



Wellbeing of Parents with Hard of Hearing Children: A Qualitative Study

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Abstract

Objective: The study aimed to assess: (i) the quality of life of parents having children with hearing disability; (ii) their adaptation to this process; (iii) their difficulties in raising their children; and (iv) the strategies involved for affronting the issue of hearing deficits.

Method: In-depth interviews using a semi-structured questionnaire form were conducted in a sample consisting of 8 parents with hearing impaired children. The children (2 to 12 years) included in the study have used at first bilateral hearing aids and then they have continued with cochlear implants. The data were thematically analyzed with ATLAS.ti 8.1.

Result: The data suggested that 3 main themes, 7 subthemes and 50 codes were present in the information collected from the questionnaires. The three main themes emerged from the data were related to: (1) The relationship between the family and the social environment; (2) The effects of hearing loss; (3) The family's access to the healthcare system.

Conclusion: These findings suggest that the use of cochlear implants at an early age with an oral communication mode is associated with a higher family satisfaction. Also, the education and the language development of the children and the effect of hearing aids are important factors for the well-being of families with hearing impaired children.

Keywords: Qualitative study; Wellbeing of parents; Hearing loss

Introduction

Families with children presenting hearing disabilities may feel uncertain about their parenting skills and they might experience difficulties in obtaining information related to proper decisions [1]. They may also face the uncertainty of how children with hard of hearing, can learn at an optimal level [2]. They might feel stigmatized and socially isolated and even feel rejected by other family members and friends [3,4].

With the increased number of neonatal hearing screening programs, hearing loss can be efficiently diagnosed before 3 months of age [5]. Clinical institutions have become more sensitive to the changing requirements of children with hard of hearing and their families. Thanks to the early diagnosis of hearing deficits, the tendency of families to use cochlear implants has increased with the widespread use of cochlear implants, the requirements of the children with hearing loss have changed and it has been suggested that the diagnosis, treatment, rehabilitation and training processes of these children are not separate entities. In the current healthcare and social system, the available resources for the children with hearing loss should be administered with a specific strategy plan, in which their families can participate [6].

Hearing loss is not the sole burden for the child, but it is a problem of the whole family [7]. The family is highly important for providing support (including physical, emotional and social facets) for children with hearing loss. Nevertheless, families with hard of hearing children often find themselves in distress, particularly when they have to cope with the stress of decision-making. The data in the literature suggest that families usually have insufficient information to make decisions

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Table 1: Demographic information of the parents.

| Participant ID | Age | Gender F/M | Education | Occupation Yes/no | Relation to child |
|----------------|-------|------------|-------------|------------------------|-------------------|
| 1 | 23 | F | High school | no | mother |
| 2 | 28 | F | basic | no | mother |
| 3 | 33 | F | basic | no | mother |
| 4 | 29 | M | High | yes | father |
| 5 | 35&40 | F&M | basic | Mother: no Father: yes | Mother & father |
| 6 | 40 | M | high | yes | Father |
| 7 | 40 | M | Basic | yes | Father |
| 8 | 43 | M | basic | yes | Father |

Table 2: Demographic information of the children.

| Child ID | Age | Gender F/M | Hearing loss | | Hearing aid | | Special education | | Cochlear implant | |
|----------|-----|------------|-------------------------|----------------|----------------|--------------------|-------------------|-----------------------|---|---------------|
| | | | Diagnosing Age (months) | Severity of HL | Onset (months) | Current Use Yes/no | Onset (months) | Current Status Yes/no | Onset (months) | Uni/Bilateral |
| 1 | 4 | M | 5 | Profound | 5 | no | 12 | yes | 1 st :12 2 nd :18 | Bilateral |
| 2 | 4 | M | 18 | profound | 18 | no | 24 | yes | 1 st :36 2 nd :42 | Bilateral |
| 3 | 3 | F | 3 | profound | 8 | no | 12 | yes | 30, same time | Bilateral |
| 4 | 5 | M | 30 | profound | 30 | no | 30 | yes | 48, same | Bilateral |
| 5 | 12 | M | 42 | profound | 42 | yes | 42 | no | 120 | Unilateral |
| 6 | 11 | M | 60 | profound | 60 | yes | 60 | yes | 96 | Unilateral |
| 7 | 7 | M | 6 | profound | 9 | yes | 96 | yes | 96 | Unilateral |
| 8 | 2 | M | 6 | profound | 9 | Yes | 9 | yes | 20 | Unilateral |

which might affect their children in the long term [1]. The purpose of this study was to assess the quality of life of parents with hard of hearing children, their adaptation to this process and the difficulties they face while they raise them. This study collected data to assess the following questions:

1. What are the quality of life indicators in families with a child with hearing loss (diagnosed at early age)?
2. What is the level of satisfaction of families with a child with hearing loss in their family life domain?
3. Which family life domains are affected by the hearing loss of their child?

