






Research Article

Family and Rehabilitation of Children with Cochlear Implant: A Qualitative Study

Mina Moradi¹, Masoud Fallahi-Khoshknab¹, Asghar Dalvandi¹, Mohammad Farhadi²,
Sadat Seyed Bagher Maddah¹, Eesa Mohammadi³

¹Department of Nursing, University of Social Welfare and Rehabilitation Sciences, Tehran, Iran

²ENT and Head, Neck Research Center and Department, Hazrat Rasoul Hospital, The Five Senses Institute, Iran University of Medical Sciences, Tehran, Iran

³Department of Nursing, School of Medical Sciences, Tarbiat Modares University, Tehran, Iran

ORCID iDs of the authors: M.M. 0000-0002-0271-0861; M.F.-K. 0000-0003-0507-0107; A.D. 0000-0001-8762-7591; M.F. 0000-0001-6303-1750; S.S.B.M. 0000-0001-6048-1481; E.M. 0000-0001-6169-9829

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Abstract

AIM: This study was conducted to explain the role of families in rehabilitating children with cochlear implants based on the participants' experiences and perceptions.

METHOD: This research is a qualitative study based on the method of contract content analysis, and it is conducted with semi-structured interviews to collect information in Iran in 2018–2019. The interview was conducted with 12 participants, including caregivers (child caregivers with a cochlear implant), and the process of data collection continued until saturation. Interviews were recorded and transcribed, and the data were analyzed using Gran Haim and Landman content analysis. This study was guided by consolidated criteria for reporting qualitative (COREQ).

RESULTS: The results of the study were formed in the main class titled the family, the effective rehabilitation factor, and two sub-classes titled supportive family and continuing professional and non-professional rehabilitation.

CONCLUSION: The findings of this study indicated that the rehabilitation process in these children will be incomplete without the presence and support of the family.

Keywords: Children, cochlear implant, family, qualitative research, rehabilitation

Introduction

Chronic diseases and childhood disabilities have significant effects on the functioning of the family and involve the family in many tasks, responsibilities, and concerns related to the child care needs, educational, medical services, tolerating cost in terms of services, ambiguous future, social isolation, and loss of social opportunities, excessive absence from work, financial, physical, and emotional problems (Hockenberry & Wilson, 2018).

Diagnosing a child's deafness is a serious problem and a critical event for parents (Sahli, 2011). It is often an unpleasant and stressful experience, and it gives a feeling of grief for many of them (Scarinci et al., 2018; Zaidman-Zait, 2007). Disbelief, guilt, anger, anxiety, and frustration are some of the feelings that parents experience during this time (Olecká & Ivanová, 2012; Talebi et al., 2018). A deaf child has educational and behavioral problems that cause much stress on parents (Quittner et al., 2010).

Parents are exposed to unique challenges. These people should adapt themselves to the significant anxiety and fear that arises

before and during surgery of their children because these rehabilitation services involve the parents remarkably during their process. The parents should obtain information about the maintenance and also removal of the defect in the cochlear implant, hence they must learn the principles in these cases (Schorr, 2005).

In the studies of Amiri et al., (2018) and Chen et al., (2013), the parents have reported about the stressful condition of being exposed and care for children with a cochlear implant; these reports can be divided into categories such as adaptation to needs and children's behaviors of implanting time and efforts spent on this adaptation, special needs and requests from parents that lead to marital stress, the problem of finding formal systems for caring these children, efforts, and tensions to parents during the intervention program of the child and also the problem in finding support systems.

The family is considered the center and the central core of care. The studies by professionals working with children with disabilities have shown that the most effective services are those that emphasize the role of the family in treatment (Riyahi

Corresponding Author: Masoud Fallahi-Khoshknab

E-mail: fallahi@uswr.ac.ir

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et al., 2019). In the mentioned studies, the stress and anxiety of families in the care and rehabilitation of children with cochlear implants have been investigated more. What phenomena the parents and mothers of children with cochlear implants experience in their lives, what are the new conditions, and how involved they are in the rehabilitation process have not yet been clarified. Given that the qualitative research approaches provide opportunities to gain new insight about parents' lives and interactions with their children and since there is very little data and information on this phenomenon, this study was conducted to identify the way of rehabilitation of children with the cochlear implant by the parents.

