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Lack of communication in families of deaf brazilian*

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Abstract

Deaf people using Libras (Brazilian Sign Language) represent part of a population who needs to integrate and interact with other people in society. We know that part of a child's good intellectual and mental growth comes with communication and deaf children are often deprived of such interactions. However, part of them does not have a common language to interact, and that can aggravate their quality of life (QoL). Therefore, this article is a review of a survey on QoL and lack of communication carried out with 60 deaf adults in Brazil in 2016-2017; thus, we focus only on the results related to the growth of the deaf adults and their entire trajectory in language acquisition and difficulties together with his family (Relationship and Social Domain). This clipping prioritizes the difficult childhood of the surveyed deaf people and their linguistic reality and expressions of their childhood the lack of interactions and communications could bring many problems to individuals, for example: no access to leisure, and mainly to medical treatment, such as consultations and psychiatrists. Thus, new studies and investments in health, education and accessibility for deaf people are necessary.

Keywords: deafness, deaf, sign language, lack of communication in childhood

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Introduction

The philosopher Bakhtin (2009) have said that language was inseparable from life and could not have the interaction of one language without thinking of the other. In that vein Lévinas (2009) explains that the best way to live in society is to maturing this dimension that every human being has of sensitivity and responsibility by the others.

One of the greatest challenges of the human being, to know what is not known in the other, to understand the being, the being, or any other concept that may describe or define the human being a distance, not a distance of fear, coldness or fear, but a distance of respect for what a person is and represents (LÉVINAS 2009).

Thus, Bakhtin (2009) and Lévinas (2009) states that it is a dialogical, social relations that occur in social, linguistic interaction, since the men established themselves, and that interaction that plays a fundamental role between the self and the other, recognizing that there is an alterity of both involved.

People without any kind of hearing loss can lean to speak and read by language, it has to be the child's first form of socialization, almost made explicitly by parents through verbal instructions during daily activities, as well as through stories that express cultural values however are learned naturally. Its most important good socialization through language, it can also occur implicitly through participation in verbal interactions that have subtle markings of roles and status. (ELY & GLEASON, 1996).

In the case of deaf people sign language users this intensifies because with the difficulty of linguistic interactions and a form of communication visual and non-auditory makes family interactions very hard, therefore, in this article, we will discuss the interaction of deaf people, and their childhood show us how hard their growth was, as well as their poor interactions (GUARINELLO *et al* 2013).

The concept that all children have the right to a full life and close relationships, with good communication and, when necessary, rehabilitation services, is very hard to find in the deaf community, even though the access of persons with disabilities to the labor market and community is a right to everyone. The concept of accessibility was previously related to structural issues, such as physical and architectural barriers (MEADOW *et al* 2004).

Nowadays, as society becomes aware of the differences between people, the concept of accessibility has broadened beyond the removal of any barriers that prevent people with disabilities from participating in everyday activities. Thus, we would like to point out briefly discuss some laws and decrees designed to ensure the accessibility of the Brazilian deaf population, and finally, to reflect on accessibility as a process that can directly interfere in lack of communication in many deaf people (Santos I.B. *et al* 2019).

One of the first Brazilian laws addressing accessibility is Law 10,098, from December 19, 2000, which in its article 1 establishes:

... General standards and basic criteria for promoting the accessibility of persons with disabilities or with reduced mobility by removing barriers and obstacles in public roads and public spaces, in street furniture, in the construction and renovation of buildings and in the means of transport and communication (Brazil, 2000).

The Law mentioned above elucidates the concept of accessibility to people with disabilities, and it can be seen that the deaf population was contemplated when it states that the barriers in the area of communication should be eliminated. This aspect was finally addressed by Law No. 10,436, which recognized the legitimacy of the Brazilian Sign Language (Libras)¹ and its use by deaf communities. This law was regulated on December 22, 2005, by Decree No. 5,626 / 05 (BRAZIL 2005).

Although this cited law and the decree recognize sign language as the language of the Brazilian deaf community can be considered an important milestone in the deaf trajectory, a lot needs to be done, however since their language was finally recognized as the official language in Brazil that is a great achievement. In addition, the access to regular education from meaningful and contextualized practices, which should consider the linguistic differences between the deaf and the hearing people was great. Discussions and current research have pointed out that the education of the deaf should be bilingual, able to contemplate the linguistic needs and social aspects of the deaf (QUADROS, 2006; PEIXOTO, 2006).

Accessibility in the area of deafness, especially regarding the difficulties that some deaf users of sign language have to interact with hearing people who use the Portuguese language, emphasizes that socialization and social interactions are fundamental so that we can constitute ourselves as beings of language. This way, it is understood that the knowledge shared by the interactions occurs from a common language, which results in a joint construction of meanings (MOUSLEY, VICTORIA L. CHAUDOIR, STEPHENIE R. 2018).

