

# Original Article Artigo Original

- Larissa de Almeida Carneiro<sup>1</sup>
  - Daniele Batista Nerv<sup>1</sup>
- Rebeca Liaschi Floro Silva<sup>1</sup>
  - Amanda Salimon<sup>1</sup>
- Thais Corina Said de Angelo<sup>1</sup>
- Camila Oliveira Souza Tamura<sup>1</sup>
  - Luciana Alves Duarte<sup>1</sup> (D)
  - Eduardo Jannone da Silva<sup>1</sup>
- Natália Barreto Frederique Lopes<sup>1</sup>
  - Adriane Lima Mortari Moret<sup>1</sup>
- Regina Tangerino de Souza Jacob<sup>1</sup> (D)

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#### Correspondence address:

Regina Tangerino de Souza Jacob Faculdade de Odontologia de Bauru -FOB, Universidade de São Paulo - USP Al. Octavio Pinheiro Brisola, 9-75, Vila Universitária, Bauru (SP), Brasil, CEP: 17012-901.

E-mail: reginatangerino@usp.br

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# Empowerment in hearing rehabilitation: translation of self-advocacy checklists

O empoderamento na reabilitação auditiva: tradução dos questionários de autoadvocacia

#### **ABSTRACT**

Purpose: To translate and cross-culturally adapt to Brazilian Portuguese four instruments for assessing self-advocacy skills of users of electronic hearing devices: the "I can" Self-Advocacy Checklist and three versions of the Audiology Self-Advocacy Checklist (ELEMENTARY SCHOOL, MIDDLE SCHOOL and HIGH SCHOOL). Methods: The translation process was adapted from the guidelines of Beaton et al. (2000). The prefinal version was pre-tested in two groups. Group 1 (G1) was composed of 14 teachers of adolescents with hearing loss. Group 2 (G2) was composed of 15 adolescent patients with hearing loss, electronic assistive device users, who use oral language as their primary form of communication. Results: The instruments were translated as Checklist de autoadvocacia "Eu consigo" e Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I, Ensino Fundamental II and Ensino Médio. G1 did not report difficulties regarding the terms used in the checklists; however, they reported difficulties completing the student's progress. The audiologists who used the checklists to interview G2 did not report difficulties regarding the use of the instrument. Therefore, after pre-testing the prefinal version, there was no need to make changes to the instruments, which were then presented as the final version. Conclusion: All Self-Advocacy Checklists were translated and cross-culturally adapted into Brazilian Portuguese and are valid instruments to measure the self-advocacy skills of students with hearing loss in a clinical context.

#### **RESUMO**

Objetivo: Traduzir e adaptar culturalmente para o português brasileiro os questionários Self-Advocacy Checklist "I can", Audiology Self-Advocacy Checklist - ELEMENTARY SCHOOL (ASAC-ES), Audiology Self-Advocacy Checklist - MIDDLE SCHOOL (ASAC-MS) e Audiology Self-Advocacy Checklist - HIGH SCHOOL (ASAC-HS), para avaliar os habilidades de autoadvocacia de usuários de dispositivos eletrônicos auditivos. Método: A tradução foi realizada por meio de uma adaptação das diretrizes de Beaton et al. (2000). A versão pré-teste foi aplicada em dois grupos. O Grupo 1 (G1) foi composto por 14 professores de adolescentes com deficiência auditiva. O Grupo 2 (G2) foi composto por 15 pacientes adolescentes com deficiência auditiva, usuários de dispositivos eletrônicos auditivos, que fazem uso da linguagem oral como forma primária de comunicação. Resultados: Os instrumentos foram traduzidos como Checklist de autoadvocacia "Eu consigo" e Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I, Ensino Fundamental II e Ensino Médio. Para o G1, não houve relato de dificuldade em relação aos termos utilizados nos protocolos, porém, relataram dificuldades em relação ao preenchimento do progresso do estudante. Para o G2, as fonoaudiólogas que aplicaram os instrumentos em forma de entrevista não relataram dificuldade quanto ao uso do instrumento e sua aplicação. Após a aplicação da versão pré-teste, não houve necessidade de fazer alterações nos instrumentos, os quais foram apresentados como versão final. Conclusão: As Checklist de autoadvocacia foram traduzidas e adaptadas culturalmente para o português brasileiro e são instrumentos válidos para a mensuração das habilidades de autoadvocacia de estudantes com deficiência auditiva em contexto clínico.

Study conducted at Departamento de Fonoaudiologia, Faculdade de Odontologia de Bauru - FOB, Universidade de São Paulo - USP - Bauru (SP), Brasil.

<sup>1</sup> Faculdade de Odontologia de Bauru – FOB, Universidade de São Paulo – USP - Bauru (SP), Brasil.

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#### INTRODUCTION

People with disabilities suffer from exclusion and disempowerment, which hinder their experience of their fundamental human rights, such as leisure, culture and education<sup>(1)</sup>.

