

Translation and cross-cultural adaptation of the Unilateral Hearing Loss Questionnaire into brazilian portuguese

Tradução e adaptação transcultural do Unilateral Hearing Loss

Questionnaire para a língua portuguesa brasileira

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ABSTRACT

Purpose: Translate and make the cross-cultural adaptation of the Unilateral Hearing Loss Questionnaire. This questionnaire will be conducted with children / adolescents and also by caregivers into the Brazilian Portuguese language. Methods: The work was divided into two parts: translation and cross-cultural adaptation of the Unilateral Hearing Loss Questionnaire into Brazilian Portuguese and application to children/adolescents and caregives through the agreement percentage. Results: The analysis of the work of Brazilian translators considered semantic equivalence, and there were only two terminological adjustments. The back-translation did not present conceptual discrepancies, only linguistic problems. A preliminary comparison showed that the agreement percentage between the answers of caregivers and children/teenagers was satisfactory. Conclusion: The Unilateral Hearing Loss Questionnaire for children and parents was translated and cross-culturally adapted into the Brazilian Portuguese language showing semantic equivalence and idiomatic. The comparative descriptive analysis of the agreement percentage between children and caregivers showed a predictor in the equivalence of responses.

Keywords: Unilateral hearing loss; Children; Adolescents; Questionnaire; Translation

RESUMO

Objetivo: Tradução e adaptação transcultural do Unilateral Hearing Loss Questionnaire para a língua portuguesa brasileira, e aplicação do questionário em um grupo de crianças/adolescentes com perda auditiva unilateral, usuárias de aparelho de amplificação sonora individual, e seus respectivos pais/ responsáveis. Métodos: O trabalho foi dividido em duas partes: tradução e adaptação transcultural do Unilateral Hearing Loss Questionnaire para a língua portuguesa brasileira e aplicação nas crianças/adolescentes e em seus pais/responsáveis, a fim de realizar a comparação entre as respostas do questionário por meio do percentual de concordância. Resultados: A análise do trabalho dos tradutores brasileiros considerou a equivalência semântica e houve apenas dois ajustes terminológicos. A retrotradução não apresentou discrepâncias conceituais, apenas problemas linguísticos. Uma comparação entre as respostas dos entrevistados permitiu realizar o percentual de concordância. Conclusão: O questionário de perda auditiva unilateral para crianças e pais foi traduzido para o português brasileiro, apresentando equivalência e semântica e idiomática. A análise descritiva do percentual de concordância entre crianças/adolescentes com perda auditiva unilateral e seus pais/responsáveis mostrou ser um preditor na equivalência das repostas.

Palavras-chave: Perda auditiva unilateral; Crianças; Adolescentes; Questionário; Tradução

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INTRODUCTION

Unilateral hearing loss (UHL) is characterized by a partial or total reduction of hearing in only one ear, being light to severe and involving various difficulties in terms of language acquisition, speech, auditory perception, academic, social, and emotional ramifications⁽¹⁻⁴⁾.

The implementation of newborn hearing screening (NHS), via the Federal Law #12.303/2010, facilitated the early identification of hearing loss, as well as possible etiologies, with the aim of formulating adequate public policy. It is known that a large portion of the etiologies are associated with genetic factors that include malformation of the outer/middle or inner ears, post-natal infections, viral and bacterial infections, sudden loss, cranial trauma, and a considerable percentage of cases for which the etiology is unknown (others of unknown origin)⁽⁵⁻⁷⁾. The need for identification comes from the increase in UHL cases. However, despite the implementation of NHS, detection of UHL continues to be delayed, frequently being discovered only at school age⁽⁸⁻¹⁰⁾.

Children/teenagers with UHL require special care in terms of academic, communicative, and socioemotional dimensions. In the last 30 years, many studies have attempted to understand and respond to the complex questions involved in guaranteeing full academic, linguistic, and psychosocial access⁽¹¹⁻¹⁶⁾.

Academic abilities are most frequently highlighted, and many children are labelled hyperactive or inattentive^(6,11-13,17). Some authors mention individualized education plans, in which attention is given completely and solely to the child, as an alternative to minimize the harm stemming from UHL^(18,19).

