Cochlear implants in children: Development in interaction with the social context

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Chapter 2

Family Counseling in the Netherlands for Turkish-Origin Parents of Deaf Children With a Cochlear Implant

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Abstract

Cultural elements such as language, beliefs about health, and family context play important roles in the uptake of rehabilitation and treatment of deafness. Because of cultural issues, minority groups often do not receive optimal care. Focusing on the Netherlands, the researchers explored how the rehabilitation and counseling of deaf children of Turkish-origin parents can be improved. The most important findings were that (a) most parents initially did not believe their child was deaf and regretted later that they did not start hearing rehabilitation earlier; (b) parents had little confidence in the Dutch health care system and sought a second opinion from a medical doctor of their own national origin; (c) parents did not know how to be actively involved in the care of their deaf child. Implications for practice aimed at improving rehabilitation and counseling for these children are described.

Introduction

Since the implementation of neonatal hearing screening, deafness is usually diagnosed at the age of approximately 3 months. A diagnosis of deafness has a profound impact on parents: They may experience grief, anger, guilt, denial, confusion, and feelings of helplessness (Steinberg, Delgado, Bain, Li, & Ruperto, 2003). Although all parents are greatly affected by the deafness of their child, not all families respond in the same way. Cultural elements such as language, beliefs about health, and family context play important roles in the uptake of rehabilitation and treatment of deafness (Louw & Avenant, 2002; Steinberg et al., 2003). With the increase in immigration from countries all over the world, Western societies are becoming more culturally diverse; consequently, cultural elements are becoming more important in the provision of health care in these societies.

In the Netherlands, immigrants from non-Western countries account for 11.6% of the total population (Statistics Netherlands, 2009). Most of these immigrants are from Turkey, Morocco, Surinam, and the Netherlands Antilles, and therefore constitute a heterogeneous community. Although some of these groups share the same language and some the same religion, they also differ in several characteristics. The largest group is of Turkish descent (2.4%), followed by immigrants of Moroccan descent (2.2%).

Family counselors at our organization, the Dutch Foundation for the Deaf and Hard of Hearing Child, noticed problems in the rehabilitation and counseling of deaf children of Turkish and Moroccan descent without understanding why these problems were occurring. In response, a group of us conducted a study (Wiefferink, Vermeij, Stege, Van der Spaai, & Uilenburg, 2008) in which we compared seven deaf children of Dutch origin with seven deaf children of Turkish origin. All of the children had received a cochlear implant (CI). The study showed that, on average, children of Turkish origin received their cochlear implant (CI) 10 months later than children of Dutch origin (i.e., at age 33 months, as opposed to the Dutch children’s age of implantation of 23 months). Furthermore, the results indicated that Dutch children with a CI had better language development 2 years after implantation: Not only was their spoken Dutch better than the spoken Dutch of Turkish children; also, their sign language was better. The researchers speculated that this poor language development by the Turkish children may have been partly caused by these children’s late implantation.

Studies on the effects of CIs on children show a stronger effect on language development when implantation occurs at a young age, particularly before the age of 2 years (I. Anderson et al., 2004; Miyamoto, Kirk, Svirsky, & Sehgal, 1999; Schauwers et al., 2004; Spencer, 2004; Svirsky, Teoh, & Neuburger, 2004; Tomblin, Barker, Spencer, Zhang, & Gantz, 2005; Wiefferink, Spaai, Uilenburg, Vermeij, & De Raeve, 2008; Zwolan et al., 2004). Studies conducted outside the Netherlands found similar results concerning the rehabilitation and treatment of deaf children from minority groups. In a study by Steinberg and colleagues (2003), parents from minority groups in the United States had difficulty making decisions about the care of their deaf child. This could be explained by difficulties communicating with professionals and by cultural differences, but also by insufficient access to information. Also, there are indications that some minority groups have less accessibility to health care. A study in the United States showed that White and Asian children received a CI more often than Hispanic and Black children (Stern, Yueh, Lewis, Norton, & Sie, 2005).

The delay in receipt of a CI by deaf children from nonmajority ethnic groups might be explained by cultural and language differences between health care professionals and parents. In general, health care systems are tailored to the needs of a country’s native-born residents, particularly those whose families have been in the country for at least several generations. Parents of children of non-Western origin might have different expectations from the health care system. In the Netherlands, for instance, parents of Turkish and Moroccan origin with children who have mental disabilities do not expect counseling from professionals, but material and practical support (Eldering, Adriani, Hamel, & Vedder, 1999).

