

Towards a toolkit for cross-neglected tropical disease morbidity and disability assessment

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Background: Neglected tropical diseases (NTDs) are a group of often chronic and disabling infectious conditions, closely related to poverty and inequities. While it is estimated that millions of people are affected, accurate and internationally comparable data about NTD-related morbidity and disability are lacking. Therefore we aimed to develop and pilot a toolkit to assess and monitor morbidity and disability across NTDs.

Methods: A cross-sectional, non-random survey design with a mixed methods approach was used. We conducted a literature review on existing tools to assess and monitor disability, followed by a Delphi study with NTD experts to compile a prototype toolkit. A first-phase validation study was conducted in Northeast Brazil among people with Chagas disease, leishmaniasis, leprosy and schistosomiasis.

Results: Instruments included were the clinical profile, WHODAS, P-scale, SRQ, WHOQOL-BREF and WHOQOL-DIS. Most questions in the various instruments were readily understood with the exception of the WHOQOL-BREF, where additional explanations and examples were often needed. The respondents were very appreciative of the instruments and found it valuable to have the opportunity to talk about these aspects of their condition.

Conclusions: Our findings support the acceptability and relevance of five of the six instruments tested and the concept of a cross-NTD toolkit.

Keywords: Disability assessment, Measurement, Morbidity, Neglected tropical diseases, Quality of life, Social participation

Introduction

Neglected tropical diseases (NTDs) are a diverse group of major, often disabling conditions that are among the most prevalent chronic infections, closely linked to health inequalities and poverty.^{1–5} Globally over one billion people are affected by NTDs. Frequently, risk areas overlap, and individuals may be affected by more than one NTD.⁶ Annually, between 500 000 and one million deaths are attributed to NTDs.^{3,7}

Nevertheless, the public health impact of NTDs is not limited to mortality; many of them lead to stigma, social exclusion, (permanent) disability and morbidity.^{2,8} The disability-adjusted life year (DALY) is one of the few available metrics that estimates the chronic effects of these infections.⁹ According to the global burden disease (GBD) estimations in 2010, NTDs are responsible for 57 million DALYs.⁷ The main NTDs are: intestinal nematode infections (hookworm disease, ascariasis, trichuriasis), leishmaniasis,

schistosomiasis, lymphatic filariasis, food-borne trematodiasis, rabies, African trypanosomiasis, Chagas disease, cysticercosis, onchocerciasis, trachoma and echinococcosis.⁹

In this article, disability was defined as in the *International Classification of Functioning, Disability and Health* (ICF), a framework for functioning and disability, including impairments, activity limitations and participation restrictions.¹⁰ The ICF classifies problems in health and health-related domains and can be used to describe, measure and compare functioning and disability at different levels.¹⁰ This classification consists of six interacting domains: health condition, body functions and structures, activity, participation, environmental factors and personal factors.¹¹ The ICF is the conceptual basis for the definition and measurement of health and disability, as well as a universal classification in this field.¹¹ It has been adopted as 'the basis for the scientific standardization of data on health and disability world-wide'.¹¹

Several global initiatives have been established to reduce the global burden of NTDs. These capitalise on the fact that NTDs have many features in common: geographical appearance, need for (preventive) chemotherapy, prevention or treatment regimens, disabilities, stigma, rehabilitation and inclusion of people living with the disabling consequences, all of which may be addressed through joint programmes.^{4,12} Since 2004, the integrated control of NTDs has been strongly advocated, because of the logistic and economic benefits.⁸

While it is estimated that millions of people have NTD-related morbidity and disabilities, accurate international data is lacking. This gap hampers important advocacy and planning for interventions, services, monitoring, evaluation and funding to address these often life-long consequences. One reason for the lack of data is that there is no consensus on the instruments to assess, map and monitor the morbidity and disability aspects of NTDs. Therefore, development of a toolkit of such instruments was identified as an urgent need by the participants of the recent NTD Cross-cutting Issues Workshop in Utrecht, The Netherlands (February 2015),¹³ confirming the earlier recommendation for such a toolkit from the Neglected Tropical Disease Non-governmental Development Organisation Network (NNN).

To address this need, we decided to develop a toolkit to assess and monitor morbidity and domain-specific disability due to NTDs. This would allow the identification of priority areas for advocacy, funding, interventions and services, and provide tools for mapping, monitoring and evaluation.

As the cross-NTD toolkit will potentially be used across the world in different cultures, it is important to have insight in the cultural validity and cross-cultural equivalence of the tools.^{14–16} We conducted a systematic literature review prior to the initial validation of the toolkit, to identify tools and collect data about validity of tools. Sixty-two articles were identified in the literature review. They provided an inventory of measurement tools currently used across the NTD field for morbidity and disability, as well as the tools currently used to assess disability in general. The review also provided data on the cultural validity of the instruments included in the eventual prototype toolkit. The tools that were developed by WHO (disability assessment schedule [WHODAS], quality of life [WHOQOL] and the self-reporting questionnaire [SRQ]) already had been culturally validated and translated into many languages.^{17–21} The participation scale (P-scale), which was validated widely among persons affected with leprosy and other conditions across cultures,^{22–24} also scored positive on cross-cultural equivalence.¹⁶ Validated Brazilian Portuguese versions of the tools were available for all.