Materials and Methods

This study is qualitative study with a grounded theory design based on the following three domains: (i) on social support and interactions; (ii) on the general effects of hearing loss and (iii) on the healthcare access of family members.

This study was approved by the Institutional Review Board (protocol number: 09.2018.199), and all the participants gave informed consent to participate in this study.

Participants

Within the scope of the qualitative research, in depth interviews were conducted with 8 parents, aged between 23 and 43 y. The participants were selected with convenience sampling and none refused to participate in the study. Detailed demographic data of the parents are presented in Table 1.

The children included in the study were aged between 2 to 12 years. At first, they have used bilateral hearing aids for a minimum period of 7 months and then a cochlear implant in at least one ear. The demographic information of the children is presented in Table 2.

During the interviews, a semi-structured survey form was used with face to face interaction. All interviews were conducted in an Audiology clinic of a University Hospital, where the children were submitted for the follow-up. The interviewer and the participants knew each other prior to the study. During the interviews, there was no other person in the room except the child, the parents and the interviewer. No prior testing of the interview form was performed before the study. No interviews were repeated during the study, since all questions in the interview form were answered and all participants were able to complete the interview.

There were no any extra physical or mental disabilities of the children who participated in this study. The parents of children with hearing loss were healthy with no other physical or psychological pathologies.

Data collection process

The semi-structured interviews were conducted by a research assistant in Audiology with a BS degree in Psychology who had and attended a course on "Analysis of Qualitative Research" on the Public Health Department for one semester during the normal PhD lectures term. The interviewer made necessary alterations in the questions and asked them in a conversation-style and supported the interviewee without violating the objectivity during the interview. The interviews were conducted face to face and the predetermined questions were asked in a certain order while the time for answering the questions was not restricted. The interviews lasted from 20 min to 60 min. The interviews were recorded after the informed consent of the participant. The participants received sufficient information on the objective of study during the informed consent process. The interviewer took notes wherever it was necessary. The data were collected with a semi-structured survey with questions on demographic information, the early diagnosis and intervention for the hearing loss, the experiences,

Table 3: Semi-structured interview form.

| | |
|----|--|
| 1 | Why did you take your child to the doctor first? (What changes have you observed?) |
| 2 | Who first noticed the changes in your child? How did he/she notice these changes? |
| 3 | What did you first feel after the diagnosis of hearing loss? What did you go through? (Inability to accept? Blame yourself or Someone else?) |
| 4 | Why do you think your child has hearing loss? |
| 5 | What is your partner's attitude in caring for your child? |
| 6 | What was your partner's attitude during the diagnosis process (Could you tell your partner easily? Any attitude changes after diagnosis?) |
| 7 | What was the attitude of the people around you during the diagnosis process? |
| 8 | How do you think hearing loss in your child affects your family life? |
| 9 | How did hearing loss affect the relationships between family elders and your child? |
| 10 | How are going meetings with relatives for you and your child? |
| 11 | What are the behaviors that make you or your child feel bad during these meetings? |
| 12 | How do you think knowledge level of the people you encounter about hearing loss? |
| 13 | How do other people react, who notice that your child is wearing hearing aids? |
| 14 | What did you experience in crowded and social areas? |
| 15 | How do you assess your child's attitude towards school? |
| 16 | How is your child's relationship with teachers and friends? |
| 17 | What difficulties does your child experience at school due to hearing loss? |
| 18 | How do you assess your child's school performance (Do you think that hearing loss affects school performance?) |
| 19 | How is your relationship with other parents and the school administration? |
| 20 | How do you assess the teacher's attitude towards hearing loss? |
| 21 | How do you support your child for school life? |
| 22 | How does having a sibling with hearing loss affect the life of a sibling without hearing loss? |
| 23 | How could your other children's healthy hear affect your or your partner's behavior towards children? |
| 24 | What do you advise families with children with hearing loss during the raising their children? |
| 24 | What do you think can be done to make your child's life easier? |

Table 4: Themes and subthemes of the study.

| Themes | Relationship with Social Environment | Effects of Hearing Device | Access to Healthcare System |
|-----------|--------------------------------------|--------------------------------------|-----------------------------|
| Subthemes | Family | Effects of Hearing Device | |
| | Relatives | Language Development of the Child | |
| | Friends | Educational Development of the Child | |
| | | Psychological Condition of Parents | |

attitudes and evaluation of the family.