Only a few studies have been conducted on how parents of deaf children of Turkish and Moroccan origin experience health care in the Netherlands. Yumusak and Hoogsteder (1999) found that parents of Turkish and Moroccan origin with deaf children had limited knowledge about how health care for deaf children is organized in the Netherlands. Even after regularly visiting an audiological center for years, these parents barely understood what services an audiological center provides. Consequently, their children's quality of care might not have been optimal. Moreover, the level of involvement of parents of Turkish or Moroccan origin in the rehabilitation of their deaf child is assumed to be lower than the level of involvement of parents of Dutch origin (Hannink, 2007). However, Nortier, Hoenderkamp, and Knoors (1996) found that although parents of non-Dutch origin felt highly involved with their deaf child, they did not know how to be actively involved in the rehabilitation and education of their child. Moreover, they often did not understand the information they received from health care professionals or teachers, either because their Dutch language was not sufficient or because their knowledge of the Dutch health care system was not sufficient.

Because the study by Wiefferink, Vermeij, and colleagues (2008) showed that the development of deaf children of Turkish origin is delayed compared to that of native deaf children, and because little is known about the reasons for this, we (the authors of the present article) decided to conduct an exploratory study in order to comprehend the nature of this problem better. The aim of the study was twofold. First, we wanted to explore how the rehabilitation and counseling of deaf children with a CI who are from immigrant groups can be tailored to these children's needs so that they might receive optimal care. Parents' and family counselors' desires, expectations, experiences, and problems regarding rehabilitation and counseling were studied, with a focus on differences between these two groups of participants. Differences between parents and family counselors are interesting because they provide clues on how to improve care. Second, we wanted to gain insight into the involvement of the parents in the rehabilitation of their child because this is an important predictor of how successful the CI is for the child (Moeller, 2000). We focused on deaf children of Turkish origin because we wanted to limit the diversity in the research group and because most deaf children of non-Western origin in the Netherlands are of Turkish origin.

Method

Study Design and Sampling

In the present study, which was an exploratory study, the Q-methodology (Stephenson, 1935; see discussed below under the heading "Q-methodology") was used to collect data from parents and family counselors). We employed a purposive sampling technique in recruiting participants. Family counselors of Turkish deaf children in all rehabilitation services for the deaf in the Netherlands were approached to participate in the study. The family counselors asked parents of Turkish deaf children who had been selected to receive a CI to participate in the study. All family counselors who had a Turkish deaf child in their care agreed to participate. However, it was difficult to recruit families for this study for various reasons. For example, some parents did not participate because the interviews were time consuming; other parents had decided against a CI because of concerns about the surgery, and therefore could not take part. Given the number of participants and the design of our study, our sample may not be representative of parents of Turkish deaf children in the Netherlands.

Study Population

Eleven Turkish parents and their family counselors (all of who were of Dutch origin) were included in the present study. At the time of the study, there are no family counselors of Turkish origin or Turkish-speaking family counselors in the Netherlands in the field of counseling for families with a deaf child. The families lived across the whole of the Netherlands, in urban as well as rural areas. At least one parent from each couple had been born in Turkey, and all of the couples had a profoundly deaf child with a CI (i.e., a child with a hearing loss greater than 90 dB prior to implantation). The children (eight boys, three girls) had received their CI between the ages of 21 and 42 months. All of the parents had normal hearing except for two fathers: One father had a moderate hearing loss, and the other father was profoundly deaf.

In nine families, the parents communicated with their deaf child mainly in spoken Turkish. In four of these families, the mother used spoken Turkish supported with signs. One family communicated only in Dutch, whereas the family with the profoundly deaf father mainly used sign language. In each family, one of the parents had been educated in Turkey, whereas the other parent had been raised—and educated—in the Netherlands. All of the parents had a low educational level, varying from primary school to lower vocational training. In two families, both parents were unemployed, in eight families the fathers had a blue-collar job and the mothers took care of the children, and in one family both parents worked. Formal evaluation with the Snijders-Oomen Nonverbal Intelligence Test (Tellegen, Winkel, Wijnberg-Williams, & Laros, 1998) showed that nine children had normal cognitive and motor development, one child had delayed cognitive and motor development, and one child had Recklinghausen syndrome (a condition whose characteristics often include scoliosis, learning difficulties, eye problems, and epilepsy).

Q-methodology

Q-methodology, developed by Stephenson (1935) and further advanced by Brown (1996) and McKeown and Thomas (1988), is a means of extracting subjective opinions in a research situation.

