

Quality of life related factors for parents of children with hearing loss

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Abstract *Hearing loss among children, particularly those with severe and profound hearing impairment, has an effect on their communication and development, which in turn can have a significant impact on their parents. This study aimed to evaluate the quality of life of parents of children with hearing loss and identify the associated factors. A cross-sectional study was carried out involving parents of children that went through phonoaudiological therapy at a public university clinic in the city of São Paulo. The research instruments used were: the World Health Organization Quality of Life Instrument, Short Form (WHOQOL-bref), the Social Support Questionnaire 6 (SSQ-6) and the General Health Questionnaire (GHQ-12). Inferential statistical analysis was performed using the Student's t-test. The study included 29 parents, 26 mothers and 3 fathers, of 27 children with severe and profound hearing impairment. The mean of the domain scores of the WHOQOL-bref, on a scale of 0-100, ranged between 40-60 and the overall score was 53. The best performance was achieved in the physical domain (60.3) and the worst in the environment domain (40.5). The main factor associated with all domains of the WHOQOL-bref, as well as overall score was being satisfied with social support.*

Key words *Quality of Life, Parents, Child, Hearing loss*

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Introduction

Hearing loss (HL) is the third most common disability in Brazil, according to the Brazilian Institute for Geography and Statistics (Instituto Brasileiro de Geografia e Estatística – IBGE), affecting 5.1% of the population. In the 0 to 15 year age range, 7.5% of children have some kind of hearing disability, and 1.3% have HL¹.

Costa *et al.*² define HL as a kind of sensorial deprivation that is characterized by an abnormal reaction to sound stimulus. It is classified by type (determined by the location of the lesion), severity (mild, moderate, severe or profound) and period when the individual was affected (pre-natal, perinatal and post-natal).

The children whose development is most effected are those with severe or profound HL. Since these children do not perceive satisfactorily auditory stimuli, they have difficulty in understanding and spontaneously learning spoken language. This compromises their communication and as a result language ability and results at school³.

The impact of the child's hearing loss on the family in general and on the parents in particular can be severe. As soon as the diagnosis is received, a process of deconstructing life dreams can begin and a number of sometimes alternating reactions may arise, including negation, hatred, confusion, vulnerability, inadequacy and anxiety⁴⁻⁶. The discovery of HL in a son or daughter can mean the loss of the image of the perfect child that was hoped for, frustrated expectations and an uncertain future⁷.

The diagnosis of HL can lead to the family making changes and adaptations that are both internal to them and also in terms of their social relations with others. One of the main difficulties that parents face is in communicating with the child⁸, and another relates to greater restrictions in social interaction and distancing from the family's former social networks, leading to a distancing from group and community ties⁹.

The literature includes studies that investigate the quality of life of parents or carers of children with certain disabilities or disorders that affect development such as autism, Down syndrome and cerebral palsy¹⁰⁻¹³, however there is little information about the parents of children with HD.

The aim of the present study is to evaluate the quality of life of parents of children with severe or profound HD and to check for associated factors.

Methods

This research project was approved by the Ethics Committee at the Anhanguera University of Sao Paulo (UNIAN-SP). All participants in the research signed and received copies of the Free and Informed Consent Terms.

This was a quantitative, transversal study. Interviews were carried out in September 2014 at the Educational Hearing Clinic for Studying Hearing and Human Communication Problems at the Phonoaudiology Department of the Federal University of Sao Paulo.

The clinic provides services to children with HD who use a Cochlear Implant (CI) and/or an individual hearing aid, with a view to developing the capacity to speak based on the ability to hear. Phonoaudiological therapies are carried out once or twice a week, with sessions lasting 45 minutes. During the period of this research, the walk-in clinic treated 28 children with HL.

The study participants were mothers and/or fathers of children (up to the age of 12) who had severe or profound bilateral HL that had been diagnosed by the audiologist and who were undergoing rehabilitation treatment for phonoaudiology. Exclusion criteria were parents of children with other associated disabilities.

Four instruments were used and applied individually by one of the researchers: a questionnaire to gather data about the family and the child, the WHOQOL-Bref, General Health Questionnaire (QSG-12) and a Social Support Questionnaire (SSQ-6).

The first general questionnaire was used to map the sociodemographic, socioeconomic and general health profile of the interviewees and to gather (sociodemographic and health) data about the children.

The WHOQOL-bref was used to evaluate quality of life (QL). It is a generic tool for evaluating quality of life, based on the WHOQOL-100 and developed by the Quality of Life Group at the World Health Organization (WHO). The Portuguese version was translated and validated at the WHOQOL Center for Brazil¹⁴.