The relevance, acceptability and cultural validity of the tools are essential aspects of a measurement toolkit. The evaluation of these aspects is the main focus of this present study.

Methods

Study design

This study used a cross-sectional, non-random survey design with a mixed methods approach. This process was done by: identifying the tools currently available; building consensus among NTD experts on priority areas for assessment and monitoring of morbidity and disability; selecting tools for these priority areas; and testing these tools in a multi-NTD sample in an endemic country.

Preparatory research: Delphi study

A Delphi study was conducted to collect and prioritise key-informants' ideas about aspects of NTD-related morbidity and disability that should be assessed and monitored, create an inventory of available tools and reach consensus on which tools should be included in a cross-NTD toolkit. The Delphi study was based on a literature review; the details of this systematic review will be published elsewhere. The experts participating in this preparatory phase of the initial validation of the toolkit met the following inclusion criteria: experience in the areas of NTDs, morbidity and disability and/or assessment tools in the NTD field; involvement in the management of several NTDs; and/or representation of a wide range of NTD-endemic countries. The Delphi panel consisted of 21 experts representing nine different NTDs: Buruli ulcer, leishmaniasis, leprosy, lymphatic filariasis, onchocerciasis, podoconiosis, schistosomiasis, soil-transmitted helminthiasis (STH) and trachoma.

The literature review and first Delphi round identified over 45 different tools. In the second survey, only tools were included that were freely available or could be obtained from the authors, that had potential for use across NTDs (i.e., that were not disease-specific), and for which evidence of cross-cultural validity existed. The instruments selected by the Delphi panel in the second and third rounds were reviewed to find published evidence of validity, especially in developing countries and across various health conditions. With the third Delphi round it was decided which of the prototype toolkit instruments should be included in the initial validation in Brazil.

Pilot study: initial validation and study population

An initial validation study aimed at collecting quantitative and qualitative data with and about the tools selected by the Delphi panel. For this purpose, interviewers administered versions of these tools among people with different NTDs in Brazil. Brazil is endemic for 13 of the 17 NTDs as defined by WHO, and is a strong example of the relationship between disease conditions and poverty.²⁵ Brazil is responsible for most of the disease burden related to NTDs in Latin America, with the largest number of registered cases of leprosy, dengue fever, schistosomiasis, Chagas disease and leishmaniasis. Approximately 100 million people are estimated to be at risk of contracting one or more NTDs in the country.^{25,26} Brazil is divided into five geographic regions (South, Southeast, Central-West, North and Northeast), with the Northeast – the location of this pilot study (Ceará State) – being the poorest and least developed region.²⁶

Participants for the initial validation were recruited through purposive and convenience sampling. The main selection criteria included having an NTD-related impairment and seeking treatment at the São José Infectious Diseases Hospital or the Walter Cantídio University Hospital of the Federal University of Ceará, both located in Fortaleza. These are referral centres for infectious diseases, especially NTDs, in Ceará State.

Participants were identified by checking medical records from outpatients visiting relevant departments. Consequently, many of the participants were expected to have a more severe form of the concerned NTD, possibly resulting in morbidity and disability. Medical records were checked on the following inclusion criteria for participation in this research: diagnosis of Chagas

disease, leprosy, leishmaniasis or schistosomiasis; receiving out-patient care for an NTD in the selected health services; being able to answer questions during an interview setting; and willing and able to provide written informed consent.

We aimed to recruit 10 people per disease, focusing on four of the NTDs endemic in Brazil. Thus, we aimed to include a total sample of 40 affected persons. In the end, our study included 34 participants, as we could only find four people affected by schistosomiasis. To increase the diversity of the participants, we sought to recruit men and women, anyone over the age of 15 and people living in differing geographical environments. We ensured that the main NTDs present in the region were represented in the study sample.

Data collection

Data collection focused on aspects of validity of the instruments in the toolkit. We investigated what individuals affected by an NTD thought of the content, acceptability, relevance and usefulness of the clinical profile, WHODAS 2.0, the shortened P-scale, WHOQOL-BREF (abbreviated) and DIS (disability) and the SRQ. Together these tools assessed four of the five ICF domains (Table 1).

We collected the results by means of a single interview per person covering the full range of instruments and investigating whether they were sensitive to detect morbidity and disability across NTDs. The research team opted for direct interviews rather than the self-administration of instruments since the latter may not be suitable for respondents with limited literacy skills. Prior to the final data collection, a pre-test was done among 13 participants. These participants were not included in the final validation of the toolkit.

The pre-test aimed to help decide whether all scales listed in the Delphi study should be part of the toolkit; verify whether the shortened versions would not exclude essential aspects vis-à-vis the complete versions; and check how the order and combination of different instruments would influence the application of the

toolkit. Additionally, we evaluated the time needed to conduct the entire interview and the interviewees' understanding of the tools. After the pre-test, minor adjustments were made to the language used in the cognitive questions.

