Italian Version of the YQOL-DHH Questionnaire: Translation and Cross-cultural Adaptation

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Abstract

Objective. To translate and cross-culturally adapt into Italian the YQOL-DHH (Youth Quality of Life Instrument–Deaf and Hard of Hearing Module), an instrument to evaluate the health-related quality of life in young deaf people. It could be useful for professionals, teachers, and parents to take care of deaf adolescents’ needs.

Study Design. Forward-backward translation, cross-cultural adaptation, and cognitive debriefing.

Setting. The cognitive debriefing was performed online with professionals and during clinical practice with deaf adolescents.

Methods. A methodological study was conducted according to the guidelines provided by the development team. The study consisted of a forward-backward translation and a cross-cultural adaptation. After the original authors’ confirmation, a cognitive debriefing was conducted with 30 professionals who work with deaf young people and with 10 deaf adolescents aged 11 to 18 years.

Results. For the linguistic translation and cross-cultural adaptation, some variations to the original instrument were made to obtain equivalence, such as the expression “deaf or hard of hearing” translated only with the Italian word “sordo.” During the cognitive debriefing, the clarity and comprehensibility of the items were reported by professionals and deaf adolescents. Eventually, the authors approved the final version.

Conclusion. The YQOL-DHH was translated and culturally adapted into Italian. The translated items were pertinent to the Italian culture and equivalent to the original ones. A validation study is suggested to make the instrument feasible for use in different clinical or educational contexts. In addition, to guarantee accessibility and autonomy for young deaf signers, Italian Sign Language translation of the questionnaire is suggested.

Keywords

translation, cultural adaptation, quality of life, youth, deaf, questionnaire

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Hearing loss is a very common disability among children and adolescents in the world; in fact, it is the fourth-highest cause of disability.1 In Italy, the incidence of neonatal hearing loss is 0.72 per 1000 infants, and it rises if there are audiologic risk factors.2,3 Hearing differences put children in a disadvantageous condition because hearing loss affects several life skills; it can cause delays in speech, language, cognitive, emotional, and social development.4 Hearing loss has effects on everyday life, but generic instruments cannot be used to determine what strongly affects quality of life (QoL) in the target population because they are not specific for children and adolescents deaf or hard of hearing. A recent study demonstrated that children with hearing loss reported lower QoL scores as compared with normal-hearing peers only in hearing-related instruments.5 This confirms the importance of using a specific tool.

QoL is defined by World Health Organization as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”6 Health-related QoL is an important measure that has to be assessed in several pathologic conditions. Even if its evaluation requires the use of ad hoc questionnaires, there are several tools used in the world to measure it in deaf children, but they are not specific. A recent review about the impact that

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pediatric hearing loss has on QoL. showed us different tools to evaluate it, but the authors concluded that “an instrument addressing the relevant domains of QoL in hearing impaired children, such as the Youth Quality of Life Instrument and the HEAR-QL [Hearing Environments and Reflection on Quality of Life], may be more sensitive in detecting differences in hearing related QoL.” In fact, only these 2 instruments are a condition-specific QoL measure in a population of children or adolescents who are deaf. The first is for 11- to 18-year-olds: the Youth Quality of Life Instrument–Deaf and Hard of Hearing Module (YQOL-DHH). The second, the HEAR-QL, has 2 versions: the HEAR-Q-26, which applies to 7- to 12-year-olds, and the HEAR-Q-28, which applies to 13- to 18-year-olds. Another important but older review showed that for children with cochlear implants, there were no specific instruments that assessed the impact of deafness on the QoL, but a recent study brought out a new condition-specific tool for children aged 6 to 12 years with cochlear implants: the QOL-Cl.

Adolescence is one of the most difficult periods of life. It is defined by World Health Organization as “the phase of life between childhood and adulthood, from ages 10 to 19 years. It is a unique stage of human development and an important time for laying the foundations of good health. Adolescents experience rapid physical, cognitive and psychosocial growth. This affects how they feel, think, make decisions, and interact with the world around them.” The QoL concept is crucial in youth with hearing loss because this period is characterized by social participation in everyday life. Still little is known about how this phase influences the QoL of teenagers who are deaf. Actually, only the YQOL-DHH and the HEAR-Q-28 are validated tools for this purpose. The first analyzes 3 domains: self-acceptance/advocacy, perceived stigma, and participation. The second analyzes 4 subscales: social interactions, school difficulties, feelings, and hearing situations. These tools are both valid instruments to evaluate QoL in adolescents with hearing loss, but the first includes a larger population in the adolescent period. This is the reason for the current translation.