In relation to the lack of access to a language, the majority of deaf people come from hearing families who are generally unaware of the sign language and prioritize only the development of oral language. However, for deaf children to acquire oral language, much more is required than just the placement of hearing aids and cochlear implants. They must be immersed in discursive, contextualized and meaningful activities. When this does not occur, it is common to see that they arrive at school without proficiency in oral language and signs. In general, they use, to interact, homemade gestures, signs, vocalizations and the act of pointing (SCHICK *et al* 2013).

In order for the deaf to acquire the sign language, it is necessary that they interact with other deaf Brazilians users of Libras, and that they are part of deaf communities (SCHEMBERG; GUARINELLO; MASSI, 2012). In this regard, Schneider (2006) states that sign language should be offered, in case of the students, in an environment that allows them to acquire, develop and use it in settings of regular education, that is, at school, in order to guarantee quality education.

Meanwhile, it is not enough to pass laws and decrees that take deaf people into consideration, and simply enroll them in a school, whether regular or bilingual. Rather, it is necessary to reflect on

¹ Libras is the sign language used in Brazil for Deaf people.

new proposals and conceptions that privilege the teaching and learning process of this population, inserting them in linguistic contexts that consider their singularities, and in the ethical and political issues that involve education in our country (HINTERMAIR, 2011).

Methods

This article is a review of the 60 (S01 to S60) deaf adults survey on quality of life developed in Brazil between 2016 and 2017; therefore, we focus only on the results related relationship and Social Domain that explain about the growth of the deaf adults and all their trajectory in language acquisition, as well as their difficulties together with his family. This clipping prioritizes the difficult childhood of the surveyed deaf people, their linguistic reality and expressions of their childhood (SANTOS I.B 2017).

This research is part of a larger study done which was carried out in Curitiba, a city located in Southern Brazil, capital of Paraná State, and in smaller towns around this capital city (Metropolitan Area) - São José dos Pinhais, Campo Largo, Pinhais and Colombo. Those towns were selected due to their proximity to the center where the research was performed, and due to the presence of many deaf people, sign language users. This study was approved by the Ethics Research Board under number 50438915.5.0000.5529.

For this study we have applied of two instruments: the WHOQOL-BREF (The WhoQOL Group, 1995), and a sample profiling questionnaire. It's covered several domains, but this manuscript will focus only on the results of the Relationship and Social Domain.

Results

A self-administered questionnaire, including demographic and injury-related information and the WHOQOL-BREF participants in Table 01 above of our research have a satisfactory perception regarding their communication and interaction with others 64.31%, due to the fact that they live with other deaf people and are part of the deaf community. A curious fact about this relatively high score is the use of a common language and in the majority of deaf people interviewed in the survey were from a specific community. Many deaf people in the sample are graduated from a University or work in universities as teachers of sign language.

TABLE 1. MEAN AND STANDARD DEVIATION SCORING OF THE QoL DOMAINS

DOMAINS	R	N /R	MEAN	MINI MUM	MAXIMU M	STANDAR D DEVIATION
Physical	54	6	58.40	35.71	92.86	11.80
Psychological	57	3	61.26	29.17	91.67	14.13
Social Relationships	46	14	64.31	25.00	100.00	21.06
Environment	57	3	54.77	21.88	84.38	14.49

SEARCH: DATA SOURCE

R = number of subjects who answered; N/R = number of subjects who did not answer.

We can see from the next table how good is their interaction and proficiency on oral, writing, reading and who uses sign language in their family.

TABLE 02 - DISTRIBUTION OF THE SAMPLE ACCORDING TO THE VIEW OF THE DEAF ON THE USE OF THE PORTUGUESE LANGUAGE (N = 60)

ACTIVITIES	FREQUENCY	%
ORAL PROFICIENCY		
VERY GOOD	16	26.67
GOOD	13	21.67
MODERATE	13	21.67
BAD	18	30.00
WRITING PROFICIENCY		
GOOD	19	31.67
MODERATE	30	50.00
BAD	11	18.33
READING PROFICIENCY		
GOOD	25	41.67
MODERATE	24	40.00
BAD	11	18.33

SOURCE: RESEARCH DATA.

The view of each participant in relation to the use of Libras and the Portuguese Language and the use of Libras by his relatives. Table 02 shows that 30% (n = 18) of the participants reported to have poor orality, while 26.67% (n = 16) reported good oral proficiency in the Portuguese language, in their opinion. Regarding writing proficiency, 50% (n = 30) of the participants reported reasonable writing, and 40% (n = 24) stated that they read reasonably.

