UNIVERSITY OF GOTHENBURG
The Sahlgrenska Academy
Institute of Neuroscience and Physiology
Unit of Audiology

Spring 2009

MASTER RESEARCH THESIS IN AUDIOLOGY, VAU280, 30 ECTS

Advanced level

Title

Parents experience when their child is diagnosed with hearing loss

Author
Kristbjörg Pálsdóttir

Supervisor
Traci Flynn
Margareta Bohlin

Examiner
Lennart Magnusson

Abstract

Parents go through various experiences when their child is diagnosed with hearing loss. The purpose of the qualitative study was to understand Icelandic parents experienced when their child was diagnosed with hearing loss. This includes the experience they got from service provided by the National Hearing and Speech Institute in Iceland. There were six parents of children with hearing loss interviewed for this study, even distribution was between sexes. The interviews were analyzed using Interpretative Phenomenological Analysis. From the analysis came the two themes; effect and experience, both with three subthemes.

The result from the six subthemes was that for the parents the diagnosis of their child’s hearing loss is difficult to receive; however, with time it becomes easier. Their child’s hearing loss has positive and negative effects on their life and feels the knowledge about their child’s future and its development is important; however, it is often uncertain. The parents experience the need for more knowledge about hearing loss and hearing aids. Support in different ways is also important for the parents, but not always perceived as needed. Overall the parents are satisfied with the treatment and service provided with improvement needed in certain parts.

Key words: Parents, hearing loss, experience, children, hearing aid, phenomenology

GÖTEBORGS UNIVERSITET
Sahlgrenska akademin
Institutionen för neurovetenskap och fysiologi
Enheten för Audiologi

VT 2009

SJÄLVSTÄNDIGT ARBETE I AUDIOLOGI, VAU280, 30 hp

Avancerad nivå

Titel

Föräldrars upplevelse när deras barn diagnosticeras med hörselnedsättning

Författare
Kristbjörg Pálsdóttir

Handledare
Traci Flynn
Margareta Bohlin

Examinator
Lennart Magnusson

Sammanfattning

Föräldrar genomgår mångfaldiga upplevelser när deras barn diagnostiseras med hörselnedsättning. Syftet med denna kvalitativa studie var att undersöka upplevelsen hos Isländska föräldrar när deras barn diagnostiserades med hörselnedsättning. Detta inkluderar upplevelsen av tjänsten de fick från den Isländska nationella hörsel- och talinstitutionen. Ett antal av sex föräldrar blev intervjuade för denna studie, med jämn fördelning mellan könen. Intervjuerna analyserades med Interpretative Phenomenological Analysis. Analysen gav två teman, de var; Effekt och upplevelse. Båda teman hade var sina tre subteman.

Resultatet från de sex subteman blev: att diagnostisering av hörselnedsättning hos barn är svår för föräldrarna men länger fram blir den lättare leva med. Barns hörselnedsättning har både positiva och negative påverkan på föräldrarnas liv och de tycker att kunskap om barnets framtid och dess utveckling är viktig dock ofta osäker. Föräldara upplever ett behove för ökad kunskap runt hörselnedsättningen samt hörapparaterna. Söd är också viktigt för föräldrarna på olika sätt, dock inte alltid erhålled enligt behov. Generellt var föräldrarna tillferdställda med bemötandet och tjänsten de har erhålled dock finnst det vissa delar som skulle behöva förbättring.

Nyckelord: Föräldrar, hörselnedsättning, upplevelse, barn, hörapparat, fenomenologi

ACKNOWLEDGMENT

First of all I would like to specially thank the parents, who participated, for their contribution to this study, could not have done it without them.

Also I want to thank; Ingibjörg Hinriksdóttir, chief physician and the responsible person for this project, for all her help and support. Other staff at the Hearing- and Speech Institute in Iceland also deserves thanks for their support.

At last, but not least, I would like to thank my family for their valuable support throughout my education.

TABLE OF CONTENT

INTRODUCTION

When audiologists are working with children with hearing loss they work a lot with the parents. All parents react in different ways when receiving the news about their child's hearing loss. There are many factors that effect on how a parent reacts to the news, these factors can be for example, child's degree of hearing loss and child's age and parents' experiences with hearing loss. What also can effect parents' reaction is the service provided and the treatment parents receive from professionals working around the child. For some parents the service around the child's hearing loss is not enough and they want more to be done. This can mean more service for the child or for the parents but parents cannot be forgotten in this process. It is the parents who have lost something, for example an idea of life, and have needs to change their life so the hearing loss fits in. Parents' prior understanding of hearing loss effects how they experience their child's hearing loss but nature and degree of the hearing loss also has their own effect.

A study investigating how parents' experience their child's hearing loss has not been done in Iceland and is needed for quality control of the National Hearing and Speech Institute in Iceland. The amount of studies around parents' experience when their child is diagnosed with hearing loss is not extensive and therefore this study would expand the current knowledge base.

BACKGROUND

The hearing loss

For each parent the experience of learning about their child's hearing loss is different. The child's degree of hearing loss might have something to say for how parents experience it, however that is not absolute. Other factors in parents' prior experience with hearing loss may also have an effect. Good contact between parents and the audiologist, as well as, other professionals is important. For that to function well, professionals need to understand parents' needs for service.