The WHOQOL-bref is made up of 26 questions, two of which are general (self-evaluation of QL and satisfaction with health) and 24 questions divided into four domains: physical, psychological, social relationships and environmental. Answers are given on a five-point scale and relate to situations two weeks prior to the interview¹⁴.

The results are given as gross scores that are then converted into a score of between 0 and 100,

whereby a higher score represents better quality of life.

The General Health Questionnaire (QSG-12) was used to evaluate psychological morbidity. The tool was developed by Goldberg¹⁵ with the aim of detecting non-severe psychiatric illnesses in the population. The original questionnaire contains 60 questions and an abbreviated version with 12 items was subsequently developed, adapted and validated in Brazil by Pasquali et al.¹⁶. The answer to each item is given in terms of the extent to which the respondent has experienced the given symptoms in recent weeks. The answers are given on a scale of 4 points, like a Likert scale. The final score is between 12 and 48.

The QSG-12 proposes a dichotomous scoring system¹⁷, whereby answers of 1 and 2 are recoded as 0 (absence of the psychiatric disturbance) and answers 3 and 4 are recoded as 1 (presence of the psychiatric disturbance), resulting in a score that ranges from 0 to 12 points, with the higher score representing a poorer state of mental health. People who obtain a score of three or above are considered to have a degree of psychiatric suffering that merits treatment. This cut-off point was adopted for the current study.

Social support was evaluated using the Social Support Questionnaire (SSQ-6). The original SSQ involves 27 questions and was developed by Saranson et al.¹⁸, having been adapted to Brazil by Matsukura et al.¹⁹. The reduced SSQ tool includes six questions (SSQ-6) and was found to have a high degree of compatibility with the original²⁰, having been used by a number of Brazilian studies²¹.

The SSQ-6 questionnaire is divided into two parts. In the first part, the respondent indicates the number of people who are considered to be a source of social support in light of different situations that are proposed (SSQ-N). Up to eight people can be identified (mother, father, brother/sister, spouse or partner, girlfriend/boyfriend, friend, colleague and other) as well as the alternatives *all* and *none*. In the second part of the questionnaire (SSQ-S), the respondent indicates their level of satisfaction with this perceived support, choosing between 1 and 6 on a Likert-type scale, where 1 means very unsatisfied and 6 means very satisfied.

Thus, the SSQ provides two scores: the first is SSQ-N, where the index N represents the perceived number of supportive people; and the second is SSQ-S, where the S index indicates the level of satisfaction with this social support. For the S index, the evaluations of each item are added together and divided by 6, which is the number of questions (simple average). The average will be between 1 and 6, corresponding to the level of

satisfaction with social support. For this study, the answers were grouped together as follows: 1 and 2 correspond to unsatisfied, 3 and 4 neutral (neither unsatisfied nor satisfied) and 5 and 6 to satisfied.

The resulting statistical analysis was done to check for an association between QL and the explanatory variables (sociodemographic, socioeconomic and health variables of the parents; sociodemographic and clinical variables for the child; social support and psychological morbidity). The categorical sociodemographic and clinical variables were grouped into binaries, while the continuous variables were grouped by averages. The Kolmogorov-Smirnov test was used to identify the normality of the variables. The Student's 't' test was used for the comparative analysis of average gross scores in the Whoqol-bref subject domains, along with the total score based on the explanatory variables. The degree of significance that was chosen was $p < 0.05$. The Predictive Analytics Software (PASW, version 18.0) was used for the analysis.

Results

The sample was made up of 29 parents, (26 mothers and 3 fathers), of 27 children with severe or profound bilateral HL. In the case of two children, both the father and mother were interviewed. Parents of just one of the children who was undergoing phonoaudiological therapy were not interviewed, since the child was being examined for other associated disabilities. There were no refusals to participate.

The parents' sociodemographic and socioeconomic variables are presented in Table 1. The parents' ages ranged from 21 to 45 (average: 31.8; SD: 2.1). The majority of parents were Catholic, married, had completed their secondary education and were from other municipalities in Sao Paulo State. In addition, a large proportion of parents had other children. The most prevalent economic class was D and the majority of parents did not have a steady job.

With regard to the 27 children with HL, 13 were male (51.9%). Their age ranged from 1 to 10 years, with an average age of 5.3 years (SD: 5.4). Of the children of school age (aged 6 or over) ($n = 13$), 12 attended school, while among the children aged 5 or below ($n = 14$), 10 attended school. Of this total, among the 22 children who attended school, 20 (90.9%) were attending a normal school and just 2 (9.1%) were in special schools.