Data preparation

For this study, a semi-structured interview survey form was created according to qualitative research techniques [8], following these steps: (i) the relevant literature was reviewed; (ii) the experiences of the families, during the early diagnosis and treatment period, as well as their opinions and attitudes were considered; and (iii) In order to increase the comprehensibility and effectivity of the questions, appropriate specialists were consulted. The semi-structured survey is presented in Table 3.

Data analysis

The data acquired were analyzed with descriptive analyses based on an inductive approach. We have followed the techniques prescribed by Miles and Huberman (1994) to analyze the data [9]. Also, the reader can find the COREQ: A 32-item checklist for interviews and focus groups were followed suggested by Tong, Sainsbury, and Craig (2007) [10].

The transcripts were prepared by using voice records and the transcripts from all the interviewed families were included in the data processing. The transcripts were analyzed with codes classified to predetermined themes/and subthemes associated to the interview questions. The themes, subthemes and codes were in a hierarchical relationship. Themes contained several subthemes, which contain numerous codes extracted from transcripts. Themes and subthemes had also horizontal relationships in addition to their vertical relations. The hierarchical visualization of themes and codes was performed with the ATLAS.ti software (version 8), with no predetermined saturation point. Two coders participated in the coding and hierarchical code tree formation processes. Converging code trees with “is a part of”, “is a property of”, “is associated with” and “contradicts with” links were created to emphasize the components of important themes and subthemes of this study. Both previously established and data derived themes were used for the analysis. The participants didn’t provide any additional feedback after the analyses.

Table 5: Subthemes with codes of related to “Relationship with social environment” theme.

| Relationship with Social Environment | | |
|--------------------------------------|-----------------------------|-------------------------------|
| Family support | Relatives support | Friends support |
| Mother’s care | Relative intervention | Environment knowledge |
| Mother’s concern | Relative relationship | Environment intervention |
| Father’s interest | Relative knowledge about HL | Environment curiosity |
| Father’s support to mother | Relative curiosity | Seeking support |
| Sibling’s support | Distant kind ship | Relationship with environment |
| Sibling’s jealousy | Consanguineous marriage | |
| Supporting spouses from each other | Relative reaction | |

Results

The data analyses suggested that the records contained 3 main themes, 7 sub-themes and 50 codes, which are presented in Table 4. The three main themes emerged from the data are: (i) The relationship with the social environment; (ii) The effects of hearing loss; and (iii) The available access to the healthcare system. Except for the last theme, the first two was divided into three or four sub-themes. The relationship with the social environment included relationships with the family members, relatives and friends and received support. The effects of hearing loss theme referred to the effects of the hearing device (including both cochlear implants and the conventional hearing aids), the language development of the child, the educational development (both for special or normal school education), and the psychological conditions (including positive and negative emotions) of the parents.

Relationship with the social environment

The first emerged theme of study was the relationship with the social environment. It included 3 subthemes namely: (i) the support of the family members; (ii) the support from the relatives and (iii) the support from friends.

In the data 19 codes were identified. These were under the main theme of “Relationship with Social Environment” and its subthemes (family support, relative support, and friend support) which are shown in Table 5. The family support included codes of “mother’s care”, “mother’s concern for the children”, “father’s interest”, “father’s support to mother”, “sibling’s support”, “sibling’s jealousy”, and “support of spouses from each other”. All of these were found to have important effects on the well-being of the parents. The subtheme of the relative’s support included codes of “relative intervention”, “relative relationship”, “relative knowledge about hearing loss”, “relative curiosity”, “distant kinship”, “consanguineous marriage”,

and “relative reaction to parents”. The friends’ support included codes of “environment knowledge about hearing loss”, “environment intervention to parents”, “environment curiosity”, “seeking support of parents”, and “relationship with environment”.

Effects of the hearing loss

Table 6 shows the sub-themes and the related codes of the theme “Effects of Hearing Loss”. The following four subthemes were identified: (i) Effects of the hearing device on the family; (ii) Language development of the child; (iii) Educational development of the child with hearing loss and (iv) the psychological condition of the parents. There were 7 codes linked to the first subtheme, which include “bilateral implantation”, “age of second ear implantation”, “better hearing with cochlear implantation”, “clasp problem of hearing device”, “adaptation of the device for the child”, “image of hearing device”, “and knowledge level of hearing device for both family and social circle”. The second subtheme was “Language development of the child” which was found having important effects on parents. The related codes were “Speech development of the child”, “Delay in speaking”, “Delay of language acquisition”, and “Speech therapy”. The third subtheme was “Educational development of the child”, which included both special and normal school education. Its related codes were “special education”, “duration of special education”, “special training practices”, “age of special education”, “reward and punishment for a child”, “homework”, and “school success”. The last subtheme was the psychological condition of parents with hearing impaired children. It included both positive and negative emotions. While the codes for the positive emotions were “happiness”, “patience” and “hope”, the negative emotions or aspects included “shyness”, “sadness”, “courtesy stigma”, “pity” and “vulnerability”.

