy, speech and language therapy and clinical psychology. Rehabilitation interventions can include exercise therapy, mobility training, activities of daily living (ADL) training, provision of aids and environmental adaptations, caregiver training and communication training.

We combined a phenomenological approach with grounded theory and content analysis[5,6]. A convenience sample of ten CRS service users awaiting community rehabilitation was recruited in summer 2011. All participants gave written informed consent. Semi-structured interviews explored participants' difficulties in life, expectations from community rehabilitation and views on disability. This was followed by the interviewer-administered WHODAS 2.0. Interview recordings were transcribed and coded. The coding of selected transcripts was reviewed by a peer.

To explore content validity, we conducted a content analysis. Interviewees' accounts of difficulties in life and expectations from community rehabilitation were compared against and mapped onto WHODAS 2.0 items. To investigate construct validity, we used grounded theory analysis to discover the conceptualization of disability within the sample. We then compared this with the construct of disability underlying WHODAS 2.0, the ICF.

References:
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Results

The sample consisted of older adults (aged 54 to 91, eight women - F1 to F8, two men - M1 and M2), who varied with respect to ethnicity, socio-economic status, medical background (neurological, orthopaedic, multiple co-morbidities) and severity of disability. Not represented were younger age groups and individuals who have lived with a disability from a young age.

Most of the interviewees' accounts of difficulties in life and expectations from community rehabilitation corresponded literally with WHODAS 2.0 content. A number of accounts (mostly medical complaints and environmental issues) could not be mapped onto WHODAS 2.0 content. This constitutes a limitation in the analysis method. Arguably, only the individual respondent could interpret how these accounts relate to WHODAS 2.0 content.

Participants conceptualized disability mainly according to the medical model, which interprets disability as a consequence of health conditions. Participant F3, an elderly woman with multiple co-morbidities and a recent injurious fall, stated: '…ill health is the problem'. Interviewees tended to compare themselves to a perceived majority norm or personal pre-morbid norm. For example, participant F6, an elderly woman recovering from hip surgery, commented that before her operation she had been 'just a person', while after the operation she had difficulty to perform basic activities of daily living. This view of disability, combined with ambiguous wording of the WHODAS 2.0 questionnaire, caused uncertainty in relation to social and environmental aspects of disability. Examples are given in Figure 1. As per the WHODAS 2.0 manual[2], the interviewer guided participants to take into account personal assistance and assistive devices available to them. This influenced scores. Figure 2 gives an example of WHODAS 2.0 scores before and after the interviewer's prompts.

Figure 1 - Participants' comments illustrating ambiguity in relation to social and environmental aspects of disability in WHODAS 2.0

Well, I don't do housework, I have a cleaner. So what do I say to that?

Participant M2, an elderly man with Parkinsonism, was uncertain about the interpretation of WHODAS 2.0 questions in the household domain if the assistance of a cleaner was available. He raised this point in response to item D5.3 ('Getting all the housework done that you needed to do').

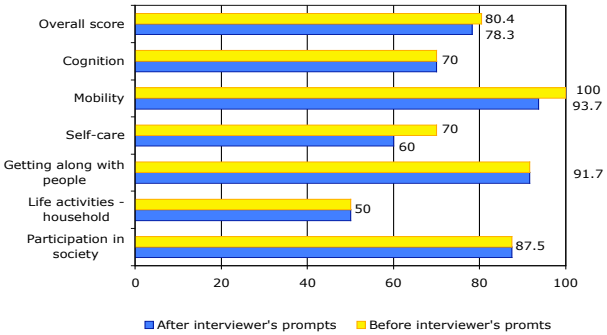
Participant F4, an elderly woman with muscular dystrophy, made this comment as she reflected on her response to WHODAS 2.0 item D5.1 ('Taking care of your household responsibilities'). Over the past decade, she had developed strategies to compensate for her gradually increasing difficulties, which included recruiting assistance from family members and using technology to alleviate chores.

I mean, yes, some I can't do, but on the whole, I mean, the thing is, it's not taking into consideration that obviously over the years I've made arrangements … so that I don't do certain things I just don't have to do!

She washes me, she puts me to bath, without help I couldn't get to a bath … There are still difficulties.

Participant F2, an elderly woman with multiple co-morbidities and reduced mobility, tended to benchmark against her younger, more able self when responding to WHODAS 2.0 items. In her rating for item D3.1 ('Washing your whole body') she found it difficulty to credit the personal assistance provided by her caregiver.

Figure 2 - WHODAS 2.0 overall score and domain scores for participant F8. Potential scores range from zero (no disability) to 100 (maximum disability).
Due to a recent spinal cord condition, this elderly lady used a wheelchair to mobilize and relied on personal assistance for self-care. She initially rated herself without considering assistive equipment and personal assistance available to her. After the interviewer explained that assistive equipment and personal assistance should be taken into account, she lowered her ratings for for three questions by one degree each, which resulted in the score difference illustrated above. Ambiguity in interpreting questionnaire items introduced variability to scores.



Discussion and Conclusion

We acknowledge several limitations to the study. Some relevant groups were not represented in the sample. The study lacked respondent validation, and peer debriefing was limited.

The findings support the content validity of WHODAS 2.0 as a generic measure of disability. However, two problems relating to the measure's construct validity became apparent: ambiguity inherent to the underlying construct of disability; and reliance on guidance from the interviewer to resolve this ambiguity.

Rehabilitation interventions at social and environmental level can constitute a central component in community rehabilitation. Ambiguity in respect to these aspects in WHODAS 2.0 may cause inaccurate scores and misrepresentation of a community rehabilitation service's effectiveness. Also, ambiguity in interpreting questions may invalidate the instrument for comparison between individuals.

Therefore, we recommend caution when applying WHODAS 2.0 as an outcome measure in community rehabilitation and where social and environmental aspects of disability are considered important. Further qualitative exploration of the measure's validity may be warranted.