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The use of everyday scenarios based on the educational tool "My World" in mothers of children and adolescents with hearing loss

O uso de cenários cotidianos baseados na ferramenta educacional *My World* com mães de crianças e adolescentes com deficiência auditiva

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ABSTRACT

Purpose: To identify the participants' opinion about the use of scenarios and characters of the educational tool "My World", in parents of children with hearing loss. **Methods:** This exploratory study analyzed the reports of participants about utilization of the tool's scenarios and characters for the development of positive parental practices. The study was conducted at a university speech-language pathology clinic in a city at the country side of the state of São Paulo, Brazil, on three mothers of children and adolescents with hearing loss, who received speech therapy at the clinic. Data were collected using a questionnaire about the tool elements. **Results:** The tool elements seemed to contribute for the mothers to more precisely identify the ups and downs in the interaction with their children with hearing loss. **Conclusion:** This study can aid the development of tools to favor the participation of family members in the auditory rehabilitation of their children, thus contributing to increase possibility of therapeutic success.

Keywords: Hearing loss; Rehabilitation; Child; Adolescents; Family

RESUMO

Objetivo: Identificar a concepção dos participantes sobre o uso dos cenários e personagens da ferramenta *My World* para o treinamento de habilidades sociais educativas cotidianas com mães de crianças e adolescentes com deficiência auditiva. **Métodos:** Estudo exploratório sobre a análise dos relatos dos participantes quanto ao uso dos cenários e personagens da ferramenta para desenvolvimento de práticas parentais positivas. O estudo foi desenvolvido em uma clínica-escola de Fonoaudiologia de uma faculdade do interior do estado de São Paulo, Brasil, com três mães de crianças com deficiência auditiva, que realizavam terapia fonoaudiológica naquele local. Para coleta dos dados, foi aplicado um questionário sobre os elementos da ferramenta. **Resultados:** Observou-se que os elementos da ferramenta parecem ter contribuído para que as mães identificassem mais concretamente dificuldades e facilidades na interação com seus filhos com deficiência auditiva. **Conclusão:** Acredita-se que este estudo possa auxiliar na implantação de ferramentas que favoreçam a participação dos familiares no processo de reabilitação auditiva, contribuindo, assim, para maior probabilidade de sucesso terapêutico.

Palavras-chave: Deficiência auditiva; Reabilitação; Criança; Adolescente; Família

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INTRODUCTION

Since the 1980s, a paradigm shift has been proposed concerning the early intervention models in hearing loss, advocating the family-centered practices as those that provide the best results for child development[1]. Within this context, a study aimed to know and describe the characteristics of daily activities that contribute to the development and improvement of communication and language, to contribute to the development of family-centered practices. Two instruments have been used for that purpose, being two variations of *La Escala de Valoración de la Enseñanza de la Lengua Oral en contexto Familiar* – EVALOF, which evaluated the perception of parents about their interaction with the children, using an interview to investigate the daily activities of four families with 5-year-old children. The language of children was evaluated using the Navarra Oral Language Test – *PLON*. The investigators observed that all children needed to improve their language development and the parents could use the daily routine to talk with their children more frequently. Therefore, they highlighted the need that the daily life of each family is the starting point of family-centered interventions, to promote changes that may be incorporated everyday[2].

Studies in the field of Audiology have demonstrated that speech therapies should be developed according to the paradigm of family-centered practices[3-5]. Thus, the auditory rehabilitation has gone through changes in its structure, increasingly emphasizing the importance of the family in this process, since the family system is fundamental for language construction of the child[6]. Children with hearing loss who present the best performance in speech therapy, concerning the development of oral language, are those in whom the therapeutic work is continued at home[7].

Therefore, in 2012, a conference was held in Austria to discuss the systematization of family-centered early interventions, in the field of hearing loss. The conference established the following guiding principles for family-centered practices: 1 - Early, fast and equitable access to services; 2 - Partnerships between families and service providers; 3 - Conscious choices and decisions; 4 - Social and emotional support to the families; 5 - Promotion of parents/children interaction; 6 - Utilization of assistive technologies and communication support; 7 - Qualified professionals; 8 - Team work; 9 - Progress monitoring; 10 - Monitored programs[8].

A literature review aimed to describe how and why the family-centered practices are fundamental for the development of communication in children with hearing loss. The authors highlighted that the main change of this type of practice is related to the change in the focus of speech therapy intervention in the child, individually, for support and capacitation to his or her communication partners. Based on the studies analyzed, the review concluded that children with greater therapeutic success are those in whom the everyday interactions are incorporated to the attendances[4].