Subsequently, quantitative and qualitative data were collected from the study population using interview-administered versions of the selected tools and by asking open questions about the tools. After the whole toolkit interview, three cognitive questions were asked (see below). The tools and cognitive questions were administered by four trained Brazilian researchers. Afterwards, aspects of item, semantic and operational equivalence were tested using the cultural equivalence framework.^{14–16} Here, 'item equivalence exists when items estimate the same parameters on the latent trait being measured and when they are equally relevant and acceptable in both cultures'.¹⁴ Semantic equivalence is about the similar meaning or effect of the words used between differing languages. The operational equivalence is related to the possibility of the practical use and methods of the questionnaire.¹⁴

Cognitive interview data

To understand the participants' thoughts about content, acceptability, relevance and usefulness of the toolkit tools, the following three cognitive questions concluded the interview:

1. 'Considering all the sets of questions we went through, do you consider that the total duration of the interview was acceptable and important to improve your care?'
2. 'Considering all the sets of questions we went through, in general terms, do you consider this exercise positive or negative? Do you have any specific comments?'
3. 'Is there something else that you want to tell us about the issues we talked about, but that were not included in this interview? Do you have some specific comments?'

In addition to these questions, the interviewers also gauged the participants' comprehension of the tools by reporting when it was necessary to give examples or to reformulate a question.

The tools included in the toolkit had already been translated to Portuguese according to strict WHO guidelines, so there was no need to translate them again. However, the interview guide was translated into Portuguese by the Brazilian research team. The translation of the interview guide was thoroughly checked by translating the instrument back into English to ensure that the meaning of the original English version was retained. Some questions were translated several times using different interpreters.

Data analysis

The quantitative data from the tools were entered into a database created using Epi-Info version 7.1.5 (CDC, Atlanta, GA, USA). The data were analysed with simple descriptive methods, such as the calculation of total scores per NTD, looking for the most notable differences in morbidity and disability between NTD groups. Qualitative data from the answers to the meta-cognitive questions were recorded, transcribed and translated into English. These transcripts were analysed using descriptive methods, resulting in a first impression concerning the validity and usefulness of the toolkit as a whole and the individual tools.

Table 1. Overview of the tools and the ICF domain they aimed to assess

ICF Domain	Tool
Impairments (body functions)	Clinical Profile
Participation restrictions	P-scale (short)
Activity limitations	WHODAS 2.0
Impairments; mental health problems	SRQ
Personal factors; quality of life	WHOQOL-BREF and DIS
Environmental factors	CHIEF
Environmental factors and personal factors; stigma	EMIC

CHIEF: Craig Hospital Inventory of Environmental Factors; EMIC: Explanatory Model Interview Catalogue; P-scale: Participation scale; SRQ: Self Reporting Questionnaire; WHODAS: WHO Disability Assessment Schedule; WHOQOL-BREF: WHO Quality of Life-BREF (abbreviated); WHOQOL-DIS: WHO Quality of Life-DIS (disability).

Ethical considerations

This study was approved by the Ethical Review Board of the Federal University of Ceará, Fortaleza, Brazil. Additionally, technical approval was obtained from the administration of both the São José Hospital of Infectious Diseases and the Walter Cantídio University Hospital. Before conducting the interview, the participants were informed about the study and their rights related to participation in the study and asked for informed consent. Data was managed carefully, kept confidential and was only accessible for those directly involved. Records were anonymised before analysis.

Results

Delphi study

According to the expert-opinion of the 21 participants in the first Delphi survey, NTDs should be assessed and monitored in line with all the domains in the ICF: impairments (including mental

health problems); activity limitations; participation restrictions; environmental factors and personal factors (including stigma and quality of life). As the domain 'health condition' merely refers to the NTDs included in this research, this domain was excluded.

In the second and third Delphi rounds, consensus was reached on the inclusion of the following tools: WHO ICF checklist for impairments of body functions and structures, SRQ, WHODAS, P-scale, Explanatory Model Interview Catalogue (EMIC), Craig Hospital Inventory of Environmental Factors (CHIEF) scale, and the WHOQOL BREF and DIS modules. A 'clinical profile' form was developed to assess body functions and structures across NTDs. The content of this new questionnaire was based on the ICF checklist, discussions with NTD medical experts and evidence from the literature concerning aspects of body functions and structures that are affected by the various NTDs. An overview of the tools included in the second and third Delphi round can be found in Table 2.

