Satisfaction and quality of life in users of auditory brainstem implant

Satisfação e qualidade de vida em usuários de implante auditivo de tronco cerebral

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ABSTRACT

Purpose: To evaluate satisfaction and quality of life of users of Auditory Implant Brainstem. **Methods:** This is a cross-sectional and descriptive study conducted at Divisão de Clínica Otorrinolaringológica of Hospital das Clínicas of Faculdade de Medicina da Universidade de São Paulo, Brazil. For the research, 19 users of an Auditory Brainstem Implant answered the following questionnaires: KINDLR (Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents), for children and adolescents, their parents and/or caregivers; WHOQOL-BREF questionnaire, for adult participants; and the Satisfaction with Amplification in Daily Life (SADL) questionnaire culturally adapted to Brazilian Portuguese. **Results:** The quality of life of children using Auditory Brainstem Implant from the perspective of their parents showed global results above average, as for most domains, except for the emotional well-being domain. Adults showed results above average for all domains. Regarding satisfaction with the device, the adult users of auditory brainstem implant were satisfied in general, except with regard to personal image. The parents of the children showed dissatisfaction in all subscales, except for the subscale of services and cost. **Conclusion:** The results indicated that although patients are dissatisfied with the device in some aspects, overall the quality of life was rated as good for most of the aspects assessed.

RESUMO

Objetivo: Avaliar a satisfação e qualidade de vida em usuários de Implante Auditivo de Tronco Cerebral. **Método:** Trata-se de um estudo transversal e descritivo realizado na Divisão de Clínica Otorrinolaringológica do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, Brasil. Para a realização da pesquisa, 19 usuários de implante auditivo de tronco cerebral responderam aos seguintes questionários: KINDL[R] (Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents) para crianças e adolescentes, pais e/ou cuidadores; o questionário WHOQOL-BREF para os participantes adultos; e o questionário SADL (Satisfaction with Amplification in Daily Life), adaptado culturalmente para o português brasileiro. **Resultados:** A qualidade de vida das crianças usuárias de implante auditivo de tronco cerebral do ponto de vista dos pais apresentou resultados acima da média para o resultado global e para a maioria dos domínios, exceto o domínio de bem-estar emocional. Os adultos apresentaram resultados acima da média para todos os domínios. Com relação à satisfação com o dispositivo, os adultos usuários de implante auditivo de tronco cerebral estavam satisfeitos de modo geral, exceto no que diz respeito à imagem pessoal, e os pais das crianças mostraram insatisfação para todas as subescalas, exceto para a subescala de serviços e custos. **Conclusão:** Os resultados indicaram que, apesar de os pacientes estarem insatisfeitos em alguns aspectos com o dispositivo, de modo geral, a qualidade de vida foi classificada como boa, para a maioria dos aspectos avaliados.

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INTRODUCTION

An Auditory Brainstem Implant (ABI) is an electronic device indicated for use when anatomic or functional characteristics do not allow use of cochlear implant (CI) or other hearing technologies, such as fully implantable hearing aids and hearing aids for sound amplification. This is usually the case of individuals with Neurofibromatosis type 2 (NF-2), malformation or agenesis of cochlear nerves and/or cochlea, as well as in cases of cochlea ossification following meningitis[1-4].

The ABI allows access to speech and environmental sounds. Results of speech perception vary widely - some studies have only reported increased attention to sound[5,6], while others[7,8] have shown that ABI users presented sentence recognition results in open context in silence of 10% to 100%.

Some authors[3] reported that few ABI users can understand speech without the aid of lipreading, and that most of these users benefit from the detection of environmental and speech sounds, presenting lower hearing performance than that achieved by CI users. However, the authors emphasized that these results significantly improve communication and the quality of life of this population.

The different speech perception results of ABI users are associated with various reasons, among them the device's setting parameters, aspects related to auditory processing, the position of electrodes in the cochlear nuclei, as well as etiology, the amount of implantable neural elements, and the general state of the central nervous system[2,8].

In the literature, some authors have observed that ABI users reported clinical improvement in quality of life after using the device[3,8]. Quality of life is a measure that reflects an individual's perception of their health condition and how they react and act with regard to various aspects, such as their emotional and psychological level, social relationships and the environment[9].