At diagnosis

Receiving the result of a child's hearing loss turns, for many parents, their life upside down. The idea about the normal family is flushed away and parents can go into shock. Parents might even feel the need to move to another place; town or country, to get better service for their child. For some parents the hearing loss is only an obstacle in their way that needs to be overcome. They deal with the hearing loss emotionally in different ways; while some might distance themselves from the situation and might even have a hard time going to work, others might feel frightened for the child since they are not certain about what the hearing loss involves (1). Other negative feelings that come along after the diagnosis include: worrying about the safety of the child, insecurity about the future for the child and worrying that someone might take advantage of their child, seeing their child's frustration when they cannot hearing can be hard on the parents (2). Also parents experience sorrow for the lost dream and the life they will not have and they need time and space to deal with their feelings. Parents describe it the way that the pain they feel never goes away, but as the time goes on it does not control them anymore (3). Although it has been mentioned often in the literature that getting the child's diagnosis of hearing loss is like the death of the child, it is only a symbolic comparison (3, 4). For other parents, who have a child with a suspected hearing loss, getting the result about the hearing loss can result in a positive emotion for as then they feel that they can move on. Others always feel behind, for an example in language development, and are always trying to catch up (5). The degree of hearing loss does not seem to have a correlated impact of how parents react and deal with the news. It has even been shown that parents to children with less severe hearing loss can be more effected by the hearing loss (4).

Treatment

Parents appreciate when professionals do not try to say what the child will or will not accomplish instead just stay in the present. Also they appreciate when professionals' give them space to make up their own mind and do not pressure them towards any decision, instead supports the parents in their decisions. It is the parents who know the child best (1).

In the beginning, parents are most concerned about the healthcare and emotional well-being. This becomes easier when the child gets their hearing aids and/or starts learning sign language. At that point parents start seeing changes in their child’s behavior and they become more confident and more aware of what is going on with the access to everyday sounds. Further on, the concern towards the child focuses more on education and support systems (2, 6).

Parents feel that professionals are sensitive when they meet them on an emotional level and are aware of the parents’ feelings. Not all parents feel this sensitivity from the professionals and not all parents are pleased about it either. The professional needs to find the golden mean when it comes to talking to the parents and finding out which approach works for each parent (7).

Service

Good service is important and to be able to give good service professionals need to get on the same level as the parents and not take anything for granted. Each child is different and parents need all the help they can get. A simple healthcare system is something that should be strived for to make it easier for parents to navigate in the system. Unfortunately, parents often need to take their children to different professionals located in different places and with limited communication between them.

Audiological service

For parents in Fitzpatrick’s (8) 2008 study the need for audiology, as well as, therapy service is very important, either clinical- or home-based. There are some parents that feel that it takes too long of a time getting hearing aids when compared to the time the diagnostics process took. They understand the importance of getting the diagnosis done but when it comes to hearing aids parents feel that the ongoing process slows down and that time is being wasted. This can be frustrating for parents (9). Connected to the importance of early diagnosis, parents often discuss the importance of universal newborn hearing screening as a part of the audiological service provided. Parents of screened and non-screened children discuss this importance (8).

When parents have gone through the beginning state of their child’s diagnostic and (re)habilitation they become more at ease and the majority become pleased with the audiological and therapy services offered. Parents' satisfaction with how they are told about their child's hearing loss varies. It is then important that they are told about the hearing loss with an appropriate approach. In a new screening program the disappointment associate with the delivery of the news can be hard to avoid until the program is fully integrated in the service (8). For parents to get a good experience of the service provided, the audiologists need to make sure that they are talking on the same level as the parents. This also helps to build up a good connection. When audiologists have sufficiently explained the situation for parents, they leave the appointment feeling more satisfied; too much detailed or complicated explanation can instead result in frustration with parents. Although the information parents get is not what they would like to hear, it is important that they hear it, for a trust to be built up between the parents and audiologist. Parents do not either want to get too little explanation about what is going on, even though they have gone through this process before with another child, they still want explanation about the situation. By being honest and open about the situation the audiologist builds up a trust in the relationship with the parents which can be very important in the future (7).

Parents seem to have a need for either a social worker or psychologist when learning about the hearing loss. Not all parents are as impressed with the service from the social worker or psychologist. This service needs to be felt as a part of the audiological service and the social worker needs to have technical and medical information about the child's hearing loss to be able to provide the best possible counseling. Parents who have received suitable service from a social worker value this service to a great extent (8).

Coordinated service

Parents have a need for the health care to be simple with coordinated service, psychological service, and easy access to information (8, 10). In some case it is confusing and the pathways of how the service works are missing. A confusing system can in some cases lead to mistrust in the provided service. The initial experience is important to feel connected to the service in the future (8). Unfortunately parents often feel that the service is complicated and do not understand why it has not been made easier for them to find their way (1). Parents have different importance for the coordinated service; some have the need for joint service of different health care systems connected to their child while others have the need for the service providers to easily share information with each other (8). Many parents feel that it would be easier if the service was in one place where they can get in to contact with different professionals (1, 8). Also, some parents have the need that one member of the team, around the child, is in control of what happens and the parents are in good contact with that key person (8, 11).

Support

A hearing loss does not only effect the child it also effects the family and their life. The family needs support in many different ways, it can be technical and emotional and it can be from professionals or others. Three of the most important supports for parents when learning about their child's hearing loss are: support from the audiologist, contact and support from other parents (12), and support from family and friends.

Support from audiologists

Emotional support is important for parents of children with hearing loss (8). Audiologists need to be able to give counseling and to be easy to talk to about feelings that come-up. Parents often seem to hold back on their emotions, at least in the beginning. They need to be comfortable around the audiologists when learning about the hearing loss and dealing with it. Patience is important for parents, they need to feel that the audiologists gives them the time they need and is not in a hurry to get things done (7).