Several things affect the QoL in deaf teenagers: the grade of hearing loss, the unilateral or bilateral nature of hearing loss, the precocity of detection and speech therapy, the devices (e.g., hearing aids, cochlear implants, and other assistive devices), the school placement, the language (i.e., spoken or sign language), and the quality of communication in different contexts of life (e.g., family vs school). It is important to analyze each of these aspects to better identify QoL levels regarding self-perception, the social relationship, and the environment. An article suggested that in a group of young people with the same degree of hearing loss, the factors that most affect their QoL are the technology used and the school setting.

Another important factor affecting the QoL in deaf or hard of hearing youth is the perceived level of difficulty in understanding conversations. It is significantly correlated to lower scores in participation, because it reflects the ability to interact with peers, and to higher scores in the perceived stigma; these are 2 domains of the YQOL-DHH.

Sufficient self-esteem is extremely important for psychological functioning. In fact, self-esteem is defined as the confidence in one’s worth or abilities, and it describes the overall subjective sense of personal value; it consists in how much you appreciate yourself. Children with hearing loss have lower levels of self-esteem in the social domains because they frequently experience lower language and communication skills. Kind of communication, type of education, and audiologic characteristics are related to self-esteem. In Italy we do not have a hearing-related QoL questionnaire for teenagers who could aid different clinicians (e.g., otolaryngologists, speech therapists, psychologists, audiometrists) and professionals (e.g., communication assistants, teachers) who work with people with hearing loss, to help them to optimize their well-being. There are different generic tools developed for adults and some others where parents or caregivers evaluate the child’s QoL, but not one is specific for age and pathology and, above all, self-reported.

The aim of this study is to translate and cross-culturally adapt the YQOL-DHH into Italian to have the first Italian QoL instrument for teenagers who are deaf.

Methods

The methodological study of translation and cross-cultural adaptation of the instrument into Italian did not require ethics committee approval.

The project started in May 2020 with first contact with the SeaQoL Group (Seattle Quality of Life Group) of the University of Washington, which developed and validated the instrument. The aim was to inform its members about the research project and ask permission to use their instrument. Prior consent was obtained and the user agreement signed.

Description of the Instrument

The YQOL-DHH is a questionnaire designed to assess the QoL of youth aged 11 to 18 years with hearing loss, whether acquired or congenital. It consists of 32 items that are separated in 3 domains: participation, self-acceptance/advocacy, and perceived stigma. The first two are positive, so a higher score indicates a better QoL, and the last one is negative, so a lower score indicates a better QoL. Each item is scored on an 11-point rating scale from 0 (not at all) to 10 (very much); the score per domain is transformed on a scale from 0 to 100. For each domain, there is a distinction between poor and good QoL.

The aim of this instrument is to assist clinicians, parents, or anyone close to deaf teenagers to better understand their QoL and better intervene according to their needs. There are 2 versions of the instrument: US English and American Sign Language. It can be administered in different ways: self-administered, paper and pencil, American Sign Language DVD, or DVD in Pidgin Signed English.

Translation and Cross-cultural Adaptation Process

This study of translation and cross-cultural adaptation into Italian was conducted according to the guidelines provided by the original authors. The process was developed in 3 phases.
Phase 1: Translation of the Original Instrument and Creation of a Reconciled Italian Version. The first step was the production of 2 independent forward translations from English to Italian and the reconciled version. Two consultants—local native speakers with knowledge in QoL and a high certified level in source language—were selected in June 2020: a speech therapist and a social worker/counselor. They independently produced a forward translation of the original source instrument (instructions, items, and response choices). In August 2020, both translators and the local project manager, who oversees the translation process, conducted a virtual meeting to create a pooled version. Both translations were compared and potential discrepancies annotated; appropriate formulation choices were then identified to solve the problems. During the reconciliation process, some variations were done according to the culture of the target country, and the original authors were contacted to discuss conceptual interpretation issues. At the end of this first phase, a reconciled version was ready.

Phase 2: Back Translation Into English and Comparison With the Original Version. The second step was the backward translation. It consisted of the translation of the reconciled Italian version of the instrument back to the source language. In August 2020, an Italian-American translator was selected (native speaker of the source language and bilingual in target language). The third consultant, blind to the original version of YQOL-DHH, produced a backward translation. The goal of this translation was to verify the reflection of the same content of the original questionnaire. A comparison between the translated version and the original source was conducted by the local project manager and the back translator during a video conference. No misunderstandings or inaccuracies in the intermediary forward version were found except for the definition “hard of hearing,” which is not used in the Italian clinical practice. Therefore, only the translation of the term “deaf” was left in the target language questionnaire. At the end of this phase, the second forward version was ready.

A report of the whole process and a translation grid in English with the discussed items were sent to the development team. Authors’ comments were received, and the prefinal version obtained confirmation.

