Families’ perception of children / adolescents with language impairment through the International Classification of Functioning, Disability, and Health (ICF-CY)

Percepção de familiares de crianças e adolescentes com alteração de linguagem utilizando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF-CJ)

ABSTRACT

Purpose: To investigate the perception of family members regarding linguistic conditions and social participation of children and adolescents with speech and language impairments using the International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY). Methods: Quali-quantitative approach research, in which a survey of medical records of 24 children/adolescents undergoing speech-language therapy and interviews with their family members was conducted. A descriptive analysis of the participants’ profiles was performed, followed by a categorization of responses using the ICF-CY. Results: All family members mentioned various aspects of speech/language categorized by the ICF-CY. Initially, they approached it as an organic issue, categorized under the component of Body Functions and Structures. Most reported different repercussions of the speech-language impairments on the domains, such as dealing with stress and speaking, qualified from mild to severe. Participants reported Environmental Factors categorized as facilitators in the immediate family’s attitudes and as barriers in the social attitudes. Conclusion: These findings, according to the use of the ICF-CY, demonstrate that the children/adolescents’ speech-language impairments, from the families’ perception, are primarily understood in the body dimension. However, guided by a broader approach to health, the findings in the Activities and Participation and Environmental Factors demonstrate a broader understanding of the participants of the speech-language impairments. The results corroborate the importance of using the ICF-CY as a health care analysis tool, by incorporating functionality and participation aspects and providing subsidies for the construction of unique therapeutic projects in a broader approach to the health of the group studied.

RESUMO

Objetivo: Investigar a percepção de familiares acerca das condições linguísticas e da participação social de crianças e adolescentes com alterações de fala/linguagem utilizando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde – Versão Crianças e Jovens (CIF-CJ). Método: Pesquisa de abordagem quali-quantitativa, na qual se realizou levantamento dos prontuários de 24 crianças/adolescentes, em acompanhamento fonoaudiológico, e entrevistas com seus familiares. Foi feita análise descritiva dos perfis dos participantes e categorização das respostas, utilizando a CIF-CJ. Resultados: Todos os familiares abordaram diversos aspectos de fala/linguagem categorizados pela CIF-CJ. Inicialmente, trataram-no como um problema orgânico, categorizado no componente de Funções e Estruturas do Corpo. A maioria referiu diferentes repercussões das alterações de fala/linguagem em domínios, como, lidar com estresse e atividade do falar, qualificados de leve a grave. Os participantes relataram Fatores Ambientais categorizados como facilitadores, em atitudes da família imediata, e como barreiras, em atitudes sociais. Conclusão: Os achados, utilizando-se a CIF-CJ, evidenciam que as alterações de fala/linguagem das crianças e adolescentes, na percepção dos familiares, são compreendidas, inicialmente, na dimensão do corpo. Contudo, pautados numa abordagem mais ampla de saúde, os achados, em Atividades e Participação e Fatores Ambientais, demonstram ampliação do olhar dos participantes quanto às alterações de fala e linguagem. Os resultados reiteram a importância do uso da CIF-CJ como instrumento de análise na atenção à saúde, ao incorporar aspectos de funcionalidade e participação, proporcionando subsídios para a construção de projetos terapêuticos singulares, em uma abordagem mais ampla de saúde do grupo estudado.
INTRODUCTION

Today, the emergence of new discourses in health care is seen from a perspective of thorough care and health promotion1,2. This study turns its focus on the health of children and adolescents with language impairments, from the perspective of their family members. It is important to recognize and value the discourse of these social actors in caring for these individuals, welcoming them and contemplating the diversity of practical and technical knowledge brought by family members and health professionals, respectively.

Here, care is understood as interaction between individuals who, based on a moral and ethical relationship, make choices about health practices at the various moments in which it is possible to understand the other, their particular way of being, aiming at achieving well-being. “This allows for welcoming care, bonding, and accountability”3.