Research Question

What is the role of the family in rehabilitating children with cochlear implants?

Method

Study Design

It was a qualitative study. The COREQ checklist completed for current study (Tong et al., 2007).

Sample

Participants were families, child caregivers, and people involved in the rehabilitation of children with cochlear implants referred to the cochlear implant centers of Tehran hospitals for cochlear implants and rehabilitation in 2018–2019. Targeted sampling was performed among the eligible individuals and caregivers of children with a cochlear implant who had experience and willingness to participate in the study, with maximum diversity (age, gender, marriage, and level of education).

Data Collection

The data collection method was open, and in-depth semi-structured interviews were performed face-to-face. Interviews with child care providers were performed in private rooms when they were waiting for their child's rehabilitation and with pre-coordinated therapists in their rooms at a specific time. The research interviewer had years of experience communicating with cochlear implant children and their families. The samples were selected by performing 12 individual interviews; the duration of each was 30–40 min.

Several general questions were used as guide questions to begin the interview. The questions asked in the interviews were: "How do you take care of your child with the cochlear implant? What do you do for these children?" Then ask the follow-up questions to clarify the topic. Participants' answers determined these questions. Interviews continued until data saturation.

Statistical Analysis

The process of qualitative data analysis was based on the proposed steps of Graneheim and Lundman, 2004: (1) implementing the interviews conducted and reviewing them several times in order to have a correct understanding of all the cases found, (2) extraction of semantic units and categorizing them as compact units, (3) summarizing and categorizing compact units and selecting the appropriate label for them, (4) arranging

subcategories based on comparing the similarities and differences in subcategories, and (5) selecting the appropriate title that can cover the obtained categories. Four criteria of acceptability, reliability, verifiability, and transferability were used to determine the accuracy of the data. In order to verify the acceptability of the data, sufficient time was spent to collect the data and interview, the coded interviews were returned to the participants, and the accuracy and appropriateness of the codes given with the participants were reviewed, as well as the text of the interviews with the supervisors and the advisor was checked. For verifiability, it was tried to adequately describe all the stages of research, including data collection, analysis, and the emergence of codes and concepts so that others can follow the process of data analysis. Attempts were made to conduct audits with a detailed description of the stages of work to confirm the reliability of the data.

Ethical Considerations

Ethical standards were observed by obtaining ethical code (Approval ID:IR.USWR.REC.1397. 008, In Date: May 29, 2018), from the University of Social Welfare and Rehabilitation Sciences, informing the participants from the objectives of the research, obtaining permission to record audio of interviews, the confidentiality of recorded information, and giving the right to withdraw at a favorite time.

Results

In this study, the participants were ten women and two men aged 34–60 years (Tables 1 and 2). From the in-depth descriptions of these participants, a concept including the family and the effective rehabilitation factor were extracted (Table 3).

The main class of this study was family, the effective rehabilitation factor, which means that the child spends much time with family members. Also, reducing the age of diagnosis to the first week after birth, as well as a cochlear implant to about 10 months, indicates that parents as parent-therapist should play a key role in rehabilitating their children. This class consists of two sub-classes which include (1) supportive family and (2) continuing professional and non-professional rehabilitation, (Table 3) which is explained as follows.

Supportive Family: This means that the family is very involved with the rehabilitation of children with a cochlear implant, participates in all children's rehabilitation programs, and is even trained in this field. So if there was no support and participation of the family in the rehabilitation of these children, these children would not have been placed under the implant surgery. This sub-class consists of open codes: (1) mothers accompanying children in rehabilitation, (2) close communication between the child and the family, (3) comprehensive education at home, and (4) the family's patient effort.