Conversely, a study indicated the difficulty to implement family-centered practices in agreement with all guiding principles established. The authors investigated, by a semi-structured interview, the information received in family-centered early intervention programs, by 12 normal hearing parents of children with hearing loss, being 11 mothers and one father. By thematic analysis of the interview reports, the authors observed that the programs are partially following the guiding principles of family-centered early intervention practices, because, according to the participants, even though the professionals instruct about the importance of interaction during everyday activities for the development of language abilities in the child, there is lack of individualized guidance specific to the reality of each child[3].

A study about the interaction of normal hearing parents and their children with hearing loss emphasized the importance of family focus for the successful development of oral communication in speech therapy. The study analyzed 18 video recordings, using the Behavior Index Scale, which promotes the communication, on nine parents of children with hearing loss and nine parents of adolescents also with hearing loss. The results revealed that parents who attended a program aiming at the development of auditory function and oral communication demonstrated adequate communication strategies when facing a controlled situation. However, for the investigators, these data did not allow to state whether these attitudes are also present in everyday situations. Therefore, they emphasized the need of studies and strategies to allow the generalization of these abilities[5].

The insufficient utilization of scenarios of everyday activities of children and their families has been reported, with negative influence for the effective utilization of child learning opportunities[9]. A Danish professional non-profit organization called *IDA Institute* has advocated the use of tools during the auditory rehabilitation process, with emphasis to *My World*, which includes the utilization of these everyday scenarios during this process. The goal of this tool is to understand the hearing loss from the standpoint of the person with hearing loss, by manipulation of its components (scenarios, characters and objects). This tool has been successfully used in children attending the university speech-language therapy clinic in a city in the countryside of the state of São Paulo.

This study proposed the utilization of scenarios and characters of the tool *My World* on mothers of children and adolescents with hearing loss, so that, in a more concrete manner and simpler language, they might manifest and enhance their parental abilities in different situations, by manipulation of its components, creating the everyday scenarios to describe the communication between father/mother-child dyads. Thus, this study aimed to identify the opinion of participants about the use of scenarios and characters of the *My World* tool for training of daily socioeducational abilities on mothers of children and adolescents with hearing loss.

METHODS

This exploratory qualitative study investigated the mothers' opinions about the use of *My World* tool for the training of everyday socioeducational abilities. This study was the first stage of a project approved in full by the Institutional Review Board (protocol n. 918.578 approved on December 9th 2014), according to Resolution 466/12. The study was conducted in a university speech-language therapy clinic in a city at the countryside of the state of São Paulo. At the time of data collection, 20 patients were undergoing treatment in the field of Audiology and all caretakers were invited to participate in the research, by an invitation letter. Three mothers attended the meeting, being named M1, M2 and M3 and their children with hearing loss were respectively named P1, P2 and P3. The sociodemographic data of participants are presented in Charts 1 and 2.

Chart 1. Sociodemographic characteristics of participating mothers

Participant	Age	Profession	Marital status	Educational level	Family income	Socioeconomic classification
M1	42 years	University professor	Married	Higher education	Above 6 minimum wages	Lower middle
M2	39 years	Housewife	Married	High school	4 minimum wages	Upper low
M3	63 years	Housewife	Married	Incomplete fundamental school	3 minimum wages	Lower low

Subtitle: M = Mother

Chart 2. Characterization of children with hearing loss

Participant	Gender	Age	Educational level	Degree of hearing loss	Device used	Number of siblings living in the same home
P1	Male	10 years	5th grade	Moderate bilateral	Bilateral hearing aids	1
P2	Female	11 years	5th grade	Deep bilateral	Bilateral cochlear implants	1
P3	Male	10 years	5th grade	Deep bilateral	Bilateral cochlear implants	2

Subtitle: P = Patient

The participating mothers were aged 39 to 63 years (mean age 48 years), and one of them worked professionally and had completed higher education. The others were housewives and had completed high school and incomplete elementary school, respectively. The socioeconomic classification ranged from inferior low to lower middle. The children were two boys and one girl, aged 10 to 11 years, attending the 5th grade at school. Two of them had bilateral deep hearing loss and used a cochlear implant, and the other had moderate loss and used hearing aids. The children had one to two siblings (Chart 2).

Sociodemographic data from both mothers and patients were obtained from their records, besides information about the hearing loss. The socioeconomic classification considered family income, educational level, occupation, number of people in the house and type of housing[10].

