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RESEARCH

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The Investigation of the Opinions of Mothers of Children with Hearing Loss on Their Needs and Support Regarding Their Children*

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Abstract

Specifying the needs and support of families who has a child with hearing loss is needed to enhance the quality of services offered to them. The aim of this study is to investigate the mothers' opinions about the needs and support related to their children with hearing loss. The study is designed as a descriptive case study. The participants of the study were 11 mothers of children who are the primary caregivers. While 10 of the children had cochlear implant, one of them had a brainstem implant. The data were collected through semi-structured interviews, the researcher's journal and document analysis. Descriptive analysis technique was used for the analysis of the data. Mothers' needs related to their children were categorized under the following titles: informational, educational, psychosocial, financial and anticipated needs. It was also revealed that the families received support from their social circle, experts, internet, government and other families of children with hearing loss. The mothers mostly expected the government to raise the financial support. They also advised other families who have children with hearing loss to look after these children well and meet their demands. It can be said that the need for information is closely related with other needs, and when the information need is met, it can fulfill some of the other needs.

Keywords: Family needs, individual with hearing loss, children with cochlear implant, descriptive analysis, descriptive case study.

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Individuals born with hearing loss are mostly the children of normally hearing parents (Mitchell & Karchmer, 2004). Since hearing loss is a new condition for them, the families do not know what to do in this new situation. Hearing loss is not a case families can cope individually (Doğan, 2017). The family is confronted with the needs of having a child with hearing loss and the need to support him/her to meet the needs of the child that arise due to hearing loss (Varol, 2006). These needs are essential for the family as well as for the child with hearing loss. While families need to receive information and have knowledge about their child this need grows as the child grows. Children with hearing loss and their families may be from various cultures and socio-economic levels with many different characteristics. The children can develop positive relationships with families by taking these into consideration (Wu & Grant, 2013).

According to the national and international literature on the needs of families with children with hearing loss, it can be observed that the needs are categorized under acquiring information, psychological support, community service, and financial support (Akçamete & Kargın 1996; Cankuvvet, 2015; Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Luterman & Kurtzer-White, 1999; Most & Zaidman-Zait, 2001). In addition to these needs, it is observed that families also need information on their legal rights (Bayguzina, 2010; Kargin, Baydık, & Akcamete, 2004). Previous studies show that the needs of families may change. In particular, the educational policies and recent developments in hearing aid technologies are expected to change the needs of families. Determining the current needs of the families will increase the quality of the future services to the families and their children. In studies that aim to reveal the families' views on the needs of children with hearing loss in Turkey, it can be seen that the families' and children's needs are studied together. In addition, the studies on determining the needs of the children with hearing loss in early childhood period, which is the most important period for a child with hearing loss, are limited. Whereas, in the international literature, the studies that examine the early childhood period are limited, and existing studies involve a certain stage, such as the diagnosis stage of the early childhood period. The data obtained in this study will contribute to the literature in terms of the improvement of regulations on language development and the developmental area regarding the needs of the children with hearing loss, along with all other developmental areas for children with hearing loss.

The opinions of the family members of the children with hearing loss are significant regarding the needs and support. The quality of education services for children with hearing loss and the quality of support services for their families may be increased with this research. It is also anticipated that the study will contribute to the organization of the language environment. Moreover, it is anticipated that the results will provide guidance to the experts who serve the children with hearing loss and their families in order to increase the quality of the service.

For these reasons, the aim of this study is to investigate the opinions of mothers who have children with hearing loss about their needs arising from having children with hearing loss. The research questions are given in the following: (a) What are their existing and future needs? (b) What are their expectations from the government, experts, society and others regarding their needs? (c) How do they receive support for their needs? (d) What are the problems they face for their needs and the necessary support? (e) How do they seek solution to their needs? (f) What are the recommendations for fulfilling their needs?

Method

Research Design

The research was carried out as a descriptive case study which is one of the qualitative research methods (Bogdan & Biklen, 2007; Davey, 1991; de Vaus, 2001). Before conducting the research, the necessary permission was obtained from the ethics committee of Anadolu University.

