Common Measures in Mental Health Science:

WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)

Background

In June 2020, the National Institute of Mental Health and Wellcome reached a landmark agreement to require the use of a common set of measurement tools in the research they fund. Since then, the International Alliance of Mental Health Research Funders has supported a wide group of funders and journals to join the effort, supported by an expert advisory board.

The fundamental mission of the Common Measures in Mental Health Science initiative is to ensure that research leads to tangible improvements in the lives of people who experience mental health issues. Given the current, fragmented landscape of mental health data, there is a need to take pragmatic action to make mental health research easier to compare, communicate and interpret.

In the interest of transparency and collaboration, we are sharing the anonymised notes from the discussions that the Common Measures in Mental Health Science Advisory Committee (CMA) had on WHODAS 2.0 on February 22 and 23, 2022.

The CMA were asked to share:

a. Their views on the concepts that underlie the questions in WHODAS 2.0

b. Their views on how well these concepts are captured by the questions

c. Their experience of using these questions with different populations

d. What they thought might be missing and needed to get core concepts

Contents

The overall performance of WHODAS2.0 across contexts

There are a lot of criticisms of WHODAS in capturing impairment in mental health. Sometimes it is unhelpful. It is hard to capture all forms of disability using a single scale – physical/sensory disability doesn't neatly translate to what barriers/challenges would look like for mental health. But also, it's universal, and it gets used, and people with mental health conditions also can have comorbid physical disabilities and other kinds of chronic health conditions.

If WHODAS is augmented with something else more tied to disability associated with mental health that would be positive. If it's standalone, it creates some concern, except if the main thing to understand is big-picture disability. There are a few questions that have more relevance to mental health: household responsibilities, community, emotionally affected, concentrating, maintaining a friendship, dealing with people you don't know, day to day work. Some things are relevant, but additional needs to be captured.

In other contexts, others have been chosen, such as the Columbia Impairment Scale, a QoL brief measure, QPR for PHENEX.

WHODAS is not comprehensive, but it taps into relevant constructs of functioning that are useful. The questionnaire was constructed to cover lots of aspects rather than capture them very well. So the question 'which aspects get which weights' is a difficult one.

WHODAS was meant to map onto the ICF taxonomy and framework. In defence of WHODAS (compared to Colombia Impairment Scale) – CIS makes several assumptions, e.g. that a person has a mother and a father (both separately asked about) and siblings. It asks about behaviour in school, assuming they are in school. Whereas WHODAS doesn't make such assumptions.

WHODAS mainly asks about day-to-day work and joining community activities.

A doctoral programme set out to show WHODAS would be inferior to a culturally embedded scale and found it easier to administer and more sensitive to change. It could be that culturally embedded scales haven't had the same amount of work to validate and improve, whereas WHODAS has had a huge amount of improvement. There is work that allows a cross-walk between WHODAS and QALYs. A big advantage is that it is generic. A more specific scale for mental health would be more sensitive and have better content validity, but it doesn't assess the marginalisation of mental health in the same way. WHODAS is the best for us now. It doesn't mean that with investment a more culturally embedded scale wouldn't be better, but at the moment the WHODAS has had such a lot of work put into improving it, it means it has better psychometric properties.

In terms of what's missing from WHODAS in relation to mental health, it is crucial to measure what is due to exclusion from spaces or social exclusion.

And context will be important. For example, culturally in some places (experience from rural Ethiopia) people have a high threshold of when they take to their bed (i.e. to become non-functional).

Views on specific WHODAS questions

- Question structure: *In the past 30 days, how much difficulty did you have in…*
- Response scale: *none / mild / moderate / severe / extreme or cannot do*

Q1. Standing for long periods such as 30 minutes

It's a straightforward question in terms of cultural competency but has other problems in that it captures only the extreme end of impairment.

WHODAS is mostly useful for the upper end of impairment, not useful for distinguishing between variations in impairment at the more functional end of things.

The intention of the question is along the lines of: "Is there something wrong with your body that makes it hard for you to stand for 30 minutes" (as opposed to "I don't have time to do it" or "I don't have the opportunity to do it").