Providing assistance to children and their families has been the focus of care in several fields of health care, such as Speech-Language Pathology and Pediatrics. When faced with children and adolescents with speech and language impairments in different conditions, such as stuttering, language delay, phonetic and phonological deviations etc., it is possible to observe a predominance of therapeutic approaches based on the biomedical model. From this perspective, objectives and goals are constructed from the deficit, i.e. the organic or pathological aspects4-6. A paradigm shift based on care and health promotion, in which the impacts of language impairments on the life of this population group are taken into consideration focusing their ability to compromise other areas - namely, education, social and family -, requires a theoretical conception that contemplates these different contexts present in the daily life of children and adolescents with speech and language impairments.

In view of this paradigm shift and recognizing the need for an approach in which the individual is seen in its entirety, the World Health Organization (WHO) has proposed the International Classification of Functioning, Disability and Health (ICF)7. It allows for the establishment of a scientific basis for research on the health determinants and their related conditions and aims to provide a common language for the description of health. The ICF uses a biopsychosocial approach to integrate biomedical and social models from various perspectives of functionality, thus trying to achieve “a synthesis of the different dimensions of health”8. In addition, it allows for interaction between research and clinical experience (practical and theoretical), and can be used in the clinical setting4,6,7 of speech and language impairments. Therefore, the interest of using it as a basis in this study is justified.

The International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY)9,10 derived from the ICF in response to the need and diversity of disabilities regarding their nature, intensity, and the impact they can have throughout the long period of child growth and development9,11-12. The national literature that makes use of the ICF-CY is scarce, and one of the first publications13 in the field of Speech-Language Pathology based on the ICF-CY is aimed at children with cochlear implants and presents important questions for audiological practice.

Reconciling the use of the ICF-CY with the need to work with family members of children and adolescents with language impairments implies individual consideration of each child/adolescent, respecting their differences in a comprehensive interpretation of health, functionality and disability14. Therefore, attention to the family assumes great relevance.

The aim of this research is to investigate the perception of family members about the linguistic conditions and social participation of children and adolescents with language impairments undergoing speech-language therapy using the ICF-CY.

METHODS

This research has been approved by the Research Ethics Committee of Faculdade de Ciências Médicas da Universidade Estadual de Campinas (UNICAMP) under protocol No. 169.575. All of the participants have signed the Informed Consent. This is a quali-quantitative study. Qualitative research is interested in investigating the particularities of human beings, with their experiences, actions, and singularities that place them in a particular historical moment15. This article is part of the doctoral thesis of one of the authors, who obtained a research scholarship from CAPES.

Twenty-four family members (herein named S1 to S24, in order to ensure confidentiality of identities) of children and adolescents (C1 to C24) with speech and language impairments (stuttering, language delays, phonetic and phonological disorders, language impairment with neurological causes) undergoing speech-language therapy at a teaching clinic in the state of São Paulo (Brazil).

The teaching clinic in which the study was conducted comprises different groups of internship in Speech-Language Pathology. The participants belonged to the group of speech-language therapy in language. This practice draws on a therapeutic approach based on comprehensive care and health promotion. Concomitantly with the individual speech-language therapy provided to children and adolescents, this internship provided periodic group care to their families.

The sample was gathered by convenience. Family members of children and/or adolescents with oral language impairments were included in the speech-language therapy for at least six months at the time of data collection and with participation in two or more groups of relatives.

The data collection procedures related to this article involved two sources: medical records and interviews. A survey of medical records of the children and adolescents was carried out to determine age, gender, time of care, speech-language complaints, as well as data from their relatives with regard to schooling, occupation and degree of kinship.
Each participant granted an interview with a semi-structured guide (Appendix A), which was recorded in audio (about 40-60 minutes each) and transcribed for later analysis of content and categorization, using the ICF-CY.

The guiding questions (Appendix A) were based on the Speech Participation and Activity of Children-SPAA-C(12), a study developed with Australian Speech-Language Pathologists who discussed the aspects they considered necessary to define normality and speech and language impairments during two workshops. Then, the ICF was presented to this group of professionals, who identified other relevant aspects, concluding that no existing questionnaire contemplated functionality and participation. Thus, McCormack et al.(12) elaborated questions for different interlocutors (child, family, siblings, teachers). In this study, the questions aimed at the family members were used to account for their view regarding the language impairments and their implications for the children and adolescents under study. In addition, three open-ended questions (Appendix A) were added in order to verify the family members’ perception with regard to the therapeutic process of children and adolescents.