Table 2. Overview of tools included in the second and third Delphi round

Domain	Tools included in second Delphi round	Delphi score (highest is best)	Included in third round?
Body functions and structures	SRQ	20	Yes
	WHO ICF Checklist	11	Yes
	PHQ-9	20	No, SRQ included instead
	DASS-21	8	No
	K10	6	No
	WHO leprosy disability grading system	4	No, too disease-specific
	BU patient's POD assessment form	2	No, too disease-specific
	WHODAS 2.0	20	Yes
	GPAS	18	No
	SALSA Scale	16	No
Activity	Washington group questions on disability	15	No
	BI	6	No
	P-Scale	20	Yes
	IPA	7	No
Participation	LHS	4	No
	SDS	2	No
	CHIEF	8	Yes
	EMIC	8	Yes
Environmental factors	SARI Stigma scale	4	No
	Jacoby scale	2	No
	Social Distance Scale	1	No
	Personal data form	0	Yes
	WHOQOL-BREF	7	Yes
Personal factors	Rosenberg Self-Esteem scale	5	No

BI: Barthel Index; BU patient's POD assessment form: Buruli Ulcer patient's Prevention Of Disability assessment form; CHIEF: Craig Hospital Inventory of Environmental Factors; DASS-21: Depression Anxiety Stress Scale-21; EMIC: Explanatory Model Interview Catalogue; GPAS: Green Pastures Activity Scale; IPA: Impact on Participation and Autonomy; K10: Kessler Psychological Distress Scale; LHS: London Handicap Scale; PHQ-9: Patient Health Questionnaire; P-scale: Participation scale; SALSA Scale: Screening of Activity Limitation and Safety Awareness Scale; SARI Stigma scale: Stigma Assessment and Reduction of Impact Stigma scale; SDS: Sheehan Disability Scale; SRQ: Self Reporting Questionnaire; WHODAS: WHO Disability Assessment Schedule; WHO ICF Checklist: WHO International Classification of Functioning, Disability and Health Checklist; WHOQOL-BREF: WHO Quality of Life-BREF (abbreviated); WHOQOL-DIS: WHO Quality of Life-DIS (disability).

Pilot study population

General profile

The pilot study included 34 participants, of whom 16 were women. The mean age was 46 (range 26–84) for people affected by leishmaniasis, 47 (range 23–74) for people affected by leprosy, 57 (range 34–81) for people affected by Chagas disease, and 61 (range 54–80) for people affected by schistosomiasis. Four participants had comorbidities or conditions: schizophrenia, HIV (two participants), and diabetes. When asked about having a disability, two participants indicated having a visual disability and six others a motor disability. In addition, when asked if their health condition caused limitations in daily living and/or restrictions in their contact with others, 11 participants indicated that this was the case.

Fourteen participants were unemployed. Among those who were employed, jobs included informal work (n=7), self-employment (6), and housekeeping (5). Most participants had received only primary education (n=14), secondary education (10) or no education (7). Only three participants had any university education. Table 3 shows a summary table displaying all mean total scores per NTD of the tools included in the validation of the toolkit in Brazil. Except for the WHOQOL-DIS that was administered to 12 participants, all tools were administered to all 34 participants.

Clinical profile questionnaire

The mean administration time of the clinical profile was 5.6 minutes (range 1–13). Not all questions were clear to the participants. Three questions, no. 4 about skin lesions, no. 15 about insufficient strength in the arms or legs, and no. 18 asking if the participant considered himself to have an impairment, needed examples and/or rephrasing for a number of participants. These will require further attention in future validation studies, because respondents were not always aware that they had the

impairment that was being asked about. All other questions were understood relatively easily by the participants.

Over half of the participants answered positively to the questions ‘Do you have any problem seeing things?’, ‘Do you often experience pain?’ and ‘Do you experience pain, loss of feeling or weakness in your arms or legs?’ Thus, these problems seemed most relevant to all participants. ‘Do you have any problems with your skin? E.g. sensitivity or irritation’ was experienced by all groups, but most frequently by people affected by leprosy. Fewer than three participants scored on hearing problems, open wounds, problems in swallowing food, or problems with the urinary system, brain, upper or lower extremities. These questions seemed least relevant to the participants in this study.

All participants indicated that the clinical profile was relevant to them for several reasons. Most frequently mentioned was that it helped people learn about their disease. Other reasons given were that the Clinical Profile helped to clarify their health status and that talking about problems provided relief. Two examples:

... It was very important because I think it is better to talk with another person, I don't have anyone to talk with, you know?... (Male, 58, leprosy).

... Now I feel freer, as if I confessed something, I opened up to someone. I liked it a lot ... (Female, 23, leprosy).

Two participants mentioned that the clinical profile may improve the situation for people with a similar health condition. Three participants indicated that they had never been asked questions like these before.

WHODAS

The mean administration time of the WHODAS was 9 minutes (range 2–24). Considering the high abstraction level of the WHODAS questions, comprehension was relatively high. Only four questions needed an example in four or more cases and

Table 3. Mean total scores per NTD for the included tools that led to scores

	WHODAS 2.0 (12-items), mean total score (range)	P-scale short, mean total score (range)	SRQ, mean total score (range)	WHOQOL-BREF, mean total score (range)	WHOQOL-DIS, mean total score (range) ^a
Maximum total score (worst possible outcome)	60	65	20	130	65
Chagas (n=10)	19 (10–29)	11 (0–41)	6.4 (0–15)	83 (67–96)	NC
Leprosy (n=10)	23 (14–28)	10 (0–15) ^b	6.1 (1–10)	90 (82–99)	NC
Leishmaniasis (n=10)	16 (9–35)	3 (0–8)	3.5 (0–8)	93 (77–110)	NC
Schistosomiasis (n=4)	20 (12–36)	15 (1–35)	7.8 (2–12)	90 (72–107)	NC
>65 years (n=8)	19 (11–35)	3 (0–21)	4.4 (0–9)	89 (70–109)	NC
All groups (n=34)	19 (9–35)	9 (0–41)	5.6 (0–15)	88 (67–110)	44 (35–52)