Mothers Accompanying Their Children in Rehabilitation: This means that as the first person the child communicates with and spends most of their time at home is the mother, a mother plays a crucial role in the child's rehabilitation. Some mothers of children with cochlear implant said the following about the interactions with their children:

Table 1.
Demographic Characteristics of the Participants

| Row | Age | Gender | Education | Job | The Relation of the Caregiver with the Client |
|-----|-----|--------|---------------------|------------------|---|
| 1 | 49 | Female | Fifth grade | Housekeeper | Grandmother |
| 2 | 40 | Female | Diploma | Housekeeper | Mother |
| 3 | 34 | Female | Diploma | Housekeeper | Mother |
| 4 | 43 | Female | Fifth grade | Housekeeper | Mother |
| 5 | 50 | Female | Secondary education | Housekeeper | Mother |
| 6 | 34 | Female | Diploma | Housekeeper | Mother |
| 7 | 52 | Female | BA | Speech therapist | - |
| 8 | 40 | Female | PhD | Speech therapist | - |
| 9 | 44 | Female | MA | Psychologist | - |
| 10 | 60 | Male | PhD | Psychologist | - |
| 11 | 40 | Male | BA | Audiologist | - |
| 12 | 54 | Female | BA | Audiologist | - |

Table 2.
Demographic Characteristics of Participants

| | |
|-----------------|--|
| Gender | 2 men and 10 women |
| Age | The average of 45 years, a minimum of 34 and a maximum of 60 years |
| Education level | Minimum secondary education to Ph.D. |
| Marital status | 9 married and 5 single |

The mother of one of the children with a cochlear implant: *"I was recording the children's show in which she was interested. We were watching by DVD two times."* (Participant 6)

"I explained her books myself; I helped him." (Participant 3)

Participant 7 of speech therapist: *"To the extent that I explain the purpose of the work, it is clear that the child does not sit to work with you, you as a mother should know that what is our purpose without our purpose in this work, you have to work with him indirectly."*

Participant 9 of the psychologist: *"Yes, we have classes, in fact, group workshops. We have individual rehabilitation and educational programs that both mothers are trained, and the child has a rehabilitation program. The mother sees the program and continues at home."*

A Close Relationship Between the Child and the Family: This means that family support is an essential element in children's development. Members of the family need close interactions and must help each other to advance. This issue is seen in families.

The mother of a family who talks about a child's relationship with her family says, *"She plays with her sister, her sister is seven years old, she plays with her father, and she rides behind her father. She wrestles, she plays with cards."*

"Fatemeh says I would like to go to school like my uncle. I will go to her room to study. I have a lesson. She likes to be with her uncle a lot. She likes her grandfather; she communicates with her grandfather and me well." (Participant 1)

Table 3.
Classes and Their Codes

| Main Class | Sub-Classes | Open Code |
|---|---|---|
| The family, the effective rehabilitation factor | Supportive family | Mothers accompanying children in rehabilitation |
| | | The child's close relationship with the family |
| | | Family's participation in educating children |
| | | The family's patient effort |
| | | Principled flexible auditory training |
| | | Long rehabilitation sessions |
| | Continuing professional and non-professional rehabilitation | Various educational techniques |
| | | Music in rehabilitation |
| | | Virtual Rehabilitation |
| | | Repetition in language learning |
| | | The necessity of attending kindergarten |
| | | Scientific guidance of the family |
| | | Compassionate families |

Family's Participation in Educating Children: This means that educating deaf children and children who have recently had a cochlear implant and have no hearing experience is difficult and time-consuming, so educating these children is not limited to the rehabilitation classes; family members, especially mothers, have to teach their children in different ways in different classes. In this study, mothers also talk about their efforts and educating the family members of children with a cochlear implant.

"Then she said, Fatemeh, what is your mom's name? What is your father's name? She showed the doll and said it is wearing a skirt, it is wearing socks, she wrote them, and we practiced at home", I am going to sleep with it, I'm telling her stories, I'm reading poetry, I've taught four kinds of poetry." (Participant 1)

"They wrote what to do, for example, I wore a skirt, they called it the verb, for example, I have a ball, they wrote them a page, we brought them at home and practiced at home." (Participant 5)

The Family's Patient Effort: This means that families enter the rehabilitation stage after surgery, gain new experiences, and spend a lot of time and effort on children with the cochlear implant. They make a wide range of efforts, from the repetition of various educational materials to different care for their child.