Participants

In this study, the participants were identified by using criterion sampling method among purposive sampling methods (Glesne, 2014; Yıldırım & Şimşek, 2018). In this respect, the study was conducted with eleven participants who had children with hearing loss in early childhood. The inclusion criteria of this study were in the

following: (a) They had a child with hearing loss in early childhood period, (b) Their child did not have any additional disabilities, (c) They were the primary caregiver for their child with hearing loss, (d) They volunteered to take part in the study.

The children were reported to receive sessions in two different special education and rehabilitation centres located in two different socio economic areas, namely Esenyurt and Şişli. While the educational level of the parents from Esenyurt ranged from primary school to university, those who lived in Şişli were mainly university graduates. It was reported that one mother from Esenyurt and four mothers from Şişli were working. The amount of income of families residing in Esenyurt ranged from 1600 to 4500 TL, the salaries of the families residing in Şişli salaries ranged from 2250 to 15000 TL. The socio-economic level of the families residing in Şişli were higher than those living in Esenyurt.

Data Collection

Triangulation in data was obtained by making use of qualitative research data collection techniques such as reflective research diary, document review, and semi-structured interview techniques (Odom et al., 2005; Yıldırım & Şimşek, 2018). The first author carried out the research by meeting regularly in order to meet the planned work schedule. The second author (also the supervisor of the study) was an expert on both the education of individuals with hearing impairment and the qualitative research methodology, and also helped the first researcher overcome the problems encountered in the process (Ekiz, 2015; Yıldırım & Şimşek, 2018).

Preparation of semi-structured interview questions. Interview questions were prepared with the guidance of the second researcher by taking both the literature and the research objective into consideration. The requirements of how a descriptive case study needed to be designed were also considered. The researcher received the supervisor's feedback while he prepared the questions with the supervisor. Prior to the pilot interview, the interview questions were presented to a faculty member specialized in qualitative research (Appendix 1 [Ek 1]). After the two pilot interviews, the interview questions were finalized.

Implementation of interviews. 11 interviews in total were conducted between the dates of 24 July-27 July 2018. The duration of the interviews was between 22 minutes 56 seconds and 64 minutes. Before conducting the interviews, the researcher met the participants and provided information about the research. The interviews were conducted in silent classrooms with the families after their written and verbal consents were taken.

Data Collection and Analysis

The data were analysed with the descriptive analysis technique (Gay, Mills, & Airasian, 2012; Yıldırım & Şimşek, 2018).

Findings

Information Needs

The information needs of the families were about the behind-the-ear device, the cochlear implant, and the education process. The information needs of the mothers regarding behind-the-ear device were about the selection of the device, its price, its qualities and the government support. The information sources of mothers on behind-the-ear device were the centres selling hearing aids, doctors and audiologists.

The information needs for cochlear implant were related to cochlear implant device, surgery, brand and double cochlear implant. The information sources of mothers on the cochlear implant included doctors, audiologists, instructors, other families with children with hearing loss, and internet. Among these sources, other families who had children with hearing loss and internet provided them the information they needed in particular.

Educational Needs

These needs included the guidance, additional lessons, family education, pre-school education and attention of the instructor. The mothers stated that they had difficulty in finding suitable centres for their children and they needed guidance. The participants who thought that the hours of education in the rehabilitation centres were not sufficient stated that increasing the course hours would contribute to the language development and academic development of the children. The mothers who expressed their opinions about their children's teachers stated that the teachers in public schools did not pay enough attention to them and their children.

Financial Needs

The financial needs were related to behind-the-ear device, cochlear implant, education and transportation. Among these, the need that mothers were strongly passionate about was about the cochlear implant. The cost of the batteries and cables within the parts of the cochlear implant particularly constituted a large part of the financial needs.