The first step in Q-methodology is to describe all possible topics that cover the situation that is being explored. In the present study, an inventory was made of all aspects of care delivered to parents of deaf children (76 aspects in all; see Appendix). The topics concerned (a) medical aspects, such as the importance of a CI and a second opinion; (b) counseling aspects, such as speech therapy, advice about communication with a deaf child, grief counseling, and support with raising deaf children; (c) the provision of information, such as written information, oral information, and flyers; and (d) logistical aspects, such as arranging for child care and addressing transportation and financial issues.

In the second step, parents as well as family counselors were asked how important, in their opinion, a topic was in the care of deaf children. Each of the 76 topics was written on a card. In interviews, parents and family counselors were asked to sort the cards according to their level of importance: very important, important, or not important. They were also asked to provide reasons why they had assigned a particular level of importance to a topic. Blank cards were also provided in order to give parents and family counselors the opportunity to add relevant topics that were not on the list. However, none of the participants made use of this opportunity. Parents were also asked about their expectations and desires concerning the rehabilitation and counseling of their deaf child.

In addition to participating in the Q-methodology process, parents took part in interviews 2 years after implantation. They were asked to reflect on their experiences with rehabilitation and counseling and on problems they had encountered. A semistructured interview with open questions such as “Looking back on the care and counseling you received, what did you miss?” and “What problems did you encounter concerning the care and counseling you received?” was used.

Analysis

Although the present study was qualitative, a cutoff score was needed in order to classify topics as very important or not important. The reason we did not include the category “important” was that we were merely interested in what parents and family counselors found most important, because parents as well as family counselors tended to rate most topics as important. If the majority agreed about the extent to which a topic was very important, it was considered to be the opinion of at least a relevant part of the population. Therefore, a topic was classified as very important if more than half of the parents labeled it as very important and was classified as not important if more than half of the parents labeled it as not important. The same was done with the family counselors.

Results

Expectations and Desires Concerning Rehabilitation and Counseling

Parents rated more topics not important or very important than family counselors did (Figure 1). Topics labeled by more than half of the parents and by more than half of the family counselors as very important included, among others, being taken seriously by physicians and other health care professionals, availability of counselors for questions by telephone, receiving an overview from the family counselor of everything that happened with the child, sign language courses, and support with making decisions about the child. Topics labeled by more than half of the parents and by more than half of the family counselors as not important were communicating with parents with a deaf or hard of hearing child through the Internet and a yearly overview of the schedule of all parental courses.

Topics That Parents Found More Important Than Family Counselors Did

Some topics were very important to parents, whereas family counselors rated them as not important.

First, in contrast with family counselors, Turkish parents in the present study had a high interest in a second opinion from a Turkish physician. Parents of seven children actually visited a Turkish physician for a second opinion, either in Turkey, the Netherlands, or Germany. Two other parents very much wanted a second opinion from a Turkish physician, but were not able to arrange this. One parent explicitly told the interviewer that she did not have any confidence in the Dutch health care system, and seven other parents expressed that they were only able to accept the fact that their child was deaf after a Turkish physician confirmed the diagnosis. Only one parent told the interviewer that she trusted the Dutch physicians. This parent declared that the Dutch physicians explained everything very well, but that she was not mentally ready to accept that her child was deaf.

Second, parents had a need to address practical issues, such as the availability of playthings for deaf children, counseling on how to read books to their child, and the availability of a babysitter. In general, family counselors classified these topics as not important. Finally, 8 of 11 parents expressed that a CI was very important to them, whereas only two family counselors agreed with this.