Based on the philosophical, scientific and social approaches of empowerment, the term "self-advocacy" emerged to encourage individuals to advocates for themselves and, thus, fight against the disempowerment promoted by society<sup>(2)</sup>.

The study of self-advocacy emphasizes the need to inform and train individuals with disabilities. Empowering individuals to become self-advocates, to fight for their rights, is a way to help them determine and achieve their goals, defend their interests, and advocate for the need to be heard and have the freedom to make decisions. Additionally, for students with disabilities, self-advocacy can also be considered a protective factor for psychosocial and academic problems<sup>(1,3)</sup>.

The importance of self-advocacy skills for adolescents is more evident, as they will soon transition to adulthood. However, the early practice of self-advocacy in children has great benefits. When self-advocacy and self-determination are stimulated since childhood, they provide a better quality of life for children with disabilities, having better preschool results and increased participation in academic activities<sup>(4)</sup>.

Young people with hearing loss (HL) who have difficulties communicating may have social and school problems. The association of psychosocial and academic factors with communicative difficulties can reflect on the development of their identity and influence their vision about themselves, that is, their self-concept<sup>(4-6)</sup>.

Thus, it is crucial to support and prepare these adolescents to develop self-advocacy since childhood and, consequently, learn strategies for conflict resolution<sup>(4,7)</sup>. Some authors have found strong evidence that children with HL are at higher risk of victimization at school when compared to the general population. In the study, 87 children and adolescents with HL, aged 7 to 18 years, users of electronic devices were analyzed. The authors concluded that this population has a significantly higher incidence of bullying than the general population, especially adolescents with HL (50.0% vs. 28.0%)<sup>(8)</sup>. They endure bullying mainly by exclusion (26.3% vs. 4.7%) and coercion (17.5% vs. 3.6%)<sup>(8)</sup>.

Due to the need for validated instruments of simple completion to identify and monitor self-advocacy in children and adolescents, authors Johnson and Spangler developed four self-advocacy checklists to be used in the school context: the "I can" Self-advocacy Checklist, the Audiology Self-Advocacy Checklist - ELEMENTARY SCHOOL (ASAC-ES), the Audiology Self-Advocacy Checklist - MIDDLE SCHOOL (ASAC-MS) and the Audiology Self-Advocacy Checklist - HIGH SCHOOL (ASAC-HS)<sup>(6)</sup>.

The instruments consist of a list of statements of self-advocacy skills and are quickly completed. The statements are divided into three areas: personal health/medical information, hearing devices and other assistive technology use, and accommodation and consumer awareness.

Originally, the instruments were designed to be completed by a teacher or a student with the help of a teacher, always with the assistance of an audiologist with experience in Educational Audiology. The teacher or student must check the statements that describe skills that the student can perform.

The "I can" Self-Advocacy Checklist does not have a final score to classify the student; however, it is possible to monitor the development of self-advocacy skills with its use.

The other instruments have a final score; the level of progress in a skill can be classified as 1 (introduced), 2 (in progress) or 3 (mastered), or the skill can be classified as "not introduced" (NI) or "not applicable" (NA). NI and NA do not add scores to the final score.

The final score is obtained by dividing the total score by the total possible points (45 if all skills are applicable, even if not all have been introduced). It is presented as a percentage and classified as follows: between 90-100%, the individual is considered proficient; between 65-89%, partially proficient; and below 65%, in development.

A developmental perspective of suggested skills expected for each age group is divided as follows: 1) foundation/support stage (3-6 years old); 2) discovery stage (6-9 years old); 3) exploration stage (9-12 years old); 4) co-empowerment stage (14-18 years old); 5) personal responsibility stage (18+ years old).

In the foundation/support stage (stage 1), the child is expected to understand and report if the amplification devices are functioning correctly.

In the discovery stage (stage 2), regarding health skills, the child is expected to understand and describe the basic principles of hearing, the basic causes of his/her HL, and the basic parameters of an audiogram (e.g., frequency and loudness). Regarding hearing technology skills, the child is expected to identify the basic parts of his/her electronic devices and manage their daily maintenance. The child should also describe how assistive technologies improve communication, identify accommodations to address personal communication needs (e.g., priority seating, sign language interpreter and captioning) and use these accommodation and communication strategies in the classroom.

In the exploration stage (stage 3), regarding his/her health skills, the child is expected to describe basic treatments and accommodations for HL, communication strategies, his/her own hearing status, basic communication implications of his/ her hearing status, HL prevention strategies, and concepts of privacy and confidentiality. Regarding his/her hearing technology skills, the child should understand and notify the teacher when devices are not working properly and understand the flexibility of devices and the basic functioning of assistive technology devices. In addition, he/she should use the devices in various environments and actively participate in training people with whom he/she lives on the use of devices. Regarding educational services and communication access, the child should describe basic characteristics of successful communication in the classroom and describe the communication challenges and strategies that work. He/she is also expected to develop a letter that identifies the needed accommodations and present them at education and access planning meetings. He/she should also describe the needed accommodations to teachers, and recognize when communication fails and use communication repair strategies. Finally, he/she should be able to understand the basic legal rights under education and disability rights laws.

