Scientific-Based Translation of Standardized Questionnaires into Sign Language of the Netherlands

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ABSTRACT

Specialized psychological and psychiatric health care for deaf and hard of hearing clients has emerged during the last 50 years. It has long been known that deaf and hard of hearing clients are often misdiagnosed with psychiatric disorders, but little scientific attention has been paid to the tests used with this group. Although these clients may have poor spoken-language skills and a different (cultural) background from mainstream clients, regular diagnostic tests are used even in specialized settings.

To enable the use of standardized questionnaires without language barriers, we have developed a guideline for adapting internationally validated questionnaires and translating them into sign language. We used this guideline to adapt and translate four questionnaires into Sign Language of the Netherlands (Nederlandse Gebarentaal, NGT). In this chapter we introduce our guideline and describe the selection and translation process of research instruments for use with deaf and hard of hearing individuals. The problems, dilemmas, and ethical issues encountered are discussed.

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One in a thousand people worldwide is born deaf or severely hard of hearing (Kennedy & McCann, 2004), and this number increases with age. These children face many challenges in acquiring the spoken and written language of their environment. Many of them have great difficulty in achieving a literacy level comparable to that of their peers (Musselman, 2005). One of the reasons for a prevalence of low literacy among deaf people is that many Western languages have an alphabetical writing system (consisting of letters or graphemes) that is based

on phonemes. Phonemes are the sounds (e.g., vowels, consonants) of a language that change the meaning of words (e.g., *hat* versus *bat* [h/b distinction] versus *hit* [a/i distinction]). When you cannot hear these phonemes, you have to memorize—for all words—which letters/graphemes represent them (e.g., what combination of characters and in which order they are used for a certain concept). An English example would be the verb "know," of which the visual image on the mouth resembles the pronunciation of the word "no"; these two written forms of the sound [no] thus need to be explicitly learned. Deaf people also cannot automatically use vocalizations when reading. This means that deaf people are able to read fluently only those words that they have read before and whose written graphemic construction they have memorized.

For many deaf and hard of hearing individuals a sign language is their natural language because they have full access to it. In the Netherlands, Sign Language of the Netherlands (Nederlandse Gebarentaal, NGT) is used. In contrast to certain other sign languages like American Sign Language and Flemish Sign Language, NGT up to now has not been recognized by the Dutch government as an official language of the Netherlands.

Over the past 25 years there have been discussions about whether deaf people have more in common with each other than just their medical condition (*in casu* their hearing status) plus the fact that many of them are sign language users. Researchers from Great Britain (Ladd, 2003) and the United States (Padden & Humphries, 1988, 2005) have convincingly defended the existence of a Deaf culture. These studies show that the Deaf communities constitute social and linguistic minorities within many Western hearing cultures. Such a Deaf cultural minority is characterized by shared experiences, values, traditions, behavioral rules, and, most important, the use of a sign language as the main mode of communication. Having a cultural identity different from that of the majority in society may have a negative effect on communication and healthcare provision (Van Wieringen, Harmsen, & Bruijnzeels, 2002). To distinguish between the audiological concept of deaf and the cultural Deaf, a capital letter is used for the latter. The designation "Deaf" is used here to include people who see themselves as culturally Deaf and as belonging to a linguistic minority group. The designations "deaf" and "hard of hearing" are used here for people who developed a hearing loss, including Deaf, deaf, and hard of hearing.

In the Netherlands, as in many other Western countries, there are limited facilities for Deaf people to ensure their full participation in the wider society. For instance, sign language support by interpreters is restricted, and medical information in NGT is scarce. In contrast to the United States, we in the Netherlands do not have a disability act. An international UN convention handles the rights of people with a disability, but the Dutch government has not yet ratified this convention. These aspects, together with lack of access to the spoken language (e.g., no incidental learning), explain why deaf and hard of hearing individuals often have less general and medical knowledge than hearing people (Barnett, 1999; Jones, Renger, & Firestone, 2005; Vernon & Andrews, 1990).

MENTAL HEALTH CARE

Little information is available on the impact of cultural and linguistic barriers on the medical care offered to and received by deaf and hard of hearing individuals (Smeijers & Pfau, 2009; Van Wieringen et al., 2002). The incidence of psychological problems is higher among these individuals than among the hearing population (Fellinger et al., 2005b, 2007). This is partially explained by the fact that people with severe hearing impairment often face social barriers due to communication problems. Another explanation is that this might be a result of the two to three times greater prevalence of sexual abuse (possibly due to communication barriers and poorer social skills) in this group than in the hearing population (Hoem Kvam, 2004).

The incidence of psychiatric disorders in deaf and hard of hearing individuals is an important subject of discussion in the medical literature. In the 1950s deaf and hard of hearing individuals in the United States were relatively overrepresented in psychiatric clinics (Pollard, 1994; Stein, Mindel, & Jabaley, 1981). These findings ultimately led to the development of specialized mental health care for deaf and hard of hearing patients. Within these specialized settings extra attention is given to the patients' cultural background and language skills. After the transfer of patients to these specialized facilities, it became evident that many of them had no psychiatric disorder. Some had a mild cognitive impairment, and some had a severe language impairment caused either by weak language skills, first-language deprivation, or a primary language disorder. Although nonspecialized clinics still report a higher incidence of

psychiatric disorders within the deaf and hard of hearing population, no evidence for this has been found in specialized settings (Pollard, 1994). Since the emergence of specialized healthcare facilities for deaf and hard of hearing individuals is only recent, the number of research instruments especially developed for or adapted to deaf and hard of hearing individuals is still low.