Afterwards, data analysis was performed based on exploratory readings of the content of interview transcripts. From the answers associated with each block of questions, related components emerged and were categorized under specific domains of the ICF-CY, which was validated by the other authors of this research(16).

In structural terms, the ICF-CY can be hierarchically divided into two parts, each with two elements: in the first one, functionality and disability are considered - they are divided into Body Functions and Structures (biological/anatomical aspect of classification, with their physiological and psychological functions present), and into Activities and Participation (execution of tasks and their involvement in daily life situations). In the second one, Environmental and Personal factors related to context are considered and ranked from the most immediate to the most general item, which can aid classification of the individual by describing their status within the fields of health care, considering the influence of their environment and context.

Each of these four components can be expressed in positive or negative terms(8) and are represented by letters: Body Functions (b); Body Structures (s); Activities and Participation (d); and Environmental Factors (e) (Personal Contextual Factors are not classified by ICF due to their wide variability)(9). The letters referring to each of these components (“b3” “s3” “d3” and “e3”) are followed by a numeric code (appropriate to the category to which they belong) and by the addition of qualifiers, which quantify the extent of functionality or disability in that item, or if this particular environmental factor presents itself as a facilitator (+) or a barrier (-). The qualifiers vary from level 0 (zero), corresponding to absence of problem or difficulty; to level 1 (mild difficulty); level 2 (moderate difficulty); level 3 (severe difficulty); up to level 4 (total or complete problem or difficulty). Level 8 indicates unspecified degree of disability and level 9, a domain that is not applicable(8).

Therefore, the ICF-CY qualifiers were used in order to qualify the degree of speech and language impairments of children and adolescents from the perception of family members.

RESULTS

Initially, the results of the family and children/adolescents profile will be presented, as recorded in the medical records. Then, we are going to present examples from the blocks of the interview guide, data analysis from the testimonies that resulted in the domains of ICF-CY; next, these are qualified and categorizes by frequency under the components of Body Functions and Structures, Activities and Participation, and Environmental Factors.

Table 1 shows the profile of the 24 family members and 24 children/adolescents.

Regarding the way the guiding questions were analyzed, in the first block of interview questions, the goal was to find out how family members perceive the children and adolescents. The answers, since they initially addressed the language problem in the organic domain (n=14), were classified under the ICF-CY component of Body Functions and Structures. In addition, other responses were categorized under the Activities and Participation component of the ICF-CY, when they involved the child’s behavioral issues (n=7) or other aspects related to cognitive functions (n=4).

In the second block, in which the activity/form of speech and language was the focus, responses were categorized under the domains of the Environmental Factors component of the ICF-CY, related mainly to the attitudes of relatives with the intention to help the children and adolescents in their speech and language difficulties, e.g. by using expressions such as “calm down, breathe, and speak slowly” (n=11), presentation of the speech model (n=3), or as interpreters of the speech of children and adolescents (n=2).

In the block addressing the impact speech and language impairments would have on individuals’ lives, responses mainly concerned the domains of the ICF-CY components of Activities and Participation and Environmental Factors, since the damage could lie in school or their professional lives (n=14), or they were not able to answer because of the age of the children (n=5) or for other reasons (n=6).

In the open-ended questions block, added to the interview guide by the researcher in charge, expectations around treatment encompassed responses categorized both in the Body Functions and Structures component - where a few (n=4) interviewees referred to achieving a “cure” for the problem (n=20) - and in the Activities and Participation component - by answering that they expected to improve their child’s participation and functionality (n=20) -, as well as in the Environmental Factors component - one participant was classified under the domain of immediate family attitudes by referring to support in order to deal with the child with respect to the use of supplementary and/or alternative communication resources.

Table 2 below shows the distribution of the frequency of qualifiers of the domains pertaining to the Body Functions and Structures component of the ICF-CY, categorized from the respondents’ answers.