Often when parents come with their children to a hearing clinic, they are referred because of suspicion about hearing loss. Despite receiving confirmation of a suspicion and information about the hearing loss, and that there is no cure, can be shocking. At this time it is more important that the audiologist gives the parents emotional support and counseling rather than load them with information (3). Around diagnosis parents go though emotional turbulence that the audiologist needs to recognize and show the family support while they grieve (13). Although there is no good way for parents to get the information about the diagnosis it gives them support when the news are told with kindness, sympathy, and in an honest way (12).

When parents of children, who have received cochlear implants (CI), describe the support they received from audiologists it can be divided into three groups; emotional-, informational- and physical support. Emotional support is shown while making the decision. Informational support is given through counseling about CI to help with decision making and presenting resources to parents. Parents' biggest need for counseling is following diagnosis but after that it decreases. Physical support contains information to parents about the child developmental progress. For parents it is reassuring to know that the child is "on track". Counseling from audiologists can result in better self-esteem and confidence for parents in addition it increases the parents' knowledge about the situation and feeling of being in control (14).

Support from other parents of children with hearing loss

Some parents experience negative changes in contact with other people they know when their child is diagnosed with a hearing loss. It is important for parents to have a good social network that supports them (15). In this context, relationships or meetings with other parents of children with hearing loss is beneficial and many think it is important after the child is diagnosed (8, 10, 11, 15). Although parents have good and supportive family and friends, the support from other parents, tends to better match their emotional and practical needs (14). Their support and assistant is the best for many parents, and it helps the parents to cope with the hearing loss (1, 15). The other parents of children with hearing loss have been in, or are in a similar situation and can help by supporting and giving advice. This contact gives opportunities for parents to obtain practical information from someone who knows firsthand how it is to bring up a child with hearing loss and how to get around in the system (1, 8, 14). They can also see what others have accomplished. Parents cannot only receive knowledge but through others interest in their child's development they can tell someone their story which is positive for parents (14).

A support group with other parents of children with hearing loss can be an emotional turning point for parents of children newly diagnosed with hearing loss. They want and need to meet other parents that have gone though the same experience (13). The other parents make them realize that they are not alone and there are others that have been through the same experience (1). Also, they become less isolated and have better emotional bonds with their child. It has also has been shown to be beneficial for the acceptance of the child’s hearing loss (15). Even meeting other children can help the parents to feel that there is hope despite their child’s hearing loss (1). During the parents meeting the children also have the opportunity to meet peers who also have hearing loss. Peer meetings can help the children’s development, to see that they are not alone with the disability (8).

This support from other parents can be clinically based and non-clinically based. There is even some who prefer it not to be clinically based (10, 11). Although not clinically based, the parents can be informed about it at the clinic and there can be cooperation between the parent group and the hearing clinic (10, 12). Luterman (12) takes this up in his discussion. He thinks the audiological service or clinic should have a list of parents of older children with hearing loss that are willing to offer some help to the parents whose child has recently been diagnosed with hearing loss.

Support from family and friends

Parents to a child with hearing loss have the need to talk about their experience to have better control of their feelings (3). They also need support form their own family, friends and employer (14, 16). The hearing loss can have an impact on all family members who also need to talk about the hearing loss. Therefore, parents prefer the whole family to be taken into consideration of the audiologist, who ought to encourage the whole family to participate in the intervention (13).

Support and involvement from extended family members in the child’s (re)habilitation is important and it is known to expand the development of the child, unfortunately it does not often occur (3, 15). The knowledge of the hearing loss and learning to deal with it can strengthen the family, and they can grow together. This is not absolute (13). For parents, of children who are CI candidates, the biggest support from family members is in the beginning around the time when the child is diagnosed and until the parents make the decision about the CI. Friends and family also support by helping with various daily tasks, like caring for the children while the parents attend appointments. It is also important for the families that other families and friends show emotional support and understanding of the situation (14). Without the support everything is much harder since they cannot get the help that is needed, physical and emotional. as discussed above

(16). Despite the difficulties of having a child who has hearing loss, this experience enriches the lives of the families. The audiologist should aim to focus on the abilities that the child and the family have, not the disabilities, and give a hope for the future (13).

Siblings of a child with a hearing loss are also affected and there for should parents not forget that they need to include all their children and remember about everyone's needs. For the parents to be able to do this they need good support and counseling from professionals (3). For parents whose children need CI, it can be stressful and difficult time both when choosing the CI, or not, and also the time after decision making. If the parents are not able to support each other, it can result in a separation (16). Parents of children with a CI have described the importance of having a partner when dealing with the child's hearing loss and implantation. Making decisions together and being there for each other in difficult situations, like during surgery, is important for parents. Being on the same track is also important for parents and their marriage. It is really difficult if parents want two different things for their child (14).

Information

How information about the child's hearing loss is told and what knowledge it contains is important for good communication between professionals and parents. Parents differ when it comes to the satisfaction of the information they are given. Parents' background can have an influence. For example, some parents have more technical backgrounds than other while others have a more medical background. Professionals need to be able to adjust to each parent when discussing their child's hearing loss.

How

For good communication between professionals and parents a few things need to be considered; parents and professionals need to have respect for each other, for each ability and knowledge, and the communication between them needs to be truthful and clear. An understanding and empathy by both parties is also important. Goals need to be an agreement between both parties and they need to share decisions and plans which are made with each other with open information sharing. This should be done without parties blaming each other for how things are. Good communication between professionals and parents results in a better outcome for the child (17).