Psychological Tests

Psychological testing of deaf and hard of hearing sign language users is usually done via written questionnaires. However, as explained earlier, using the written language of the hearing minority may be problematic in this population because its members have an inadequate mastery of the local spoken/written language (Musselman, 2005). More often than not these questionnaires are translated ad hoc by sign language interpreters because very few test instruments are available in sign languages (Munro & Rodwell, 2009). If an interpreter interprets a written questionnaire ad hoc into sign language, the interpreter may make nonstandardized linguistic and cultural adaptations. Such adaptations can of course influence the replies to the questionnaire and thus the general outcomes. In most situations the interpreter will also interact with the deaf or hard of hearing test participant who is filling out the questionnaire. A common pitfall is that the results of questionnaires that were administered by ad hoc interpreters are analyzed as if they are standardized questionnaires, while the questionnaire was actually converted into a sort of interview.

Research on ethnic minority groups has demonstrated that the mental and physical well-being of the group members is influenced by their cultural identity (Guillemin, Bombardier, & Beaton, 1993). Therefore, health-related quality of life (HRQoL) questionnaires can be used for people whose linguistic and cultural identity are different from that of the original target group only *after* an accurate process of translation and cultural adaptation (Guillemin et al., 1993; Hocker, 2010). Furthermore, online surveys that use a recorded sign language translation of a written questionnaire are more suited to reach deaf persons (Graybill et al., 2010; Hocker, 2010). However, as far as we know, only one adapted and translated HRQoL questionnaire for deaf people exists, and this instrument is in use in Austria (Fellinger et al., 2005a). A limited guideline is available for translating questionnaires into sign language (Crowe Mason, 2005).

However, we could find no comprehensive guidelines that cover the whole process of translating and adapting the questionnaires for use by deaf and hard of hearing respondents. When we planned to conduct an epidemiological study on the health and healthcare needs of deaf and hard of hearing individuals in the Netherlands, we became aware of the enormous problems posed by the lack of suitable instruments for this group. To help solve these difficulties we developed guidelines that we adapted during the process of translating four questionnaires into NGT for our research project.

METHODOLOGY

Procedures

Founded on current guidelines for translating and adapting HRQoL questionnaires for spoken languages (Hocker, 2010; Pollard, 1994; Ravens-Sieberer et al., 2005; KIDSCREEN Group Europe, 2006) and referring to our own trials and experiences, we have developed guidelines for translating international written questionnaires into a sign language (Figure 1). A group of Deaf NGT communication experts, a physician/NGT linguist, a second NGT linguist, NGT interpreters, and a master's student in Deaf studies translated the selected questionnaires into two different variants of NGT. After backward translations (i.e., from NGT into written Dutch), consultation between experts, and reviews by deaf and hard of hearing test participants, the signed questionnaires were adapted to the cultural and linguistic needs of deaf and hard of hearing individuals.

Besides the two NGT versions, a sign-supported version (spoken Dutch with simultaneously produced NGT signs) and a written Dutch version were also provided. All of the questionnaires were placed in a secure online environment. We used Unipark software, which allowed us to create our own layout and has a direct link to a database (Hocker, 2010; www.unipark.de). The guidelines are presented in appendix 1, while their development is discussed in this chapter.

Instruments

One of our first challenges was to select test instruments that were suited for translation into NGT and that were reliable also when used by