In the co-empowerment stage (stage 4), regarding his/her health skills, the adolescent is expected to develop a script for disclosing hearing status information and required accommodations and identify relevant medical/health specialists, credentials, supporting roles, and how to locate them. Also, he/she should know how to use resources to identify and access services and describe healthrelated privacy laws. Regarding his/her hearing technology skills, the adolescent is expected to demonstrate the ability to solve problems in all personal and hearing assistance technology, to know how to use the connectivity of personal and assistive devices with other technologies/equipment and demonstrate how to manipulate technology for various listening situations within the school and in the community. The adolescent should describe features of other assistive technologies (e.g., phone, activate captioning and device alerts, text messaging) and the cost of purchasing and maintaining hearing aids/cochlear implants/assistive technology devices, warranty and service plans, and funding options. He/she is also expected to know how to use the web and other sources to learn and find up-to-date information regarding HL treatment and necessary accommodations. Regarding educational services and communication access, the adolescent is expected to assert as a defender of him/herself, set boundaries, and voice complaints and needs. He/she should consistently employ communication repair strategies, identify academic needs, explain educational strengths and challenges, and describe and differentiate pertinent education and accessibility laws related to HL. In addition, the adolescent should describe the resources and services offered by institutions, organizations and agencies.

Finally, in the personal responsibility stage (stage 5), the young adult is expected to master all the skills mentioned above<sup>(6)</sup>.

These checklists and their respective scores allow quick identification of self-advocacy skills and, if necessary, the need for intervention.

For these instruments to be used in Brazil, their translation and validation into Brazilian Portuguese are necessary<sup>(9)</sup>. Therefore, this study aimed to translate and cross-culturally adapt to Brazilian Portuguese these four checklists for assessing self-advocacy skills of users of electronic hearing devices: the "*I can*" *Self-Advocacy Checklist* and the three versions of the *Audiology Self-Advocacy Checklist* (ASAC-ES, ASAC-MS and ASAC-HS)<sup>(6)</sup>.

#### **METHODS**

The study was approved by the Research Ethics Committee of the Bauru School of Dentistry, University of São Paulo, under numbers 3.718.085 and 2.909.498. All participants in the validation process signed the Consent Form.

The authors of the original version of the four checklists ("I can" Self-Advocacy Checklist, ASAC-ES, ASAC-MS and ASAC-HS)<sup>(6)</sup> authorized this study, the translation of these instruments into Brazilian Portuguese and confirmed their originality by electronic correspondence.

# Translation and cross-cultural adaptation

The translation and cross-cultural adaptation of the instruments to Brazilian Portuguese were conducted by adapting

the methodology designed by Beaton, Bombardier, Guillemin and Ferraz (2000). The methodology delineates guidelines for a process of cross-cultural adaptation that aims to produce equivalency between source text (instrument written in the language of the country in which it was created) and target text (instrument translated into a different culture). For that, they describe six steps that include both linguistic translation and cross-cultural adaptation<sup>(9)</sup>.

There are six steps described in the guidelines<sup>(9)</sup>: (1) Initial translation: at least two translators whose mother tongue is the target language produce the two independent forward translations; (2) Synthesis of the translations: the translators and a recording observer produce a consensus synthesis of the results of the translations; (3) Back translation: at least two translators, whose mother tongue is the source language, blinded to the original version, translate the text back into the original language; (4) Expert Committee: health professionals, language professionals and all the translators produce the prefinal version of the instrument for field testing; (5) Test of the prefinal version: a test is conducted between 30 to 40 individuals to assess the comprehension of the instrument in the target audience; (6) Submission: all versions are sent to the developer of the instrument or to the commission that is analyzing the process of translation and cross-cultural adaptation.

In this study, due to time restrictions, one translation and one back-translation were performed, which eliminated the second step of the guideline. It is important to note that the steps of translation and back-translation were conducted by professional translators, specialized in the Brazilian Portuguese-English translations.

#### Initial Translation

The commented forward translation of the checklists was the first step of the process.

The checklists were translated into Brazilian Portuguese (T) by a bilingual translator who graduated in Portuguese-English translations. In this step, consistency, style and semantic, idiomatic, experimental and conceptual equivalences were considered.

#### Back translation

With no knowledge of the original checklists, a second bilingual translator performed a back-translation (RT) into English, the original language of the source text.

# Expert Committee

According to the methodology employed<sup>(9)</sup>, a meeting was held with an expert committee to achieve cross-cultural equivalence. The committee was composed of the forward and back translators, one audiologist, and one professional specialized in the Brazilian Portuguese language. They compared and analyzed the original material (O), the translation (T) and the back translation (RT) to produce a prefinal translation (TF).

Before the consensus meeting, all participants were instructed by e-mail to consider the meaning and relevance of the concepts in the target audience's language and culture to define whether the four areas of equivalence had been achieved: semantic, idiomatic, experiential and conceptual.

