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Neglected tropical diseases (NTD) morbidity and disability toolkit validation: A cross-sectional validation study of the EMIC-AP stigma scale for affected persons and the WHOQOL-DIS scale in Papua, Indonesia

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Summary

Background: There is a lack of information about the burden of neglected tropical diseases (NTDs) in terms of morbidity and disability. Therefore, there is a need for agreed instruments that can provide this information. This study is a first phase validation study of the EMIC-AP and the WHOQOL-DIS instruments conducted in Papua, Indonesia. Leprosy and Lymphatic filariasis are common NTDs in Papua. The research question was: "How valid are the EMIC-AP and the WHOQOL-DIS of the NMD toolkit among people affected by the NTDs leprosy or lymphatic filariasis living in Papua, Indonesia?"

Methodology/Principal Findings: Data were gathered using translated interview-administrated versions of the questionnaires. The sample included participants with leprosy ($n = 16$) and lymphatic filariasis ($n = 18$) experiencing disabling consequences from their NTD. The study focused on item equivalence (relevance and acceptability), semantic equivalence (understanding and meaning) and operational equivalence (format of administration and questions, and suitability of response scales). Testing of the item equivalence showed that 94% thought the questions of WHOQOL-DIS were relevant and 90% felt comfortable with the topics. Concerning the EMIC-AP, 93% thought the questions relevant, and 90% felt comfortable. Semantic equivalence was more problematic with 51% and 23% having difficulties in understanding the WHOQOL-DIS and the EMIC-AP, respectively. Seventy-three percent was positive about the format of the EMIC-AP, while only 58% was positive about the WHOQOL-DIS format.

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Conclusion: The item equivalence was good for both the WHOQOL-DIS and EMIC-AP, and the operational equivalence showed room for improvement for the WHOQOL-DIS. The semantic equivalence was relatively poor. This was especially true for the WHOQOL-DIS. The main reason for this is that there are over a 250 different languages in the province of Papua. With minor adjustments, it is likely that the EMIC-AP can be used under the condition that the participants speak sufficient Bahasa. The WHOQOL-DIS does not appear suitable for use with this population.

Author Summary This study tested two instruments that measure stigma (EMIC-AP) and quality of life (WHOQOL-DIS) among people affected by leprosy or lymphatic filariasis in Papua, Indonesia. The interviews comprised questions of both instruments and additional questions to get the participants opinion about the instruments. The focus of this study was on whether the participants understood the questions, whether they were relevant and acceptable and if the design of the questionnaires were clear. Using the answers to the additional questions, we could check whether the translations of the instruments were applicable for persons affected by NTDs in Papua. Results showed that the WHOQOL-DIS was not considered suitable for use with NTD-affected people in Papua. In contrast, the EMIC-AP can be used in Papua after some minor adjustments and if participants are fluent in Bahasa Indonesia.

Introduction

Neglected Tropical Diseases (NTDs) are a group of communicable diseases that are endemic in tropical and subtropical environments, and affect over a billion people worldwide.[1,2] Until recently, these diseases have been neglected by funders, researchers and policy-makers.[3] Even though more awareness has been created regarding the NTDs, there is still a serious need for more information concerning the burden of NTDs in terms of morbidity and disability.[4] This gap is partly caused by a lack of agreed instruments to assess the morbidity and disability aspects of the effect of NTDs.

To overcome this gap, a cross-NTD Morbidity and Disability (NMD) toolkit was developed by the Netherlands Leprosy Relief (NLR) and the Disease Management, Disability and Inclusion (DMDI) Working Group of the NTD NGDO Network (NNN). This toolkit consists of nine existing instruments that were selected to cover the domains of the International Classification of Functioning, Disability and Health (ICF) framework.[5,6] These domains are: body functions and structures; activity; participation; environmental factors; and personal factors.

A first phase validation study of the NMD Toolkit was conducted in North-Eastern Brazil with promising results.[5] The study assessed the cultural validity, including the relevance and acceptability of six instruments included in the NMD Toolkit among people with several different NTDs. The investigators showed that five out of the six instruments were well understood and considered to be relevant and acceptable for the included NTDs. To establish evidence of the cultural validity of the complete NMD toolkit across NTDs, languages and cultures, there is a need for more validation studies in various countries with other NTDs and additional instruments.