Psycho-social Support Needs

Regarding the psychological and social needs, the mothers stated that their children experienced psychological difficulties due to the hearing impairment. The majority of the support they received came from their close social circle. All of them stated that the psychological support provided by an expert would be beneficial, while only one mother stated that she received professional support in the past. Another source of psychological support for mothers was reported to be faith. It was observed that the mothers were supported by their faith in expressing the psychological problems they experienced in relation to their children. They expressed their opinion that their situation was a test for them and they should not rebel.

The mothers who revealed the societal expectations and unwanted situations were disturbed by certain questions and attitudes directed to them regarding their children by the society. One important issue under this heading was the interaction of families. All mothers expressed that the interaction with each other was important for them. This interaction provided benefits such as psychological support, socialization, and information sharing.

The mothers expressed their views on their anticipated needs. A significant number of them were related to education. They voiced their concerns about the schools their children would attend in the future. The main source of these concerns was the fact that these classes were very crowded. They thought it would be difficult for their children to listen to the class because of the crowd, and that their teachers would not be able to care for their children sufficiently. Eight of the mothers said that they would send their children to private schools if they had financial means to do so.

Discussion and Conclusion

Information Needs

The ability of the mothers to reach the right information at the right time may prevent them from experiencing different needs. The need for information was considered to be an umbrella concept that contained other needs. The mothers reported that they received the information through the internet, other families and experts. The experts occupied relatively little place among these sources. In previous research, it was observed that the families could not obtain enough information regarding cochlear implant prior to the implantation and they needed information regarding this process the use of the cochlear implant (Cankuvvet, 2015; Fitzpatrick et al., 2008; İçyüz, 2016; Most & Zaidman-Zait, 2001). Although the findings of this study largely overlap with previous studies, an additional information need was related to the cochlear implant brand the families would choose.

The results of the study also confirmed the findings that the mothers especially needed information about the devices their children would use along with the communication training (Akçamete & Kargın, 1996; Fitzpatrick

et al., 2008; Most & Zaidman-Zait, 2001; Porter & Edirappulige, 2007; Sass-Lehrer, 2016). It is believed that providing the information needs for the future will help the mothers focus more on their current situation and also help reduce their anxiety. The fact that the information needs of the mothers are mostly similar to the literature shows that these needs still exist and remain valid. The content of these needs and the nature of the support they receive for remediation may change. One of the reasons for this change can be the innovations brought by the developing technology for individuals with hearing loss. The support families receive may also change what they need. In 1996, Akçamete and Kargin (1996) stated that the families received support from experts, other families and written sources in order to meet their information needs. Fitzpatrick et al. (2008) and Cankuvvet (2015) stated that the internet was also among the sources from which families received support. Although these families were from different cultures, these families utilized internet for their information needs (Fitzpatrick et al., 2008; Porter & Edirappulige, 2007).

In the decision phase, the families needed to have sufficient information to make the best decision for their children and themselves (Wainscott, Sass-Lehrer, & Croyle, 2008). It is thought that the content of the information the families receive will help them make the right decision. The internet, which is among the support sources of the families, may ensure access to the right information. Although the internet is a rich source of information, the reliability of this information is a questionable in many cases. False information from the internet may prevent them from making the right decisions (McCormick & Archbold, 2003; Porter & Edirappulige, 2007).

Educational Needs

The participants considered the guidance of the doctors, audiologists and other parents who had children with hearing loss when deciding on an educational institution. They also paid attention to the distance of the education centres to their home. As the information needs change over time with developing technologies and practices, these needs also change with new laws and time. In his research, İċyüz (2016) stated that the families needed for guidance on the education centres they would choose. Two different studies concluded that the families needed information regarding their legal rights on the centres where their children would receive education and regarding the authorities to which they could submit their inquiries when they had problems regarding the quality of education offered by these centres (Bayguzina, 2010; Kargin et al., 2004). Some of the families who participated in these studies indicated that while deciding on the special education and education centre, they preferred centres in which only children with hearing loss received sessions.

The mothers in this study thought that their children should receive preschool education. However, they also stated that pre-school centres did not wish to admit their children due to hearing impairment. They indicated that the classrooms in the state schools were crowded, and that they were worried that teachers would not be able to pay enough attention to their children and that their children's devices might receive damage. They expressed that they had difficulty in sending their children to the private schools due to financial reasons. The parents needed information about their legal rights and to whom they should talk in order to solve their problems. The results of Bayguzina's (2010) research confirm the findings of this study.