The tool *My World* was created by professionals at *IDA Institute*[11], who create and share innovative knowledge, to help hearing health professionals to face the psychological and social challenges of hearing loss and apply patient-centered care methods. The tool is available on the website for free download, and instructions in Portuguese were prepared by a group of Brazilian speech therapists.

The *My World* tool assists the understanding of hearing loss from the standpoint of the person with hearing loss. Their scenarios consist of three different environments (a classroom, a house and an outdoor area), characters that allude to the family, school and friends, objects that remind the daily life and cards with icons that express positive and negative feelings. The individual can put movable figures in several environments, to describe the successes and challenges of everyday communication. By playing with the tool components, the hearing loss may be exteriorized to discuss how the individual communicates with the others, in a concrete and non-threatening manner. Thus, the tool provides information about the communication patterns of the person with hearing loss, reinforcing positive patterns and formulating strategies to deal with all every day challenges.

To evaluate the pertinence of the use of scenarios and characters of the tool, a questionnaire was used with the following questions: What did you think about the scenarios and characters? Can the utilization of scenarios and characters somehow help you to reflect about the parent-child relationship?; What would you change and/or add to these scenarios and characters?

The utilization of scenarios and characters of *My World* educational tool was developed in seven stages: 1 - Contact with professionals from *IDA Institute*, to authorize the use of their scenarios and characters; 2 - Establishment of partnership with the educational technology sector of the school where the study was conducted, for re-design of the tool elements; 3 - Presentation of the project, with emphasis on utilization of the tool, for groups of Speech Therapy trainees who performed the therapy on children and adolescents with hearing loss; 4 - Distribution, by the trainees, of an invitation letter to the mothers of children; 5 - Signature of invitation by the mothers; 6 - Presentation of the different environments, characters and figures contained in the tool for the mothers; 7 - Completion of the questionnaire regarding the mothers' opinion about the use of such tool.

Stages 5 and 6 were conducted on mothers who attended the previously scheduled meeting, which was held at a different time from speech therapy of the child with hearing loss. All mothers were invited, regardless of the child's age group and scheduling of speech therapy. At the time of the meeting, 20 patients (children and adolescents) with hearing loss were enrolled in the therapy. Initially, the project was presented by a conversation wheel. Subsequently, the purpose of the meeting was emphasized. The tool elements were arranged on a table in the room and, after brief explanation, the participants were invited to come closer, handle the material and represent, using the elements available, a situation experienced in their everyday life in which they presented some difficulty.

From the environments contained in the tool, the following scenarios were proposed: home, school (site of meetings of parents and teachers and area where the parents leave and pick their children), shopping mall and an external area. The characters and objects were made in a similar manner as the existing. During the evaluation, the participants' reports were recorded.

RESULTS

The mothers evaluated the scenarios and characters of the *My World* tool, according to questions on the scenarios and characters, and the following main aspects were identified:

1. What did you think about the scenarios and characters?

- Mothers presented positive comments:

M1. Exploring everyday sites should be the starting point;
M2. It aids the parents in a playful manner;
M3. The parents need to learn how to educate their children. They are not born knowing about it.

2. Can the utilization of scenarios and characters somehow help to reflect about the parents-child relationship?

- The mothers agreed:

M1 and M2. The home is the more intimate space; they shall have the opportunity to share knowledge acquired in the family;
M3. It helps to reflect about what has to be changed, in a concrete manner.

3. What would you change and/or add to these scenarios and characters?

- All suggested some change:

M1. I would change the home scenario to something closer to the everyday life of most of our children;
M2. I would include educational toys;
M3. I would include a grocery store. This is an environment where they need to learn how to behave.

The analysis of mothers' reports about the tool components were categorized according to the scenario, characters and objects analyzed, as follows.

- School scenario:

M1: She indicated as the "*main site*" and emphasized that the teachers also need training on socioeducational abilities. She was touched to be in contact with this scenario and reported that her child had recently been victim of *bullying*, related with the hearing loss. She highlighted the importance of the presence of parents in this environment, creating strategies to have access to teachers, coordinator and director.
M2: She mentioned that "[…] *this is the environment where the parents have more difficult access*" and emphasized the importance of strategies to allow the parents to achieve school support to cope with the hearing loss.
M3: She emphasized that "[…] *it is very important that the family establishes a good bond with the school*" and reported no difficulties in this aspect, with easy access to her daughter's teachers.

None of the mothers suggested changes in this scenario.