Several countries showed interest in this project, among which is Indonesia. Indonesia has some of the highest concentrations of NTDs, with especially high prevalence numbers in the

Papua province.[7,8] Well-known examples of NTDs that occur in Papua are leprosy and lymphatic filariasis.[8] Indonesia accounts for almost 10% of the world's new cases of leprosy, and for 9% being at risk for lymphatic filariasis.[7] Since the Papua province in Indonesia is one of the hotspots of NTDs, Papua is considered a suitable candidate for a NMD toolkit validation study.[8]

This validation study included two instruments of the personal factor domain of the ICF framework: the WHO Quality of Life Disabilities module (WHOQOL-DIS) and the Explanatory Model Interview Catalogue – Affected Persons (EMIC-AP). The study was carried out as a collaboration between the Papua Provincial Health Office, the Public Health Office of the Cenderawasih University (UNCEN) and the Netherlands Leprosy Relief (NLR). The aim of this study was to test the cultural validity of the WHOQOL-DIS and the EMIC-AP among those affected by leprosy or lymphatic filariasis in Papua, Indonesia.

Methodology

STUDY DESIGN

A cross-sectional design was used for the instrument validation in this study. Mixed methods were used, as both quantitative and qualitative methods were included. The quantitative data from the first part of the interview was collected using interview-administered versions of the questionnaires. The qualitative data came from additional questions regarding these questionnaires.

STUDY POPULATION AND SAMPLING

Interviews were conducted among people affected by leprosy and lymphatic filariasis living in Papua. Data were mainly collected in the region in and around Jayapura. Participants were eligible for inclusion when they (1) experienced disabilities as a result of one of the two selected NTDs, (2) were above the age of 15, (3) were willing to participate, evidenced in the form of written or verbal consent, and (4) lived in the province of Papua, Indonesia. Participants were excluded if they (1) spoke Bahasa insufficiently, or (2) were affected by multiple NTDs. The participants were recruited with a purposive sampling strategy, mainly with the help of the Provincial and District Health Offices who are responsible for NTD control in the area and could assess participants whether they experienced disabilities of the NTDs or not.

DATA COLLECTION

This validation study was based on the framework of Stevelink & van Brakel,[9] which is an augmented version of the Herdman framework.[10] This framework defines five categories of equivalence that can be used for the validation of culturally adapted instruments, in order to assess to what degree an instrument is appropriate for use in multiple cultures. These categories of cultural equivalence are: conceptual, item, semantic, operational and measurement equivalence. As this is a first phase validation study with a small sample size, this study focuses on the item, semantic and operational equivalence. Item equivalence is achieved when items estimate the same parameters on the underlying trait they are intended to measure and when they are equally relevant and acceptable in both cultures. Semantic

equivalence is optimal when there is a transfer of meaning across languages, achieving a similar effect on respondents who speak different languages. Operational equivalence is about the possibility of using a similar questionnaire format, instructions, mode of administration and measurement methods.

Data regarding these equivalences were gathered using interview-administrated versions of the EMIC-AP and the WHOQOL-DIS, and additional questions elaborated below. The Explanatory Model Interview Catalogue – Affected Persons (EMIC-AP) is a questionnaire that can be used to measure the experience and fear of discrimination, and the awareness of negative attitudes regarding their condition as experienced by illness-affected people, also called 'perceived stigma'.[11] The version of the EMIC-AP that was used in this study, consists of 14 items in the form of a question, which can be answered with yes, possibly, uncertain or no. These answers can then be scored from 2 to 0, with yes indicating a score of 2, possibly indicating a score of 1, and no or don't know indicating a score of 0. The overall perceived stigma level is evaluated by the sum of these items. A higher score indicates a higher level of perceived stigma.

The World Health Organization Quality of Life (WHOQOL) tool gives individuals the chance to share their own views and experiences about their quality of life. The WHOQOL instrument consists of the WHOQOL-BREF and WHOQOL-DIS. This study used the WHOQOL-DIS because this questionnaire assessed the quality of life of persons with physical and intellectual disabilities.[12] The WHOQOL-DIS questionnaire consists of 13 questions and a 5-point Likert scale with the following answer options: not at all, a little, moderately, mostly and totally. The lowest quality of life was seen when participants answered 'totally' on question 1 till 4 and 'not at all' on question 5 till 13.