Participant 2 states, *"During all these forty days, we were all careful not to hit her head anywhere, not to cry, not to have a fever, not to have a cold, not to take out the bandage, we were careful not to take out the stitches. "We brought her at home; we put the device in her ear, she was annoying, she touched her ear, then we were careful not to take it all out, she took it out, we put it in her ear."*

"We worked very hard for him. I explained everything to her from the beginning." (Participant 6)

Continuing Professional and Non-Professional Rehabilitation: This means that cochlear implant rehabilitation is multi-professional. In addition to the various professions involved, families participate in the rehabilitation of these children in various comprehensive ways, and with great patience, continue rehabilitation programs that are performed in the planting centers with the training that you see.

This sub-class consists of nine open codes including (1) principled flexible auditory training, (2) long rehabilitation sessions, (3) various educational techniques, (4) music in rehabilitation, (5) virtual rehabilitation, (6) repetition in language learning, (7) the necessity of attending kindergarten, (8) scientific guidance of family, and (9) compassionate families.

Principled Flexible Auditory Training: This means that the auditory training and auditory rehabilitation of these children are done according to the principles of auditory rehabilitation and the child's developmental age and previous learning. The participant 7—speech therapist states the following about this: *"You have to change the procedure according to*

the age and then you reduce the stress. The child must communicate properly. Also, children who have many problems are different."

Participant 8—speech therapist states: *"So first we teach the sound and the perception of sound and friendship with the sound, the perception of the sound and the different sounds. I try to start the sounds, and it becomes like the word, and the letters are heard in this way, and the letters enter the word, and we work the words from the beginning of the differences of the sound and the frequency of the sound, for example, the ice cream ball and the two words become the sound, so the child becomes skillful."*

Long Rehabilitation Sessions: This means that it takes a long time for rehabilitation of these children to reach the desired point, as some participants say *"At the cochlear implant center, it is told to bring for speech twice a week until a year later, and when she is a year old, they tell you to take a speech therapist in your city."* (Participant 4)

"I used to take my child at school in the morning, and I would take her to speech therapy in the afternoon, speech therapy was vital, I took her until she was 12 years old," says mother 5.

Various Educational Techniques: This means that today, with the advancement of technology and increasing the awareness of families, a variety of educational methods are used to educate children.

Participant 8—speech therapist states: *"For example, when I open a book", she says, "which one is baby, the baby is crying, wow, she is crying, but I do not tell her anything by looking at her just auditory. When she is hearing, she shows that it is crying, and I am asking her what it is doing, and I ask for an answer. She answers, it is crying."*

Participating 1—grandmother states *"I take her to the park, she loves to go to her friend, we have two twin girls next door, I take her to them, she has two friends; when she goes there, she stays there for three hours."*

Music in Rehabilitation: This means that music enhances children's self-esteem and helps to prevent and reduce anxiety. It is a rehabilitation method that introduces new concepts of sound.

Participant 11, audiologist states: *"Many things need facilities and conditions; it is not needed to be said. The doctor himself knows that music is used in many countries. Music plays a great role in the advancement of children and the separation of sounds and the recognition of sounds and the betterment of these children; some people take the children to the music class."*

Virtual Rehabilitation: This means that due to the vastness of Iran and the remoteness of rehabilitation centers, today, the first virtual rehabilitation center in the field of cochlear implantation has been started in the country, which can be constructive by familiarizing families with this type of rehabilitation.

Participant 10, psychologist states: *"However, their familiarity with the use of cyberspace as a context that can use the virtual rehabilitation program in one or two face-to-face sessions of training, then in the form of different contexts from the software. We arrange the rehabilitation programs for families to the children to be able to see the rehabilitation programs as live; this is very helpful. However, the families that do not have these facilities, we send them virtually through mobile to get more information."*

Repetition in Language Learning: This means that educating children is a complex process, and repetition in learning helps a lot in teaching. The children with cochlear implants do not have auditory memory (in this study), so they need to use repetitive content to learn better.