Thus, it is important to note that a limited number of studies in the area investigate quality of life in this population. ABI-related studies generally analyze users' hearing and language performance and fail to provide information about the functionality, self-esteem, and quality of life of these individuals, as well as their level of satisfaction with the device.

Thus, the objective of this study was to evaluate satisfaction and quality of life in users of Auditory Brainstem Implant.

METHODS

This is a cross-sectional and descriptive study conducted at the Divisão de Clínica Otorrinolaringológica of Hospital das Clínicas of Faculdade de Medicina da Universidade de São Paulo (HCFMUSP) in the city of São Paulo, Brazil. The project was approved by the Research Ethics Committee of Faculdade de Medicina da Universidade de São Paulo (FMUSP) under process nº 673.905/2014. All individuals and legal guardians who participated in this study signed the Informed Consent.

Participants were selected by means of data collection and subsequent invitation of all users of Auditory Brainstem Implant who are seen and followed-up at HCFMUSP.

For the study, children and adults using an Auditory Brainstem Implant who are followed-up at HCFMUSP were selected. The sample consisted of 19 ABI users, of whom 10 post-lingual adults aged between 25-58 years (mean = 39 years and 6 months), with ABI usage time ranging from 6 months to 8 years and 7 months (mean = 3 years and 10 months), and 9 pre-lingual children aged from 4 years and 9 months to 14 years (mean = 8 years and 2 months) and usage time of ABI ranging from 2 months to 8 years (mean = 3 years and 6 months).

The speech perception abilities of the children using ABI were classified according to the classification of hearing skills development proposed by Geers[10]: Category 0 - does not detect speech; Category 1 - detects the presence of speech signal and environmental sounds; Category 2 - differentiates words by supra-segmental traits; Category 3 - differentiates words in a closed set based on phonetic information; Category 4 - differentiates words in a closed set that presents the same vowel sound, but contains different consonants; Category 5 - differentiates words by recognizing consonants; Category 6 - word recognition in an open set.

The language skills of the children included in this study were classified according to the rating suggested by Bevilacqua et al.[11]: Category 1 - does not speak and may present undifferentiated vocalizations; Category 2 - speaks only isolated words; Category 3 - builds simple sentences; Category 4 - builds complex sentences; Category 5 - is fluent in oral language.

All of the children participating in this research are in the process of learning Brazilian Sign Language (LIBRAS) along with Portuguese language and undergo speech-language therapy at least once a week.

With regard to adult ABI users, speech perception was classified by the percentage of speech recognition only by the auditory pathway in a closed context, that is, it presupposes knowledge of the material presented.

All participants used the ABI speech processor on a daily basis for at least nine hours. Chart 1 presents the sample characterization.

In order to evaluate the quality of life in children, the Portuguese version of KINDL^R questionnaire (Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents)[12] was used only for parents of children using ABI. This instrument is a generic questionnaire which assesses the quality of life in children and adolescents and does not refer to a specific disease or condition. It has four versions, where each one refers to an age group. In this study, the following versions were used for parents: Portuguese version of KiddyKINDL^R, applied to children between 4 and 7 years old; the Portuguese version of KidKINDL^R, applied to children between 8 and 11 years old; KiddoKINDL^R, for children aged between 12 and 16, translated into Brazilian Portuguese[13]. These versions are similar in number of items, answer choices, and with regard to the application of the questionnaire. Each version consists of 24 items distributed among six subscales (physical well-being, emotional well-being, self-esteem, family, friends, and school) and one scale of answers with 5 alternatives. The six KINDL^R scoring subscales are converted into a 100-point scale, where 0 represents minimum quality of life, classified