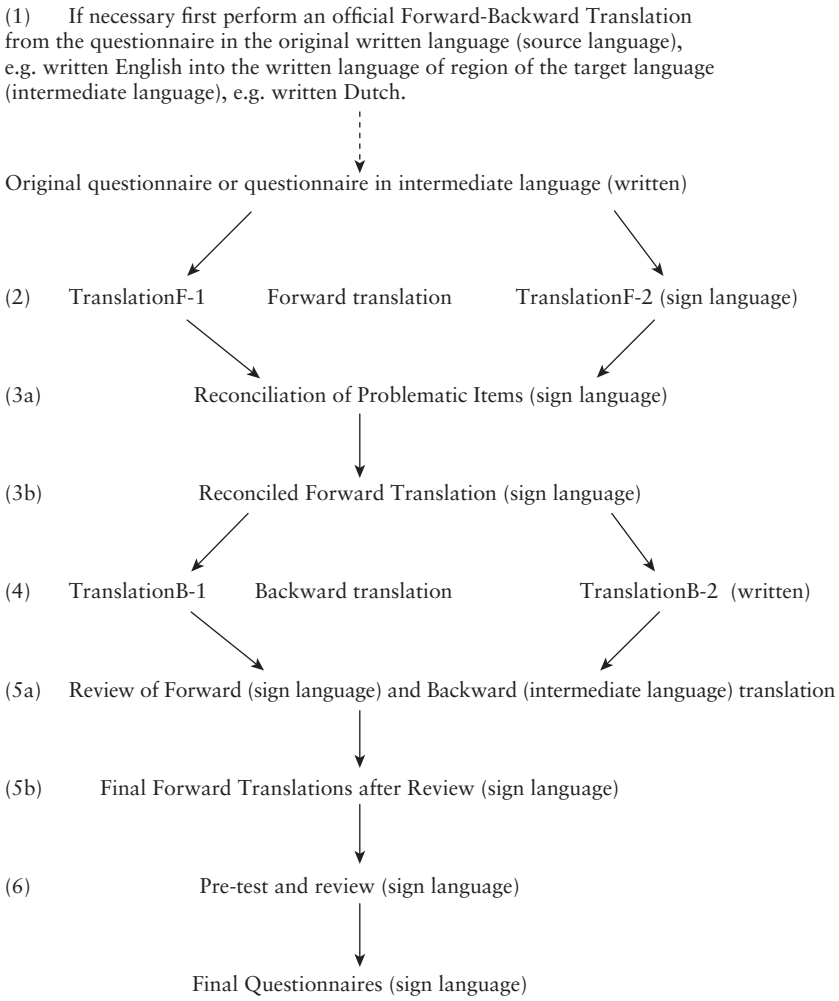

FIGURE 1. *Guidelines for translating questionnaires into a sign language.*

people who have weak language skills and minority cultural backgrounds. The selected questionnaires for this study are as follows:

– World Health Organization Quality of Life-BREF (WHOQoL-BREF): This is an internationally standardized questionnaire that has been translated and validated in more than a dozen languages and has been widely field-tested, which makes the instrument methodologically strong (WHOQoL Group, 1998). Numerous questionnaires have been designed to measure all sorts of aspects of quality of life. Quality of life questionnaires that explicitly evaluate

participants' physical health are less common. We chose the WHOQoL-BREF because it was the only short questionnaire that met both our content demands and our methodological demands.

- General Health Questionnaire (GHQ): This is a screening instrument to identify minor psychiatric disorders. It can be used in the general population or with clients in nonpsychiatric clinical or primary care settings. We have used the GHQ-12, the shortest version, especially designed for research studies (Goldberg & Williams, 1988). One of its strong points is that it is a short, reliable questionnaire.
- KIDSCREEN: This is a generic quality of life instrument that has been designed and normed for (hearing) children and adolescents between the ages of 8 and 18 years. KIDSCREEN can be used as a screening, monitoring, and evaluation tool in health surveys (Ravens-Sieberer et al., 2005; KIDSCREEN Group Europe, 2006). It covers ten health-related quality of life dimensions, whereas many QoL questionnaires for children cover only psychological and schooling domains. It is an internationally standardized questionnaire that does not require a high language level.
- Deaf Acculturation Scale (DAS): This is a 58-item scale that measures deaf and hard of hearing individuals' degree of acculturation to both Deaf and hearing cultures. It consists of two overall acculturation scales: a Deaf acculturation scale (DASd) and a hearing acculturation scale (DASh). Both measure acculturation in five domains (Maxwell-McCaw & Zea, 2011). The DAS is the only validated international scale that provides information about the cultural status of deaf and hard of hearing individuals. Having a cultural identity different from that of the majority in society may have a negative effect on an individual's communication (Van Wieringen et al., 2002). The DAS can be used to evaluate such effects among deaf and hard of hearing individuals.

Issues Encountered during Selection and Translation of Questionnaires

Our project consisted of five phases: 1. choosing the questionnaires; 2. producing the forward translation; 3. producing the backward translation and harmonization; 4. testing; 5. taking the survey. We encountered

linguistic, cultural, and technical issues during all phases of selection and translation of questionnaires. Later we describe these issues and how we dealt with them.

Selection Criteria for Questionnaires

It is difficult to perform a validation study on questionnaires to be used by sign language users because of the small number of such persons in the population, as mentioned earlier. Therefore, one has to be very sure of the potential and the characteristics of the questionnaire. We preferred to use only internationally validated questionnaires that had already been successfully translated into a number of languages and have been used in various cultural settings, not questionnaires that were validated in only a limited number of European countries or only the United States. From those we chose the ones that showed the most potential for cultural and linguistic translation. For instance, questionnaires that use a great deal of figurative speech are more difficult to translate into another language, as are questionnaires with many semantic weaknesses (see example 1). We also took the required language level into account. Since the medical knowledge of deaf and hard of hearing individuals is often limited, we excluded questionnaires that use a large proportion of medical jargon or require a high language level.

Example 1. ***(from GHQ)***
Have you felt capable of making decisions about "things"?
"Things" is semantically weak and therefore a difficult concept to capture in translation.

Selecting Signers

The main but elementary difference between a written questionnaire and a signed one is the need for a signing interviewer on the screen. The person who is recorded signing the questions will automatically function as the interviewer. As with any interviewer, this individual may cause some bias. To minimize the bias, the signers must be carefully selected.

