

Preliminary results from cognitive testing of psychosocial functioning questions in South Africa

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Cognitive testing: Goals

- **Assess respondents' interpretation of the questions**
- **Identify potential response problems that could impact on data quality**
- Evaluate the cross-cultural equivalence of the questions
- Conclude on the performance of the selected questions and their suitability in including people with psychosocial disability. Some of these people could have already been counted in (included) with the existing questions and others not.

Cognitive testing protocol: Participants

- 10 - 30 participants –representing 3 groups:
 - People with a known severe mental disorder but no physical or sensory impairment
 - People with a known physical or sensory impairment but no known severe mental disorder
 - People without any known mental disorder or physical or sensory impairment.
- 18 years old and 60 years *(to avoid compounding factors of possible cognitive impairments)*
- Men and women
- Any educational level

Aspects to consider in analysis

- What the respondent was thinking about when responding and providing examples to substantiate this
- Pattern of responses and interpretations for the selected questions across the 3 groups of respondents
- Need for repetition of the question or some parts
- Requests for clarification and any qualified responses provided
- Difficulty in using response options

Cognitive testing protocol : Structure of questionnaire

- Socio-Demographic questions/data
- WG Short Set (6 questions)
- WG Extended Set
 - Cognition questions – 3 additional
 - Affect questions (excluding questions on medication use)
 - Anxiety – 2 questions
 - Depression – 2 questions
- 7 Psychosocial disability questions with cognitive testing probes
- 5 additional questions on quality of life and impact of condition on everyday life (asked without probes)

South African testing context

- Ethical approval from the University of Cape Town's Human Research Ethics Committee
- Cape Town urban area
- English
- Participants from a halfway house for people recovering from severe mental illness – not with acute psychiatric symptoms
- 16 interviews with people with a known psychosocial disability (8 males and 8 females)
- 3 people without a psychosocial disability (1 male and 2 females)

Range of psychiatric disorders

Primary condition

- Major Depression
- Bipolar mood disorder
- Schizoaffective disorder
- Schizophrenia

Comorbidities:

- Diabetes
- High blood pressure
- Autism
- Cerebral palsy
- Arthritis
- Learning disability
- Brain tumour and stroke

- All recovering and working or spending the day at the halfway rehabilitation house in South Africa
- Learning new skills
- All interviews conducted in English
- We asked about the difference between at the moment (in recovery) and when have an acute episode

Basic demographics

- With psychosocial disability: N = 16
 - 8 males and 8 females
 - All completed some high school grades or higher
 - All unemployed and mostly receiving a disability pension/social assistance grant
 - Mean age: 41 years
- Without Psychosocial disability:
 - 1 male and 2 females
 - Student, professional nurse and retiree

Q1: Do you have difficulty getting along with people who are close to you?

- Generally no need for repetitions and clarifications, except for definition of 'close' (with and without disability) for 3 respondents
- Response options are understood and used appropriately based on examples provided
- Broad notion of interactions – not just verbal
- One referred to strangers rather than close family

Examples

- Some difficulty: I feel it's got to do with my mother as a reference point; she means well but I don't always have that ability to appreciate it at that point. – illness attribution but some attribution to mother.
- Some difficulty: Thinking of my family...one sister and brother have distanced themselves from me. The in-laws do not understand me. My expectations to get on with family are not always met – because of stigma; they do not embrace me.
- A lot of difficulty: I cannot always satisfy my family. Cannot always do what they want to do. Not up to their standards.

Q2: Do you have difficulty dealing with people you do not know well?

- All examples and narratives support an 'in scope' interpretation
- Examples support the response option selected
- No difference between 'with' and 'without' psychosocial disability in terms of interpretation

Q2: Examples

- No difficulty: Generally I have good communication and interpersonal skills. I studied drama and therefore know how to communicate with others even if I do not know them.
- Some difficulty: I am always nervous around people. I was bullied at school and I don't feel comfortable around people. I fear that they are going to hurt me.
- Some difficulty - without disability: If I don't know someone then it is sometimes difficult because I am shy. I am not a conversationalist with people I do not know well.
- A lot of difficulty: If people won't communicate with me how am I supposed to know how you are feeling; there's no empathy from others; When I have relapse - can't sleep; then my ability won't be good

Q3: Do you have difficulty maintaining friendships?