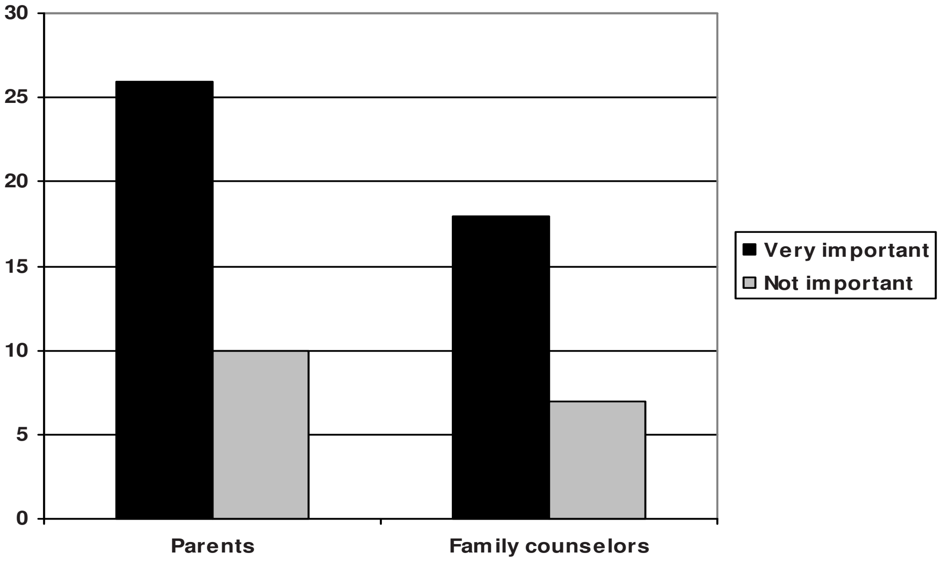

Figure 1 Number of Aspect-of-Care Topics Rated Very Important and Not Important by Parents and Family Counselors

Parental Involvement

Most family counselors expressed the view that, in general, Turkish parents were less involved in the care of their deaf child than parents of Dutch origin. This does not mean that Turkish parents had no involvement at all with their child. As one of the family counselors put it, Turkish parents were highly involved with their children, but minimally involved in the professional care their child received. Another family counselor stressed that although some families tried very hard, they often did not know what they could do, probably because of language problems and cultural differences. For instance, Turkish parents did not stimulate their children to communicate as much as Dutch parents did; specifically, they did not stimulate the hearing and language development of their child.

Some parents did not realize that the family counselor could teach them how to communicate with their child. In one family, the mother thought that the family counselor's role was to do exercises with the child, but she did not realize that the goal of the exercises was to teach the mother how to communicate with her child. In this family, the mother was also not aware that she had to do these exercises with her child. In this example, it is possible that the mother did not know what was expected of her due to language problems. But it is also possible that this misunderstanding was caused by cultural differences, because the mother was accustomed to a culture in which health care professionals take over the whole rehabilitation process from parents, whereas Dutch family counselors are trained to teach parents how to communicate with their child.

Another reason for relatively low involvement in the professional care of their child might be that Turkish parents had difficulties accepting the deafness of their child. Parents and family counselors both expressed that Turkish parents have problems accepting that their child is deaf. Most parents said that they did not believe it at first. They hoped that the deafness would disappear over time, much like an illness that could be cured. Some parents also felt ashamed that their child had a disability, and consequently did not inform their relatives immediately, especially not their relatives in Turkey. The fact that Turkish parents had difficulty accepting their child's deafness caused a delay in the cochlear implantation in some instances. Two years after their child received an implant, a few parents remarked that they regretted not having had it done earlier. They realized that children who received a CI at a younger age had better language development.

Discussion

The results of the present study show that Turkish parents and family counselors have different views on some aspects of the care of deaf children with a CI. Our findings are in line with those of other studies regarding the influence of cultural elements in health care. For example, the fact that most parents did not believe that their child was permanently deaf and that they thought of deafness as an illness that could be cured is consistent with the findings of a study by Eldering and colleagues (1999). Also, the fact that parents and family counselors had different perspectives on how to communicate about decisions concerning rehabilitation and counseling is in line with the findings of other studies (De Graaff & Eitjes, 2004; Steinberg et al., 2003). Non-Western immigrant parents want to hear what the best solution to their problem is: "Most people from ethnic minorities do not want a good conversation but good care. They expect that the health care professional will help them and not only talk to them" (De Graaff & Eitjes, 2004, p. 23, translated from the Dutch).

Limitations of the Study

The present study was designed as an exploratory qualitative study. Given the sample size and design, the results cannot be generalized to non-Western immigrant parents or even to parents of Turkish origin. Despite this, some patterns were revealed regarding problems with the Dutch health care system experienced by Turkish parents with deaf children. Moreover, other studies show that other non-Western immigrant groups experience problems similar to those of the immigrants from Turkish origin in our study (De Graaf & Eitjes, 2004; Eldering et al., 1999; Steinberg et al., 2003). Because of the large numbers and diversity of the Turkish people and other immigrant groups, a larger study would be necessary, in which parents of other minority groups were included, to enable a fuller understanding of the influence of cultural elements in health care for deaf children.

Implications for Practice

The present study provides some clues for improving rehabilitation and counseling for deaf children of Turkish origin with a CI.