TABLE 03 - DISTRIBUTION OF THE SAMPLE ACCORDING TO THE VIEW OF THE DEAF ON ITS INTERACTIONS (N = 60)

ACTIVITIES	FREQUENCY	%
LIBRAS'S FAMILY USERS		
NO	45	75.00
YES	15	25.00
WHO USE LIBRAS IN FAMILY *		
MOTHER	14	
BROTHERS	06	
HUSBAND	02	

SOURCE: RESEARCH DATA.

Regarding the use of sign language Libras table 03 indicate that deaf people interact with sign language with the family, only 25% (n = 15) in their interactions.

These data give us a warning because we realize how hard and poor are all communication in their family, the lack of communication is very visible, 14 deaf have said that they used Libras with their mothers, only 06 with their brothers and remarkably, no daddy was mentioned in the research as a sign language user to communicate with your deaf children.

Discussion

The WHOQOL-Bref instrument explains that personal relationships are important for people's QoL (THE WHOQOL GROUP, 1995). Thus, interactions with others depend on the use of a common language, since it is fundamental to our constitution as subjects of language. In this regard, Vaccari & Marschark, (1997) mentions that the deaf need the help of the other, who can be a teacher, a mediator, a tutor or an instructor, to interact socially. Thus, there must be a partnership

^{*} Note: The question on the use of Libras in the family can have multiple answers.

with the other and a common language for this interaction between hearing and deaf people to happen.

In this regard, Chaveiro *et al.* (2014), when consulting several international surveys, realized that deaf people have lower QoL compared to people without hearing problems, and this occurs due to lack of energy, adverse emotional reactions, social isolation and difficulties in relating to the community. According to Chaveiro, this occurs due to Lack of Communication.

Moreover, Chaveiro (2011) noticed in the aforementioned surveys that the gender issue is differentiated among the deaf, that is, deaf women have an even lower QoL than deaf men. There is also a relationship between the degree of hearing loss and QOL, which for people with severe hearing loss is lower, especially in the domains of social relations.

Research studies, such as Vaccari & Marschark (1997), Steinberg *et al.* (1999), Marschark, (2007), Santana (2007), Quadros (2006), Kushalnagar *et al.* (2007) and Fernandes (2005) demonstrate that access to communication at home, at school and with colleagues is of utmost importance for the development of the language of the deaf, andthis reflects in their QoL.

Meadow *et al.* (2004) also reported that deaf children who share the same language as their parents, for example, in a family in which "everyone is deaf", usually have social and emotional development comparable to that of hearing children although these families are the minority, since more than 96% of deaf children are from hearing parents, who, in general, find it difficult to establish an adequate linguistic contact with their children. They feel more comfortable using an oral language, and their children, to interact, use visual forms as homemade gestures. (VACCARI, MARSCHARK (1997), MITCHELL, KARCHMER (2004)).

Remarkably, we find similar data in Brazil. Quadros (2006) reports that 95% of deaf Brazilian children from hearing parents, who have limited or no knowledge of Libras, and this is hinders the process of language acquisition.

In this respect, Witkoski (2009) reports that in some families there is even prejudice regarding the use of sign language:

The mother refuses to learn Sign Language to communicate with her own daughter. Subjected to family segregation, that causes an annihilating feeling due to exclusion; the child, in his communicative isolation, shouts out his revolt, which is perceived as a typical picture due to deafness. The mother presents a reaction of estrangement to the girl's good behavior in the classroom. Prejudices are so assimilated, that she abandons the right to the exercise of full motherhood, and also disregards her maternal duty to promote a satisfactory interactional condition within the family environment (WITKOSKI, 2009: 571).

Therefore, the linguistic interaction that should exist between hearing parents and deaf children sometimes does not occur. In addition to family relationships, which are of great importance, school relations are also central to the development of children. Often, however, when the deaf child is confronted with the school environment, a common language is not used between deaf and hearing students, which can have negative consequences for the deaf, according to Schick *et al.* (2013).

Another aspect, also pointed out by the same authors, is that the deaf, when studying in schools with listeners, often isolate themselves, due to the lack of oral and written languages and the lack of command of the Sign Language by the listeners. This author points out, like Gerich & Fellinger (2011), that in schools where there are more deaf students studying, better QoL prevails because the greater the number of deaf students, the more they can relate linguistically.

Regarding linguistic socialization and its influence, Hintermair (2011) also examined the QoL in a group of German elementary school students with hearing loss (n = 212), using the QoL Inventory for Children and Adolescents, which comprises (1) school, (2) family, (3) social contact with peers, (4) interests and leisure activities, (5) physical and mental health, - 6) general quality of the question of life). The results showed that children with hearing loss, between mild and moderate degrees, had significantly higher QoL than deaf and severely deaf students.

Hintermair (2011) also assessed the student's perception of hearing loss in relation to the interactions established with teachers and classmates. For the author, there is a correlation between the interactions in school with colleagues and the mental health and QoL of students with hearing loss. The author explains that school is a place where children spend much of their life in their early years, and therefore seems to have great influence on their potential for development, their psychosocial well-being and relationships.