Families access to healthcare

Table 7 shows the codes of the theme “Access to healthcare

Table 6: Subthemes with codes of related to “Effects of Hearing Loss”.

| Effects of Hearing Loss | | | |
|---|-----------------------------------|---|---|
| Effects of hearing device (Cochlear Implant and Hearing aid) | Language development of the child | Educational development of the child (special and normal education) | Psychological condition of parents (Positive & negative emotions) |
| Bilateral implantation | Speech development | Special education | Shyness |
| Second ear implantation age | Delay of speaking | Duration of special education | Sadness |
| Better hearing with Cochlear Implant | Delay of language acquisition | Special training practices | Vulnerability |
| Clasp for hearing device | Speech therapy | Age of special education | Happiness |
| Device adaptation | | Reward and punishment for a child | Patience |
| Image of hearing device | | Homework | Hope |
| Knowledge level on hearing device for both family and social circle | | School success | Courtesy Stigma |
| | | | Pity |

Table 7: The codes of the theme of "Access to healthcare system".

| Access to healthcare system |
|--------------------------------------|
| Wrong diagnosis of the child |
| University hospital |
| Failure to complete the hearing test |
| Hospital follow up process |
| No/Delay in diagnosis |

system". No subthemes were identified and the data suggest that this theme is related with the following codes: "Wrong diagnosis of the child", "University hospital", "failure to complete the hearing test", "problem for the hospital follow up process", and "No/Delay in diagnosis".

Discussion

Social relationship with the environment

The first theme was "the relationship with the social environment of parents having hard of hearing children". It included three subthemes as "Family support", "Relative support" and "Friends support". All of those subthemes affected the well-being of parents. Analysis of the family responses indicated that the assessed families were largely satisfied with the domains of family life and social environment. This finding is consistent with the data from Tanksley, who suggested that there is no significant difference between hearing and deaf and hard of hearing mother/child pairs on interaction [11]. Also, for the family support, Henggeler et al. suggested that there is no difference in the marital satisfaction of parents with children with and without hearing loss [12]. One family member stated, "I'm so happy about my spouse's interaction with my child. She is always taking care of him, follows his homework and his clinical process very carefully". However, the responses from that particular couple showed that they were dissatisfied with the relatives' intervention, the consanguineous marriages, and the curiosity and knowledge level of the people in their social circle. As one family member stated, "I was so lucky because of my neighbors. When I was raising my child with hearing loss, they supported me. For example, when I was bringing my child to the school, I could easily entrust the other child to them for a short while. They also know every process about hearing loss like me. At first time when my child diagnosed as hearing loss, even my relatives didn't believe me, but my friends supported me for all time". Also, the other family member stated, "We went to a picnic, me, my husband, my sister in law etc., there we couldn't find the new hearing device of my son no matter how much we've searched for. Then, everyone related or not, have searched for the device together. They've used their phone torch lights to search the device. A stranger finally found it".

Effects of hearing loss

Analysis of family members' perceptions on the progress of children with hearing loss indicated a noteworthy difference in satisfaction between types of amplification (cochlear implants and hearing aids), and various communication modes. Families who use oral communication along with a cochlear implant were found more satisfied with the speech and the perception development of their children. They were also more satisfied with their child's speech and sound perception in comparison to the families whose children use hearing aids alone. These findings corroborated previous data in the literature. Nikolopoulos et al. found a highly family satisfaction with communication outcomes following a cochlear implantation [13].

Also, many studies suggested that children with a cochlear implant have better speech perception skills following cochlear implantation [14,15]. As one parent stated, "we couldn't believe that our child has a hearing impairment because he reacted to sound very well after the cochlear implantation".