Each expert received a table comparing all materials (O, T and RT) sentence by sentence and, to indicate the experts' evaluation, each sentence should be classified as equivalent item (+1), partially equivalent item (0), and non-equivalent item (-1). If the item was classified as 0 or -1, the expert should specify the area of equivalence to be reviewed during the meeting.

## Test of the prefinal version

According to the methodology, the field test of the translated instrument should be conducted on subjects or patients from the target setting<sup>(9)</sup>.

The prefinal version was tested in two groups:

Group 1 (G1) was composed of 14 school teachers from the state of São Paulo who answered the checklists according to their experience with students with HL. They were invited by e-mail to answer the checklists. Six teachers answered the Checklist de Autoadvocacia em Audiologia - Ensino Fundamental I (ASAC-ES); seven, the Checklist de Autoadvocacia em Audiologia - Ensino Fundamental II (ASAC-MS) and one, the Checklist de Autoadvocacia em Audiologia - Ensino Médio (ASAC-HS). Participants in this group did not answer the Checklist de autoadvocacia "Eu consigo" ("I can" Selfadvocacy Checklist) because they were not unavailable at the time. These teachers were participating in a course at the institution where this study was being developed. Therefore, they were not connected to Group 2, and the unequal distribution of teachers between the education stages (elementary, middle and high school) is justified;

Group 2 (G2) was composed of 15 patients from the institution's Audiology Clinic (Chart 1). They are all users of hearing aids (HA) or cochlear implants (CI) who use oral language

as the primary form of communication and are considered a level five in the language category<sup>(7)</sup>. The participants were divided into three groups according to their school level, with seven participants from elementary school (F1), four from middle school (F2) and four from high school (EM).

# Sample characterization

For the G2, five audiologists read the statements for each participant and checked the answers in the checklists. The interview happened individually; the participant and the interviewer were by themselves in an office room. The interview model was chosen due to the educational difficulties presented by students with HL and their limitations in answering the checklist on their own, in paper and pencil format, in a previous pilot study<sup>(10)</sup>. Therefore, in this study, the intervention of the interviewers was necessary: five audiologists with experience in Clinical and Educational Audiology read the statements and, during some moments, used communication strategies to explain the statement better.

# Analysis of results

The data collected by the checklists were transferred to a Microsoft Excel spreadsheet and quantitatively analyzed through box-plot charts.

# **RESULTS**

All modifications performed on the prefinal version of the *Checklist de autoadvocacia "Eu consigo"* ("*I can" Self-Advocacy Checklist*) and of the *Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I* (ASAC-ES), *Ensino Fundamental II* (ASAC-MS) and *Ensino Médio* (ASAC-HS) are available for access in the Supplementary Material (Comparative Table - Modifications) and summarized in Figure 1.

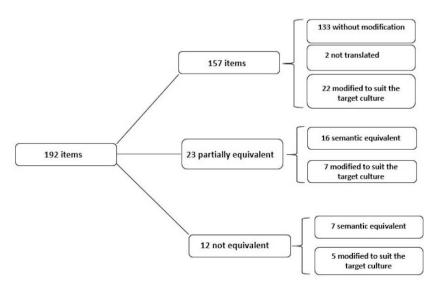


Figure 1. Illustration of the results of the expert committee meeting Caption: ES1<sub>G1</sub>: Elementary School - Group 1; F1<sub>G2</sub>: Elementary School - Group 2; F2<sub>G1</sub>: Middle School - Group 1; F2<sub>G2</sub>: Middle School - Group 2; EM<sub>G1</sub>High School - Group 1; EM<sub>G2</sub>: High School - Group 2

Chart 1. Demographic data of G2 participants regarding chronological age, hearing age, sex, school year, the average educational level of parents/quardians, socioeconomic status<sup>(8)</sup>, type and degree of hearing loss, electronic devices used and whether he/she uses FM System.