The mothers found the guidance their received from the centres were adequate. However, the content of the family guidance they received was not sufficient. The reason why the families thought that their parent guidance was adequate and positive was because of the fact that they did not have a chance for comparison or a set of quality criteria as defined in the literature (Gestwicki, 2004; Ünal, 2010).

Financial Needs

The mothers' financial needs were related to the hearing technologies used by their children. Although the mothers received financial support from the government in various amounts, they thought that this support was not sufficient. Similar to İċyüz's (2016) study, the financial needs of the families included the behind-the-ear devices and the parts of the cochlear implant. Most and Zaidman-Zait (2001) revealed that the families had financial needs despite the government support. However, when the government support for cochlear implants in

Turkey is compared with other countries (Detsky, 2003; Peters, Wyss, & Manrique 2010), it can be argued that the support offered in Turkey is better.

One of the financial needs included expenses related to education such as the toys and other materials as confirmed by İċyüz (2016). Transportation costs were the last financial need. The mothers who did not receive any support for transportation costs met these needs through their own means. Akçamete and Kargin (1996) also stated that the transportation costs were among the financial needs of the families. In Istanbul, where this study was carried out, it is seen that the free transportation support offered by the municipality to the persons with disabilities do not cover the individuals with hearing-loss.

Psycho-social Needs and Supports

Sass-Lehrer (2016), Luterman and Kurtzer-White (1999) stated that the families who had children with hearing loss may experience psychological conditions such as shock, sadness, and non-acceptance following the diagnosis of the hearing impairment. During the cochlear implant surgery, the families experience the difficulty of making an irreversible decision for their children and worry about the risks of the operation (Incesulu, Vural, & Erkam 2003; Most & Zaidman-Zait, 2003). The mothers who participated in this study indicated that they were shocked and upset following the diagnosis and they were worried during the operation stage due to the risks of the operation. It was observed that the area which families received support the most was for their psychological needs. It can be asserted that all mothers receive psychological support from at least one of the following: Their close social circle, psychologists, and their faith.

While all of the participants thought it would be helpful to receive support from a psychologist regarding their psychological needs about their children, one mother received this support. This may be due to the fact that the family members are not aware of the support they can receive from a professional because they have never received psychological support before. It can be ensured that the mothers receive this support by the experts.

The mothers reported that they received psychological support from their spouses, friends and relatives. This support helped families overcome the psychological difficulties they experienced. This finding coincides with the finding of Akçamete and Kargin (1996) that revealed that the families who had children with hearing loss needed to talk to the individuals in the family about their children.

Another source for psychological support for ten of the mothers was their faith. According to Treloar and Bahçekapılı (2012), the families believed that the disability of their children helped them be resilient. Bennett et al. (1995) stated that faith was seen as a source of support for families with disabilities. The finding of this study confirms the findings of previous studies (Bennett et al, 1995; Treloar & Bahçekapılı, 2012).

The mothers were upset about the negative situations they encountered with their children in their social lives. Previous studies including families who had children with mental disabilities, autism spectrum disorders and hearing impairment concluded that the families needed support on explaining their children's condition to each of the family members (Akçamete & Kargin, 1996; Sucuođlu, 1995). In this study, the mothers needed to explain what hearing impairment was to the society.

The mothers expressed the positive effects of coming together with other families. The interaction of families provided mutual support on information sharing, psychological support and socialization. Previous studies indicated that the families with children who had hearing impairment needed to come together with each other (Akçamete & Kargin, 1996; Luterman & Kurtzer-White, 1999; Fitzpatrick et al., 2008; Most, Zaidman-Zait, 2001). While the gathering of families is especially important, the severity of this need is thought to decrease in relation to the quality of the family education that will be offered to families.