Good communication between the audiologist and the parents results from a good explanation from the audiologist. This explanation includes using a suitable register which is explained thoroughly in context. Good communication also results from sensitivity, inclusiveness, and honesty from the audiologist (7). Parents have suggested written information is needed when a child is diagnosed with a hearing loss. They have the need for professionals to offer information about available intervention options for their child (13).

Knowledge

Parents have different wishes for information about the child’s hearing loss and there is some information that is asked more for than others. The information that often concerns parents is the cause of hearing loss, although in many cases it is unknown. Parents often think they have done something wrong. Understanding the audiogram is also information that is important for parents, but more for parents of children with mild to moderate hearing loss. As the time goes on it only gets harder to ask for an explanation of the audiogram, which makes it important to explain it thoroughly in the beginning for parents. Parents of children with severe to profound hearing loss seem to put the understanding of audiogram lower on the priority list (18).

Fathers seem to know less about their child’s disability than mothers, but with a family program the short and long term knowledge can be significantly increased (19). Parents need good access to up-to-date technical and medical information, in books, journals for professionals, video, or internet recourses (8). Although, professionals do not have all the answers for parents, their honest and helpful approach towards the parents is appreciated. Parents also value the thoughtfulness towards their emotional stage. They have the need to make their own decisions based on the information they are given and will seek the professional who will support them in their decisions (13).

Satisfaction

Parents tend to be satisfied with the technical information, like hearing aids, and medical information regarding the hearing loss, language, and communication (8, 11).

Despite this, some parents feel the information they receive about hearing aid and maintenance is not always sufficient (13). Also the information about therapy options is satisfying but sometimes the information about where to find the therapy is missing. Information about community resources, like educational support, is not as satisfying for the parents. The information about the child’s developmental prediction is often lacking, the parents want to see the success the child is making and have something to compare to (8, 11). Parents often feel lack of options for intervention and the need for more guidance when it comes to forming suitable expectations (13).

Parents want the audiologist to speak more in layman terms. Audiologists and other professionals need to think about what they say to the parents and how they say it. Parents need to be able to understand what the professional says, regarding the child’s hearing loss and technical information (1, 13). For the professionals, they can get in to a routine which can result in inappropriate way of telling the parents about their child’s hearing loss. For most parents, it is a new reality that changes their life forever. It is not every day their child is diagnosed with a hearing loss. Professionals need to make sure that they do not offend the parents (1).

Many parents, whose children have received a CI, are satisfied with the information they have gotten about the intervention. This information was mostly received through the intervention program. Parents conduct research and obtain more information themselves and get in contact with other parents of children with CI. Although many parents are satisfied with the information they get though the program there are always parents that get surprised by some events, especially technical aspects (16).

Icelandic studies around parents experience

Parents seem to experience how they are given information in different ways, while some feel they have not been treated is a suitable way others feel satisfied. Sadly, professionals do not always act in a professional way and there are parents who feel that there is a lack of professional support, for example a social worker or others. Parents, who have been told where they could seek a social worker, or a psychologist, admit that they feel that it is difficult to do it themselves; however they say they would have opened the door if someone had come to them. It is hard for parents to admit that they need help and to seek it themselves. For some parents they don’t even see that they needed help until long time afterwards. Although parents have a negative feeling towards the system, they seem to be positive towards the personnel working at the clinic where the child is being treated. A team around the child can open up a pathway to other parents in a similar position (20).

The diagnostic and (re)habilitation process in Iceland

Today with newborn hearing screening, children who fail the first screening come to the hearing clinic for re-test within a few days. The first screening is completed at the hospital at a five day check-up. If the child fails the screening again an ENT-doctor checks the baby and performs an AABR. If the child fails the AABR a diagnostic ABR or ASSR is preformed within 2 weeks from the failed AABR. The child is also fitted with hearing aids after the diagnostic ABR/ASSR, if warranted. Test aim is to have the child fitted within 2 weeks after the failed AABR. For older children the aim is also to start (re)habilitation with hearing aids within 2 weeks from suspicion. All children are sent for a general research package to help find the appropriate treatment; the aim is to have it done within 3 months. For children who are born deaf and are CI candidates the aim is to have them operated by 18 months of age. The general research package for the children include; seeing a pediatrician for developmental check-ups, an ophthalmologist, and CT and often an MRI of the anatomy of the hearing mechanism. Blood and urine (blood in urine) research is also done. Other researches, like gene researches, are done if needed (21).

During the years 2002 to 2006 there were 13-30 children diagnosed with hearing loss in Iceland each year. Of these children 73% got hearing aids, 71% were fitted bilaterally and 29% unilaterally. By 2006 it could be seen that there were between 10-20 children diagnosed with hearing loss in each age group in Iceland (22). Since the start of newborn hearing screening in Iceland in April 2007 the incidence of diagnosis per year are evident to increase. Several children have already been diagnosed with hearing loss through the newborn hearing screening.

AIM

The aim of this study is to understand Icelandic parents' experience when their child was diagnosed with a hearing loss. This includes the experience they received from the service provided by the National Hearing and Speech Institute in Iceland.

RESEARCH QUESTIONS

- How do parents experience their child's hearing loss?
- How do parents experience the service provided?
- How do parents experience the support offered?
- How do parents experience the information presented?