Many studies consider the innumerable difficulties of children/ teenagers with UHL, mainly in situations of competitive noise, which frequently affect student behavior. Selecting the voice of the speaker and maintaining their attention is a challenge reported by children/teenagers, as well as by their parents^(5,18-26).

Since the 1980s, Bess and Tharpe⁽¹²⁾ had reported in their research that a portion of the problems confronted by children with UHL was explained by phenomena of binaural hearing, which include: binaural summation, which is the ability of the auditory system to integrate and utilize information captured by the two ears; and the head shadow effect, which is the capacity for attenuation of sound from one ear to the other, allowing one to perceive which side the "squelch" effect is coming from, which is the ability of the auditory system to separate sound and background noise from distinct sound sources⁽¹⁹⁾.

Recent studies have considered amblyaudia in individuals with UHL. Amblyaudia is an interference in the integration of binaural signals regarding the midbrain and the auditory cortex. These deficits can have harmful effects on hearing and language development when treatment is not realized early on with the aid of hearing and auditory ability therapies⁽¹²⁾.

One of the resources to mitigate the challenges faced by individuals with UHL is the indication of electronic devices, such as the hearing aids (HA), frequency modulation system (FM) and cochlear implant (CI). The degree of hearing loss and the full evaluation of the difficulties that children and teenagers present are the most important factors to consider in the choice of the technology to be tried out⁽²³⁾.

The objective of the HA is to provide, in a comfortable manner, maximal access to speech stimuli for children/teenagers, also considering the level of discomfort in the frequencies^(3,24,25).

In the Guidelines for Pediatric Amplification, The American Academy of Audiology (AAA), stipulates that children with UHL are candidates for amplification in the ear presenting hearing loss. Studies show that early diagnosis and treatment are of extreme importance from the outset on discovering the hearing loss, to reduce auditory impairments and the extent of cortical reorganization⁽¹⁾.

An ever-growing cohort of children with UHL is a reality for hearing health services and steps for adaptation and verification of HA are included in the optimal practices recommended by the aforementioned guidelines⁽³⁾. A gap remains, however, in the validation step, which includes protocols and questionnaires. In the Brazilian literature, no specific questionnaire for UHL was encountered. Within the context of a topic currently so amply investigated such as UHL, principally in children, these questionnaires respond to the needs and innovation in validating the adaptation process for HA in children with UHL, as well as to understand the place of the parents in this process, as active participants and observers of the child's behaviors of fatigue, attention, and frustration.

This study aimed to produce a translation and transcultural adaptation of the Unilateral Hearing Loss Questionnaire for Brazilian Portuguese and apply the questionnaire in groups of children/teenagers with UHL and who use of HA, and with their respective parents/caregivers, with the aim of comparing, by way of the percentage of agreement, the responses of the children/teenagers and the parents/caregivers.

METHODS

This study was approved by the Ethics Committee for Research with Human Beings of the ISCMSP, on January 17, 2019 – protocol number 003024/2019.

The study was carried out in two steps: in the first, the translation and transcultural adaptation of the Unilateral Hearing Loss Questionnaire to Brazilian Portuguese was realized. Following this, the instrument was applied to obtain the data, seeking to compare the responses to the questionnaire by way of the agreement percentage between the answers of the children/ teenagers and the parents/caregivers⁽⁹⁾.

In the first step, the translation and transcultural adaptation of the instrument followed the model of Beaton et al.⁽¹¹⁾. Initially, two Brazilian translators, one from the field of Audiology and the other not, worked by comparing two versions to formulate a single version. The latter was sent for 'retrotranslation' by a native English speaker who did not know the original version. The version was compared by the authors of the present study. After the comparisons, the questionnaire was sent to two more speech therapists for suggestions and adaptations of cultural terms and expressions, to guarantee the fidelity of the translation to the intentions of the author of the original version in English. The questionnaires in the versions translated to Portuguese were labelled: Unilateral Hearing Loss Questionnaire – Parents/ Caregiver (UHLQ-P).

The questionnaires UHLQ-C and UHLQ-P contained 15 specific questions, with six related to hearing behavior, regarding attention and fatigue; four related to sensory perception of sound; four related to acceptance and one, to satisfaction with HA. The questionnaires were scored according to the Likert scale and the answers express the opinions of the child/ teenager and parents/caregiver.