Families also reported that the largest impact of hearing loss was on their emotional well being, particularly they experienced negative emotions like sadness, guilt, vulnerability, stress, shyness, guilt, denial of hearing loss, sadness, remorse, and pessimism. Nevertheless, families with hard of hearing children also experienced positive emotions like happiness, patience and hope. As family member stated, "the process of our acceptance of hearing loss took a while. We accepted the hearing loss only after he received the implant. We understood and accepted his hearing problem, especially after he began hearing the phone or the doorbell. Conversely, he was not reacting to sounds when he was using a hearing aid. He changed after the implant." The satisfaction after cochlear implants and impact of hearing loss on parent wellbeing, particularly increased stress and extra time demand, are also consistent with previous data in the literature. According to Calderon et al. families spent extra time for activities related to therapy, which limits the time for household tasks and the needs of other family members [1]. As one family member stated, "we, as a family with an implanted child, expect too much from him. When my son was too young, I was waiting for when he was going to talk. The other children were talking already, but my son was not talking yet, despite receiving the implant. I really made an effort to make him speak like the other children" Furthermore, the analysis of the education network showed that the special education provided at home and integrated into the school education was vital for children with hearing loss. In addition to the duration, age of onset and administration place of the special education, the attitudes of the families towards special education and their children (including rewards and punishments) play an important role. For example, families reported that they used rewards for their children to make easier their adaptation to school. As one parent stated, "I always buy an ice cream to my son in order for him to go to school". Also, in this study, it was found that families were largely satisfied with areas of school lives of their children, their children's adaptation to both special school and normal school, school practices, teacher's interest to children. They were all have good relationship with children's school. Furthermore, they were sensitive for choosing a special school for their children. One family member stated, "I always bring my child to a special school and watch him when he practices".

Families access to healthcare system

The healthcare seeking behavior has been defined as, "any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy". The access to a healthcare system (one of the main themes of study) showed that this behavior was associated to difficulties/delays in the clinical diagnosis. As the parents struggled for the correct and complete diagnosis, they chose university or private hospitals as healthcare provider institutes. However, their journey usually ended in university hospitals for the diagnosis of hearing loss. So, families with a hard of hearing child had demands in order to locate and access audiologists and physicians able to respond to their child's special needs. As one family member stated, "When my son was born, there was no ABR (Auditory Brainstem Response) testing in our hospital. That's why we had to go to a bigger city to find the proper facilities. When my son was diagnosed, we had to

start a special education program but again in our city, there was no teacher well educated for deaf children. That's why we had to move to a bigger city for our son's education". This is consistent with the previous data in the literature, stating that parents have difficulty finding health care providers who are responsible for serving their hearing-impaired children [16]. However according to other studies, the age of the child is an important factor because parents with young children presenting hard of hearing are more satisfied with the service providers, in comparison to parents with older hard of hearing children [17,18].

Conclusion and Suggestions

The findings of the present study suggest that the use of cochlear implants, at an early age, with an oral communication mode is associated with a higher family satisfaction for the child's speech production and sound perception. Furthermore, the themes of "educational development, language development and effect of hearing aid over the family" are the main important themes which significantly affect the wellbeing of the family.

Neonatal hearing screening programs provide an acceptable service if the infants with hearing loss are identified early. However, the psychological support to the families in denial during the initial period of diagnosis of hearing loss is important. The diagnosis may also affect the relationship between mother and father who might also need psychological support. The Physicians and Audiologists have to provide sufficient information to the families to prevent any potentially hazardous intervention to the child's ear (e.g. treating external ear canal with oil, etc.). For the adaptation process to the cochlear implant, both children and families require support. The family has to avoid treating the child with the hearing loss as privileged and behave in a normal mode.

Furthermore, the information on hearing loss, provided by mass media, has also importance in raising social awareness. The data from this study showed a rather low level of hearing-loss knowledge in the close social circle of families with hearing loss. Frequently, the families attend the healthcare system with some delay, because they do not consider important the issue of hearing loss. With the help of media, the public can be informed on the timing and features of developmental stages of speech in their children. The fathers are generally satisfied with the child care and attention shown by the mothers; however, they should be more encouraged to participate in the special training process in order to share the burden of disability. Also, fathers may lag behind in terms of information, due to their occupation requirements (i.e. only one member of the family follows closely the developments of the child, while the other is working). Since family elders has generally negative effect on the testing of hearing loss, this negative effect may be limited with raising awareness in families.

Finally, the communication skills of the special education teachers may be improved with specific training. The curriculum of the special education courses may be improved in terms of language and speech topics. Since the teachers do not always have the specialized knowledge to identify hard of hearing students, audiologists may provide the interested families with detailed information on the capabilities of children with hearing loss and the severity of hearing

loss. Child psychologists should also play an active role in supporting the well-being of the families with hard of hearing children, during their auditory training process.

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