The age of the child at the time of the HL diagnosis was between 0 and 4 years, and the aver-

age was 1.6 years. The parents had received the diagnosis of HL between 1 and 10 years prior to the time of the interview, with the average period of time that the parents knew about the diagnosis being 3.7 years (SD: 2.4). The children had participated in phonoaudiological therapy for between 6 and 108 months, with an average of 34.4 months of therapy (SD: 29.3). The majority of treatments (74.1%) were carried out once a week.

With regard to the general evaluation of QL in the WHOQOL-bref, the majority (65.6%) of parents evaluated their quality of life to be good or very good, while 24.1% considered it to be neither good nor bad, and 10.3% as bad or very bad. With regard to satisfaction with health, 51.8% reported being satisfied or very satisfied with their health, 34.5% neither satisfied nor unsatisfied and 13.7% unsatisfied.

Graphic 1 shows the QL scores by major domains of the population involved in the study, ranging from a scale of 0 to 100. It is noteworthy that the domain that is best evaluated is the physical, followed by the psychological. The lowest average score is for the environment.

The average score for QSG-12 among parents was 28.2 points (SD: 7.1). The scores ranged from 17 to 44. After recoding the answers, the average score for the sample was 4.3 (SD: 3.4). The scores ranged from between 0 and 12 points. With a cut-off score of 3, a large proportion (65.5%) of parents were shown to face a level of psychiatric suffering that merits treatment.

The results obtained with regard to the number of people perceived to provide support (SSQ-N) showed there to be an average of 1.5 people that the interviewee reported being able to count upon in a variety of situations that were described in the questionnaire. The source of support that was most commonly cited by interviewees was spouse, followed by mother.

In relation to levels of satisfaction with the level of social support received (SSQ-S), 3 (10.4%) parents reported being unsatisfied, 13 (44.8%) neither satisfied nor unsatisfied and 13 (44.8%) as satisfied with the social support received.

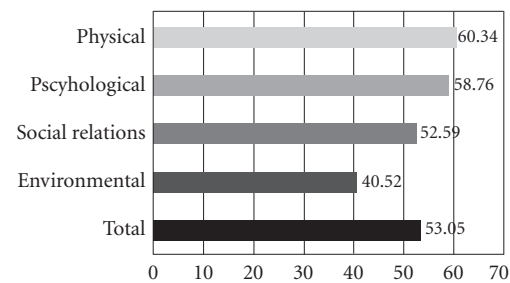
Table 2 shows the significant associations of the sociodemographic and clinical variables of the parents of children with HL, in the QL areas set out in the WHOQOL-bref.

The results showed that the variables having a son with HL and being satisfied with the social support received were associated with a better QL in the physical area. In the psychological domain, not having psychological problems and being satisfied with the social support received were associated with a better QL. In the domain

Table 1. Sociodemographic and socioeconomic characteristics of parents of children with severe and profound hearing loss (n = 29).

Characteristics	N	%
Gender		
Female	26	89.7
Male	3	10.3
Marital Status		
Married/ Stable relationship	25	86.3
Single	3	10.3
Separated/ divorced	1	3.4
Religion		
Catholic	19	65.5
Evangelical	7	24.1
Spiritist	1	3.4
No religion	2	6.9
Practicing (religion)		
Yes	20	69.0
No	9	31.0
Schooling (maximum level attained)		
Nursery	2	6.9
Primary	4	13.8
Secondary	19	65.5
Higher	4	13.8
Other Children		
Yes	20	69.0
No	9	31.0
Residence		
Sao Paulo (city)	13	44.8
Other municipalities	16	55.2
In paid employment		
Yes	13	44.8
No	16	55.2
Social class*		
B	2	6.9
C	4	13.8
D	16	55.2
E	7	24.1

Note: * Based on IBGE categories.



Graphic 1. General analysis of the domains of the WHOQOL – bref.

of social relationships, only satisfaction with social support was associated with a better QL. In the environmental area, a better QL was associated with working, belonging to social classes B or C and having a child who uses an electronic hearing device or CI.

With regard to the total score of the WHO-QOL-bref, being satisfied with the social support received was the only factor that proved to be statistically significant.

Discussion

The present study evaluated the quality of life of 29 parents and 27 children with severe and profound HL who were undergoing phonoaudiological therapy at a clinic in a public university hospital in the city of Sao Paulo.

With regard to the parents' sociodemographic data, the majority of respondents were women (89.7%), in the young adult age range (51.7% were under 30 years of age), married or in a stable relationship (86.3%), completed their secondary education (65.5%) and not involved in remunerated work (55.2%).