Participant 5, mother states: *"I did something practical, I said I was explaining a very important repetition of food coloring, I was explaining the taste of food and books, just repetition and practice, it is very important."*

The Necessity of Attending Kindergarten: This means that human is a social being and attending in society is one of their needs. Due to communication deficits (being hearing-impaired and unable to communicate much with their peers), children with cochlear implants are more prone to loneliness, depression, and behavioral disorders. In the meantime, the cochlear implant and the onset of hearing in social environments such as kindergarten at an early age will greatly help children in better rehabilitation and development, as seen in the participants' speeches.

Participant 1, grandmother states: *"In the planting center, everyone tells us, why did she look at the cartoon all times? Why didn't you talk? Your talk is too little, why half of it? Be sure to leave it in kindergarten. Kindergarten is very important and helps these children. We also wrote kindergarten. It helps a lot."*

Scientific Guidance of the Family: This means that the family is the main context of rehabilitation in cochlear implantation, so family education and guidance is one of the important tasks of rehabilitation centers.

Participant 10, psychologist states, *"It is a discussion of research-based programs which are prepared. In various meetings with the family, however, the family receives them,"*

"Practically, the child has no delay in verbal skills. Parents learn how to manage the child's ear with hearing aids. Parents learn how to keep the environment acoustically appropriate to the child to be able to use speech signals to the extent that they can hear, parents learn how to make eye contact with the child and communicate face to face." (Participant 7).

Compassionate Families: This means that at the cochlear implant center, families will be meeting each other at different times. They also try to learn from their experiences. The cochlear implant centers use these opportunities and tendencies of families and offer different pieces of training in the same groups.

Participant 10, psychologist states: *"Yes, this is one of our common programs using groups that are for parents in cyberspace."*

"Using the virtual rehabilitation programs that we have, it is also presented in groups. First, mothers and fathers will be familiar with each other and each other's experiences. However, it can be conducive to the issue of coping with what to do with the deaf disability." (Participant 10).

Discussion

The family plays an important role in rehabilitating children with a cochlear implant. Research by professionals who have worked with children with disabilities has shown that the most effective services are those that emphasize the role of the family in treatment, not therapists (Allen & Petr, 1996). In the present study, the main class of the family was effective as a rehabilitation factor, which indicates that families should cooperate in the rehabilitation of children with the cochlear implant.

In the present study, the first sub-class of the family is supported, which consisted of open codes of mothers accompanying children in rehabilitation, close communication between the child and the family, comprehensive education in the home, and the family's patient effort. In a qualitative study of Fathizar et al. (2016) conducted on the experiences of mothers with children with the cochlear implant, one of the main themes extracted from the data was engagement. Engagement means the practical and mental involvement of mothers. Practical involvement means the mother protecting the child from head impact, as well as special care from them for their child after cochlear implant surgery. Mental involvement also refers to counting the minutes of the mother to set up the audio processor to ensure that the operation is effective (Fathizar et al., 2016). In the present study, mothers talked about their postoperative care to 40 days after implantation and tried to adapt to the external part of the cochlear implant device and always accompanied their children in rehabilitation, child care, and all stages of the cochlear implant process.

In addition to mothers, other family members are also involved in the child's issues. In this study, the family is with the child from the beginning of the hearing and communicate with the child at home. Even in various rehabilitation sessions, they are directly and indirectly learning rehabilitation to teach their child at home. Today, the concept of family-centered services is recommended in many countries. Parents are invited to collaborate in their child's care (Ingber & Dromi, 2010).

The second sub-class of this study was continuing professional and non-professional rehabilitation. Rehabilitation of these children with different techniques is done for a long time with much patience; one of the open codes obtained in this sub-class was the principled and flexible auditory training, which states that flexible auditory training while following a certain pattern varies according to the age and characteristics of the patients. Ebrahimi stated in his study that audio training consists of methods and hierarchy that will help children with a cochlear implant in the proper use of the device. He also states

that every family and every child is unique, and several factors affect the child's progress (Ebrahimi, 2008).