Chart 1. Sample characteristics

	Individuals	Gender	Etiology	Age at surgery	Time of use	Age at assessment	Speech processor brand	Speech perception (Closed context)	
ADULTS	1	Male	Meningitis	39 years	6 months	39 years	Cochlear	Recognition of segmental aspects 42%	
	2	Female	Meningitis	51 years	2 years	53 years	Cochlear	Recognition of supra-segmental aspects 50%	
	3	Male	Meningitis	56 years	2 years and 1 month	58 years	Cochlear	Recognition of supra-segmental aspects 50%	
	4	Male	Neurofibromatosis type 2	23 years	7 years and 9 months	31 years	Cochlear	Sentence recognition 80%	
	5	Male	Neurofibromatosis type 2	27 years	2 years	29 years	Cochlear	Recognition of segmental aspects 23%	
	6	Female	Meningitis	53 years	3 months	53 years	Cochlear	Recognition of segmental aspects 58%	
	7	Male	Meningitis	21 years	4 years and 7 months	25 years	Cochlear	Sentence recognition 40%	
	8	Male	Meningitis	29 years	1 year and 2 months	30 years	Cochlear	Recognition of segmental aspects 41%	
	9	Female	Meningitis	41 years	2 years and 1 month	43 years	Cochlear	Recognition of segmental aspects 58%	
	10	Male	Neurofibromatosis type 2	26 years	8 years and 7 months	34 years	Cochlear	Recognition of segmental aspects 50%	
								Language Category	Hearing Category
CHILDREN	1	Female	Cochlear Nerve Aplasia	4 years	5 years	9 years	Cochlear	2	1
	2	Male	Mondini dysplasia type 2	5 years and 11 months	1 year and 6 months	7 years and 5 months	Medel	1	1
	3	Male	Cochlear Nerve Aplasia	3 years and 8 months	1 year and 9 months	5 years and 5 months	Cochlear	1	1
	4	Female	Mondini dysplasia	4 years and 4 months	5 months	4 years and 9 months	Cochlear	2	1
	5	Male	Cochlear Nerve Aplasia	2 years and 11 months	5 years and 8 months	8 years and 7 months	Cochlear	3	2
	6	Female	Cochlear Nerve Aplasia	6 years	8 years	14 years	Cochlear	1	1
	7	Female	Cochlear Nerve Aplasia	5 years and 6 months	2 years and 1 month	7 years and 7 months	Medel	2	2
	8	Female	Inner Ear Malformation	4 years and 7 months	2 years	6 years and 7 months	Medel	1	1
	9	Female	Meningitis	11 years and 1 month	2 months	11 years and 3 months	Medel	2	1

as poor, and 100, maximum quality of life, classified as good. Thus, it is possible to calculate a single score which represents their global quality of life.

With regard to the quality of life questionnaire for adults, the abbreviated version in Portuguese of the Quality of Life Assessment - WHOQOL-Bref[14] was used. This instrument is an abbreviated WHOQOL-100 questionnaire, which was developed by the World Health Organization Quality of Life group in 1997[14-17]. The WHOQOL-Bref consists of 4 domains: Physical, Psychological, Social Relationships, and Environmental, and contains 26 questions. Two questions regard general quality of life (General domain) and 24 questions represent each of the facets that make up the original instrument (WHOQOL-100). The statistical software IBM SPSS Version 22 and Excel 2010 were used to analyze results. The results were transformed into percentage, where 100% represents a maximum value for quality of life, being classified as good, and 0%, the minimum value, classified as bad.

The Satisfaction with Amplification in Daily Life (SADL) questionnaire[18], adapted culturally to Brazilian Portuguese[19], was applied to assess satisfaction. The instrument consists of 15 questions divided into four subscales: Positive effects (regarding acoustic and psychological benefits); Service and cost (regarding professional competence, product price and number of repairs); Negative factors (regarding amplification of environmental noise, presence of microphony and telephone use); and Personal image (regarding aesthetics and the stigma related to use of the device).

For application in this research, the questionnaire was modified from its original version, where questions number 7 (referring to microphony) and 14 (referring to the price paid for the hearing device) were excluded. In order to answer the 13 questions about satisfaction, an equal interval scale of 7 points was used. The points corresponded to a categorical scale ranging from "not at all satisfied" to "extremely satisfied".

In order to calculate the overall SADL score, the arithmetic mean of the values attributed to the answers obtained in the 13 questions applied was calculated, where 7 was the maximum score, which indicates maximum satisfaction. In order to score each subscale, the arithmetic mean was calculated with the score referring to the answers given to the questions that make up each subscale.