The greater prevalence of mothers replying to the questionnaire, while accompanying their child for treatment, is consistent with the data reported in the literature, which points to the fact that functional attributes that are still largely attributed to the mother and valued by the family²²⁻²⁴ include taking care of the education of the child with special needs, providing emotional support to the family and looking after the organization of the house^{12,23,25,26}.

This study reported a greater proportion of parents who were married or in a stable relationship. Brazilian and international studies that address the issue of disability also report a similar prevalence among interviewees^{23,24,26}.

The present study showed that a majority of interviewees (65.5%) completed their secondary education, which is different to other studies that have showed a lower level of schooling among parents of children with disabilities in Brazil^{12,26}.

The average family income reported by the majority of participants in this study ranged from between double and four times the minimum wage, which, according to the Brazilian Institute for Geography and Statistics corresponds to Class D, a finding that is consistent to that

Table 2. Significant associations ($p < 0.05$) of sociodemographic and clinical variables in different domains of quality of life of the WHOQOL-bref, and total score (average \pm SD).

Variables	Physical	Psychological	Social relations	Environmental	Total WHOQOL
Work					
Yes	n.s.	n.s.	n.s.	11.92 \pm 2.39*	n.s.
No	n.s.	n.s.	n.s.	9.50 \pm 2.38	n.s.
Health problems					
Yes	n.s.	n.s.	n.s.	12.19 \pm 2.94	n.s.
No	n.s.	n.s.	n.s.	9.89 \pm 2.25*	n.s.
Social class					
B + C	n.s.	n.s.	n.s.	13.08 \pm 1.99*	n.s.
D + E	n.s.	n.s.	n.s.	9.86 \pm 2.38	n.s.
Child's gender					
Female	12.44 \pm 2.70*	n.s.	n.s.	n.s.	n.s.
Male	15.02 \pm 2.11	n.s.	n.s.	n.s.	n.s.
Electronic Device					
IHD	n.s.	n.s.	n.s.	10.07 \pm 2.57*	n.s.
Implant	n.s.	n.s.	n.s.	15.00 \pm 0.71	n.s.
GHQ-12					
Yes	n.s.	12.78 \pm 2.51*	n.s.	n.s.	n.s.
No	n.s.	14.81 \pm 2.10	n.s.	n.s.	n.s.
SSQ-S					
Satisfied	15.71 \pm 1.66	14.78 \pm 2.39	15.44 \pm 2.24	12.08 \pm 2.18	14.27 \pm 1.37
Unsatisfied + neutral	12.23 \pm 2.37*	12.40 \pm 2.18*	10.22 \pm 3.48*	9.37 \pm 2.39*	11.24 \pm 1.96*

Notes: n.s.: not specified; IHD: Individual Hearing Device; GHQ = General Health Questionnaire; SSQ-S = Social support questionnaire/ satisfaction with support received.

* $p < 0.05$.

reported in similar studies^{12,23,26}. These results possibly reflect the type of patient who is treated in Brazilian public health services, which is the majority of studies are carried out.

The fact that the majority of mothers in the study did not have a fixed income may also contribute to the low family incomes reported. These data reflect information found in the literature, whereby young mothers with a formal education are able to participate in the labour market, but choose to take on alone the responsibility for their child's treatment²⁷.

Among the 27 children with severe or profound hearing loss who participated in the study, there was a gender balance between boys and girls and an average age of 5.3 years.

The majority of children were attending school (either nursery or primary education) and of these, 90.9% were in a normal school. This result reflects the changes that have occurred with regard to the education of children with disabilities as a result of public education policies, known as Inclusive Education.

The 2001 Directives for the National Curriculum for Special Education in Primary Education that were published by the Brazilian Ministry of Education stated that 'Inclusive Education' means regular schools taking on new responsibilities. These include proposing in the curriculum activities that support social inclusion and distinctive educational practices that meet the needs of all students, as well as preparing schools and training teachers. This model is currently being embedded in Brazil and has been seeking to establish improvements²⁸.

In this study, the average age of children at the time of the HL diagnosis was 1.6 years. This finding is different to the one reported by Pinto *et al.*²⁹ which found that average age of diagnosis at a Hearing Clinic in Sao Paulo was 5.4 years.

One possible reason for the earlier diagnoses found in this study could be to do with the establishment of a National Policy for Aural Health³⁰, which sets out the need for carrying out earlier diagnoses and interventions with a view to ensuring better prognoses in terms of the language development. Another possibility that may explain the early diagnoses in this study is the establishment of awareness-raising campaigns among the general population and among health professionals about the importance of identifying HL, along with the greater perception of parents about the indicators for the absence of hearing among babies³¹.