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Student	Chronological age (years)	Hearing age (years)	Sex	School year	Average level of education of parents/ guardians	Socioeconomic status	Type and degree of hearing loss	Electronic device used	Use of FM System
S1	19	13	F	finished HS	finished HS	upper-low class	sensorineural severe bilateral	bilateral HA	No
S2	13	13	F	MS - 9 <sup>th</sup> year	finished HS	upper-low class	sensorineural profound bilateral	bilateral CI	No
S3	17	13	М	HS - 1 <sup>st</sup> year	finished HS	low class	sensorineural profound bilateral	Bilateral Cl	Yes
S4	14	14	F	MS - 9 <sup>th</sup> year	finished HS	upper-low class	sensorineural profound unilateral (RE)	unilateral HA	Yes
<b>S</b> 5	14	3	F	MS - 9 <sup>th</sup> year	-	upper-low class	sensorineural moderate bilateral	bilateral HA	Yes
S6	10	6	М	MS - 6 <sup>th</sup> year	finished HS	upper-low class	sensorineural moderate bilateral	bilateral HA	Yes
<b>S</b> 7	8	8	М	ES - 3 <sup>rd</sup> year	finished HS	lower-low class	sensorineural severe unilateral (RE)	unilateral HA	No
S8	16	13	М	HS - 3 <sup>rd</sup> year	completed HE	upper-low class	sensorineural moderate (RE) and severe (LE)	bilateral HA	Yes
S9	10	10	М	ES - 4 <sup>th</sup> year	finished HS	upper-low class	moderate conductive unilateral (RE)	unilateral HA	Yes
S10	10	9	F	-	finished HS	upper-low class	sensorineural profound bilateral	bilateral HA	
S11	7	2	М	ES - 2 <sup>nd</sup> year	finished HS	upper-low class	sensorineural moderate bilateral	bilateral HA	No
S12	9	9	F	ES - 4 <sup>th</sup> year	finished HS	upper-low class	sensorineural moderate unilateral (LE)	unilateral HA	No
S13	19	15	F	finished HS	completed HE	М	sensorineural profound bilateral	CI (RE) and HA (LE)	
S14	13	6	М	MS - 8 <sup>th</sup> year	completed HE	lower-average	sensorineural moderate bilateral	bilateral HA	No
S15	8	4	М	ES - 2 <sup>nd</sup> year	completed HE	lower-average	sensorineural profound (RE) and severe (LE)	CI (RE) and HA (LE)	No

Caption: F: Female; M: Male; S: Student; RE: right ear; LE: left ear; HS: high school; MS - middle school; ES: elementary school; HE: higher education; HA: hearing aids; CI: cochlear implant

Figure 2 presents the results obtained in the *Checklist de Autoadvocacia em Audiologia – Ensino Fundamental I* (ASAC-ES), *Ensino Fundamental II* (ASAC-MS) e *Ensino Médio* (ASAC-HS). The results are presented according to the scores calculated through the two groups' answers  $(F1_{G1}, F1_{G2}, F2_{G1}, F2_{G2}, EM_{G1}, EM_{G2})$ .

In G1, the teachers reported their main difficulty was completing the student's progress (NA - not applicable, NI - not introduced, 1 - introduced, 2 - in progress and 3 - mastered), which is defined by calculating the final score and percentage. One teacher completed more than one level of progress on the

same item; eight teachers miscalculated the percentage; five were unable to calculate the percentage; one teacher correctly calculated the sum and the proficiency percentage.

They did not report difficulties regarding the terms used in the instruments.

For G2, audiologists did not report any difficulties regarding the use of the instruments in the interview. For this reason, no standardized assessment was used to measure the difficulties. The perception of difficulties was subjective and individual. When the interviewee/participant presented difficulties, each audiologist noticed and then used communication strategies to measure the level of progress. According to the audiologists,

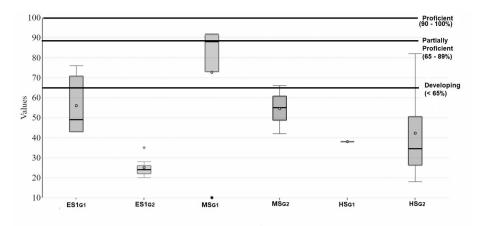


Figure 2. Results obtained in the Checklist de Autoadvocacia em Audiologia – Ensino Fundamental I (ASAC-ES), Ensino Fundamental II (ASAC-MS) e Ensino Médio (ASAC-HS) answered by the two groups participating in the study

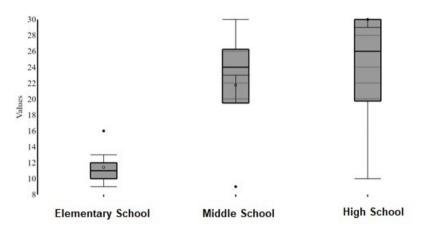


Figure 3. Results of the Checklist de autoadvocacia "Eu consigo" ("I can" Self-advocacy Checklist) answered by G2

the testing process with the instruments was quick and easy. The checklists presented a clear, simple language, and the terms that were unfamiliar to the participant were related to skills to be developed.

Figure 3 presents the results of the *Checklist de autoadvocacia* "Eu consigo" ("I can" Self-advocacy Checklist) answered only by G2.

After the pre-test, there was no need to modify the *Checklist de autoadvocacia* "Eu consigo" ("I can" Self-Advocacy Checklist) and of the *Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I* (ASAC-ES), Ensino Fundamental II (ASAC-MS) and Ensino Médio (ASAC-HS). They were presented as the final version and are available for download at the Supplementary Material (Self-advocacy Checklists).

#### DISCUSSION

#### Translation and cross-cultural adaptation

The Checklist de autoadvocacia "Eu consigo" ("I can" Self-Advocacy Checklist) and the Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I (ASAC-ES), Ensino

Fundamental II (ASAC-MS) and Ensino Médio (ASAC-HS) were translated and adapted appropriately according to the cross-cultural adaptation standards. No difficulties in the process of understanding the checklists were identified. The steps of linguistic translation and cross-cultural adaptation between different cultures are necessary to maintain the validity of the content at a conceptual level for the instrument to be used in other countries<sup>(9)</sup>.