METHOD

In this study, 14 Icelandic parents of seven children with hearing loss in (re)habilitation at the National Speech and hearing Institute in Iceland participated. They live in the capital area of Reykjavik and were sent a letter with information (see appendix #1) about the research with an invitation to participate. Of the 14 parents six parents were individually interviewed on one occasion. The interviews were open-ended, semi-structured (see appendix #2), and lasted from 10 to 50 minutes. The interviews were conducted in a place familiar to the parent or at a neutral zone. All interviews were recorded with a digital dictaphone, then transcribed and analyzed using the Interpretative Phenomenological Analysis (IPA) (23). All participating parents consented to participate in the study and for access to their child's medical journal at the National hearing and speech institute in Iceland for important data for the study. The study was completed with phenomenological approach, a qualitative method. Phenomenology is a method developed within philosophy and focuses on the meaning of how the interviewee experiences his/her life world and tries to make the invisible visible. With phenomenology, the researcher tries to directly describe interviewee's experience without thinking about where it originates. Within phenomenology, prejudiced meaning is not prohibited but the researcher needs to critically analyze his/her own prejudiced meaning. Also the researcher needs to be aware all he/she knows about the world is from his/her own point of view and experiences (24). There exists different types of phenomenology, and IPA was used in this study. With IPA the researcher tries to find out how interviewees, understand their own world at the same time as they themselves are trying to understand its own world. The meaning of a certain experience or situation for the participant is what is important within IPA. There is no single right way of doing IPA; here are only offered suggestions about how it could be done. Researchers adjust the method to the focus of the research and their own way of working (23).

The researcher interviewed the participants and then transcribed the interview word for word as it happened, including both the interviewer's questions and the interviewed answers. The transcription became the raw data for analysis. When starting the analysis the left-hand margin of the paper was used for writing what was interested of what the interviewed said, divided into parts that have the same meaning, meaning units, which helps the analysis. The right-hand margin was then used to write the meanings, from the left, more abstract; this to understand the psychological meaning of the participant expression that is relevant to the phenomenon being researched. Thereafter, a clustering of themes was carried out using the meaning units to describe the psychological structure of the participant's experience. This was completed twice. Next the clusters were put together in themes and these themes clustered into superior themes, each with their own subthemes (23, 25). This study resulted in two superior themes, both with three subthemes.

Material

A study done in spring 2007(22) showed that the mean age of diagnosis was over 6 years of age. According to the study, prevalence of hearing impairment is 2.6 per 1000 life born in Iceland or between 10 to 20 children in every age group per year in Iceland.

In the current study, parents' had children who were diagnosed after the 1st of January 2007 and before the 31st of December 2008. Another criterion when selecting parents was the use of Icelandic as the main language at home. Parents were found through their child's journals at the Icelandic speech and hearing Institute, where the child had been diagnosed and (re)habilitated. Since the limited time to conduct the research and economical reasons, it was decided to only ask parents in the capital area of Reykjavik to participate; being aware of that it might affect the answers. The researcher of the study had not been a part of the (re)habilitation of their child.

To get a variation among invited parents, a few factors were checked when selecting the parents including; where in the rehabilitation phase they are, the degree of hearing loss, and the age at diagnosis. Since there was a limited interest of parents to participate, the use of these factors became restricted.

The participants were three pairs of parents or six individuals. For discretion, the children's sex will not be revealed. One pair of parents had a child diagnosed with mild hearing loss at six years of age and had been using hearing aids for few months at the time of the interview. Another pair of parents had a child diagnosed with profound hearing loss at two years of age. The child later got CI and had been wearing it for couple of months at the time of the interview. A third pair of parents had a child diagnosed with a hearing loss at little over six months and got CI within a year. The child had been wearing the CI for a couple of months at the time of the interview. Of the six interviewed parents, five were at aged between 30 and 40 years old and one parent was under 30 years old. All families consisted of a mother, father and two to three children.

Ethical consideration

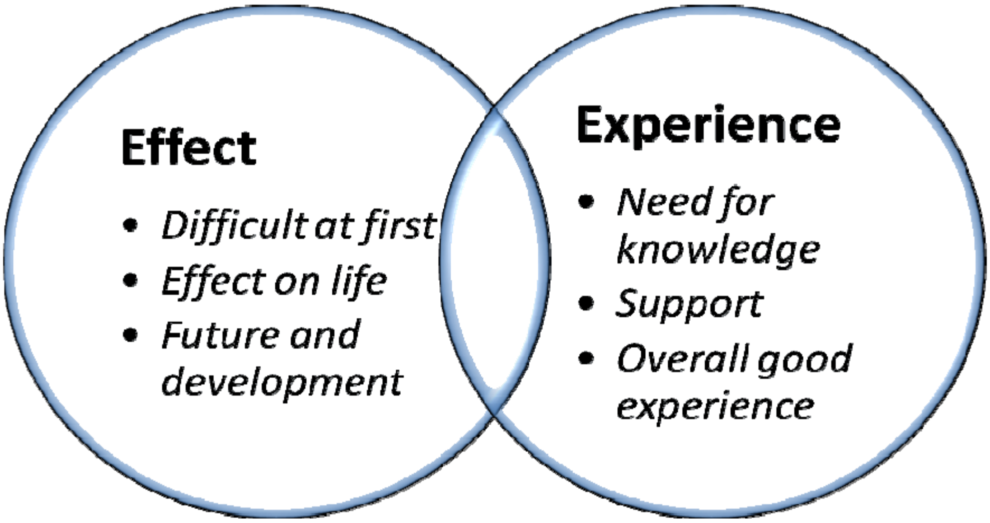
An informational letter was sent to each parent, inviting him/her to participate. They were informed that the participation was voluntary and they could end the participation at any time without any effect on the child’s service. The researcher’s telephone number and e-mail address were listed for parents to contact. Parents were also invited to contact an audiologist if they felt the need to talk to someone else after the interview. Parents were assured discretion and confidentiality and therefore the quotations from parents are given alphabetical letters. All digitally recorded interviews were deleted after transcription and all transcription were disposed of accordingly at the end of the study.