Phase 3: Cognitive Debriefing and Approval of the Final Version. The prefinal version was ready for the cognitive debriefing. The aim was to cognitively debrief the translated questionnaire on a small sample of participants to “determine whether it is acceptable, understood, and whether the language used is simple and appropriate.” The Translation and Cultural Adaptation Manual for Seattle Quality of Life Group Instruments suggests,

The comprehension test should be performed through face-to-face cognitive debriefing interviews during which the interviewer may propose or test alternatives of translations (if this problem had been anticipated), or ask the person to propose alternatives. A report on the interviews should be produced in English: it should outline the number of subjects interviewed, their age, the time it took to complete the questionnaire, the difficulties encountered, the solutions suggested and retained and how the third version of the questionnaire was produced.

The result should be the final version of the questionnaire that has to be submitted to the instrument developers.

Unfortunately, due to the COVID-19 pandemic, this phase could not be done with deaf teenagers. Therefore, in November 2020, a panel was chosen consisting of 30 professionals who work with teenagers who are deaf: 14 speech therapists and 16 psychologists. They assessed the clarity, simplicity, and adequacy of the language for youth aged 11 to 18 years without cognitive disabilities and the comprehensibility of the items.

After a few months, it was possible to administer the questionnaire to deaf adolescents. The results were positive; thus, no item was modified, and the prefinal version became the final version of the instrument, approved by the original authors.

The flowchart in Figure 1 shows the process that had as its objective the conceptual equivalence between the instrument in its source language and that translated in the target language.

Results

During the first virtual meeting for the synthesized version of the forward translations between the local project manager and the translators, the best versions of the items or a combination of them was chosen, and the first Italian version was ready.

During the second virtual meeting between the back translator and the local project manager for the assessment of the conceptual equivalence between the backward translation and the original version, some changes were done. Therefore, the authors were contacted to make some variation to the original instrument according to the cultural adaptation. In fact, Italian clinical practice does not have 2 different terms to explain “deaf” and “hard of hearing”; just the translation of “deaf” is used, and the degree of hearing loss is specified. Thus, in the second Italian version of the instrument, “persona con difficoltà uditive” (person with hearing impairment), used to translate “hard of hearing,” was eliminated and only “deaf” was left (Table 1).

At the end of this process, the equivalence between the target language version and the original version was obtained, and the prefinal Italian version of the YQOL-DHH was ready for the last phase of cognitive debriefing.

As shown in the Methods section, this phase was made with a panel of experts. To have feedback about the instrument, the prefinal version was tested on 30 professionals who work with deaf teenagers and know their difficulties. The panel was composed of 14 speech therapists and 16...
psychologists. Their characteristics are shown in Table 2. The prefinal test was proposed to other figures, such as communication assistants, otolaryngologists, and audiometrists, but they did not participate.

For each item, questions were asked about the comprehensibility, the difficulty in answering, and the adequacy in the Italian culture. It was explained to these experts that the questionnaire is for deaf youth aged 11 to 18 years without any other difficulty.

The experts reported good understanding, clarity, and simplicity to answer the questions, with a percentage $>90%$. Only for item 26 (“Ho la sensazione di perdermi ciò che è importante per me perché sono sordo”) did some experts (13.3%) express doubts and uncertainties regarding the interpretation, but no variation was proposed because a percentage $>85%$ was considered good (Figure 2). As a result, in the content analysis, the agreement index was $>85%$ in all items.

Since February 2021 the phase of cognitive debriefing for the pretest stage was carried out with a small sample of the target population. The Italian version of the instrument (printed form) was administered to 10 deaf adolescents with different clinical and demographic characteristics (Table 3). For application of the questionnaire, the estimated self-administered time for the paper-and-pencil version was 10 to 15 minutes (mean $6$ SD, 12.5 $6$ 3).

The participants answered all items and reported good general understanding of the instrument. Three adolescents expressed doubts regarding item 1 (“Da persona sorda, ritengo che i miei genitori mi lascino lo stesso grado di indipendenza che viene dato ai miei coetanei”); they found it difficult because they did not know the meaning of word “indipendenza” (independence). Another adolescent reported difficulties in comprehending item 2 (“Mi sento incluso nelle attività da fare insieme in famiglia”), as he did not know the

Table 1. Items Changed for Cultural Adaptation to the Italian Clinical Practice.

| Original version | As a person who is deaf or hard of hearing . . . |
|------------------|-----------------------------------------------|
| Italian version 1 | Da persona sorda o con difficoltà uditive . . . |
| Back translation 1 | As a person who is deaf or with hearing impairment . . . |
| Italian version 2 | Da persona sorda . . . |
| Back translation 2 | As a deaf person . . . |
| Prefinal Italian version | Da persona sorda . . . |