During the expert committee meeting, the influence of sociocultural status and education level of the target audience (e.g., students with HL and teachers of students with HL) in understanding the instruments' statements were highly considered. Therefore, the wording of some items was modified to adapt some terms to the target setting. For example, "pitch" and "loudness" were expressions preserved in the steps of translation and backtranslation because they are commonly used in Audiology in Brazil. However, the expert committee decided to translate them and add examples. Thus, "pitch" was translated to "frequência (grave e agudo)" (frequency (low and high)) and "loudness" to "intensidade (forte e fraco)" (intensity (strong and weak)) because some participants might have difficulties in understanding them. In the same way, the expressions "continuum de audibilidade"

(audibility continuum) and "estática" (static) were modified to "limiar auditivo" (hearing threshold) and "chiado" (wheezing), respectively.

In the statement regarding the development of a script for disclosing hearing status information and required accommodations, the examples "sentar próximo à fonte sonora, uso de cortinas e cortiças, não sentar perto de janelas e paredes, etc." (sitting close to the sound source, using curtains and cork boards, not sitting near windows and walls, etc.) were added.

In the topic regarding the use of electronic devices, the options "aparelhos de amplificação sonora individual (AASI) ou implante coclear (IC) ou aparelho auditivo ancorado no osso (exemplo: BAHA) e Sistema FM ou microfone remoto" (hearing aids (HA) or cochlear implant (CI) or bone-anchored hearing aid (example: BAHA) and FM system or remote microphone) were added. In addition, each item was subdivided in this topic so the patient could specify in each statement to which type of device he/she is referring.

The broad term "lingua de sinais" (sign language) was adapted to "Libras," which refers to the Brazilian Sign Language, and "leitura da fala" (speech reading) to "leitura orofacial" (orofacial reading), a term commonly used in the national scenario.

The laws and acronyms referring to the resources and support services mentioned in the original instruments refer to the North American context; therefore, they were modified to follow Brazilian laws and settings. In the original context, self-advocacy skills are objectives of the Individualized Education Program (IEP) as determined by the Individuals with Disabilities Education Act(11). In Brazil, the inclusion of students with HL in school is ensured by the public authorities through official documents, among them, the Lei de Diretrizes e Bases da Educação Nacional - LDBN/9394/96 and recently Lei nº 13.146/15, which institutes the Lei Brasileira de Inclusão da Pessoa com Deficiência (Brazilian Law for the Inclusion of Persons with Disabilities)(12). The Plano Educacional Individualizado (PEI) (Individualized Educational Plan), present in the Brazilian translation, refers to the content to be worked at the school in a personalized way: the content has to consider the needs of each student, the learning of Libras or the use of assistive devices, e.g., the FM System.

## Checklist pre-test

The original instruments were developed for the school context, to be completed by a teacher or by a student with the help of a teacher and with the assistance of an audiologist with experience in Educational Audiology. In North American, speech-language therapists and audiologists are independent professions; however, these professions are the same in Brazil. The professional is called "fonoaudiólogo," a term used in the Brazilian translation for "audiologist".

In addition, Educational Audiology is an area of expertise recognized by North American institutions, such as the American Academy of Audiology<sup>(13)</sup> and the American Speech-Language-Hearing Association<sup>(14)</sup>. According to the documents *Scope of Practice in Audiology* published by the American Speech-Language-Hearing Association<sup>(14)</sup> and *Educational Audiology* 

Scope of Practice published by the Educational Audiology Association<sup>(15)</sup>, the audiologist working in the educational environment must support the academic and social performance of school-age children and adolescents with HL, participating as a member of the school's multidisciplinary team. The North American Individuals with Disabilities Education Act<sup>(16)</sup> also directs the audiologist's activities in the school context.

In Brazil, according to *Lei 6965/81*, which regulates the *fonoaudiólogo* profession, the professional must part of the guidance team and participate in the school planning, including preventive measures regarding audiology concerns. However, unlike the North American context, we do not have educational audiologists in schools since this is not a specialty recognized by the *Conselho Federal de Fonoaudiologia* (Brazilian Federal Council of Speech Therapy and Audiology)<sup>(16)</sup>.

On December 11, 2019, the *Lei 13.935* was enacted, regulating psychology and social service professionals' activities in elementary, middle and high schools through multi-professional teams to meet the needs and priorities defined by education policies. However, despite the demand for *fonoaudiólogos* (speech therapists and audiologists), these professionals were not included in this law<sup>(17)</sup>.

In Brazil, teachers receive students with different needs, and they often are not prepared to teach students with HL who use electronic hearing devices<sup>(18,19)</sup>. In addition, they usually do not have specialized support/guidance from health professionals. Thus, we emphasized the importance of the audiologist in the educational setting as part of the multi-professional team.

In this study, during the course at the institution, teachers (G1) who completed the checklists (prefinal version) had previous contact with REMIC<sup>(20)</sup>, a website about assistive technologies for students with HL. Therefore, these teachers became familiar with audiology concepts even before being invited to answer the instruments, which justifies their easy understanding of the terms used in the statements. So, there were no changes in the wording of the prefinal version of the instruments at that time.