A striking finding of the study was that some parents regretted that their child did not receive a CI at a younger age. They saw that children who had received a CI at a younger age had better language development than their own child. To support parents with decisions concerning hearing rehabilitation, health care professionals could focus on the regret that parents have by anticipating this regret. In health education and health promotion, this tactic, called *anticipated regret*, is often used. Anticipated regret refers to feelings of regret that people anticipate they will experience if they refrain from a certain behavior. It is assumed that decision makers anticipate the experience of negative emotions, and take them into account when making decisions (Zeelenberg, Van Dijk, Manstead, & Van der Pligt, 2000). If people expect to experience feelings of regret when refraining from a certain behavior, this might influence their decision. This might also be the case for parents with a deaf child. The importance of anticipated regret as a predictor of behavior has been shown in several studies (C. J. Anderson, 2003; T. Connolly & Reb, 2005; Humphrey, 2004; Kellar & Abraham, 2005; Nordgren, Van der Pligt, & Van Harreveld, 2007; Zeelenberg, 1999). If parents are aware at an early stage of the fact that a delay in commencing hearing rehabilitation can cause feelings of regret, this might convince them to start rehabilitation as soon as possible, including cochlear implantation.

One way to anticipate the regret of parents and the accompanying negative emotions might be to ask other parents from the same ethnic group to tell their own story about how they experienced the first years of their deaf child's life, how they made their decisions, and how they felt afterward. Also, referring parents to a physician of the same ethnic group for a second opinion at an early stage might prevent a delay in cochlear implantation. This physician would be able to take the same cultural perspective as the parents. This could help convince the parents that their child was deaf and that it was important to start hearing rehabilitation as soon as possible.

Communication between the parents and health care professionals was not always optimal, often partly due to differences in preferred language. In the opinion of family counselors, access to the services of a speech interpreter is very important, whereas parents think it is less important. There might be several reasons why the parents in our study did not think an interpreter was needed. First, they might have become convinced that they had mastered the Dutch language. Second, they might have asked a relative to act as an interpreter. Finally, they might have feared that their private life would become public in their own community. If parents do not master the Dutch language fully, family counselors might want to persuade them to ask for an interpreter. In this case, it is important to explain that professional interpreters are free of charge and that they maintain strict confidentiality. Even if the parents do master the Dutch language fully and it is not necessary to use an interpreter, it is important that family counselors check on a regular basis how the parents interpret the counseling information they receive. Moreover, it is important that family counselors summarize parents' responses in order to check whether they understand the parents.

Cultural differences are probably responsible for the fact that family counselors and parents seem to have opposite perspectives when it comes to how to make decisions about rehabilitation and counseling. Parents prefer physicians and other health care professionals to make the decisions and tell them what is best for their child. By contrast, health care professionals in the Netherlands usually provide parents with objective information, including the advantages and disadvantages of different options, so that parents can make their own decision. The parents in our study did not seem to appreciate this: After all, the health care professional is the expert! The fact that the Dutch health care system does not work this way might explain why Turkish parents have little confidence in the Dutch health care system. Consequently, these parents seek the opinion of a health care professional they do trust.

In our study, most parents went to a Turkish doctor for a second opinion. Only when this doctor confirmed that their child was deaf were they ready to decide in favor of a CI. However, the problem is that they usually consulted a Turkish doctor while they were on holiday in Turkey. This meant that valuable time passed without optimal hearing rehabilitation, and this might inhibit or delay the child's language development. Health care professionals should be aware of this situation and try to convince parents that starting rehabilitation early is very important for the language development of their child. One way to do this is to refer parents for a second opinion to a physician specializing in ear, nose, and throat who is of their own ethnic group and who resides in the Netherlands.

Another important finding was that parents did not know how to be actively involved in the care of their deaf child. Ethnic minorities in Western societies are usually more collectivistic than native inhabitants (Kagitcibasi, 2005). According to Kagitcibasi (2005), heteronymous morality is the norm in a collectivistic culture. This means that the individual is subject to another's rule; that is, the individual is governed from outside. In contrast, in more individualistic cultures an autonomous morality is the norm; that is, the individual is subject to his or her own rule.