NC: Not calculated, as this instrument was only administered to 12 participants. No score available; P-scale: Participation scale; SRQ: Self Reporting Questionnaire; WHODAS: WHO Disability Assessment Schedule; WHO; WHOQOL-BREF: WHO Quality of Life-BREF (abbreviated); WHOQOL-DIS: WHO Quality of Life-DIS (disability).

^aNo distinction was made per NTD for the WHOQOL-DIS, as this instrument was only administered to 12 participants.

^bThe original P-scale consisting of 18 questions was administered instead of P-scale short (113 questions).

only three questions needed rephrasing in four or more cases. Questions that were less clear were no. 5, asking about being emotionally affected by the health problem, and question H3, asking for 'the number of days that the participant cut back or reduced their usual activities, not counting the days that they were totally incapacitated in the past month.'

Overall, highest scores were reported for question 1 about standing long periods, question 5, and question 7 about walking long distances. Problems with these activities were especially relevant for participants with Chagas disease or leprosy. Fewer difficulties were experienced in maintaining a friendship (question 11) and dealing with unknown people (question 10). NTD-related mean total scores were highest for participants with leprosy.

All 34 participants agreed on the relevance of the WHODAS questions. The main reason for this was that participants became more aware of their health situation as is illustrated in the following quote:

... Because you are opening my mind, my disease, we know more things, what I am able to do and what not ... (Female, 61, Chagas disease).

In addition, participants indicated that their increased awareness from having answered the questions may benefit others in disability prevention or improvement. The following quote explains this:

... Hopefully this will serve as an example for people and that those who get this disease will seek to be cured, right? Because it took me so much time and that is why I am having these difficulties, you know? ... (Male, 52, leprosy).

Another reason given for the relevance of the WHODAS questions was that it helped the respondents talk and share their feelings and experiences about the disease. This is of special importance since some of them mentioned that they were afraid to talk with other people about their disease. Also important for the positive results on the relevance of the WHODAS was that participants, especially the ones with leprosy and leishmaniasis, indicated that the questions fit their health situation and the difficulties they experienced.

P-scale

All, except one participant (who could not identify a peer and could not recall conditions before and after the disease), were interviewed with the P-scale. For most NTDs, the P-scale short (PSS) version (13 questions) was deemed appropriate and was used; however, researchers used a longer version for persons affected by leprosy (v4.6 with 18 questions) in order to comply with Brazilian Ministry of Health guidelines for this disease and the routine protocol established in the University Hospital. The average administration time was 6.9 minutes (range 3–26), and questions were relatively well understood. Question 9 ('Do you move around inside and outside the house and around the village/ neighbourhood just as other people do?') and question 12 ('In family discussions, does your opinion count?') needed examples and rephrasing most often. The concept of 'discussion' from question 12 was often interpreted as 'having a fight', in Brazilian Portuguese.

The highest levels of restriction were found for the first and second questions ('Do you have equal opportunity as your peers to find work?' and 'Do you work as hard as your peers do?') and

among participants with Chagas disease or leprosy. Almost no restrictions were reported for questions 7 ('Do you have the same respect in the community as your peers?') and 13 ('Are you comfortable meeting new people?'). The NTD-specific mean total scores were highest for participants with schistosomiasis (n=3) and Chagas disease (10).

The main reason for the strong positivity regarding the relevance of the PSS questions was their appropriateness for persons with Chagas disease, leprosy and leishmaniasis. The experience of participation restrictions as encompassed in the P-scale were confirmed by participants affected by the NTDs in this study. The following quotes support the relevance of the questions:

You commented that you are withdrawn, does that have to do with the disease or have you always been like that? (Interviewer);

No, it was after leprosy, because when I had my crisis, I was part of a church, when I arrived at the church no one sat next to me, because I was full of lesions, unwashed, and smelly too, since I could not get perfume, I had to bathe only with sulphur soap. It made me insecure; from the beginning until now I am like this. Before I was more outgoing, I won't lie (...) it changed my way of being ... (Female, 36, leprosy).

The participation restrictions described above also seemed to result in persons having difficulties talking about their disease. Many participants reported to be grateful for the opportunity to talk freely about their experiences, stimulated by the P-scale questions.

SRQ

The mean administration time, including the reading of the introduction, was 3.8 minutes (range 1–16). An overview of the average SRQ score for each NTD can be found in Table 3. The 12 participants who indicated they had an impairment or that their daily life suffered because of their condition, had a mean score of 8.3.