The translation and transcultural adaptation were authorized by the author of the original questionnaire, Dr. Sarah McKay, an audiologist at the Philadelphia Children's Hospital.

Following these steps, the questionnaire was applied with children with UHL and their respective parents/caregivers. The children were being monitored at the Clinic for Educational Audiology at the Irmandade da Santa Casa de Misericórdia São Paulo (ISCMSP) during the period from 2018 to 2019 and used HA. To obtain the percentage of agreement, the questionnaires were presented during patient visits to the Clinic for Educational Audiology at the ISCMSP and read aloud. The parents/caregivers were invited to respond to the UHLQ-P in a separate room, while the children/teenagers remained in the same room in which they were with the researcher, answering the UHLQ-C questionnaire.

Exclusion and inclusion criteria

Inclusion: children/teenagers with permanent UHL of a light to severe degree, aged between 9 to 13 years old, treated at the Educational Audiology sector of the ISCMSP, as well as their respective parents/caregiver.

Exclusion: children/teenagers with multiple impairments.

Participants

During the period from 2018 to 2019, 15 children/teenagers with UHL were sent to the Educational Audiology Clinic of the ISCMSP.

Of the 15 children/teenagers, five were excluded from the study for not fitting within the inclusion criteria. Therefore, 20 individuals participated (ten children/teenagers and ten parents/caregivers).

All the parents and caregivers were aware of the study procedures, giving their authorization in writing, by way of the Informed Consent Form (ICF). Children/teenagers signed the Informed Consent Term (ICT) according to the recommendations of the Committee of Ethics and Research with Human Beings of the institution.

Due to being a qualitative study, the data were tabulated and processed on a spreadsheet elaborated using Excel. This allowed for the descriptive analysis of the data by calculating the percentage of agreement between parents/caregivers and children/teenagers.

To illustrate the percentage of agreement, the results were presented in colors: the light grey area presenting strong agreement (parents and children strongly agreed with one another), the grey area for agreement (parents and children agreed, but not strongly) and the black area for disagreement (parents and children disagreed). The percentage of agreement consists solely of calculating the number of times that participants agreed with one another, independently of the category on the Likert scale (Figure 1).

RESULTS

Translation and retrotranslation

Only two questions from the Unilateral Hearing Loss Questionnaire underwent transcultural adaptation for Brazilian Portuguese after the translation and retrotranslation: question #1, which considers the behavior of the child/teenager in their social environment, and question #8, regarding sensory perception of sound by the child/teenager.

The adaptations of the questionnaire with the translation and transcultural adaptation are presented in the Chart 1.

Only one word amongst the alternatives of the Likert scale underwent adaptation for Brazilian Portuguese. The alternative to the original questionnaire is "improved"; in the translation, it was adapted to "better"; in the retrotranslation, to "got better" and in the adaptation, to "improved".

In the last question, (#15), the authors opted for not placing the subject in the alternatives. Both the question, and the translation and retrotranslation presented the subject in the phrases, however, in the adaptation, the authors opted for removing it. The adapted questionnaires are found in Appendix 1.

Parents/caregivers		Children/teenagers				
	Strongly disagree	Disagree	No change	Agree	Strongly agree	Total Score
Strongly disagree						
Disagree						
No change						
Agree						
Strongly agree						
Total Score						
% Agreement		%				

Figure 1. Agreement percentage of results: high agreement for light gray; grey for agreement and black for disagreement

Chart 1. Adaptation of two questions from the Unilateral Hearing Loss Questionnaire for Brazilian Portuguese

QUESTIONS (#)	TRANSLATION	RETRO TRANSLATION	ADAPTATION
1. Is less tired/fatigued at the end	1. Eu estou menos cansado/	1. Am less tired/fatigued at the	1. Eu estou menos cansado/
of the day	fatigado no final do dia	end of the day	exausto no final do dia
8. What is being said from a	8. O que é dito de longe (em outra	8. What is said from far away (i.e.,	8. O que é dito a uma certa
distance (e.g., from another room	sala ou fora de casa, por exemplo)	in another room or outdoors)	distância (em outra sala ou fora
or outside) has	sala ou lora de casa, por exemploj		de casa, por exemplo)