As mentioned above, all parents signed a letter of consent. This signed consent was done to have a formal approval both for the researcher and the parents to lean upon. The researcher made sure the parents had gotten the information and agree to it, at the same time the researcher needs to respect what information can be gotten from the child’s medical journal. All information gotten from medical journals were only used for this study and disposed of accordingly at the end of the study.

The study was reported to the Icelandic Data Protection Authority as according to the request. Ethical approval, from the National Bioethics Committee in Iceland, was also sought for this study. The ethical approval was granted and given the reference number 09-021-S1.

RESULT

The two superior themes (see figure 1) found in the study can be explained: a) Hearing loss effects life, but with the knowledge the hearing loss can become a positive effect and b) with more support and more concrete information the experience of service and treatment around hearing loss and hearing aids can be improved.



These are the two superior themes and the six subthemes revealed in the study.

Figure 1

Effect

It seems that parents, in different ways, mention that their child's hearing loss affects their life. It also differs how they are affected. Hearing loss appears to have more negative effects in the beginning right after diagnosis, which often that has to do with the prior experience of hearing loss. A prior experience of hearing loss often appears to be a negative discussion in society. After the parents have gotten the information they are offered about the hearing loss and had a discussion about future possibilities for the child they appear to have more positive thoughts towards the hearing loss. Parents even mention that having a child with a hearing loss is an important experience that has changed their view on life and would not want to miss out in this experience.

> *"…[1]I thought it was a terrible/…/[2]one thinks ones child isn't 100% even though [my child][3] is, you know" [4] (Interview person #E)*

> *"…You know, everything would be harder/…/first it was of course just like, or just a little bit sadness, knowing that I would never be able to talk to [my child], you know express to [my child] my love …" (Interview person #B)*

> *"Yes of course, our life is all about this [child's hearing loss]/… / so this is of course a lot of change for everybody in the family", "… this has slowed down life a little bit… I just think that is good" (Interview person #C)*

Difficult at first

There are mixed feelings with parents of children with hearing loss at diagnosis. They often descend in to negative feelings towards the hearing loss in the beginning after the diagnostic result. Some parents even hope that the diagnosis is wrong or could easily be fixed.

> *"I thought it was terrible… you know, this will just be fixed, it is just earwax" (Interview person #E)*

> *"Yes… it, of course was a big shock, a bit sorrowful" (Interview person #C)*

Some parents experienced the diagnosis as a confirmation of suspicion that they have had for awhile; however, there are also those who sense gladness that it is not worse, they are aware of that there are other things that are worse than child's hearing loss. The type of hearing loss and the reason for the hearing check-up, which could be; suspicion,

---

[1] ... => hesitation or a pause

[2] /.../ => there is a text between of less importance for the contents

[3] Personal pronouns not used to protect identity, [child] becomes instead of he/she

[4] All citations are translated by the author

further diagnosis or just to rule out. Appear to be somewhat associated with parents' reaction to the diagnosis.

> *"…maybe I'm just thankful for that it is just it [hearing loss] and nothing else" (Interview person #E)*

> *"This was just of course, just like that, actually a confirmation on what we thought" (Interview person #D)*

Participants gave the impression that they experience a difficult time when they realize the hearing loss could have been diagnosed earlier. They feel they are the ones to blame for not realizing the problem. Despite this, parents seem to accept that it can take time to fully diagnose the hearing loss, especially when the cause of the hearing loss in uncertain. One parent expresses the importance of newborn hearing screening, which can help children to get an early diagnose.

> *"So, but at the same time what, you know, what, maybe we should have turned over every stone because of, why the child hadn't started talking normally, that could also be it" (Interview person #F)*

Some participants mentioned their experience of commentary from different people around them. These comments can be frustrating for parents and even feel inappropriate. For example, daycare personnel mentioning to a parent the luck for having a girl so she could cover the hearing aids with her hair. This parent did not feel the need for covering the hearing aids and does not feel ashamed of the hearing aids. Not all parents think this way, at least not in the beginning. One participant described his/her own thoughts as ridiculous and feels ashamed of self thinking that way.

> *"That I should let [my child] grow hair to cover the hearing aids", "I still, sometimes, catch myself thinking like; yes, now [my child] is wearing a hat, then [my child] looks healthy, no one can see that something is wrong" (Interview person #E)*

These thoughts seem to, express the parents' desire of the child having normal hearing, like other children. However at the same time the parent does not want to have this feeling, which means that the child is not healthy because of the hearing loss. The parent appears to be effected by society's own negative understanding of hearing loss.

> *"[Dad] refuses to use hearing aids, thinks it's disgusting/.../ it has been like that in my home, you know, negative discussion about hearing aids and hearing loss" (Interview person #E)*

According to the participants when they understood the hearing loss, hearing aids and their function, and their child's progress, their experience became more positive. Although with time, participants seem to be able to adapt to the hearing loss and the hearing aids and the hearing loss becomes easier to live with. They appear not to have forgotten the first feelings they had for the hearing loss and the hearing aids.

> *"I have, for the most part, stopped thinking about it [the hearing loss]/… /at first we thought it was a big deal/… /but today I don't think about this" (Interview person #E)*

> *"…of course there goes through your head that [my child] will not be like other children/…/ of course it is also ignorance/…/just like, everything is so new" (Interview person #C)*

Effect on life

The effect of the hearing loss differs for each parent and they cope in different ways. Some parents consider the hearing loss just as something to deal with and make the best out of it and experience no unique emotions associated to the hearing loss. Despite this feeling the hearing loss has an effect on the parents' life. Other parents acknowledge feeling emotionally affected by the hearing loss and have a different view on life. They become more open to other things. For example, they are more open to the importance of a child learning sign language parallel to learning to speak Icelandic.