After the SADL scores were calculated, the data was tabulated and compared to the normatization found by the authors of the questionnaire, presented in Table 1. From these reference values,

the patients' profile was determined for the subscales and for the overall satisfaction score. Patients with a score below the normative value corresponding to the 20th percentile were considered "dissatisfied", while those with score above the 80th percentile were considered as "very satisfied", and those with score between the 20th and 80th percentile, as "satisfied".

For statistical analysis of the data, the Kruskal-Wallis test was used, in which the domains and subscales of each questionnaire were compared and a statistically significant result of $p < 0.05$ was considered.

RESULTS

The quality of life of children using ABI from their parents' viewpoint presented, in general, above-average results (>50%) both globally and for most domains, except for the emotional well-being domain (Table 2).

Regarding the quality of life of adult ABI users, all domains presented above-average results (>50%) (Table 3).

With regard to satisfaction with the device, Table 4 describes the results obtained from the parents of children using ABI, for the global score and for the four SADL subscales: mean, standard deviation, median, maximum and minimum values.

The data in Table 5 describes the results obtained by adult ABI users for the global score and the four SADL subscales, with respect to mean, standard deviation, median, maximum and minimum values.

Regarding comparison among the domains and subscales of each questionnaire, the results showed that there was no statistically significant difference.

Table 2. Results of KINDL [R] questionnaire from the perspective of parents of children using ABI

Domains	Mean (%)	SD	Minimum (%)	Maximum (%)
Physical well-being	50	0	16	58
Emotional well-being	29	0.4	25	58
Self-esteem	75	0.5	0	100
Family	100	0.8	8	100
Social contacts	100	0	100	100
School	86	0.3	8	100
Global	74	0.1	44	90
p*	0.198			

*Kruskal-Wallis test, p<0.05= statistically significant

Table 1. Values of mean, standard deviation, 20th and 80th percentiles for the global score and the scores of each SADL subscale by Cox and Alexander[18]

Score	Mean	Standard Deviation	20th Percentile	80th Percentile
Global	4.9	0.8	4.3	5.6
Services and Cost	4.7	1.2	4.5	6.5
Positive effects	4.9	1.3	3.8	6.1
Negative effects	3.6	1.4	2.3	5.0
Personal image	5.6	1.4	5.0	6.7

Source: Cox and Alexander[18]

Table 3. Results of the WHOQOL-BREF questionnaire for adult users of ABI

Domains	Mean (%)	SD	Minimum (%)	Maximum (%)
Physical	76	18.4	36	100
Psychological	76	19.2	46	96
Social	66	23.3	25	100
Environmental	66	19.8	38	96
Global	66	26.3	38	100
p*	0.143			

Table 4. Levels of satisfaction and values of mean, standard deviation, maximum and minimum values for the global score and scores of each SADL subscale for parents of children using ABI

SADL	Mean	Standard Deviation	Maximum	Minimum	Level of satisfaction
Global	2.9	0.4	3.5	2.0	Dissatisfied
Positive effects	2.7	0.9	3.8	1.0	Dissatisfied
Service and Cost	6.1	2.5	7.0	0.0	Very satisfied
Negative factors	1.0	0.5	2.3	0.3	Dissatisfied
Personal image	3.0	0.6	4.3	2.0	Dissatisfied
p*	0.189				

*Kruskal-Wallis test, p<0.05= statistically significant

Table 5. Levels of satisfaction and values of mean, standard deviation, maximum and minimum values for the global score and scores of each SADL subscale for adult users of ABI

SADL	Mean	Standard Deviation	Maximum	Minimum	Level of satisfaction
Global	3.6	0.4	4.5	2.8	Dissatisfied
Positive effects	4.1	0.1	6.1	3.6	Satisfied
Service and Cost	5.1	0.1	7.0	0.0	Satisfied
Negative factors	2.4	0.1	4.3	1.0	Satisfied
Personal image	3.2	0.5	4.3	2.6	Dissatisfied
p*	0.176				

*Kruskal-Wallis test, p<0.05= statistically significant

DISCUSSION

It is important to investigate satisfaction and quality of life of ABI users in order to assess the multidimensional impact of hearing loss and ABI use on the lives of children and adults, complementing objective results not only on performance with the use of this device, but also on the users' perceptions and positioning[20].