Both questionnaires were translated into Bahasa, as it was the first time these questionnaires were used in Indonesia. In order to estimate the same parameters, the translation was based on the relevance and acceptability of the underlying trait that they are intended to measure.[11] An interview guide was made to help structure the interview. An audio recorder was used to record the interviews. The interview itself consisted of four parts: questions regarding participant characteristics; WHOQOL-DIS with five additional questions regarding the opinion of the respondent regarding the questionnaire; EMIC-AP with identical questions as used for the other questionnaire; questions regarding the interview in general. The five additional questions were: (1) Did you experience any problems in understanding the questions? (2) Are there any topics you felt uncomfortable to talk about? (3) Do you think these questions are suitable/connecting with your experiences of leprosy/filariasis? (4) What did you think of these answer options (Show participant the answer options) and (5) Is there anything else you would like to add or change in the questionnaire? These questions regarding the questionnaires covered the acceptability and relevance of the interview, the understanding of the items, whether the interview was experienced as positive or negative, and whether there were additional comments regarding the questionnaires. The whole interview was first pilot tested before the official data gathering.

DATA ANALYSIS

The recorded interviews were transcribed in Bahasa and translated into English. The English transcripts were analysed using an open coding technique. In this process a coding sheet was created that consists of 29 codes. The programme that was used for the coding was MAXQDA12. The quantitative data collected during the interviews was entered into a SPSS

22 database. Descriptive statistics were used regarding the characteristics of the participants and their answers to the questionnaires.

ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the Ethics Committee at the University of Hasanuddin, Makassar, Indonesia. Before the interviews, the participants were informed about the research and asked for a written or verbal consent. The information given to the participants included their rights, the purpose of the study, and the procedures of the interviews. In order to thank the participants, a polaroid picture was taken as a reminder of the interview. Additionally, the interviewers were accompanied by a doctor or nurse in case any medical attention was needed for the participants. Data were processed anonymously and will always be handled with care and therefore it will not be given to extern parties.

Results

CHARACTERISTICS OF THE STUDY POPULATION

A total of 34 participants were included in this study, of whom 53% were diagnosed with lymphatic filariasis and 47% with leprosy. From these 34 participants, 44% were female. The age of the group in total varied between 17 and 75 with a mean of 36. The majority (59%) of participants were unmarried and 59% had children. The number of children varied between one and eight. Twenty-eight percent of the participants had no education; primary school was finished by 25% and another 28% finished senior high school. Forty-one percent were interviewed in the provincial capital Jayapura, 29% was interviewed in Koya, a village in the Jayapura region and the remaining 29% was interviewed in the rural area of Keerom.

SEMANTIC EQUIVALENCE WHOQOL-DIS

Several steps were taken before the final instrument was created. The English version of the instrument was translated into Bahasa and back translated by an independent person with no medical background. The language interpretation differences were adjusted by the researchers. A new version was created and again translated to Bahasa. These steps were repeated until the fourth version of the questionnaire. This last version was pilot tested. During this pilot study small changes were still made, and after seven pilot interviews the final version of the instrument was created. The seven participants of the pilot study were needed to test and optimise the instruments and were excluded from the official data collection.

For the WHOQOL-DIS there were problems in question 1 and 5. Question 1 was a difficult question to start the WHOQOL-DIS instrument with. The question was “Does your disability have a negative (bad) effect on your day-to-day-life?” In the original WHOQOL-DIS instrument was no example given, so an example helped with answering the question: “Does it limit you in doing activities like going to the supermarket, cooking or work?” Question 5 asked, “Do you feel in control of your life?” Many participants needed an example for this question, because they thought that God was in control of their life. That is why they often needed the added example “do you feel like you can make your own decisions regarding your life?” The following two questions, number 6 and 7 were also about making decisions in

your life. “Do you make your own choices about your day-to-day life?” And “Do you get to make the big decisions in your life?” The problem was that these three questions look very similar and that is probably the reason why many participants did not understand these three questions directly.

Almost half of the participants (45%) experienced difficulties in understanding the questions of the WHOQOL-DIS instrument.