> *"I look at this as a project /… /think much more about the solutions than what is happening" (Interview person #F)*

> *"…you start having less prejudice in the society when yourself are in the minority group" (Interview person #B)*

> *"…I value life much more or you know, to have a child that something is, like this, wrong with… learn just to value it, to value life" (Interview person #A)*

The news of the hearing loss may shock parents. They do not always expect the hearing loss or have made their own explanation about what is happening. When they then get the news about what is really going on it can be hard to accept and have more effect than they first realized. While some parents just want to keep their child's hearing loss to themselves, others are more positive towards this experience they have gotten and feel it has taught them a lot. It has gotten them in contact with many people which they feel positively about. This is an experience they would not want to have missed out on, although it means that they need to be emotionally strong. There are parents that believe that hearing loss opens up a new side of life in the end, which give a positive and healthy experience.

> *"…this will be fixed, this is just earwax or something", "this has just been like an inside matter, here" (Interview person #E)*

> *"…this is a special feeling or like that, you go though some process with your child, and through all valleys, shock, sorrow, happiness… disappointment", "I would not have wanted to miss out on this…" (Interview person #C)*

One participant also mentioned the awareness of the hearing loss having effect on upbringing strategies. The planed strategy might not work so the parents need to be flexible to change strategies, which will fit the child's possibilities. Parents can even feel powerless in their role as parents.

Future and development

Parents talk about the importance of the child's language development but that is a concern when the child is diagnosed with hearing loss. There are parents that are concerned the child might not develop language as expected, but that is hard for parents. Parents are seldom experts in language development and therefore feel the need for reassurance that the child is developing speech at an acceptable tempo based on the hearing loss from someone who has professional knowledge. Parents notice themselves becoming more aware of sounds in the environment and want to do everything to help their child. Some might even feel they need to make big changes, while others would just like to know what to expect.

> *”I feel [my child] talks clearly today, so I think he doesn’t need it [speech therapy] but that is of course because I’m used to [my child] and I understand, you know, I also understood [my child’s] nonsense that came out of [child], this fuzzy that came out of [my child] before [my child] got the hearing aids”, “someone who could guide me, like how I can make better sound quality at home” (Interview person #E)*
>
> *“I of course think mostly about the language development” (Interview person #C)*

Parents who are aware of sounds might like to make some changes for example in the home or feel the need to contact an expert. They also mention the need for a list at the hearing clinic of who to contact.

Future development can be difficult to predict, but there are parents who experience the need to get information about what to expect, or look for, at certain ages. They feel that that is lacking.

Experience

Initially when parents describe their first experience of the service and treatment at hearing clinic, everything seems to be like it should be. When inquiring more, it becomes more obvious the parents’ experience that there are things that should be, or could be, different. On the other hand parents have an overall positive experience of the hearing clinic. Parents appear to require more information and professional support from an audiologist, a doctor or other professionals. Parents’ experiences the lack of information in various ways. Some parents find the hearing aid information not to be sufficient enough, while others find the medical information difficult to understand. There is a need for the diagnostic and (re)habilitation process to be clearer.

> *“So… there I think support is needed… and then maybe, and then I mean much more high tech support/…/it is more than likely that there*

> *is the experience that 90% of the users of these equipment, uh, they can’t use it /…/but then I think it is sad to be pulled in to that window” (Interview person #F)*

Need for knowledge

Parents who have no previous knowledge about hearing loss often feel a shortage of information about the hearing loss and the hearing aids. It seems to be the norm, throughout society that there is a lack of knowledge about hearing loss and hearing aids. This is also reflected in other professions that meet and are working with children. Parents’ experience is that it does not occur to these professionals that hearing loss could be the reason for the child’s problem, even though the professionals have been educated to work with children. There are parents that feel they have been letdown and that is only a coincidence that their child is diagnosed. Parents are uncomfortable with this knowledge. This can result in children going around undiagnosed for longer than needed.

> *”…I mean all these highly educated people in the day care just attributed that [my child] was tardy and needed speech therapy and this and that/…/I mean, [my child] had been with three speech therapists and [child] had been made do all these tests and it is not until one asked [mother] if [my child’s] hearing has been checked” (Interview person #F)*

> *“…in the 1 ½ year check up with the physician, then the physician recommended us not to do anything” (Interview person #D)*

The results indicate large amount of variance in what parents want to know about the hearing loss or the hearing aids but it seems that parents feel they have too little understanding of both. There are parents who think things happen too quickly after getting the diagnosis, when they are supposed to choose hearing aids which can be stressful for parents. Even if parents are given the choice to come back later and pick hearing aids they do not seem to want to because they feel every day is important. There are those who afterwards feel that they should have gone home to process the news and come back a few days later. There are always some parents who feel the need for more information about either hearing loss or hearing aids. Understanding of how the hearing aids are fitted, and work is understood to be important for some parents and they are interested in the technique. Without the understanding of how the hearing aid works, they can feel skeptical towards the usefulness of the aids. There are parents that prefer in-depth knowledge about the hearing aid technique but get the feeling there are things they are not supposed to know, since they do not get all the information they feel they need. A seminar about technique would be appreciated. Some parents feel that they are always asking for more information and it becomes difficult to always ask. There are also parents that feel the need to be able to control their own accessibility to information and prefer the technical information to be given in steps since they feel it is hard for them to remember everything that is said. Parents like looking at the internet for facts, but feel the information from the audiologist is important.