Table 2. Characteristics of the Experts’ Panel.

| Variable                   | No. (%) |
|----------------------------|---------|
| Profession                 |         |
| Speech therapists           | 14 (46.7) |
| Psychologists               | 16 (53.3) |
| Age, y                     |         |
| 25-29                      | 17 (56.7) |
| 30-34                      | 6 (20) |
| 35-40                      | 2 (6.7) |
| >40                        | 5 (16.7) |
| Clinical experience, y     |         |
| 1-5                        | 15 (50) |
| 6-10                       | 9 (30) |
| >10                        | 6 (20) |

Figure 1. Flowchart of the translation and cross-cultural adaptation process.

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| >10                        | 6 (20) |
meaning of word “incluso” (included), and interpreting item 13 (“Da persona sorda, sento di avere sufficienti opportunità di fare cose con persone esterne alla mia famiglia”). Another participant did not know the meaning of word “coetanei” (peers) in item 11 (“Da persona sorda, sento che i miei coetanei sono disponibili ad aiutarmi quando ne ho bisogno”). The items were not modified after the pretest because it was sufficient to explain the meaning of the words to the adolescents. The prefinal version thus constituted the final version of the scale.

The Italian version of the YQOL-DHH is now ready for the validation process and is reported in the Appendix (available online).

**Discussion**

This study described the process of translating and cross-culturally adapting the YQOL-DHH questionnaire into Italian. The semantic, conceptual, and cultural equivalence was obtained between the original and the final version, and a few modifications were made for the items to be appropriate to Italian clinical practice. In fact, adaptation is necessary to obtain the tool’s pertinence to the target culture.

This instrument can be used for QoL evaluation in young deaf, and it is the first Italian instrument for this purpose. It is a useful tool for clinicians and researchers or anyone who deals with teenagers who are deaf. The Italian version of the YQOL-DHH can be easily integrated in the usual clinical care of the deaf patients for routine assessment and outcome measurement. It could be a practical instrument in the follow-up of patients with hearing loss and in the decision making for appropriate therapeutic interventions such as psychotherapy.

**Table 3. Sample Characteristics Submitted to the Pretest Stage of the YQOL-DHH (Italian Version).**

| Variable                  | No. (%)   |
|---------------------------|-----------|
| Age, y                    |           |
| 11-14                     | 5 (50)    |
| 15-18                     | 5 (50)    |
| Sex                       |           |
| Female                    | 6 (60)    |
| Male                      | 4 (40)    |
| Language                  |           |
| Italian                   | 9 (90)    |
| Bilingual                 | 1 (10)    |
| Hearing loss              |           |
| Moderate                  | 3 (30)    |
| Severe                    | 3 (30)    |
| Profound                  | 4 (40)    |
| Hearing devices           |           |
| Hearing aids              | 6 (60)    |
| Cochlear implant          | 4 (40)    |
| Etiology                  |           |
| Genetic                   | 3 (30)    |
| Unknown                   | 3 (30)    |
| Syndromic                 | 1 (10)    |
| Other                     | 3 (30)    |
| Onset age, y              |           |
| ≤3                        | 4 (40)    |
| >3                        | 2 (20)    |
| Unknown                   | 4 (40)    |
| No additional comorbidities| 10 (100)  |

**Scoring**

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Discussion

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Strengths of the Study
The translation and cross-cultural adaptation of the Italian version of the instrument was performed following the guidelines provided by original authors. It represents the first Italian hearing-related QoL questionnaire for teenagers with hearing loss.

Limits of the Study
The sample size of adolescents is quite small; we sampled the minimum of 10 participants as suggested by the guidelines. For the cognitive debriefing phase, we relied on professional perspectives. In a future psychometric validation study, we will have a larger sample of participants, and we will ask them about the clarity, simplicity, and comprehensibility of the tool to have more information.

Conclusions
The translation of the YQOL-DHH has proven to be linguistically and culturally accurate; the translated items were pertinent to the Italian culture and equivalent to the original ones. It is easy to understand and adequate to the targeted population. In addition, a validation study of this instrument is required for assessment of the psychometric properties to make it feasible for use in different clinical or educational contexts. An Italian Sign Language translation of the instrument is also suggested to guarantee accessibility and autonomy for young deaf signers.

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Author Contribution
Manuela Gragnaniello, concept design, presentation of the research, drafting the manuscript; Claudia Celletti, design and presentation of the research; Alessandra Resca, conduction and analysis; Giovanni Galeoto, data analysis; Filippo Camerota, design and presentation of the research

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Supplemental Material
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