Long rehabilitation sessions were one of the classes of this study. Peter et al. stated that the children's rehabilitation for more than several years continues with a cochlear implant (Peters, 2003). The results of a study by Liu et al. in 2011 showed that the longer the duration of use of rehabilitation programs after implantation, the more effective these programs are.

In this study, families emphasized various educational techniques and repetition in education, including the use of music in children's rehabilitation. The study of Hatami and et al. points to the effect of music on increasing children's reading skills and progress by cochlear implant (Hatami & Nouri, 2017), and some studies have suggested music training for children with a cochlear implant (Abdi et al., 2001; Chen et al., 2010).

One of the problems that many families pointed out was the distance and scarcity of rehabilitation centers, which has been resolved with the start of the virtual rehabilitation process, as described by therapists in the present study. This type of rehabilitation is currently used only in the United Kingdom in 2016 to solve children's problems with a cochlear implant (Cullington et al., 2016).

Also, the most important challenge of cochlear implant rehabilitation is the lack of progress in children's mental and social development compared to their hearing peers. Loneliness and lack of close friendships are reported in such environments despite academic progress, almost equal to hearing peers in their combined environments, and they often have difficulty with social, emotional, and communication functions with other children (Cook et al., 2008). Therefore, attending kindergarten emphasizes both improving speech and social relationships. In the present study, one of the subcategories was the need to be present in kindergarten.

Parents of deaf children often become frustrated by the treatment of people in society, family, friends, and relatives with their child and by their suggestion, advice, or misunderstandings and misconceptions about their child (Ingber & Dromi, 2010). Mothers' lack of scientific knowledge about the process of the cochlear implant causes them to face negative experiences while using the sound processor. To solve such problems, the scientific guidance of the family, such as training about how to maintain the device, parents' expectations from planting, and training about how to rehabilitate the child were among the things that were taught. Using the experiences of similar groups was among the cases obtained in this study where families used the experiences of similar groups to cope with this problem and to be aware of the current and future situation of the child.

Study Limitations

The limitation of the study was that it is not possible to interview deaf parents due to the impossibility of communication.

Conclusion and Recommendations

Families are the main factor of success in rehabilitating children with cochlear implant. Family-centered education and rehabilitation are used in a variety of ways in the rehabilitation of these children, so it is recommended that family-centered education and rehabilitation should be done systematically with different techniques according to the involvement of these families in addition to social support so that everyone can benefit from it. Action research studies are recommended in this regard.

According to the results of the study, the clinical application of the study is as follows:

1. Education should focus on families, especially mothers because they play an essential role in children's rehabilitation.
2. Pediatric rehabilitation nurses, according to their roles, include:
 - a. Care coordinator: designs and implements a unique family-centered strategy focusing on the family as an essential member of the rehabilitation team.
 - b. Rehabilitation team member: collaborates with other specialists, patients, and family in reviewing, planning, implementing, and evaluating an interdisciplinary individual care program (Association of Rehabilitation Nurses, 2021). They can assist the families as members of the rehabilitation team by contributing to health education and promotion as a leader, counselor, advocate, caregiver, and researcher.

Also, creating short-term cochlear implant rehabilitation nursing courses can be helpful for nurses at ENT departments. On the other hand, due to continuous and long professional and non-professional rehabilitation in cochlear implantation, especially now because of the COVID-19 pandemic and the consequently reduced communication, virtual rehabilitation can be extended. Thus, by conducting cochlear implants, this findings can help families and children's rehabilitation.

Ethics Committee Approval: This study was approved by Ethics Committee of University of Social Welfare and Rehabilitation Sciences (Approval ID: IR.USWR.REC.1397.008, In Date: May 29, 2018).

Informed Consent: Verbal informed consent was obtained from individuals who agreed to participate in this study.

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