A central point in this is that the respondents to the questionnaire must feel comfortable with the signer, who may be asking very personal questions. Although the respondents will be aware that the signer on the

film will not see the answers, the signer will unconsciously exert influence nonetheless. Interviewer bias can also be caused by gender, age, status, cultural and ethnic background, language, and/or linguistic style.

To minimize potential bias, we decided to make different versions. One version was signed by a deaf woman who is a teacher of NGT and Deaf culture and is well known in the Deaf community. The second version was signed by a hearing male NGT interpreter who has much experience in working in psychiatric settings but has no personal attachments to the Deaf community. In the Netherlands the Deaf community is rather small, and most of its members know each other. By choosing one interviewer who was well known in this community we created an opportunity for the participants to be questioned by someone familiar and trusted. By also selecting an NGT interpreter without personal attachments to the Deaf community and who works only in a small, specialized setting, we provided an opportunity for the respondents to be questioned by an unfamiliar, more neutral person. In addition, NGT has five regional variants, all of which are mutually understood by native signers. For educational reasons, a standard version of NGT's most basic lexicon was introduced in the 1990s and is firmly established today. The two signers of the questionnaire came from different parts of the country. They were both instructed to sign in as standard a manner as possible, but they did so with a slightly different NGT accent.

Two-thirds of the participants finally chose the Deaf woman as the sign model. This model also resulted in fewer respondent dropouts than with the male interpreter as the sign model. This supports our hypothesis that the current practice of using ad hoc, noncultural Deaf sign language interpreters to administer nonculturally adapted tests may cause bias and a false sense of feeling that the participants' needs are sufficiently met.

Adaptations in Translating the Questionnaires

While translating the questionnaire, one must understand both the underlying reason for the questions and the frame of reference of the target group related to them. One of the issues that we encountered during translation was that the items on some questionnaires are written in the first person, for example, "I feel sad." This is done to encourage the participant to internalize the item. Since sign language is a visual language, an interviewer will always be present. If a question is written in the first person, the interviewer will always have to use a form of direct

speech (i.e., the interviewer will point to himself while asking the question). It is arguable whether with the original purpose of first-person use, more internalization of the question is reached in this situation. We found that second person (e.g., signer points at respondent [= viewer] while asking the question [e.g., "Do you feel sad?"]) is a more direct and more suitable form for sign languages. Therefore we adapted the first-person phrases, for example, in some of the questions in the American DAS questionnaire (see example 2).

EXAMPLE 2. *(from DAS)*

Original question	**Adapted question**
I call myself Deaf (yes/no) ->	Do you call yourself Deaf? (yes/no)

One of the questions that was adapted for person.

An example of cultural issues during translation was the question "Are you a member of a club or society?" (yes/no). The purpose of this question is to test social involvement, but it was placed between mainly medically oriented questions. Within a hearing population this will not cause any problems, but within the Deaf community, lobby groups and associations of Deaf or hard of hearing persons are often also seen as clubs or societies. We transferred the question to the section where other social questions were asked and added the word "socially" to avoid "yes" answers when the respondent was actually not socially active ("Are you a member of a socially active club or society?").

Technical Issues of Translation

Our questionnaires consisted of 151 questions. This meant that, including formal introduction and instructions, we had to translate 170 items. We estimated that it would take approximately 8 hours to produce the first forward sign language translation (translationF) and 4 hours to film the adaptations. We expected the backward translation (translationB) to take 2 hours. For the production of the sign-supported version we reserved 4 hours. Our estimations for the sign language version turned out to be very accurate.

Although no full translation had to be made, it turned out that it is as time consuming to film a sign-supported version as it is to produce a sign language version. In our case we also used a signer who was not

accustomed to being filmed, which possibly caused some extra delay. It took a total of 12 hours to film the first sign-supported version.

For all of the recordings on different filming days, the signer has to wear the same clothes, which should be neutral in color but contrasting with the background. When the camera is positioned, one has to make sure that the whole signing area (picture) is captured. The signer's hands should not go outside the filmed area, not even during breaks between contiguous sentences. Moreover, the signer must always look directly into the camera. Often a helper will be standing next to the camera or a text will be put up next to the camera; alternatively, an autocue can be used. When the signer looks at this person or the text during the filming, the signer's eye direction changes, which may have grammatical consequences in most sign languages. Since "person" in NGT, like in most sign languages, is expressed by pointing at a certain locus (localization[1]), the question will seem to be directed to a third person rather than to the viewer/participant (second person).

Presentation

Since sign language is a visual language and deaf and hard of hearing individuals are visually oriented, it is imperative to pay special attention to the layout of the recordings and how the films are presented online (Baker, van den Bogaerde, & Woll, 2008). The combination of yellow and blue is known to provide the best contrast and be the most comfortable to read; therefore we chose a light yellow background and a dark blue font. We placed the film clip with the NGT question in the center of the screen because this is the most important item. To create a layout that would be familiar we placed the written text below the clips on the screen, as in subtitles. A bar at the top of the screen shows the participants what percentage of the questionnaire they have filled out (Figure 2).