Participants scored highest on question 13 ('Is your daily work suffering?'), question 6 ('Do you feel nervous, tense or worried?'), question 9 ('Do you feel unhappy?') and question 20 ('Are you easily tired?'). None of the participants responded affirmatively to question 16 ('Do you feel that you are a worthless person?') or to question 17 ('Has the thought of ending your life been on your mind?'). Question 14 ('Are you unable to play a useful part in life?') was found to be difficult to understand; it needed an example 15 times and had to be rephrased 14 times.

All participants indicated that the SRQ questions were relevant for them because of the problems touched upon by the tool. The other reason mentioned most often (eight participants) was that it provided a way to open dialogue and to get things off their minds. One participant said:

... It meant a lot to me, it is very exciting, isn't it? A person talking like this with someone else, right? Blow off steam a little, you cannot blow off all steam because it's a lot, but at least one piece we tell to a person is good, it's good we feel a little relieved (...) because few people know about our suffering, right? Acquaintances, neighbours, do not know everything, they think we have a wonderful life, don't they? It is different from what the neighbours think ... (Male, 58, leprosy).

During the interviews, it was apparent that the SRQ stirred up emotions, especially among leprosy patients. Two participants affected by leprosy wept during administration of the SRQ.

WHOQOL-BREF

The WHOQOL-BREF was used to interview all participants, focusing on their quality of life. Topics assessed with this tool included satisfaction with health, relationships, enjoyment of life and the feeling of safety. The mean administration time was 9.1 minutes (range 5–33). Overall, it took time before the participants understood the questions. Many questions needed rephrasing or examples before being understood. Only question 21 ('How satisfied are you with your sex life?') did not need an example or rephrasing. In particular, questions 4 ('How much do you need any medical treatment to function in your daily life?'), 8 ('How safe do you feel in your daily life?'), 11 ('Are you able to accept your bodily appearance?'), 13 ('How available to you is the information that you need in your day-to-day life?') and 15 ('How well are you able to get around?') were not well understood. Question 13 ('How available to you is the information that you need in your day-to-day life?') needed to be rephrased in 16 cases.

All participants indicated that the WHOQOL-BREF was relevant to them. Most participants thought the WHOQOL-BREF was relevant because it made them think about their life and understand things and because the interview was a good opportunity to talk about how they felt. One participant said,

... Because it is always good have time to express yourself, tell people things I haven't told anyone about this exact problem. So for me it was good to tell someone ... (Male, 30, leishmaniasis).

Other participants mentioned that the WHOQOL-BREF talks about emotional issues and that the instrument is relevant for all patients, because it discusses problems that are relevant to everyone's daily life.

WHOQOL-DIS

The WHOQOL-DIS was administered to 12 participants, including five people affected by Chagas disease, two with leishmaniasis and five affected by leprosy. The WHOQOL-DIS was only administered to the twelve participants who indicated they had a disability or experienced limitations in daily living or restrictions in their contact with others due to their health condition. The mean administration time was 6.1 minutes (range 4–9). The WHOQOL-DIS was relatively well understood. Some questions needed rephrasing, but only for one participant. Question 41 ('Are you satisfied with how your environment is adapted to your limitation?'), an additional question in the Portuguese version, was considered the most difficult; it had to be rephrased in three cases and needed an example in one case.

All participants who completed the WHOQOL-DIS indicated that it was relevant to them. Most participants found it relevant because it discussed important issues. One participant said:

... These questions were very important to [me], because all these questions that have been asked, (...) all of them were important, about power, about how I move, how I picked up things, how I lead my daily life, many things are difficult, but

we must not be discouraged by this. We will go on ... (Male, 54, leprosy).

Overall interview

All participants found participation in the research a positive experience. They thought that it was a good opportunity to learn new things and improve people's lives. One participant said:

... Positive, and very nice, I was in treatment for eight years and nobody ever asked me about this, congratulations! ... (Female, 23, leprosy).

Another participant said:

... Yes, I hope that those who study this will make the government think about it and [treatment] will improve. Not everyone is equal, not everyone has limitations, the lack of respect is high (...) through studies we will know what people really think, not through a book and say that there are limits to everyone (Female, 36, leprosy).

The duration of the interview was found to be acceptable. Only one participant indicated that it took a long time to complete the interview. Most patients were grateful for the opportunity to talk. Overall, all scales were found to be relevant.

Discussion

The prototype toolkit was identified in all phases of this study as potentially for assessment and monitoring NTD-related morbidity and disability. For many of the major NTDs, not death, but disabilities are the most important consequences.^{7,9} These consequences may be physical, such as disease complications or impairments, but they may also affect activities or social participation and inclusion. Therefore, a holistic approach is needed to the assessment of the physical, psychological and social implications of NTDs. If such assessments are used to guide subsequent interventions they are likely to have a positive impact on the lives of the people affected by diseases of poverty.²⁷ In addition to providing a situational analysis, the toolkit provides a framework for monitoring and evaluating the outcomes of interventions to prevent and manage disabilities, as well as to collect data for advocacy purposes.