Key: # = question number

	Questions	Light gray area	Gray area	Black area	Total
	1	100%	0%	0%	100%
Behavioral issues	2	80%	10%	10%	100%
Benavioral ISSUES	3	60%	20%	20%	100%
	4	60%	30%	10%	100%
	5	60%	20%	20%	100%
	6	60%	30%	10%	100%
	7	70%	20%	10%	100%
Sensory perception of	8	90%	0%	10%	100%
sounds	9	40%	60%	0%	100%
	10	50%	40%	10%	100%
	11	70%	10%	20%	100%
Hearing device acceptance	12	70%	30%	0%	100%
	13	70%	10%	20%	100%
	14	50%	50%	0%	100%
Satisfaction	15	50%	50%	0%	100%

Figure 2. Descriptive analysis of agreement percentage between children/ teenagers and parents/ caregivers

The synthesis of the work of the Brazilian translators took semantic equivalence into account.

Characterization of the answers of the questionnaires

Figure 1 shows, both in the light grey area, which represents strong agreement, and in the grey area, which represents agreement between the answers of the parents with those of the children, that to a greater extent, parents/caregivers, and children/teenagers agreed regarding the block of behavioral aspects, sensory perception of sound, acceptance and satisfaction with the use of HA.

The black area represents disagreement between the answers, which shows the percentage being low or zero (0).

Participants

Of the 10 children/teenagers who were part of the sample, 4 were female and 6 were male, with an average age of 11.2 years. Seven (70%) children/teenagers presented moderate hearing loss, one (10%) light, one (10%) severe and one (10%) profound. Six children/teenagers reported making effective use of the HA and 4 reported not making effective use.

Of the 10 parents/caregivers, 80% were mothers, 10%, fathers and 10% grandparents. The mean age varied between 32 and 64 years.

Percentage of agreement:

Figure 2 shows the results of the comparison between the answers of the UHLQ-C and UHLQ-P. The light grey area represents strong agreement, that is, children/teenagers and parents/caregivers agreed equally. The grey area shows that, to a greater extent children/teenagers and parents/caregivers agreed regarding the blocks of the behavioral aspects, sensory perception of sound, acceptance, and satisfaction with the use of the HA. The black part represents disagreement between the answers, that is, children/teenagers and parents/caregivers disagreed with one another. It is notable that generally, the percentage of strong agreement (light-grey color) and agreement (grey) was observed for most of the questions and that there was a small percentage of disagreement (black area).

The questionnaire included 14 questions that were compared for the children/teenagers and parents/caregivers. In the following, the percentage of agreement regarding what they responded about how much they agreed or disagreed with the statements, beginning with the affirmation "Since I was fitted with a hearing device..."

 I am less tired/fatigued at the end of the day: one child reported strongly disagreeing and their parents also strongly disagreed. A second child disagreed with the statement, as well as their parents; 5 children and their respective parents agreed that there was no alteration; 2 children and their parents agreed with one another and one child, together with their parents, strongly agreed. Therefore, all (parents/caregivers and children) agreed equally 100% between the options;

- 2) Pay more attention When spoken to directly: 6 children and their parents agreed with one another; 2 children and their parents agreed strongly with one another; one child agreed strongly and their parents only agreed; one child agreed strongly, however their parents disagreed. Total agreement: 80%;
- 3) Am more able to directions When being spoken to: 2 children and their parents agreed with one another that there was no alteration; 2 children and their parents agreed with one another; 2 children and their parents strongly agreed; one child agreed while their parents disagreed and 2 children agreed while their parents strongly agreed. Total agreement: 60%;
- 4) Am less frustrated When listening from a distance or in noisy places: 6 children and their parents agreed with one another; one child disagreed and their parents reported no alteration; 2 children agreed while their parents reported no alteration and one child agreed while their parents disagreed. Total agreement: 60%;
- 5) Am more likely to start a conversation with others: 6 children agreed with their parents; one child agreed and their parents disagreed; one child disagreed and their parents agreed; one child agreed and their parents reported no alteration. Total agreement: 60%;
- 6) Am more willing to take part in group activities: 6 children and their parents agreed with one another; one child disagreed and their parents reported no alteration; one child strongly agreed and their parents reported no alteration; 2 children strongly agreed and their parents agreed. Total agreement: 60%;
- 7) What's being said in a noisy listening environment: 7 children agreed with their parents that there was improvement; one child reported improvement and their parents reported no alteration; one child reported great improvement and their parents reported improvement; one child reported a worsening and their parents reported improvement. Total agreement: 70%;
- What's being said from a distance (from another room or outside): 9 children agreed with their parents that there was improvement; one child reported improvement while their parents reported worsening. Total agreement: 90%;
- 9) Where sound is coming from has: 4 children agreed with their parents that there was improvement; one child reported improvement while their parents reported no alteration; one child reported no improvement while their parents reported a worsening; one child reported no improvement while their parents reported an improvement; one child reported a worsening, and their parents reported no improvement. Total agreement: 40%;
- 10) What someone says When speaking toward my side/ ear that has hearing loss has: 4 children agreed with their parents that there was improvement; one child and their parents agreed that there was no improvement; one child reported improvement while their parents reported