When answers were only short phrases (e.g., yes/no/don't know), these could be provided only in writing because, when several clips are placed on one screen, the overall view is reduced, and a great deal of viewing time is required. Although using NGT instead of written text improves Deaf respondents' comprehension, it is also more time consuming to look at movies than to read. When the answers are only short phrases, these side effects compromise the positive effect of NGT on comprehensibility.

Other researchers have tried to compensate for the difficulty of displaying sign language answers by making the answer options more visual in written text (Graybill et al., 2010; Hocker, 2010; Munro & Rodwell, 2009)

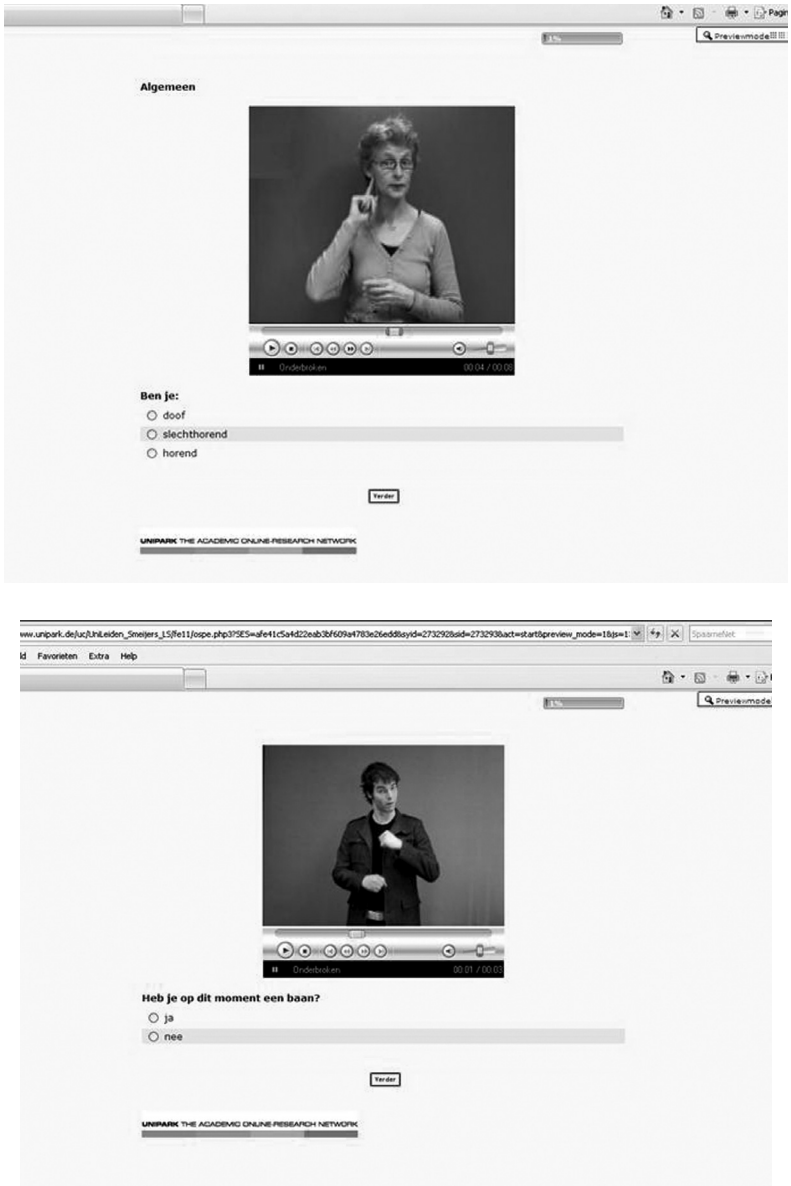

FIGURE 2. *Examples of layout.*

(e.g., color-coding [green for a positive answer, red for a negative one], the use of illustrations such as thumbs up, flat hand, thumbs down for good, moderate, poor, respectively], or smiley faces). However, because colors or illustrations might impart a positive or negative connotation to the answers and thereby possibly add a bias, we decided not to use these.

Some computer-based tests require an answer to every question before the respondent can proceed to the next question. We used this restriction only for the most crucial questions (e.g., "date of birth"). We gave the participants the option of skipping questions because the written questionnaires also have the option of leaving a blank in case the test participant does not understand the question or does not know the answer or does not want to answer the question. Filling out an answer just to be able to continue the test would compromise the reliability. Although it was possible to do so, none of our respondents left blanks while filling out the questionnaires.

Testing the Questionnaires

Pretesting can be done by many different methods. For the questionnaires we used a cognitive interviewing method based on paraphrasing as a variant of the think-aloud method (KIDSCREEN Group Europe, 2006) (asking the respondents to repeat the item in their own words immediately after answering the item). This technique permits the researcher to find out whether a respondent understands the question and interprets it in the manner intended. It may also reveal weak wordings of items.

Additionally, using the general probing method (KIDSCREEN Group Europe, 2006), the participants were asked whether the items were comprehensible and clear and whether they were easy or difficult to answer. During the translation process the review committee (a committee designed to assess the entire forward-backward process in order to provide a final forward translation) noticed a difference in focus of the two forward translation teams. The forward translation team that was producing the Deaf woman sign model was focusing more on comprehensibility and cultural adaptation, whereas the team that was producing the male interpreter model focused more on making the translation as literal as possible. After consultation, the former team was instructed to translate more strictly, and the latter team was instructed to focus more on a conceptual than a literal translation.