This toolkit was developed based on a literature review and a Delphi study among NTD experts, and has undergone an initial validation among persons living with Chagas disease, leprosy, leishmaniasis or schistosomiasis in the North-eastern region of Brazil.

The initial validation study suggests that the clinical profile questionnaire is suitable for use with the NTDs included in the present study. The clinical profile does not give a quantitative measure or overview of the state of participants' body functions and structures as reported by the affected person. While this does not represent a diagnosis, it does represent problems experienced by the person. To our knowledge, besides numerous disease-specific instruments, only two general instruments exist to assess body functions and structures. These are the earlier discussed ICF Checklist for body functions and structures¹⁰ and the Language Independent Functional Evaluation.²⁸ The Language Independent Functional Evaluation is a video animated, language-free instrument to assess the extent and nature of

disability.²⁸ The video animated structure of the instrument makes it unsuitable for use in very poor populations with scarce resources. The ICF Checklist is only suitable for use by physicians. Based on chapters within the ICF domain 'body functions and structures', we developed questions that would allow screening of key signs and symptoms of NTD-related complications by non-medical assessors. A disadvantage of this method is that the clinical profile is not able to detect whether problems are due to the NTD, or to another condition. Some of the other problems reported may also have been due to old age, as people's functional state tends to decline as their age increases.²⁹ Respondents were positive about the clinical profile and considered it relevant to their condition.

Participants were also positive about the relevance of the WHODAS 12-item version, since it raised awareness and stimulated verbal expression of the problems they experienced. Participants reported the highest disability levels with mobility, participation, and life activities, such as school and work. The high level of activity limitations obtained in the leprosy group is in agreement with two previous studies in which the Screening of Activity Limitation and Safety Awareness (SALSA) scale was used,^{30,31} and with another in which the self-administered version of the WHODAS 2.0 (36-items) was used.³² The Delphi panel ranked the SALSA scale below the WHODAS. Given that it only focuses on activity limitations, the administration of the SALSA scale is easy and practical.³³ The SALSA scale has been validated in people affected by leprosy, diabetes mellitus,³³ and other locomotor disabilities (Jansen et al., manuscript submitted). The relatively high level of comprehension found in this study and in two other studies in Brazil, one among pregnant women³⁴ and one among patients with musculoskeletal pain,³⁵ as well as a thorough validation in many countries during the development phase favour inclusion of the WHODAS.

For similar reasons as for the WHODAS, the PSS was seen as a very relevant tool. Because of the sample size and non-random sample, no generalisations can be made from the findings regarding the frequency of participation restrictions among using the PSS. The administration time of the PSS was much shorter than in the original development study.²² This can of course not just be due to the omission of five items in the short version. It is likely that the respondents in the current study were better educated and perhaps had less severe disabilities on average. The PSS was reported to be easy to understand, except for the fact that the word 'discussions' in question 12 was interpreted by some to mean 'having a fight'. Such a misinterpretation was not mentioned in a previous similar study in Brazil,²² or in Ghana, Benin²⁴ and India.^{36,37} It is likely that the word used for 'discussion' was open to be misinterpreted. Therefore, it is recommended to replace the word 'discussion' with 'decisions'. Finally, the fact that many participants indicated the personal relevance and appropriateness of the PSS encourages its use in health care settings.

The evidence from the initial validation in Brazil suggests that the SRQ is suitable for use among persons with the NTDs included in the present study. Participants considered the SRQ a relevant instrument and the questions were easily understood. The visceral leishmaniasis group scored surprisingly low in this study. To our knowledge, no studies have been conducted on visceral leishmaniasis and depression or anxiety to date. Yanik and colleagues studied depression and anxiety of patients with cutaneous

leishmaniasis in Turkey, using the Hospital Anxiety Depression Scale.³⁸ They found patients with leishmaniasis to have significantly higher anxiety and depression scores than the controls. It should be noted, however, that the leishmaniasis group in the present study had no visible signs in contrast to the group studied by Yanik and colleagues.³⁸ We also noted that people who reported having disabilities had the highest SRQ scores. Two other studies that used the SRQ to assess mental health among patients with leprosy found physical disability to be strongly associated with mental distress.^{39,40} Ormel and colleagues⁴¹ screened primary health care patients for mental disorders using the General Health Questionnaire in 14 countries, including Brazil. They found mental disorders to be associated with increased disability.⁴¹ However, it should be noted that the sample of the present study is not representative and any associations found will need to be confirmed by future larger studies. Finally, the SRQ resulted in strong emotional reactions in some participants. Therefore, interviewers using this instrument should be aware of this and make appropriate arrangements for referral or follow-up care as needed.