The mothers stated that the appointment waiting times were long and they had difficulty in making an appointment. Sass-Lehrer (2016) emphasized that it was important for the families who had children with hearing

loss to be able to find appointments at appropriate times from professionals such as audiologists and doctors. In this study, it was observed that the families needed to reach and consult the specialists.

Anticipated Needs

Six of the participants wanted to send their children to a private school due to their belief that teachers would not be able to take care of their children as the state schools could be crowded. Another reason for this belief was the fact that their children would not be able to hear their teachers in crowded classrooms. It was observed that the the families made some suggestions for other families who had children with hearing loss. Families can also motivate and provide advice to each other in addition to disseminating information (Ainbinder et al., 1998; Henderson, Johnson, & Moodie, 2014).

It was observed that the different socioeconomic levels of the two centres where the children of the participation received education and the districts where these centres were located had a direct effect on the needs. The mothers whose children received education at the centre in Esenyurt did not report any negative opinions about the children with disabilities other than hearing loss. In Şişli, the mothers of children who received sessions at the centre only with those with hearing impairment reported that this was the reason they preferred the centre. Apart from this, the financial needs of mothers may vary depending on their own means and experiences which are independent of the centres.

Conclusion

It can be said that the families have various needs regarding their children with hearing loss. Although the aforementioned needs are common, the severity of the needs varies according to the specific characteristics of the family. In this study, the mothers advised other families to take care of their children. They stated that the processes they experienced with their children could be difficult both financially and spiritually, but they should take care of their children without giving up.

Ekler

Ek 1: Yarı yapılandırılmış görüşme soruları

1. Kendinizi tanıtır mısınız?
2. Doğum öncesi dönemde neler yaşadınız?
3. Çocuğunuzun işitme kaybı olduğunu nasıl öğrendiniz?
4. Çocuğunuzun işitme kaybı olduğunu öğrendiğinizde neler hissettiniz, kimlerden destek aldınız?
5. Çocuğunuz işitme kaybı tanısı aldığı anda maddi gereksinimleriniz neler oldu?
6. Çocuğunuzun işitme kaybı tanısı aldığı dönemde hangi bilgilere gereksinim duydunuz?
7. Çocuğunuzun cihazlandırılması dönemindeki maddi gereksinimleriniz neler oldu?
8. Çocuğunuzun koklear implant süreci nasıl gerçekleşti?
9. Çocuğunuzun koklear implant sürecinde hangi bilgilere ihtiyaç duydunuz?
10. Çocuğunuzun koklear implant olma dönemindeki maddi gereksinimleriniz neler?
11. Çocuğunuzun koklear implant döneminde psikolojik gereksinimleriniz ilgili düşünceniz neler?
12. Çocuğunuzun eğitimi nasıl başladı?
13. Çocuğunuzun eğitimiyle ilgili beklenti ve destekleriniz neler?
14. Şu an çocuğunuzun eğitimiyle ilgili gereksinimleriniz neler?
15. Çocuğunuzla bir gününüzü anlatır mısınız?
16. Çocuğunuzun eğitimi için maddi gereksinimleriniz neler?
17. Çocuğunuzun gelecekteki gereksinimleri hakkında neler düşünüyorsunuz?
18. Çocuğu işitme kaybı olan ailelerin bilgi gereksinimleri için ne düşünüyorsunuz?
19. Çocuğu işitme kaybı olan ailelerin maddi gereksinimlerine ilişkin ne düşünüyorsunuz?
20. Çocuğu işitme kaybı olan ailelerin psikolojik gereksinimlerine ilişkin ne düşünüyorsunuz?
21. Çocuğu işitme kaybı olan ailelerin birbiriyle olan etkileşimiyle ilgili ne düşünüyorsunuz?
22. Sizin gibi ailelere önerileriz neler olur? Örnek verir misiniz?
23. Bugüne kadar yaşadığımız dönemlere ilişkin beklentileriniz neler?
22. Bugüne kadar yaşadığımız dönemlere ilişkin beklentileriniz neler?
24. Eklemek istediğiniz başka bir konu var mı?
25. Sizinle tekrar görüşebilir miyim?