After the pre-test, the teachers presented difficulties in filling the student's progress in the checklists, despite their knowledge about the concepts mentioned in the statements. This is because the progress' level of students with HL is measured subjectively and depends on the knowledge and experience of who completes the checklists.

Considering the factors mentioned above, we believe the Self-Advocacy Checklists should not be used at schools. If the teacher does not have knowledge and experience about the topics covered in the statements, the score of the student's progress will not be reliable.

Given the previous experience of testing the checklist in a pilot study, we chose to interview the participants rather than the students completing the items themselves. In one study<sup>(21)</sup>, the researchers assessed the written language performance of children with HL and reported that most children in all the groups that were assessed underperformed the academic test. School performance below expectations is common for children and adolescents with HL<sup>(10)</sup>, whose school difficulties are caused by the limited communication with teachers and colleagues caused by their hearing loss<sup>(21,22)</sup>.

Since G2 did not report any difficulty completing and scoring the instruments, we recommend the instruments be used in a clinical context, specifically by professionals who work in hearing rehabilitation. Thus, the checklists can be used to guide students with HL, their family and their school about the self-advocacy skills developed and in progress.

# Importance of working with self-advocacy skills in the hearing rehabilitation process

The development of self-advocacy skills makes it possible to break the cycles of disempowerment<sup>(23)</sup>. The knowledge of oneself and one's rights are fundamental elements of self-advocacy. Individuals must understand and know themselves before expressing their needs and desires to others<sup>(24)</sup>. Self-advocacy skills should be encouraged from the beginning and can facilitate moments of transition during life<sup>(25)</sup>. It is worth mentioning that all participants in G2 had already attended or were attending therapy with audiologists at the institution; however, even with therapy and despite the scores getting higher with age (Figure 3), none showed proficiency in self-advocacy skills (Figure 2). Since awareness is an essential component for the development of self-advocacy, these findings confirm that students with HL should be taught from childhood the responsibility for their hearing devices and their use for access to communication and rights in the school and work environments<sup>(6)</sup>.

Researchers<sup>(26)</sup> studied the variables that facilitated or hindered the academic success of students with HL. Among the results, they reported that self-advocacy was a facilitator for nine (36%) of the 25 students evaluated. In agreement with that study, other researchers<sup>(2)</sup> also emphasize that implementing interventions such as self-advocacy is a strategy to support students with HL. Training these skills results in greater autonomy to appropriately use assistive technologies and the required accommodations for students in the classroom environment<sup>(7)</sup>.

Currently, there are no instruments to assess the self-advocacy skills of students with HL in the national literature; therefore, the Brazilian Portuguese translation of these checklists can contribute to filling this gap. We suggest the instruments be tested in a larger sample to evaluate the psychometric parameters.

#### **CONCLUSION**

The Checklist de autoadvocacia "Eu consigo" ("I can" Self-advocacy Checklist) and the Checklists de Autoadvocacia em Audiologia - Ensino Fundamental I (ASAC-ES), Ensino Fundamental II (ASAC-MS) e Ensino Médio (ASAC-HS) were translated and cross-culturally adapted to Brazilian Portuguese and are valid instruments to measure the self-advocacy skills of students with hearing loss in a clinical context. We suggest they be analyzed in a larger sample to evaluate their psychometric parameters.