In general, relatives are usually more important for non-Western immigrant parents, including parents of Turkish origin, than for Dutch parents (Kagitcibasi, 2005). Relatives can influence parents: They can be supportive, but also a source of stress. Either way, it is important to involve relatives in the child's care. An intervention that empowers parents and at the same time involves relatives is the Family Group Conference (FGC) model, an intervention developed in New Zealand. The FGC model aims to turn the traditional decision-making process on its head: Rather than a meeting of family members that is dominated by the presence and agenda of professionals, the FGC is predominantly a meeting of the family group (M. Connolly, 2006; Lupton, 1998). Professionals attend in the capacity of information givers, rather than as the involved professionals. The family uses the information gathered at the conference to formulate a plan. Responsibility rests with the family, and professionals should allow the family to carry out the plan, however unconventional, unless the plan causes harm to the child. Currently, we are implementing the FCG model at the Dutch Foundation for the Deaf and Hard of Hearing Child.

In conclusion, the present study shows that Turkish parents and family counselors have different views on the care of deaf children with a CI. Care in the Netherlands is insufficiently tailored to the needs of Turkish parents. It is plausible that this is also true for other immigrant groups, not only in the Netherlands but also in other countries with several minority groups. With the global growth of immigration, it is important to tailor care to the needs of these immigrants. In this way, hearing rehabilitation will be more beneficial for deaf children from minority groups.

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Appendix

Interview Topics

1	Information about schools.
2	A second opinion from a Turkish physician.
3	Counseling with a physician or audiologist.
4	Cochlear implant (CI).
5	Clear report about the development of my child.
6	Explanation about CI and the surgery.
7	Taken seriously by physicians and other health care professionals.
8	Explanation of the results of diagnostic tests.
9	Information about hearing loss during regular visits of family counselor.
10	Counseling about the future of my child.
11	Support with making decisions about my child.
12	Playthings suitable for my child.
13	Immediate counseling after learning that my child has hearing loss.
14	A hearing aid as soon as possible.
15	Counseling on how to communicate with my child.
16	Receiving an overview from the family counselor of everything that happened with my child.
17	Learning how to develop a good connection with my child.
18	Counseling on how to read books to my child.
19	The child should be seen as a normal child and not as a problem.
20	Availability of counselors for questions by telephone.
21	Explanation about medical and audiological aspects.
22	Sign language courses.
23	Written information about hearing aids and how to use them.
24	Written information about CI and the surgery.
25	Physicians and other health care professionals inform each other and are familiar with the care others provide.
26	Explanation about the cause of the hearing loss.
27	Support with organizing devices and other aids.
28	Detection of hearing loss by means of diagnostic tests.
29	Explanation about the functioning of hearing aids.
30	Explanation about the consequences of hearing loss in daily life.
31	Information about several types of hearing tests.
32	Counseling on what can be expected in the coming year.

33	Speech therapy at home.
34	Consultation on the use of sign language.
35	Consultation on the use of spoken language and speechreading.
36	Written information on how to communicate with my child.
37	Answers to practical questions such as whether my child can cycle on a public road.
38	Support with financial aspects.
39	A reliable babysitter.
40	Support from a social worker.
41	Counseling on problems and distress.
42	Support with child-raising issues.
43	Time to learn how to deal with the hearing loss.
44	Relatives and friends learn how to communicate with my child.
45	Learn how to enjoy my child.
46	Courses on how to deal with my deaf child.
47	Support with teaching my child spoken language.
48	Visiting the audiological center.
49	Support with the daily use of hearing aids.
50	I decide what is going to happen with my child.
51	Information and counseling for teachers at my child’s nursery school.
52	Learn how to pay attention to the other children in our family.
53	As few health care professionals visiting our home as possible.
54	Written information on deafness and hearing loss.
55	Information on devices at home.
56	Written information on what to expect in the near future.
57	Transport to the audiological center.
58	To be left alone as much as possible.
59	Support in case of stress between me and my partner concerning the care of our child.
60	Courses on how babies communicate by means of babbling, smiling, crying, watching, etc.
61	Courses in sign language for the whole family.
62	Attending a special baby or toddler nursery school.
63	Meet other deaf or hard of hearing children and adults.
64	A deaf adult who is doing well should be held up as an example.
65	Support with teaching my child the Turkish language.

66	Information on deafness for relatives and friends.
67	A deaf child who is doing well should be held up as an example.
68	Meet other Turkish parents with a deaf or hard of hearing child.
69	The presence of a Turkish interpreter during family counselor visits.
70	Course on how young children learn to speak.
71	Family counselor of Turkish origin.
72	Information about parent organizations.
73	Family counselors communicate with my relatives.
74	Communicate with parents with a deaf or hard of hearing child through the Internet.
75	Meet other parents with a deaf or hard of hearing child.
76	Yearly overview of the schedule of all parental courses.