It was observed that, regardless of the condition that led to the speech or language impairment, all of the relatives (n=24) considered as problems the domains of articulation functions (b320) and speech fluency and rhythm (b330) at different levels,
such as mild (n=9), moderate (n=8), and severe (n=7), in both domains. Such findings demonstrate their relatives’ concern about the organic dimension of children/adolescents’ language issues, as exemplified in the excerpt from S3’s testimony:

Table 1. Profile of the 24 family members and 24 children/adolescents drawn from the medical records

<table>
<thead>
<tr>
<th>FAMILY MEMBERS</th>
<th>n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age range (in years)</strong></td>
<td></td>
</tr>
<tr>
<td>≤30</td>
<td>02(8.3)</td>
</tr>
<tr>
<td>31-40</td>
<td>13(54.2)</td>
</tr>
<tr>
<td>41-50</td>
<td>08(33.3)</td>
</tr>
<tr>
<td>≤51</td>
<td>01(4.2)</td>
</tr>
<tr>
<td><strong>Degree of kinship</strong></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>15(62.5)</td>
</tr>
<tr>
<td>Father</td>
<td>08(33.3)</td>
</tr>
<tr>
<td>Uncle/Aunt</td>
<td>01(4.2)</td>
</tr>
<tr>
<td><strong>Educational level (in years of schooling)</strong></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>01(4.2)</td>
</tr>
<tr>
<td>1-8</td>
<td>05(20.8)</td>
</tr>
<tr>
<td>9-11</td>
<td>14(58.3)</td>
</tr>
<tr>
<td>≤12</td>
<td>04(16.7)</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
</tr>
<tr>
<td>Self-employed/Business owner</td>
<td>07(29.2)</td>
</tr>
<tr>
<td>Home worker</td>
<td>08(33.3)</td>
</tr>
<tr>
<td>Nurse</td>
<td>02(8.3)</td>
</tr>
<tr>
<td>Student</td>
<td>01(4.2)</td>
</tr>
<tr>
<td>Informal worker</td>
<td>04(16.7)</td>
</tr>
<tr>
<td>Formally employed worker</td>
<td>02(8.3)</td>
</tr>
</tbody>
</table>

| CHILDREN AND ADOLESCENTS |      |
| Gender |      |
| Male | 15(62.5) |
| Female | 09(37.5) |
| **Age (in years)** |      |
| From 2 to 5 | 07(29.2) |
| 6-10 | 10(41.7) |
| >11 years old | 07(29.2) |
| **Time of care (in months)** |      |
| 6-12 m | 06(25) |
| 13-24 m | 10(41.7) |
| >24 m | 08(33.3) |

This excerpt shows that relatives’ concern is focused on the form, on the organic, i.e. on how the children/adolescents produce their speech, whereas the actual content of their messages remains in the background.

Table 2 presents the distribution of the frequency of qualifiers of the domains pertaining to the Activities and Participation component of the ICF-CY, categorized from the respondents’ answers.

In addition to the initial concern about the organic problem of speech and language impairments, most of the family members (n=22) discuss how they interfere in aspects of the domain of dealing with stress and other psychological demands (d240), qualifying them as a mild problem (n=16), in their majority with repercussions on the daily life of the child/adolescent, as seen in the speech of S12:

> […] there was a time, when she started school… It bothered her a lot that children began to ask what was her problem, why she spoke like that. […] I used to tell her they didn’t mean any harm… But she was tired of having to explain it over and over during the breaks, instead of eating her snacks. (S12)

Another recurrent domain in the participants’ testimony was the speech activity (d330), being considered a problem of varying degrees (n=19), such as mild (n=8), moderate (n=6), or severe (n=5). This domain affects the possibility of the child/adolescent expressing themselves and on the way in which this speech is understood by the people surrounding them, as shown in S7’s testimony:

> His speech is still loaded with things we don’t understand, you know? But I understand practically everything… Although in its fits and starts, I understand everything. (S7)
Saying that they “understand in fits and starts” evidences the family’s effort to understand what the child says and, at the same time, the effort of the speaker to make himself understood - evidencing the influence of the language impairment on the child’s own life and in the family interaction dynamics.