- Home scenario:

M1: She reported no interaction problems at home. She suggested changes, so that the represented home could be "*humbler*", to characterize more accurately the socioeconomic level of most families attending the clinic. The mentioned that "[…] *each parent should portray their home in a drawing*" and that this environment "[…] *might not be a predetermined scenario*".
M2: She emphasized that the home is a site of family interaction. She reported "[…] *difficulty to arrange the environment so that her daughter might do her homework without being distracted*" and stated to believe that the use of this scenario might be helpful to better visualize which would be the adequate environment. She did not suggest any changes.
M3: She reported the difficulties in making the child follow the rules established by the parents and highlighted that she often applies punishment. She believes that this environment may "[…] *be helpful to understand why the rules are not followed*". She also did not suggest any changes.

- External scenarios:

M1: She mentioned that she would not change these environments and was more focused on the school and home in the evaluation.
M2: She highlighted that these are "[…] *the areas where it is the most difficult to control the child behavior, because of being in public areas*" and questioned "[…] *how to control the child in front of other people?*". She did not suggest changes in these environments.
M3: She emphasized the need that parents should know how to educate their children so that they may have autonomy in free places, yet she highlighted that she does not allow her daughter to leave without her supervision, because she considers her "*very innocent*" and questioned "[…] *how to prepare her to face the world outside?*". She suggested the creation of an additional external environment (grocery store), since in this place she has great difficulty to control her daughter's behavior.

- Characters and objects:

M1: She did not suggest any changes.
M2: She suggested changing the color of the cochlear implant (which is portrayed in white color) and the inclusion of educational toys (games).
M3: She also suggested changing the color of the cochlear implant.

DISCUSSION

This study aimed to contribute to family-centered practices, suggesting the use of *My World* tool on family members of children and adolescents with hearing loss, to facilitate the acquisition of abilities that may be applied in their everyday lives. For this purpose, the tool elements were presented to the families of children with hearing loss. Alike other studies on parents, there was no participation of fathers[12-15]. Even concerning the participation of mothers, the number of participants was reduced, indicating a gap of the present study. This highlights the need to think about strategies that may favor the participation of a larger number of parents and the inclusion of fathers.

Family-centered intervention practices have been highlighted because they contribute more effectively for child development[1], emphasizing that interventions should have the daily lives of families as a starting point, to facilitate the incorporation of practices in their daily life that contribute to this development[2]. In the field of Audiology, such practices have been shown to provide better results than conventional therapy[4,7]. However, studies have indicated pointed out that there is still a need for new strategies to bring patients and families closer to their daily lives[3,5]. The present study can help to minimize this gap and meet the type of demand inherent to these practices.

The utilization of tools has been shown to be a possibility of intervention consistent with the proposal advocated by family-centered practices, to allow greater proximity of the

child and family to daily interactions[4]. This study proposed the utilization of *My World* tool scenarios with mothers as a strategy that could contribute to this process. According to the participants' reports and questionnaire responses, it was generally observed thatthe tool elements seem to have contributed for the mothers to identify, more concretely,the ups and downs in the interaction with their child with hearing loss, in the different environments represented (home, school and external environment), which in turn may help to generalize the contents addressed during the rehabilitation process. Based on analysis of the participants, the tool elements were maintained. Thus, concerning the home environment, in which M1 suggested that each family member might drawtheir own house, it was emphasized that the objective was to present something concrete to the parents, so that they could express themselves in this environment. An effort was made to emphasize the flexibility of external environments, in the sense of not being a fixed location. The mothers were also informed that the neutral color of the cochlear implant aimed to allow the parents to customize it, making it more similar to the child's implant, since it is usually found in different colors.

It is believed that the use of these scenarios and characters is in line with the guiding principles of family-centered interventions, such as the establishment of emotional support for the families and promotion of parent-child interaction[8].

CONCLUSION

This study can contribute to patients and families to express the ups and downs experienced in their everyday life, at different environments, as emphasized by the participants, thus contributing to greater success in oral language development of children with hearing loss.

The literature reported that hearing loss may be a variable that negatively interferes with the parent-child interaction, emphasizing the need of parents of children with hearing loss to participate in programs that aim to develop and/or improve the parental practices considered as positive. The proposal to use scenarios of *My World* tool on parents of children with hearing loss, associated to intervention programs that aim to improve this interaction, can help in the development and/or improvement of educational social skills related with everyday life. In turn, this can contribute to speech therapy concerning the everyday use of abilities developed within the therapeutic context.

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