For example: “*There are answer options so I did not experience any problems in understanding and I do not need to give a detailed explanation” (male, age 39, leprosy).* Or: “*You speak nicely but I just do not get the question clearly” (male, age 43, LF).* Another example was: “*Yes, I did not really understand” (male, age 50, LF)*, and another participant just answered, “*Difficult” (female, age 30, leprosy).*

ITEM EQUIVALENCE WHOQOL-DIS

Item equivalence focuses on whether the items of the WHOQOL-DIS instrument are relevant and acceptable. This assessment criterion was assessed in two cognitive questions. The first cognitive question covering the item equivalence was “Are there any topics you felt uncomfortable to talk about?” Most participants answered ‘no’ (90%). A second cognitive question covering the item equivalence was “Do you think these questions connect with your experiences of leprosy or filariasis?” Almost all participants answered ‘yes’ to this question (94%). Reactions such as ‘yes’, ‘appropriate’ or ‘suitable’ were part of most answers. An example is: *“Yes, very suitable. All the questions are suitable with what I feel every day” (male, age 31, leprosy).* Questions covered a broad range of topics, which most of the participants perceived as relevant.

OPERATIONAL EQUIVALENCE WHOQOL-DIS

The operational equivalence concerns the format and design of the WHOQOL-DIS instrument. The design of the instrument was almost the same as the original WHOQOL-DIS. All introductory text is located at the same places within the instrument, and the questions are asked in the same order. The main difference with the original WHOQOL-DIS is the use of an additional smiley answer board. This smiley board was created as most participants never participated in research with Likert-scale options. The smileys are linked to a specific answer option, in order to facilitate the choosing of an answer option. Data was collected by an interview-administered questionnaire. This means that people did not really see the format and design of the instrument. However, a smiley flashcard was standing in front of the participant, so they could read the answer options and could point to the answer options with corresponding smiley. In this study, the answer options were pre-tested in a pilot study and evaluated after the data collection.

The participant could give their opinion about the instrument by answering two additional questions. The first was “What did you think of these answer options?” Slightly more than half of the participants were positive about the answer options (58%). In general participants said that the answer options were helpful.

The second question was “Is there anything you would like to add or change in the questionnaire?” Almost all participants said ‘no’ (97%). One participant suggested that these questions could help to create more awareness in society. Specific suggestions for improvement of the WHOQOL-DIS instrument were not given.

SEMANTIC EQUIVALENCE EMIC-AP

Fifty-seven percent answered to have no problems understanding the EMIC-AP, 23% said they did have problems in understanding, and the answers of the remaining participants could not be classified the above named categories. An example of an explanation of a participant that had trouble understanding the questionnaire was: "*Slightly difficult in answering some questions because of the language, so perhaps change the language to make it more clear to understand" (male, age 45, leprosy).* From the people whose answers could not be categorized, some people did not give an answer even though they were asked the question multiple times or they started talking about a completely different subject, suggesting they did not understand the question or wanted to avoid the question.

Additionally, all questions were analysed to see which were more difficult to understand. For every question we noted whether the question was understood immediately, whether an example or reformulation was needed or both, and whether a question was not understood. Question 2 and 11B were the only two questions where less than 80% of the participants understood the question immediately. Question 2 is: "Have you discussed this problem with the person you consider closest to you?" If not understood, the following example was provided: "For example, your best friend or your family". With inclusion of this example, 90% was able to understand the question. 11B is: "Has this disease caused problems in your marriage?" Sixty-seven percent of the participants understood this question immediately. The remaining participants needed a reformulation or both a reformulation and an example.

Unfortunately, the meaning of question 3 was lost in the final adjustments of the EMIC-AP. The meaning of the question that was tested in this study was: "Do you think people have less respect for you because of this problem?" instead of "Do you think less of yourself because of this problem?" This was noticed too late to correct.

ITEM EQUIVALENCE EMIC-AP

To the additional questions that followed the EMIC-AP, 90% answered they felt comfortable to talk about the topics that were covered in the questionnaire. Additionally, 93% considered the questions of the questionnaire relevant to their experiences with the NTD they had.

OPERATIONAL EQUIVALENCE EMIC-AP

To make the questionnaire suitable for the study population in Papua, a change was made to question 10. The original question was: "Do you feel that your problem might cause social problems for your children in the community?" However, this question led to confusion in the pilot when people had no children. Therefore, the question was separated into an A and a B version. This division was based on question 11 where there were separate questions for married and unmarried people. Question 10A remained as it was for people with children. Question 10B for people without children became: "If you have any children in the future, do you feel that your problem might cause social problems for your children in the community?"

The answer options remained the same as in the original questionnaire. However, to help participants with these answer options, an answer flash card was created. Seventy-three

percent of the participants were positive about this flash card. Ten percent were negative about the answer options, because they did not understand them due to illiteracy.