The domain pertaining to relationships/interactions refers to actions and behaviors to establish basic relationships with others, whether they be family, friends, or strangers interacting contextually and socially in an appropriate manner, although less frequent, but in a way that indicated difficulties for children/adolescents, varying their qualifiers as a mild to severe problem; family relationships - d760 (n=15), informal social relations - d750 (n=13), and interpersonal interactions - d710 (n=11); they also show the difficulties in how others deal with the language impairments of children and adolescents, as shown by S6:

With the people he doesn’t see much, sometimes, he speaks better than with those he is more closely in touch with. A stranger, for instance, who never spoke to him, he stutters [...] (S6)

Table 4 presents the distribution of the frequency of qualifiers of domains pertaining to the Environmental Factors component of the ICF-CY, categorized from the respondents’ answers.

The Environmental Factors can have their domains categorized as barriers (negative attitudes) or facilitators (positive attitudes) depending on how they are perceived, in this case, by family members. The domains related to attitudes concern the way in which customs, beliefs, and values are observed and, consequently, their impact on the children/adolescents’ lives. Table 4 shows that the domain of immediate family attitudes (e410) was considered a facilitator by 14 interviewees, being mild (n=9) and moderate (n=5) depending on the way in which they affect children and adolescents, as seen from S11’s testimony:

...And he asked the Portuguese teacher not to read in class, to read things just for her. He said that he doesn’t want to read for the entire class because they stare at him and keep saying ‘come on, C6, get it over with, C6’, so he gets nervous and can’t read, you see? (S6)

**DISCUSSION**

The results indicate a predominance of mothers as more frequent caregivers. These findings are similar to those of another study[17]. It should be noted, however, that the findings also point to the involvement of fathers. The educational level of the group studied is close to that of the Brazilian population in general[18], where 29.9% have had between 11 and 14 years of schooling. As for mothers, a significant portion plays multiple roles, since in addition to caring for their children they work, formally or not.

The findings related to the Body Functions and Structures component, particularly in the domains of articulation and fluency, reflect relatives’ concern with the organic dimension of speech, i.e. focusing on the deficit, the predominant traditional view in Speech-Language Pathology[19]. A similar result[19] points out that the Body Functions and Structure component is usually more valued by professionals than the other components of the ICF-CY in several countries, since it is the most traditional model of monitoring language impairments.

When work with children or adolescents with language impairment is directed at the difficulties of the body, one tends
to label them, framing them in a similar way\(^{(20)}\) and excluding particularities and functional aspects that are essential to structured assistance for health promotion and comprehensive care.

The findings are the same as those of another study\(^{(21)}\) with regard to the fact that language impairments present varied effects on the social relations and attitudes of the immediate or extended family. These authors emphasize that, in the domain related to dealing with stress, emotional issues are commonly observed by parents, since they participate in situations of interaction of children and adolescents, in the family and social daily life, and thus they perceive more frustration when the interlocutor does not understand them.

The results of Activities and Participation and Environmental Factors show a broadening of the family’s perception of language impairments, in addition to the organic dimension. The Environmental Factors are important for health care of children and adolescents if one wishes to modify the traditional model of care (biomedical, centered in the organic, in the damage) to allow for a more comprehensive and global (social) model, which considers that favoring language activities in the social context aids (re)habilitation of language impairments\(^{(22,23)}\). Attention to Environmental Factors, particularly attitudes classified as barriers or facilitators\(^{(22)}\) in speech and language impairments, are key components for clinical practice alongside family members, as they demonstrate which working strategies, individually or in groups, could help/modify an attitude or belief of the population studied.

The findings show that the attitude of family members is an important facilitator in the life of the child and adolescent as they seek ways for them to acquire greater independence, in addition to the therapeutic process. Authors \(^{(10)}\) consider this domain key to the therapeutic process precisely because of the family’s participation. It is worth noting that society, or the family itself, does not always have attitudes that contemplate the child or adolescent in their particularities with a view to minimize their difficulties, which can cause greater damages and obstacles for health care, as it constitutes a barrier for its development.

An Australian study highlights the great value of including the family in the process of counseling and clinical intervention, such as speech-language pathology\(^{(13)}\). For the authors, family members are aware of the impact that difficulties have on children and adolescents - an important factor to be considered in the definition of the priorities of therapeutic follow-up and to minimize parents’ anxiety and frustration, which corroborate the findings of this research.