- Description of context determining response – e.g. when interacting with people with similar condition it is easier
- No difficulty with question and response options.
- Examples and narratives are ‘in scope’ and explain the response options selected

Q3: Examples

- Some difficulty: Make a friend and then after a while I then get rejected. I blame myself but it is not always my fault.
- Some difficulty: People do not want to always help you- to be a burden on them. They want to avoid you. They do want to be around crazy people.
- Some difficulty: Because of my lack of communication and their lack of communication with me.
- A lot of difficulty: I have not been able to maintain friendships-they lose interest in me. My illness has played a big part.
- Cannot do at all: I'm unsure of how people will be tomorrow and so can't really trust the relationships. When I have a relapse - then there will be no communication with anybody; that will be worsened.

Q4: Do you have difficulty making new friends?

- 'In scope' interpretations
- Narratives and examples reflect the Responses selected
- No difficulty: narrative of befriending a neighbour
- Some difficulty: I keep myself back. I think they don't want to be my friend. It is just a belief and something I feel. (Internalised stigma)
- A lot of difficulty: I do not know how to make friends ... resistance to starting a new relationship – because of stigma and my paranoia (Attribution = self and others/stigma)
- A lot of difficulty: I never get a chance to run into new people (Unclear)
- Cannot do at all: I don't have any friends – really just an inability of people to communicate with me. (Attribution = Others)

Q5: Do you have difficulty controlling your emotions when you are around people?

- 'In scope' narratives and response options selected fit with examples provided
- No difficulty: I know that I have to listen to people when they speak; That's the general rule really; I think I understand the rules quite well and I can maintain the rule.
- Some difficulty: Sometime I get tearful (part of my depression) - tears come flowing- comes down to my depression- hits me hard. No control over that.
- Some difficulty: At home when I am close to psychosis. I become very paranoid and think they are stealing/hurting me. I become rude and emotional when nearing psychosis.
- A lot of difficulty: People push my buttons and I cannot control my emotions. I get angry and the other evil side of me comes out.

Q6: How does this compare to someone just like yourself only without you health condition? (same, little different, very different, completely different)

- Did not require clarifications and repetitions except for one person.
- Examples match the responses given
- Same: I am basically a normal human being. Only [have difficulties] when I have an episode (once a year for 2 – 3 weeks).
- A little different: everyone has different degrees of mental illness. I am therefore only a little different.
- Very different: Most people don't have to manage the stigma, chip on shoulder ... we are a joke to others.
- Completely different: It's with simple things. I become anxious and my mind goes into overdrive when I am asked to do simple things such as get keys to unlock a door.

Q7: In everyday life, do you have difficulty forming relationships with other people?

- Did not need clarifications or repetitions
- Examples are consistent with responses given
- No difficulty: gave example of meeting someone and becoming romantically involved
- A lot of difficulty: getting out of my comfort zone. Introducing myself to another person is too much for them to take on – people do not know how to interact with mental illness.
- Cannot do at all: my mother she forms relationships everywhere and with everybody, but I can't do it and I don't know why.
- Cannot do at all: I am very paranoid with people. I feel different. I expect to be like other people but I am different – a person with a psychosocial disability.

Q8: Do you have difficulty controlling your behaviour?

All the time, most of the time, sometimes, rarely, never

- Did not require clarifications and repetitions
- Examples are appropriate and match the responses given
- Sometimes: At home - Illness builds up at home to the point of explosion. Family know it is my illness. Not often though.
- Sometimes: Linked to the emotions question and I will withdraw when it happens. (without disability)
- Rarely: I was brought up in a catholic school where bad behaviour was punished. I have learnt therefore to always behave calmly.
- Rarely: This is because of misunderstandings. I do not come across well – I come out abruptly – sounds rude what I say. It's not what I feel.

Summary – some preliminary observations

- Questions generally work well
- Response options are easy to use and narratives support ‘in scope’ interpretations
- Attribution of difficulties varies:
 - Attribute difficulties to illness (few)
 - Attribute to attitudes of others (majority)
 - Lack of insight as one symptom of illness
- Learnt ability to cope – e.g. keeping quiet and not engaging and reporting either no difficulties or cannot do at all.
- Difference between acute and recovery phases – more severe in acute phases
- People with psychosocial disability report more difficulties than people without (but too few participants as yet to conclude)
- **THESE ARE FIRST RESULTS AND ONLY THE BEGINNING!**

Next steps

- Revise cognitive testing protocol?
 - Reduce number of questions?
 - Do more comparative analysis between questions?
- Further testing – especially with people without psychosocial disability
- Translate and test
- Compare profiles on WG SS and psychosocial disability questions for people
 - with and without psychosocial disability
 - Different levels of severity

- Volunteers?