These measures of satisfaction and quality of life can provide important information about ABI users' daily life in terms of physical, psychological, and social and personal well-being[21].

In face of the interest in investigating this population, this study aimed to verify the satisfaction and quality of life of ABI users.

The results of this research revealed that the parents of children using ABI have rated their quality of life as good, i.e. they presented above-average results for the following domains: physical well-being (50%), self-esteem (75%), family (100%), social contacts (100%), school (86%) and global score (74%). On the other hand, the emotional well-being of children using ABI was classified by their parents as poor, i.e. this aspect presented results well below average (29%). Emotional well-being is related to the ability to manage and control emotions and to the expression of feelings[22]. In addition, in the present study,

children using ABI have difficulties in expressing themselves, which directly affect their emotional well-being, since 44% of children using ABI use differentiated vocalizations, 44% communicate with isolated words, and 12% communicate using simple sentences with 2 to 3 elements.

It is worth noting that there are few studies in the literature contemplating satisfaction and quality of life of ABI users, which hinders comparison with this study's results.

With regard to adult ABI users, the results of this research presented values above average, i.e. ABI users rated their quality of life as good in all domains (physical, psychological, social relationships and environment).

Regarding satisfaction with the device, the parents of children using ABI are very satisfied with the subscale of services and cost only, which is related to professional competence for services received, maintenance and number of repairs. The other subscales, such as personal image, positive and global effects, and negative factors showed results below the minimum expected for each subscale, i.e. parents of children using ABI are dissatisfied with regard to acoustic and psychological benefits, telephone use, speech understanding and the ABI speech processor aesthetics. This is because, in this study, children using ABI presented restricted speech perception results, i.e. They have only the ability to detect speech, even after a considerable time using the device and undergoing speech-language therapy, having to resort to the aid of lipreading and LIBRAS to communicate. As to parents, despite having received guidance and information about the prognosis with ABI, they presented high expectations regarding the hearing performance of these children.

According to Yamada and Bevilacqua[23], each family experiences the impact of surgery in their own way. Thus, the benefit of using the device depends not only on the individual's skills, but also on the emotional support provided, as well as on the expectations of family members. Therefore, guidance and counseling are essential aspects during the rehabilitation process of ABI users, so that the prognosis is well accepted and worked on by family members and professionals involved in this process.

With regard to the adult ABI users who participated in the study, results indicated that they are satisfied with regard to the subscales of positive effects, negative factors and services and cost, and are dissatisfied with regard to the global score and the personal image subscale. These results revealed dissatisfaction with the feelings generated by the use of the device and the way the social environment sees the ABI, which interferes with self-image and, in particular, with personal relationships. On the other hand, although users feel dissatisfied, they maintain daily use for at least 9 hours a day, which evidences that the ABI provides effects that are not measured on the questionnaires, nor on perceptual tests, such as safety and comfort.

It is important to note that the Service and Cost subscale obtained the highest score for both parents of children using ABI and adult users, indicating great satisfaction with the services received and the device's maintenance. The ABI is a high-tech and high-cost piece of equipment, and carrying out a lot of repairs can affect these results, since there is still no guideline in force that guarantees repair and maintenance of the device.

Regarding satisfaction, it is important to consider that some individuals may demonstrate dissatisfaction with the ABI because they fail to fully enjoy the device's benefits. This can be explained by the fact that different people use very different criteria to judge whether they are "satisfied", and this also depends on the adequacy of their expectations to a realistic level. However, it is important to remember that satisfaction is dynamic and may vary over time, as the device is used[24].

CONCLUSION

The results indicated that, although parents of children using ABI were dissatisfied with the acoustic and psychological benefits, speech comprehension, and ABI speech processor aesthetics, parents rated the children's quality of life as good with regard to physical well-being, self-esteem, family, social contacts, school, and in general.

Adult ABI users rated quality of life as good for all aspects analyzed (physical, psychological, environment and social relationships) and were dissatisfied with the feelings generated by the use of the device.

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Author contributions