Discussion

The aim of this study was to test the validity of the Bahasa translations of the EMIC-AP and WHOQOL-DIS of the NMD Toolkit among people affected by leprosy or lymphatic filariasis in Papua. These instruments measure, respectively, anticipated and experienced stigma and quality of life. This was done to contribute to the evidence of the validity of the NMD Toolkit instruments across different NTDs, languages and in different cultural settings.

SEMANTIC EQUIVALENCE

To test the semantic equivalence of both instruments, two assessments were done. Firstly, the participants were asked if they experienced any problems in understanding the questions. Seven out of 24 participants experienced problems in understanding the questions of the EMIC-AP, which was a positive result compared to the almost 50% of participants who experienced difficulties in understanding the questions of the WHOQOL-DIS. This is in contrast to the study of van't Noordende *et al.*,[5] who reported that the WHOQOL-DIS instrument was easily understood among participants in North-eastern Brazil. This was not the case in the current study. To better understand the results of the semantic equivalence testing, we looked at the influence of education level and place of residence on the understanding of the questions of both the WHOQOL-DIS and EMIC-AP. As expected, the results suggest that higher education results in a better understanding of the questions. Place of residence also seemed to play a role in the understanding of the questions. When looking at the results of this study, the questionnaires were better understood in urban areas than in rural areas that were visited. It is likely that these two factors can be associated, since we found that the level of education was lower in the rural area than the urban area. The latter finding is confirmed by literature that states that in Papua the literacy rate is lower in the rural areas compared to the cities.[13] Even though the above named results regarding the influence of education level and place of residence on the understanding of the questionnaires are consistent with literature, they are not to be interpreted as hard fact due to the small sample size off this study.

Secondly, we looked at the understanding of each question separately. Question 2 and question 11B of the EMIC-AP scored relatively low compared to the other questions, but were better understood in addition of an example. Therefore, it is suggested that in future research this example is included. Rensen *et al.*[14] did a validation study of the EMIC-AP in India, and did not mention the need for examples in their results. However, adding standard examples to questions is common practice in questionnaire research.[11] It is important that examples are adapted to the cultural context when the instrument is adjusted to a new setting. If an example is not appropriate for a new cultural context, it can be deleted without changing the meaning of the question.[11]

ITEM EQUIVALENCE

Both instruments seemed appropriate from the perspective of item equivalence. The majority of the participants said they felt that the questions were relevant to their experience

of leprosy or LF. In addition, participants felt comfortable with the topics that were discussed. This confirms the findings for the WHOQOL-DIS in a first-phase validation study in Brazil.[5]

OPERATIONAL EQUIVALENCE

The first question of the WHOQOL-DIS instrument was a difficult question to start the interview with. The question was "Does your disability have a negative (bad) effect on your day-to-day-life?" Because no example was given in the original WHOQOL-DIS, the following example was created in consultation with the co-investigators: "Does it limit you in doing activities, like going to the supermarket, cooking or work?" This example made it easier to answer this question when participants experienced difficulties. However, it would be recommended to start the instrument with one or two relatively easy questions that every person could answer.

One caveat for both questionnaires is that it is possible that the number of participants that understood the questions directly is lower than suggested by these results, due to the use of multiple-choice answers. As we expected this problem, the interviewers were instructed to talk with the participant about the subject in case there was reason to believe the participant did not understand the question. However, if participants gave an answer directly without any doubt it was assumed that they had understood the question. Therefore, there is the possibility they did not always understand the question. According to De Vaus,[15] participants are known to sometimes give socially desirable answers. He claims that the chance for this is greatest when data gathering is done by an interviewer.

When using a 'don't know' option, like the one used in the EMIC-AP, participants are known to get lazy in answering the questions.[16] However, this did not appear to be the case in this research. It might be that the participants felt they could not admit they did not know. Therefore, there is a chance that participants randomly chose answer options even when they did not know what to answer. Some of the participants said that the interview was relatively long with both questionnaires and additional questions being included. This is not surprising as the interviews with people who had trouble understanding the questions could take up to two hours. People might have become reluctant to answer the questions correctly, as reluctance is increased if the data gathering takes a long time.[15]