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#### REFERENCES

- Ainscow M. Special needs in the classroom: a teacher education guide. Paris: UNESCO: 1994.
- Dantas T. Vivências de empoderamento e autoadvocacia de pessoas com deficiência: um estudo no Brasil e no Canadá. Educação Unisinos. 2017;21(3):336-44. http://dx.doi.org/10.4013/edu.2017.213.07.
- Michael R, Zidan HM. Differences in self-advocacy among hard of hearing and typical hearing students. Res Dev Disabil. 2018;72:118-27. http:// dx.doi.org/10.1016/j.ridd.2017.11.005. PMid:29128783.
- Kleinert JO, Harrison EM, Fisher TL, Kleinert HL. "I Can" and "I Did": selfadvocacy for young students with developmental disabilities. Teach Except Child. 2010;43(2):16-26. http://dx.doi.org/10.1177/004005991004300202.
- Antia SD, Rivera MC. Instruction and service time decisions: itinerant services to deaf and hard-of-hearing students. J Deaf Stud Deaf Educ. 2016;21(3):293-302. http://dx.doi.org/10.1093/deafed/enw032. PMid:27179117.
- Spangler, C. Supporting wellness and social-emotional competence. In: Johnson CDC, Seaton JB. Educational audiology handbook. 3rd ed. San Diego, CA: Plural Publishing; 2020. p. 363-401.
- Bevilacqua MC, Delgado EMC, Moret ALM. Estudos de casos clínicos de crianças do Centro Educacional do Deficiente Auditivo (CEDAU), do Hospital de Pesquisa e Reabilitação de Lesões Lábio-Palatais-USP. In: Anais do XI Encontro Internacional de Audiologia; 1996; Bauru. Bauru: HPRLLP-USP: 1996. Vol. 30.
- Warner-Czyz AD, Loy B, Pourchot H, White T, Cokely E. Effect of hearing loss on peer victimization in school-age children. Except Child. 2018;84(3):280-97. http://dx.doi.org/10.1177/0014402918754880.
- Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine. 2000;25(24):3186-91. http://dx.doi.org/10.1097/00007632-200012150-00014. PMid:11124735.
- 10. Nery DB, Silva RLF, Duarte LA, Salimon A, Medina C, de Angelo TCS, et al. A autoadvocacia na rehabilitação auditiva: tradução e adaptação transcultural do self-advocacy checklist. In: Anais do 25° Congresso Fonoaudiológico de Bauru; 2018; Bauru. Bauru: USP; 2018.
- IDEA: Individuals With Disabilities Education. Act of 2004, P.L. 108-446.
  Washington: IDEA.
- 12. Brasil. Lei nº 13.146, de 6 de julho de 2015. Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). Diário Oficial da União; Brasília, 7 jul. 2015; Seção 1, p. 2.
- AAA: American Academy of Audiology. Scope of practice in audiology. Reston: AAA; 2004.
- ASHA: American Speech-Language-Hearing Association. Scope of practice in audiology. Rockville: ASHA; 2018.
- EAA: Educational Audiology Association. Educational audiology scope of practice. Pittsburgh: EAA; 2019.
- CFFa: Conselhos Federal e Regionais de Fonoaudiologia. Lei nº 6.965/81.
  Código de Ética da Fonoaudiologia. Brasília: CFFa; 2004.
- 17. Brasil. Lei nº 13.935, de 11 dezembro de 2019. Dispõe sobre a prestação de serviços de psicologia e de serviço social nas redes públicas de educação básica. Diário Oficial da União; Brasília; 12 dez. 2019. nº 240, Seção 1, p. 7.
- Esturaro GT, Novaes BCDAC, Deperon TM, Martinez MAN, Mendes BDCA. Uso de sistema de transmissão sem fio e desempenho de estudantes com deficiência auditiva na perspectiva de professores. Distúrb Comun. 2016;28(4):730-42.

- Carvalho DS, Pedruzzi CM. Uso do sistema de frequência modulada por escolares com perda auditiva. Distúrb Comun. 2019;31(1):12-21. http:// dx.doi.org/10.23925/2176-2724.2019v31i1p12-21.
- REMIC. [Internet]. Bauru: REMIC; 2020 [citado em 2020 Mar 10]. Disponível em: http://remic.fob.usp.br/
- Penna LM, Lemos SMA, Alves CRL. Auditory and language skills of children using hearing aids. Braz J Otorhinolaryngol. 2015;81(2):148-57. http://dx.doi.org/10.1016/j.bjorl.2014.05.034. PMid:25458255.
- 22. Long G, Stinson MS, Braeges J. Students' perceptions of communication ease and engagement: how they relate to academic success. Am Ann Deaf. 1991;136(5):414-21. http://dx.doi.org/10.1353/aad.2012.0455. PMid:1799179.
- Beresford P. Empowerment and Emancipation. In: Albrecht GL, editors. Encyclopedia of disability. Thousand Oaks: Sage Reference; 2013. p. 593-601.
- 24. Test DW, Fowler CH, Wood WM, Brewer DM, Eddy S. A conceptual framework of self-advocacy for students with disabilities. Remedial Spec

- Educ. 2005;26(1):43-54. http://dx.doi.org/10.1177/07419325050260010
- Paradiz V, Kelso S, Nelson A, Earl A. Essential self-advocacy and transition. Pediatrics. 2018;141(Suppl 4):S373-7. http://dx.doi.org/10.1542/peds.2016-4300P. PMid:29610420.
- Reed S, Antia SD, Kreimeyer KH. Academic status of deaf and hard-of-hearing students in public schools: student, home, and service facilitators and detractors. J Deaf Stud Deaf Educ. 2008;13(4):485-502. http://dx.doi.org/10.1093/deafed/enn006. PMid:18344539.

#### **Author contributions**

DBN, RLFS, AS, LAD, ALMM, RTSJ and NBFL wrote the project. NBFL and AS reviewed it. LAC, DBN, RLFS, COS and LAD collected the data. LAC, DBN, RLFS, TCSA, COD, LAD, EJS, ALMM and RTSJ analyzed the data. LAC, DBN, RLFS, AS, TCSA, COS, LAD, NBFL, ALMM and RTSJ wrote the manuscript. EJS advised the discussion and conclusion of the study. ALMM and RTSJ advised all the stages of the study

#### SUPPLEMENTARY MATERIAL

Supplementary material accompanies this paper. Comparative Table - Modifications Self-advocacy Checklists

This material is available as part of the online article from https://www.scielo.br/j/codas