During the testing phase differences also surfaced. Testers who were deafened early in life preferred the Deaf woman sign model because they felt that the language used in that version was slightly more accessible. Testers deafened at a later age tended to favor the more literal male interpreter model. Six persons were asked to test all 170 items. They considered only one item to be difficult to understand because there is no proper translation for the concept "leisure activities" in NGT (see example 3). This is because the concept of leisure time seems to be unfamiliar in the Deaf community.

Example 3. *(from WHOQoL-BREF)*
"To what extent do you have an opportunity for leisure activities?"

Conducting the Questionnaire

In contrast to written questionnaires, questionnaires in sign language cannot be filled out using paper and pencil. Some sort of visual technical support is needed. We placed our questionnaires in an online environment. Participants filled out our questionnaire at home on their own computer. Several meetings at Deaf clubs and a center for elderly deaf persons were organized. People who did not possess enough computer skills to fill out the questionnaire at home could receive help at these meetings. Assistance was given by three members of our team who were trained to provide only technical assistance; none with regard to content was given.

During the first phase of the study the questionnaire was made available at a secure Internet site. After signing a written consent form participants received a personal login for the questionnaire. During the second phase of the study this was altered because the procedure seemed to hinder both Deaf and hearing people in their study participation. The Dutch Deaf community is a small, close-knit community. Some of its members reported to us that they had doubts about the anonymity because they had to write their name on the informed consent, while some Deaf community members were team participants. In addition, some of the possible candidates for our hearing control group reported that the written informed consent procedure was too time consuming.

During the second phase of our study we tried to overcome these barriers by placing the questionnaire in a secure environment without login authorization, enabling people to give online consent instead of written consent.

Participant Recruitment

We generated much publicity about the project with articles and announcements in patient group newsletters, magazines, national and local newspapers, and websites of Deaf clubs and/or organizations for people with hearing impairment. General information about the study was provided at gatherings of the Deaf community, symposia for people with hearing impairment, and medical symposia. In addition, participants were recruited through snowball sampling and newsletters of hearing aid manufacturers.

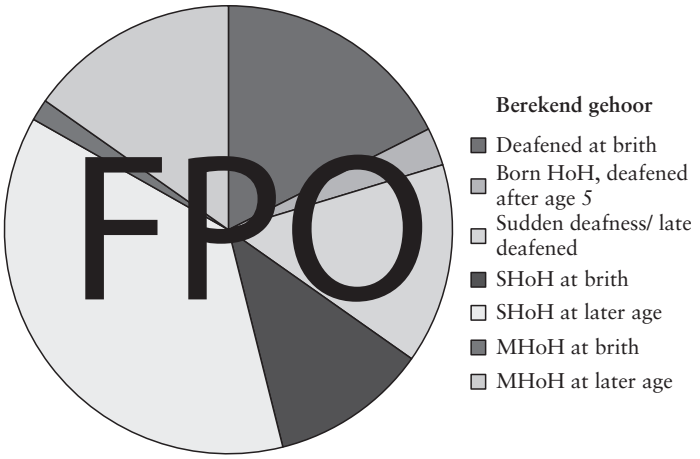

FIGURE 3. *Hearing status of our participants based on self-report (SHOH = severe hard of hearing, MHOH = mild hard of hearing).*

Informed consent was obtained by providing information brochures and consent forms both in written Dutch and NGT. All of the information was customized for people with weak language skills.

A total of 274 deaf and hard of hearing individuals filled out our questionnaires. The audiological characteristics based on self-reports are shown in Figure 3. Twenty-eight percent of our participants described themselves as members of the Deaf community; 19.7% had at least one deaf parent; and 15% had a cochlear implant. Of the 76 participants who were deafened at an early age and described themselves members of the Deaf community, 37% filled out one of the sign language versions of the questionnaire; 4% filled out the sign-supported version; and 59% chose the written Dutch questionnaire.

GUIDELINES

The most important differences between guidelines for spoken language translations and translating for deaf and hard of hearing individuals are the following:

- Current guidelines always advise translating the original questionnaire using one native speaker of both languages. However, often no native speakers of both the target sign language and the source language are available. Therefore a full forward and backward

translation to the written form of the local spoken language (intermediate) has to be made first, in accordance with international guidelines, before starting the forward translation into the sign language of choice.

- We advise setting up a multidisciplinary team instead of making the translation with one person alone. These teams should include at least the following:

  a) a professionally trained sign language interpreter
  b) a native user of the target sign language, preferably a Deaf communication specialist or Deaf sign language teacher

If possible, the team should also include the following:

  c) a linguistic specialist in sign language (sign linguist)
  d) a psychologist/psychotherapist with experience in the development of psychological tests

All of the team members must be familiar with the target sign language and the cultures of both the region of the source (written) language and the target (sign) language and have experience with psychological testing.