The current study indicates that participants had difficulties understanding many of the questions in the WHOQOL-BREF, requiring frequent examples and rephrasing. This is surprising, because this instrument has been used in several low and middle-income countries, including in Brazil, and for several health conditions. The WHOQOL-BREF has also been validated in Southern Brazil.⁴²⁻⁴⁵ These studies tested the WHOQOL-BREF among outpatients with major depression,⁴² smokers,⁴³ older adults⁴⁴ and a combination of in-patients and volunteers.⁴⁵ There may be three explanations for the difficulties in comprehension: due to chance variation, a high proportion of persons in the sample had difficulty understanding the questions (possibly due to a lower-than-average education level); the Portuguese used in our study area may be somewhat different from that used in Southern Brazil, where the original translation was done and previous validation was conducted; and the instrument is not suitable for the population in the present study, e.g., because of the level of abstraction of the questions. The second explanation is not likely since linguistic variations are smaller between regions than are social and economic differences. The third explanation is also unlikely, since the WHOQOL-BREF has been used successfully in several other low and middle-income countries including India and Zimbabwe⁴⁶ and for several NTDs including leprosy,^{40,47,48} lymphatic filariasis,^{49,50} and Chagas disease.⁵¹ However, one other study, conducted in Bangladesh, found the WHOQOL-BREF in its current form not culturally or linguistically suitable for people affected by lymphatic filariasis.⁵⁰ They reported 22 of the 26 questions to be problematic, mainly because of wording and conceptual difficulties, and found the whole instrument to be overly formal. We recommend that the translation of the WHOQOL-BREF be checked carefully with a sample of people with similar education level as the target group.

Our findings suggest that the WHOQOL-DIS is suitable for use among people with the NTDs included in the present study. Participants considered the WHOQOL-DIS a relevant instrument and the interview a positive experience. The questionnaire was easily understood. Power and Green,⁵² who describe the development of the WHOQOL-DIS, emphasise that the WHOQOL-DIS is an add-on scale to the other WHOQOL instruments. For a comprehensive assessment of quality of life, the WHOQOL-DIS should

be used in conjunction with the WHOQOL-BREF. Therefore, we used both together in the present study. The WHOQOL-DIS may be sufficient if only an assessment of disability-related quality of life is needed.

During the literature search for evidence of validity for the instruments proposed in the Delphi rounds, it became clear that many aspects of validation have been ignored in instrument validation studies. For example, conceptual equivalence was not mentioned in any of the validation studies. This finding is supported by a study by Stevelink and van Brakel⁵³ who found that cultural equivalence for participation instruments has often not been tested sufficiently and propose that better standards for validation should be adopted. This emphasises the need for further validation using state-of-the-art validation protocols.

The present study has a few limitations. The first is that only a limited number of instruments in the toolkit were included. The number of NTDs included was limited, as was the selection of validation ‘tests’ used. No definitive conclusions can therefore be drawn from the present study about the suitability and validity of the cross-NTD toolkit. The second limitation is the convenience sampling and the limited number of participants. This means that the findings regarding prevalence of disabilities cannot be generalised. Although the participants were enrolled in only two hospitals in Ceará state, these were reference hospitals playing a central role in treating people affected by NTDs and thus the patients attending these hospitals are still broadly representative of those affected by NTDs in the Ceará State. We believe, therefore, that the findings regarding acceptability and relevance of the toolkit still contribute to the body of evidence supporting the validity of the NTD Morbidity and Disability (NMD) toolkit.

Future research should focus on validation of the complete toolkit among persons with other NTDs, living in differing environments and cultures. It is recommended to use larger sample sizes and representative samples in order to assess prevalence of the complications and different aspects of disability and to describe the cultural equivalence of the instruments, including their measurement properties.¹⁴ Such studies may also compare using the PSS in combination with the WHODAS 2.0 or the SALSA to decide which of the two activity tools fits the aim of the toolkit best. Furthermore, we recommend that the translation of the WHOQOL-BREF be checked carefully with a representative sample of people in the target area. This is to ensure adequate semantic and item equivalence. We also recommend exploring the use of a symbol flashcard for the answering options of the WHOQOL-BREF and WHOQOL-DIS, to avoid having to read aloud the answering options after each question. Alternate instruments to assess quality of life should also be considered.

Conclusions

The prototype NMD toolkit includes one or more tools to assess each domain of the ICF. Five of the six instruments tested in the present study are potentially suitable for assessing and monitoring different aspects of NTD-related morbidity and disability in Northern Brazil. The translation of the WHOQOL-BREF should be adapted and retested. Our findings support the acceptability and relevance of the instruments tested and the concept of a cross-NTD toolkit. They provide a basis to build a body of evidence supporting the validity of the NMD toolkit. An important future research priority is to replicate the NMD toolkit validation study in

multiple settings with other NTDs, also including assessment of the statistical measurement properties of the instruments.

Authors' contributions: ATN, HK, WHB and LM conceived and designed the DELPHI study and the first version of the pilot study. ANRJ, JCB, SMFP and DH conceived and revised the final version of the pilot study in Brazil. JCB, SMFP, EAS, TAF, MMAP, ATN and HK were responsible for the data collection of the pilot study. ATN, HK, JCB, SMFP, EAS, TAF and MMAP, were responsible for data analysis. ATN and HK drafted the paper. WHB, LM, ANRJ, JCB, SMFP, DH, EAS, TAF and MMAP revised the draft of the paper. All authors approved the final version of the paper. WHB, LM, ANRJ and DH are guarantors of the paper.

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