Q2. Taking care of your household responsibilities

This has limited use to compare across cultures, but if it can compare within cultures to look for change after an intervention then it is useful.

The question implies providing for a family.

It is vague; household responsibilities could have many meanings and it is not necessarily consistent within a culture (e.g. India with caste system). It could be subject to too many interpretations.

A better way to do this would be to ask in two parts: first, "Is this something that you do", then look at impairment.

Impairment is subjective more than symptoms - if you don't have household responsibilities then you're not impaired. This is reflective of a particular world model.

3. Learning a new task, for example, learning how to get to a new place?

No comments

4. How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

No comments

5. How much have you been emotionally affected by your health problems?

These questions seem to have more relevance to mental health issues.

But learning a new task can be too broad. The tool is trying to be broad to be inclusive but makes it unclear. Everyone has strengths and weaknesses – would it be for skills that they already have?

Joining community activities feels problematic in severe mental illness, e.g. if you hear voices in a public place. You could physically be there but would be a triggering place. Or if you experience social anxiety. Do you interpret it as “physically can I do it”, or “would I feel able to do it because of my experiences”?

If your main health problem is with mental health, question 5 would be confusing. People want to be understood. If we’re trying to get at something more meaningful this seems to conflate much.

The discussion we are having would be very difficult if we were trying to understand why a person has difficulty engaging in social interactions. But could work if the goal is to have a broad disability scale. The issue is that the specificity negates something brief and usable across countries and cultures.

6. Concentrating on doing something for ten minutes

There would potentially be cultural issues on what ‘concentrate’ means.

There is a question on what ’10 minutes’ of concentration means in terms of impairment for different mental health conditions and what is the content validity of this item.

7. Walking a long distance such as a kilometre [or equivalent]

No comments

8. Washing your whole body

No comments

9. Getting dressed

Youth with depression or anxiety could be irritated when asked these questions.

There is a risk of being insulting. This might have to be framed as ‘trying to capture all aspects of disability’. Expressed concern with the use of disability language. Unusual that there is a specific point on washing the whole body (makes sense with physical ability – can they reach), but unspecific in other areas. Similarly, walking could feel different if you live in a dangerous area and some might not have experience of trying to walk that far.

On showering and mental health, it's not that you physically can't; it's about motivation and care. The questions are worded to get at physical ability. There is a self-interpretation of these questionnaires – it's not stigmatising to say you can't get into a non-accessible shower, but to rate yourself as unable to shower due to mental health could be. A measure designed to get at 'self-care' would frame questions very differently.

This raises the risks of stigmatising. A research question could be whether there are questions that get at the same construct but don't cause such a reaction; more capability-focused questions would be less stigmatising.

10. Dealing with people you do not know

Introversion, extraversion, and context could matter here. It may be useful if someone wants to be known.

The item is very broad, several conditions might affect that – phobia, hearing or sight loss, being bed-bound etc.

But this kind of ambiguity is wanted/deliberate. People can often rate their impairment specific to their own expectations. They can compare their ability to deal with people they didn't know before their health issue arrived and judge if there is a decline. There are difficulties in comparability as to the underlying meaning, but it's not feasible to get a good measure on a 12-item scale.

It's an example of a question that can be made broader e.g., do you have difficulties with people you know or people you don't know? The measure developers had the conceptual idea and then found the best items they could, which is why some items are more specific than others.

Experience shows this question could be gendered in places such as rural Ethiopia.

It could be culturally impacted also between neighbourhoods.

11. Maintaining a friendship

People living with severe mental illness often lose their previous friendships. "Maintaining" could be ambiguous here. Would it be after the onset of illness, in which case it pushes it on to individuals 'losing' friends when they become ill, which is stigmatising.

Unclear what the 30-day timeframe means in this context. Would loss over 6 months be more reasonable than 30 days?

The question would also vary when considering online friends.

12. Your day-to-day work/school

No comments

General comments

Some questions would be better if framed as capability rather than impairment.

The challenge with WHODAS is that lots of people living with severe mental illness do have comorbidities. So, some could be offended by questions, but some do have these difficulties. If trying to capture comorbidity then you might need an additional column to explain what each is due to. This is done with intersectionality/discrimination research.