- As prescribed in international guidelines, at least two separate translations should be made, differences discussed, and adaptations made. International guidelines advise proceeding with one version after performing the first forward and backward translation. The experiences of both translators and translation groups are used to improve what is considered to be the stronger translation. Ideally, when adapting to and translating into a sign language, one should start with four translations (two signed by a sign language interpreter, and two by native Deaf signers), choosing the best version of both groups to continue with. Depending on possible local cultural issues, more versions might be necessary. Since resources for carrying out this kind of project are often limited, it will frequently be unfeasible to start with four or more translations. In this context we advise performing two translations using the experiences of the two translation groups to improve both versions. Continuing with at least two versions also serves to minimize the interviewer bias. At least one of the versions should be signed by a Deaf native signer of the target sign language. Other personal characteristics, depending on local culture, should be taken into account.

CONCLUSIONS

Specialized mental health care for deaf and hard of hearing clients has emerged during the last 50 years in many Western countries. The deaf and hard of hearing client group poses additional linguistic and social challenges to (mental) health care providers. This makes the process of diagnosing and treating deaf and hard of hearing clients more challenging than that for hearing clients. Various diagnostic tests have been used for these clients over the years. However, these tests were not specifically developed for this group or were translated only ad hoc. The reliability of such testing is questionable.

We advise the use of internationally validated written questionnaires in this population. However, questionnaires have to be carefully selected, translated, and modified both linguistically and culturally. If this is not properly done, bias can occur, potentially resulting in the misdiagnoses of many clients. With this chapter we hope to raise the awareness of this group's special needs, and we propose a set of guidelines (see Figure 1) for practitioners and researchers who would like to use standardized tests for deaf and hard of hearing sign language users.

NOTES

1. *Localization* refers to pointing to a specific place in space, whereby the pointing acquires semantic meaning (e.g., "first person" is pointing at yourself, while "second person" is pointing at the interlocutor or at the space directly in front of the signer).

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Appendix 1.

Translation Methodology for Translating Questionnaires into Sign Language

1. INTRODUCTION

This guideline is based on the WHOQoL (WHOQoL Group, 1998) and KIDSCREEN (Ravens-Sieberer et al., 2005; KIDSCREEN Group Europe, 2006) guidelines for translating questionnaires between written languages. Our adaptations conform to these international guidelines for translating into sign languages.

2.1. Overview

The translation process should focus on achieving conceptual equivalence of all versions rather than linguistic/literal equivalence. With regard to the translation methodology the forward-backward-forward technique should be applied.

In Step 1, the translation of the original questionnaire into the local written language (called the "intermediate language") should conform to the international forward-backward translation guidelines.

Step 2: Two independently working translation teams should translate the questionnaire into the local target sign language (TranslationF-1 and TranslationF-2) (cf. Figure 1, step 2).

In Step 3 (the following reconciliation), the two forward translation teams and one member of the research group review the two forward translations into the target sign language in order to create the reconciled forward translation. They identify problematic items, discuss the original formulation and intention of these items in the source language, and consider possible ways of translating them into the target language while meeting all of the demands of conceptual equivalence with the original questionnaire in the source language (cf. Figure 1, steps 3a and 3b).

In step 4, the reconciled forward translation should be translated back into the intermediate language (translationB-1 is the backward translation

of translationF-1, and translationB-2 is the backward translation of translationF-2). This should be done by independent professional sign language translators meeting the criteria as described later (cf. Figure 1, step 4).

In step 5 the members of the research group (and, if available, external experts with experience in instrument development and translation) and the forward translation team compare TranslationB-1 and TranslationB-2 with the original, source language version, thus reviewing the reconciled forward translation. If necessary adaptations are made, this version is considered the final forward translation (cf. Figure 1, steps 5a and 5b).

In step 6, subsequent to the generation of the final forward translation all reviews and translation data are sent to the developers of the original questionnaire for documentation and consultation. The objective of the consultation is to resolve both inadequate concepts of translation and all discrepancies between alternative versions (cf. Figure 1, step 6).

2.2. Pretranslation Phase

There are often no native speakers of both the target sign language and the original language available. Therefore a full forward-backward translation, conforming to international guidelines, must be made before starting the forward translation into a sign language.

2.3. Forward Translation

All of the translators working on the project should not only be professional and experienced translators but preferably also have experience with psychological and/or psychiatric testing or even test development.

We recommend that the forward translation team and the review committee be formed as a multidisciplinary team consisting at least of a professionally trained sign language interpreter (often a nonnative signer) and a native user of the target sign language. The team should also include a deaf communication specialist or a deaf sign language teacher, a linguistic specialist in sign linguistics, and a psychologist/psychotherapist with experience in the development of psychological tests.

All of the team members need to be:

- Signers of the target sign language
- Knowledgeable about the source language, the intermediate language, and the target sign language

- Familiar with the cultures of the region of the source language and of the target language/community (e.g., local Deaf culture)
- Experienced in test development and/or psychological testing of deaf and hard of hearing clients

Two translation teams should translate the questionnaire independently from each other into the target sign language. The translators are asked to use natural and acceptable language for the broadest audience and to be simple, clear, and concise in their formulations.