The time which children spent in phonoaudiological therapy varied from between 6 and 108

months, which is consistent with findings in the literature which report that the therapeutic process for people with HL is long and varied³².

The degree of satisfaction with QL and health among parents evaluated was less than in other studies with parents and carers of children with disabilities such as deafness and Down syndrome^{12,23}.

The average scores for the different domains obtained using the WHOQOL-bref tool suggest that parents' quality of life is jeopardized, mainly in the domain of environment. The domain with the best results was physical, which may be a reflection of the parents' ages, since most were young. In this age range, it is common that, in general terms, physical health is reported as more satisfactory than among older individuals.

Other studies that involve the parents of children with some sort of disability and that use the same research tool also reported that the physical domain in the WHOQOL-bref was the least affected and the environmental domain was most affected^{12,23,25,33}.

However this study reported a lower score in relation to the environmental domain compared with the other studies cited, and this trend is repeated for the other domains in the WHOQOL-bref.

With regard to psychological morbidity evaluated by the QSG-12, 19 parents (65.5%) reported that their psychological well-being was negatively affected, in other words that were found to be faced with psychiatric suffering that may merit treatment.

In the area of social support, few people in this study were perceived by the parents as being a source of support. The person who was most commonly perceived to act as a support was the spouse, which was also reported in other studies^{19,21,34}.

It is also worth pointing out that since they are parents of children with disabilities, they may be more limited in their possibilities for maintaining or growing their network of friends, due to a lack of time, opportunity or willingness to commit themselves to relationships and social activities. This finding is supported by a separate study that points to the fact that mothers of children with special needs have a smaller number of people in their support networks²¹.

Despite having relatively few people in their social support network, the majority of parents are satisfied with the support they have received, although this result differs to the one reported by Rezende *et al.*²⁶ who reported weak to moderate levels of satisfaction regarding their social sup-

port among carers of children with Down syndrome.

One of the most significant factors associated with parents' QL was social support which was perceived as satisfactory and was associated with all domains in the general score of the WHO-QOL-bref.

Studies demonstrate the importance of social support and its relationship with physical and psychological well-being, as well as with self-knowledge and self-esteem^{19,35,36}.

Rigotto³⁶ reports that individuals who do not have a social support network tend to demonstrate characteristics that include emotional instability, difficulty to express their feelings, insecurity, introversion, impulsivity and aggression.

Chor et al.³⁷ argue that social support is associated with behaviors such as adhesion to treatment, a sense of stability and psychological well-being.

Some factors were associated with a poorer evaluation of the environmental domain, including parents who did not have a regular source of income and those who belonged to classes D and E. Minayo et al.³⁸ point out that low income and unemployment have a negative impact on the quality of housing, access to basic services, infrastructure and family leisure, which in turn have a negative impact on QL.

Psychological morbidity was associated with worse results in the psychological domain of the WHOQOL-bref. The characteristics of the child's HL, including the timing of the diagnosis and the time in therapy did not show any relationship with the parents' QL. It was expected that a more recent diagnosis could have a negative impact on the parents' QL, and that this impact would be reduced as therapy went on, as these were the results reported in a prospective study by Burger et al.⁴

This study is one of the first of its kind to address the issue of QL of parents of children with

HL and to identify associated factors. The results can help to highlight specific needs for interventions that are focused on this particular target group. Support and psychosocial guidance provided to parents of children with HL can prove useful in improving QL, principally with regard to its psychological components, and social relationships. Group interventions offered while the children are receiving phonoaudiological therapy can provide these parents with a space for listening, support, guidance and reflection, as well as an opportunity to share experiences with other parents who are in the same situation.

Nonetheless, the study's limitations also need to be pointed out. Given the study's cross sectional design and the lack of a control group, it is not possible to establish a direct relationship between parental QL and their children's disabilities, using the results presented in this study. Further studies are necessary with a larger number of participants and a longitudinal design, in which parents are accompanied from the time of the diagnosis of HL and during the period in which the child undergoes rehabilitation.

Conclusions

This study reports that the quality of life of parents of children with severe or profound bilateral hearing loss is negatively affected in general terms, and most significantly with regard to environmental issues.

Satisfaction with social support was the main factor associated with QL. Another important finding was that there is considerable psychological morbidity among a large proportion of the parents interviewed and this merits treatment and has an effect on the psychological elements of quality of life.

Collaborations

CMN Ramires participated in drafting the study, literature review, data collection and writing of the article. FCA White-Barreiro and ETP Peluso conducted the orientation of research and participated in the drafting of Article.

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