worsening; 4 children reported no improvement and their parents reported improvement. Total agreement: 50%;

- 11) Comfort of the device: 7 children and their parents agreed with one another; 3 children disagreed with their parents. Total agreement: 70%;
- 12) How the device sounds: 7 children and their parents agreed with one another; 3 children disagreed with their parents. Total agreement: 70%;
- 13) How the device looks: 7 children and their parents agreed with each other; 3 children disagreed with their parents. Total agreement: 70%;
- 14) Overall satisfaction with the device: 5 children and their parents agreed with each other; 5 children disagreed with their parents. Total agreement: 50%.

DISCUSSION

The translation and adaptation of the unilateral hearing loss questionnaires, named by the authors as Unilateral Hearing Loss Questionnaire – Children (UHLQ-C) and Unilateral Hearing Loss Questionnaire – Parents and Caregivers (UHLQ-P), seeks to redress the scarcity of materials for validation of the adaptation process for amplification devices in this specific population. Being questionnaires that investigate opinion, they allowed for the opening of a deeper dialogue regarding the benefits and satisfaction resulting from the use of HA, both with children with UHL and with their parents or caregivers.

Its use in hearing health services facilitates the evaluation and understanding of the expectations of this population. Evaluating weak and strong points in qualitative questionnaires helps to identify and resolve emotional and technical problems, optimizing the use of HA – when there are benefits -, reducing conflict between parents and children/teenagers, strengthening self-esteem, and helping to validate clinical practices. Even if it presents subjective characteristics, it is an important instrument when one compares the perception of parents regarding the auditory behavior, sensory perception of sound, acceptance and satisfaction with HA to the perspective of the child/teenager. (Appendix 2)

McKay⁽²¹⁾ was concerned with evaluating the perception of the family and of the child/teenager with the aim of comparing diverse behaviors that could be related not to the use of sound amplification, but rather to other questions, such as prejudice against the use of HA or immaturity.

Studies used other instruments to evaluate the linguistic competence of children or satisfaction with the use of HA, but did not determine a parameter for comparison of the benefits between parents and children^(9,20,25).

In the present study, all the children/teenagers used the conventional, multi-brand HA. Time for daily use of the device was not considered (Datalog).

Of the ten children/teenagers who participated in the study, only three were discovered to have UHL at birth, not through the Newborn hearing screening, however, but via a diagnostic hypothesis of genetic syndrome and non-genetic syndrome (malformation of the outer ear, genetics and VACTERL syndrome). Some authors describe, in their studies, the importance of the Newborn hearing screening for the early identification of UHL, as well as its probable etiologies^(13,22,24,27). In the present study, no child/teenager was diagnosed by Newborn hearing screening, which agrees with a previously published study, in which the detection of UHL was delayed, often discovered at school $age^{(28)}$.

It is known that there are people with UHL who do not present any complaints. Therefore, these numbers do not appear in medical checkups or even at clinics for the use of electronic devices. However, using the observed numbers, it is possible to enumerate and learn about the difficulties involved. Many studies, therefore, are increasingly showing more results related to the academic, social, and emotional difficulties faced by these individuals. The aim of this study, currently, was to propose a validation model for the adaptation process for the HA.