The following guidelines may be given to the translators:

- The translators should always focus on conceptual equivalence rather than on literal word-for-word translation. They should always try to grasp the most relevant meanings of the original terms and translate them accordingly.
- The translators should try to be simple, clear, and concise in their formulations; long sentences with many clauses should be avoided.
- The translators should take into account what typical respondents will understand when they see the items.
- The translators should take the age of the respondents into consideration and thus not use any jargon or terms that would be difficult to understand. The translation has to be clear, simple, and comprehensible. Double negatives should be avoided.

The two forward translators provide two forward translations: TranslationF-1 and TranslationF-2. The two versions are then reconciled in the next step.

2.4. Reconciliation of Items

Participants in the reconciliation procedure review the two forward translations. These participants should include the following:

- The two forward translators
- One member of the research group with good knowledge both of the source language and of the target language

To reconcile the two independent forward versions a reconciliation meeting should be held so that the two translations can be compared and assessed with regard to their conceptual equivalence, comprehensibility, and clarity of signs relative to the original questionnaire.

Participants in the reconciliation procedure should document their assessments item by item and, if neither is adequate, suggest another translation. They should focus on differences in culture and linguistics that may cause difficulties when transforming the source version into the target languages. The reconciled versions are to be derived by means of a subsequent discussion between the participants. In contrast to most international guidelines we advise that, after doing this, the participants proceed with both versions to minimize the interrogator bias. At least one of the versions has to be signed by a Deaf native user of the target sign language.

The reconciliation procedure may also produce valuable clues to differences in culture and/or linguistics that are relevant to the whole translation process.

2.5. Backward Translation

Designed to assess the conceptual equivalence of the reconciled forward translation and the source questionnaire, the backward translation serves as an instrument to measure the quality of the reconciled forward translation. The backward translation and the intermediate language version are supposed to be very similar, and if they are not, discrepancies such as problematically translated items will thus become manifest and can be corrected.

The backward-translator must be a professional sign language interpreter (if possible, a native signer) and should have familiarity with the cultures, both of the original language/ country as well as of the target signers (ecg local Deafculture), have experience in test development and/ or psychological testing of hearing impaired participants.

The reconciled forward translation is translated into the intermediate language by the backward translator, who should not have worked with the questionnaire before. The guidelines as described earlier (guidelines for forward translators) may also be given to the backward translator. The result of the backward-translation process is a translated version of the reconciled forward translation in the intermediate language.

2.6. Review of the Forward and Backward Translation

The review is designed to assess the entire forward-backward process in order to provide a final forward translation. Participants in the review procedure should include the following:

- Two members of the research group with good knowledge of both the source and the target sign language
- One of the forward translators
- If available, external experts with experience in instrument development and translation

Focusing on conceptual differences, the backward translation (in the intermediate language) is to be compared with the original, source language questionnaire. The participants review the translation process item by item by comparing the TranslationB items to the original source language items and suggesting a version for the final forward translation in the target sign language. This is done either by confirming the results of the reconciliation process or by suggesting an alternative translation if necessary. All changes in wording or meaning of the items are to be undertaken while generating the final forward translation.

In this final process, the review board is expected to ensure that the translation is simple, clear, and concise and, most important, that there are no conceptual discrepancies between the original (source language) and the final forward translation (target sign language). The focus should be on achieving conceptual equivalence and clarity as well as on using colloquial language.

2.7. Assessment of Conceptual Equivalence and First Harmonization of Problematic Items with the Developers of the Original Questionnaire

International harmonization is intended to ensure the comparability of the translated questionnaires. The reviews and translation data of problematic items will be sent to the developers of the original questionnaire. The objective of the consultation is to resolve inadequate concepts of translation as well as all discrepancies between alternative versions.

This is done to ensure and, if necessary, generate interconceptual equivalence.

2.8. Pretest (Cognitive Interviews)

The pretest is expected to show whether all of the items are comprehensible and acceptable.

Test participants should be provided with a quiet place for testing. With regard to their contribution to the test development procedure, tested individuals are to be informed of the objective of the pretest.

Pretesting is critical for identifying questionnaire problems such as misunderstandings about the intended meaning of items. Problems with item content, including confusion about the overall meaning of items, as well as misinterpretation of individual terms or concepts, can also be identified. Pretesting incorporates many different methods. We propose a cognitive interviewing method based on paraphrasing as a variant of the "think-aloud method" (asking respondents to repeat the item in their own words immediately after answering it).

This technique permits the researcher to determine whether the respondent understands the question and interprets it in the manner intended. It may also reveal better wordings for items.

Additionally, when using the "general probing method," respondents will be asked whether the items can be considered comprehensible and clear and whether they were difficult to answer.

2.9. International Harmonization

All translation reviews and translation data will be sent to the developers of the original questionnaire for documentation and consultation. The objective of the consultation is to resolve inadequate concepts of translation and all discrepancies between alternative versions.

The international harmonization procedure should be carried out by one or two members of the research group, if possible those who have already been involved in the review procedures. A telephone or Skype conference with one member of the questionnaire group should serve as a platform to discuss all questions about conceptual and cultural aspects of the item translations.

The final questionnaire versions are generated in the process of international harmonization and should preferably be subsequently tested in a validation study.