The use of the expression bilingual by S16 seems to refer to the fact that deaf people use Libras and are proficient in the written Portuguese language as well, which is in agreement with the Decree Law 5626/05, as already explained in the theoretical chapters of this work.

Although such a decree does not address oral use during the deaf students' school year, the responses in this study indicate that the deaf subjects, who declared themselves as making good use of orality and writing, were the ones who had a better academic background and better QoL scores.

In research with university students from the Brazilian educational system, Guarinello *et.al.* (2009) and Santos I.B (2017) investigated the literacy conditions of these students (performance in reading and writing activities). The investigated students demonstrated comprehension in some aspects, but had difficulties in the interpretation of texts.

According to the authors, the reason was the reading and writing practices that many deaf people underwent during their education, which did not take into account sign language and significant written language practices. It is also noteworthy, in the collected data, the little use that, in general, the relatives of users of Libras makes of this language. In the following reports, the two participants emphasize the tendency of parents to use orality alone to communicate with their children:

(S10) "No, just speaking oral"

(S08) "No", forbidden "use sign language at home, only oral speaking"

In the response above, by S08, the participant writes the word "Forbidden." This word has been emphasized in the area of deafness, throughout the history of humanity, especially during the

Congress of Milan (1880), in which the use of sign languages in the Education of the Deaf was banned. This congress was organized, sponsored and led by many hearing specialists, all advocates of pure orality: 56 were French oralists and 66 were Italian oralists, out of a total of 164 delegates; thus, there were 74% of oralists in France and Italy. Alexander Grahan Bell had great influence in this congress. The only countries against the ban were the United States and Britain, with deaf teachers who also attended the event. However, they did not have their voices heard and were excluded from their voting rights (STROBEL, 2006).

It is necessary to comment that out of the 60 participants in our study, nine (09) wrote the word "forbidden" when questioned about their interactional way with their families. In addition, only 25% of the sample said that they used Libras with their families, and among the most cited relatives, mothers prevailed.

(S03) Daddy never use sign language, he always angry ...

The figure of the father was not mentioned by S03 even once as a user of Libras interacting with his deaf children. Reports like this seem to demonstrate that there is still some prejudice regarding the use of the Libras by relatives. Hearing parents may have a strong desire for their child to learn to speak or maintain and improve their speaking skills. You might worry that if you learn sign language, she won't continue to develop speech. (KUSHALNAGAR *et al* 2007)

Still on the prejudice in relation to the use of Libras, Garcia (2016) complements "I have a hearing family who does not know the Libras, and made the choice of the oral language, stimulating the development of speech, ignoring the importance of the deaf culture and deaf people's language itself (GARCIA 2016 pg.84).

Witkoski (2009) reveals that there is still an obstinacy on the part of the families about the training of the spoken word and its reading as a normalization measure, disregarding the damages to the shaping of the identity, and the cognitive and psychic development of the deaf subject, such facts are already known in the literature with a socio-anthropological approach, but disregarded by the arguments of the medical sciences.

Regarding the use of sign language by deaf families, Kushalnagar *et al* (2007) in their study with family members of deaf children, explain that many parents feel incapable of caring for a deaf child, and they often seek help but do not obtain proper information. Their study reveals that parents lack information about deafness and its consequences, and that they try to do their best for their deaf child. In general, they unknown the sign language, opt for orality, often advised by the professionals who diagnose deafness and guide their families about the options and consequences of hearing loss for deaf children, emphasizing only the importance of oral language (ZÖLLER MET & ARCHER T 2015).

Final Considerations

Brazilian deaf individuals are able to establish themselves and feature more critical attitudes to the social demands. In addition, one can conjecture that the increase in the QoL research in our country can provide a more complete picture of Brazilains' real needs, including the deaf users of Libras, and could help us understand and create mechanisms to help them. This research was limited to interviewing a small portion of the population with deafness, and they had a high level of education and training, and oral and written proficiency in the Portuguese language. However, this clipping of reality allowed us to make important notes about QoL and verify how hard it is the lack of communication.

Despite the broad formulation of public policies, aimed at supporting the accessibility of deaf people, by means of Libras laws and inclusion and accessibility laws, such as laws 13,146 / 15, the data presented in this study show that the low affordability of the sign language in the health area has not happened yet. In childhood, the lack of interactions and communications could bring many problems to individuals, for example: no access to leisure, and mainly to medical treatment, such as consultations and psychiatrists, made the domain very low in our research. We noticed that more QOL surveys among deaf people throughout Brazil can provide a more complete picture of the real needs of the deaf Brazilians, including the deaf users of Libras, and could help us understand and create mechanisms to help them.

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