It is common to encounter in successive studies results related to the social, emotional, and academic difficulties of this population^(4,5,8-10,17), which justifies the importance of an instrument which evaluates the benefits and satisfaction with the use of the HA.

Assuming a commitment to a more aware treatment regarding the needs and conflicts of children with UHL is an important factor in the emotional relationship and support between parents and children. The decision between the choice to use HA or not for children/teenagers with UHL is a difficult and frequently fraught process, given that in the end, it is they who hear. Therefore, comparing the opinions of children and parents represents a positive step, since it allows for the opening of a space for issues that often go unacknowledged.

Despite the number of participants having been reduced to carry out a statistical analysis, moments of growth in the relationship between parents/caregivers and children could be observed. They were lighthearted moments, when both parties shared the same opinion, or even when their opinions diverged. Future research is recommended for the validation of the instrument.

CONCLUSION

The unilateral hearing loss questionnaire for children and parents was translated into Brazilian Portuguese, presenting equivalence and idiomatic semantics. The descriptive analysis of the percentage of agreement between children/teenagers with unilateral hearing loss and their parents/caregivers was found to be a predicter in the equivalence of the answers.

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Appendix 1. Unilateral Hearing Loss Questionnaire – Children and teenagers (UHLQ-C)

Patient Name:	
Device:	

DN:_____ Today's date:_____

Please check how much you agree or disagree with the following statements					
Since being fit with a hearing device, I	Strongly disagree	Disagree	No change	Agree	Strongly agree
Am less tired/fatigued at the end of the day					
Pay more attention when spoken to directly					
Am more able to follow directions when being spoken to					
Am less frustrated when listening from a distance or in noisy places					
Am more likely to start a conversations with others					
Am more willing to take part in group activities					
Additional comments:					

Please check the best answer to complete the following statements						
Since being fit, my ability to understand	Greatly worsened	Worsened	No change	Improved	Greatly improved	
What is being said in a noisy listening environment (e.g, in a group or restaurant) has,						
What is being said from a distance (e.g , from another room or outside) has)						
Where sound is coming from has						
What someone says When speking toward my side/ear that has hearing loss has						
Additional comments:						

Please rate your satisfaction with your hearing device						
Very Dissatisfied Dissatisfied Neutral/ not sure Satisfied Very satisfied						
Comfort of the device						
How the device sounds						
How the device looks						
Ovewall satisfaction with the device						
Additional comments:						

How do you feel about your decision to get a hearing device? (check one box)

□ Wish we had not done it

□ Wish we had waited until later

 \Box Glad we did it

 \square Wish we had it sooner

 \square Not sure

Is there anything else (positive or negative) that you would like to share about your experience since being fit with a hearing device?

Appendix 2. Unilateral hearing Loss Questionnaire - Parents and Caregivers (UHLQ-R)

Patient	Name:
Device:	_

DN:_____ Today's date:

Please check how Much you agree or disagree with the following statements						
Since being fit with a hearing device, my chid	Strongly disagree	Disagree	No change	Agree	Strongly Agree	
Is less tired/fatigued at the end of the day						
Pays more attention When spoken to directly						
Is more able to follow directions when being spoken to						
Is less frustrated When listening from a distance or in noisy places						
Is more likely to start a conversations with others						
Is more willing to take part in group activities						
Additional comments:						

Please che	Please check the best answer to complete the following statements					
Since being fit, my child's ability to understand	Greatly worsened	Worsened	No change	Improved	Greatly improved	
What is being said in a noisy listening environment (e.g, in a group or restaurant) has,						
What is being said from a distance (e.g , from another room or outside) has)						
Where sound is coming from has						
What is being said Where someone speaks toward his/her side/ear that has hearing loss has						
Additional comments:						

Please rate your satisfaction with your hearing device						
Very dissatisfied Dissatisfied Neutral / not sure Satisfied Very satisfied						
Comfort of the device						
How the device sounds						
How the device looks						
Ovewall satisfaction with the device						
Additional comments:						

How do you feel about your decision to get a hearing device? (check one box)

- \square Wish we had not done it
- \Box Wish we had waited until later
- \square Glad we did it
- \Box Wish we had it sooner
- \square Not sure

Is there anything else (positive or negative) that you would like to share about your experience since being fit with a hearing device?