Participation of family members in the therapeutic process, the strengthening of this relationship, demonstrates how their attitudes toward children and/or adolescents favor changes, broadening the focus on the organic - the problem - to encompass a view of the individual, the practice of care, such as attention, exchange and encounter.

The results reaffirm the importance of recognizing the family as a complete system of interconnected relationships, in which particular facts and events affect the whole, reflecting on the entirety of this structure and influencing the relationship of care, as discussed by several authors\(^{(24-26)}\).

It is important to emphasize that concerns around the body will always be present as long as there is a complaint, derived from an “organic” view. However, the findings show that using the ICF-CY allows for analysis aimed at recognizing language impairments in the scope of health status and in a more comprehensive manner, including contextual and participation factors, in addition to the organic ones.

A study by McLeod and Threats\(^{(10)}\) states that developing countries spend a lot of resources to address food and infrastructure issues. Thus, establishing new partnerships and strategies that favor language, in order to contribute to the quality of life of society, is an important justification for health care and assistance in a comprehensive and humanized way.

Using the ICF-CY allowed to aggregate aspects of participation and functionality to the analysis of categories derived from the interviews with relatives, offering a comprehensive view of the child/adolescent, from a differentiated understanding of the individual, in order to create unique therapeutic projects\(^{(27)}\).

**CONCLUSION**

The findings show that the children and adolescents’ language impairments initially show the relatives’ concern in the organic dimension, regardless of the ICF-CY qualification of this problem.

On the other hand, the theoretical framework adopted in this study, consistent with the therapeutic approach developed with the group studied, showed a broadening of family members’ perspective, evidencing Activities and Participation and Environmental Factors components in the categories derived from the interviews. In this way, children and adolescents can be evaluated in a comprehensive manner, recognizing the influence of the environment for their development in order to promote health and care opportunities in the life of this population group.

Using the ICF-CY in the analysis of interviews with family members reiterates its applicability, providing subsidies for the construction of unique therapeutic projects, in a broader approach to health. However, since the ICF-CY does not detail how it should be applied, and considering that the theoretical framework influences research data analysis, the results can not be generalized.

**REFERENCES**


Author contributions

DTO conducted this study as part of her doctoral thesis under the guidance of MLZ and co-advisor RYSC; the three authors participated in all stages of writing this manuscript.
Appendix A. Semi-structured interview guide

Interview with semi-structured guide
A) Guiding questions based on the Speech Participation and Activity of Children - SPAA-C:

Tell me about your child
- What does your child like to do?
- What is important to your child and your family?
- What would be a typical weekly timetable? Who are all the people your child would speak to within a normal week?
- Does s/he get invited to play at other children’s homes/invited to birthday parties?
- Is there anything that makes your child particularly unhappy/sad/angry?

Your child’s speech
- Describe your child’s speech
- What differences do you notice about your child’s speech compared to his/her siblings and friends regarding:
  - The amount of talking
  - How well s/he is understood
  - Contexts and people where s/he is comfortable talking
  - Contexts and people where s/he is uncomfortable talking
- When your child isn’t understood:
  - What does your child do?
  - What do you find helps?
- What things is your child good at that do not require him/her to speak well?

The impact of your child’s speech difficulty
- What is the biggest impact of your child’s speech difficulty at home and school?
- How does this speech difficulty limit him/her?
- Has s/he been excluded from social situations because of his/her speech?
- What things does your family do to ensure your child is included in social situations?
- How aware/frustrated is s/he about his/her speech difficulty? Does s/he get embarrassed about his/her speech?
- Have you observed differences between different confidence levels and communication skills at: mealtimes, school, with friends, with his/her grandparents and other family members, during hobbies and extracurricular activities?
- How do other people react to your child?
- What have others told you about your child’s speech?
- Do you get frustrated/embarrassed about your child’s speech?
- What goals would you like to achieve with your child’s communication skills?

Open-ended questions regarding the therapeutic process of children/adolescents:
- My expectations around therapy are...
- What changes have taken place in your relationship during therapy?
- How important are these changes to you?