To help participants with the answer options, a flashcard with linked answer options was created. The participants were asked their opinion about the answer options. A large majority were positive about the answer options of the EMIC-AP and slightly more than half were positive about the answer options of the WHOQOL-DIS instrument. Participants said that the smiley flashcard of the WHOQOL-DIS really helped to answer the questions. In literature, pictorial answer options are mainly used for adults with intellectual disabilities and children. However, pictorial answer options also help people with low education and may help participants to distinguish between the response options.[18] Also, the study of van't Noordende *et al.*[5] recommended to use a flashcard for the WHOQOL-DIS instrument, to prevent having to repeat the answer options with each question. Even though this sounds promising, the use of smileys or symbols should be pre-tested among the study population to see whether these flashcards are considered helpful or not. The results in this study suggest that the smileys make the answer options easier for the participants. However, the answer options themselves might be too difficult for the population of Papua.

MEASURES TO INCREASE THE VALIDITY OF THE DATA

Two measures were taken to increase the validity of the data. The first was careful evaluation in the pilot study before the actual data collection. In total, the questionnaires were evaluated five times and therefore adapted four times. Additionally, seven people were involved in the discussions that led to the adaptations made. These were the on-site supervisor, the back-translator, the three translators and the two researchers. This means that the changes that led to the final WHOQOL-DIS and EMIC-AP instrument were based on a consensus opinion.

The second measure taken was the creation of flashcards. The flashcard of the WHOQOL-DIS showed the answer options with the matching smileys, in case people could not read. In most interviews, this smiley flashcard of the WHOQOL-DIS was necessary, because there were too many answer options. People used it to remember the answer options and to select their answer. Interviews would probably have been more difficult, without the use of the smiley flashcard. The flashcard of the EMIC-AP could not be matched with smileys and therefore only consisted of the answer options in words. This was helpful for the participants that were able to read, because not having to repeat the answer options after every question smoothens the process of the interview. However, for people that could not read, the flashcard had no added value.

STUDY LIMITATIONS

Limitations of this study were the small sample size and the number of languages spoken. Papua has more than 250 different major languages.[18–19] This means that not everyone easily understood the Bahasa version of the WHOQOL-DIS and the EMIC-AP instrument. Therefore, readers have to keep in mind that the results of this study are applicable only for Northern Papua and cannot be generalised to the whole of Papua.

A final limitation was that the participants were not very talkative. This was mainly noticed during the open questions after the instrument' questions. When the participants were asked to elaborate on an answer, it was observed that some participants were not able to do so. Especially in the rural areas this seemed to occur regularly. Therefore, there was little input on the open questions. According to Mangundjaya,[20] one of the reasons for this could be their general custom of showing respect towards older people and people perceived to have a higher social status. For the majority of the participants, it was the first time to be interviewed or be involved in a survey. This might have also caused the participants to hold back. The article of Mangundjaya[20] also states that Indonesian people prefer stable and predictable conditions. As this was the first time for the majority of the participants, the interview may have been out of their comfort zone.

FUTURE RESEARCH

The EMIC-AP showed promising results in the first phase validation. However, before the cultural validity of a questionnaire can be properly assessed, all equivalences should be tested. The current study did not assess conceptual equivalence. In order to include this equivalence, it is recommended to start with a focus group to address the concept stigma and quality of life in the context of Papua. This is needed to complete the first-phase validation study of the EMIC-AP scale and the WHOQOL-DIS instrument.

Conclusion

This study gave insight into the cultural validity of the EMIC-AP and WHOQOL-DIS instrument among participants with leprosy and LF in Papua, Indonesia. With both questionnaires we encountered difficulties regarding the understanding of the items (semantic equivalence). Especially the WHOQOL-DIS was not easily understood by the participants. In a setting like Papua, where many different languages are spoken by relatively small population groups, questionnaire-based data collection will remain a challenge since instruments cannot be translated separately in every language. Considering the setting, the results regarding the understanding of the EMIC-AP can be considered relatively good. Even in its adapted form, the WHOQOL-DIS was too difficult to understand in Papua. Both instruments seem to have appropriate topics and the questions of the instrument were considered relevant to the NTD-related experiences of the participants (item equivalence). The format of the EMIC-AP (operational equivalence) worked well with the addition of the flash card. Yet, with the WHOQOL-DIS we still experienced some problems with the format. The WHOQOL-DIS is therefore not considered suitable for use with NTD-affected people in Papua, Indonesia. With some minor adjustments, it is very likely that the EMIC-AP can be used in the field under the condition that the participants are sufficiently fluent in Bahasa Indonesia.

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