> *"…one needs, of course, to ask to get to know/…/ I at least don't remember it [the information]… so… I can't explain it [the information] better than that" (Interview person #B)*

> *"the child is getting a very advanced equipment in their hands and I was most surprised about what little knowledge I got about the technique, its possibilities and little information about… that is how they are calibrated" (Interview person #F)*

Good examples of limited knowledge in society about hearing loss are school age children thinking that hearing aids are cell phone accessories like Bluetooth, as reported by one parent.

Support

According to the participants, every parent gets some kind of support but they do not all realize they are getting the support. The perceived professional support is mostly gotten from information about hearing loss or hearing aids from the audiologist or a doctor. Some parents even feel there are other kinds of professional support needed than is offered. For example parents feel they miss psychological or technical support. Parents experience a shock and feel the need for help working with their emotions. When listening to the parents, it can be heard that it can be difficult to ask for extra support, whether it is audiological support or other support from outside the hearing clinic. According to some participants there is a lack of follow-ups service, although parent experience the need in different ways. Participants also mention they have been told that they can contact or come at any time. They feel it is positive to be able to contact the clinic at any time, but there are parents who feel the need for more structure, support and guidance. Even though parents want to, they feel they lack the independency to ask for help themselves. Often they are going through this for the first time and do not know what is too much contact and what is too little. Getting more follow-ups, both from the audiologist and the speech therapist during the first months after diagnosis would have been appreciated by parents, irrespective of the hearing loss degree.

> *"We haven't gotten any support from professionals"; "I would maybe have sometimes wanted to talk to someone who knew something more" (Interview person #A)*
>
> *"sometimes it is needed to push more on it [to get people to come for check-ups], yes, I would have wanted that it would had been more, you or, had wanted to be pushed to come, not just tell us to come when… you understand… because sometimes everything… or it is hard to approach someone… sometimes you need to get someone to come… that's how I would have wanted it" (Interview person #B)*

Parents who have received professional contact outside the hearing clinic are positive towards that experience and view it as a great support.

Parents vary in the experience of the importance to meet other parents of children with hearing loss. Parents of children with more severe hearing loss feel the experience is more important, since the hearing loss has a bigger impact on the parents' life.

> *"I can't say that, that I have any interest or need to meet other parents of children with hearing loss" (Interview person #F)*

Those participants who meet with other parents of children with hearing loss seem to only meet them once, after the initiative from the hearing clinic. However, there seems to be a positive experience of the meeting, which helps them understand the upcoming event and they become familiar with what can be accomplished. Even though they just meet once this meeting is well appreciated. According to the participants who have a child who has gotten CI, they have a very positive experience of talking to other parents about the surgery. They experience the explanation which better matches their needs. When a child has more hearing difficulties than a CI can help with, parents experience a lack of other parents to meet. The variety of parents the hearing clinic has contact with is not great enough to be able to help all different cases of hearing loss.

> *”…you know, I think it is really fantastic, you know, meeting other parents that are in the similar position and you know, understand me/…/ it is a very good support talking to people in the same position that understand me, you know” (Interview person #A)*
>
> *“nnno… or just me, have met one mother/…/ but we don’t have any communications today, because there isn’t any way for these parents to meet… it is not offered” (Interview person #C)*

Parents value firsthand information, even though it is in a seminar form, from other parents about the experience of bringing up a child with hearing loss or from a person living with hearing loss from a young age or birth. The parents gave the impression they do not have the initiative to meet regularly without the involvement of the hearing clinic, although there seems to be an interest for meetings. At the same time, parents of children who attend daycare, which is specialized for children with hearing loss, see each other regularly when picking up their children; they do not seem to have conversation together.

The support from family and friends varies. There are parents who experience they do not get any support from their own family, while there are others who experience the opposite and get great support from their family. This support from family and friends can be experienced indirectly, where parents feel positive towards people around them asking how the child is doing and are interested about the hearing loss and the hearing aid. Also being able to have someone babysitting is a support for parents. However they feel that there are only few who can babysit, since not everyone understands the child’s needs when dealing with severe or profound hearing loss. Although family is willing to support, parents realize that the family is not able to fully understand the emotions they are going through, but the support is appreciated.

> *"I, maybe, see that there are few, that knows about this [the hearing loss], that it doesn't touch, that asks me how it is going [with the hearing loss]/…/ I don't think it is uncomfortable, maybe more comfortable than anything else" (Interview person #F)*

> *"That [support form family] has been limited… hu! [scandalized laughter] if I should say like it is" (Interview person #B)*

> *"Everybody conspire to help, that is how it is/…/ that is how families are, good families and we are just that lucky" (Interview person #C)*

The participants also mention the importance of not forgetting the sorrow the extended family also goes through. They also need their support.

Overall good experience

All participants have had an overall good experience with the service and treatment at the hearing clinic. They also have a positive experience of the service they received and the will of the professionals to assist. One parent specially mentions the positivity feelings towards the general researches the child goes through to make sure no other medical conditions are missed.

> *"Very good, we got good treatment and nothing to complain about there, not at all" (Interview person #B)*

> *"It has been very good to all extent" (Interview person #D)*

However, parents feel that some things could be better. One of the things that could be improved is the clarity of how the system around hearing loss works. There are parents who find the system to be confusing and lacking structure, which makes them unsecure. Parents feel the worse their child's hearing loss, the more service they receive. When parents get a good explanation of what is going to happen and how long it takes, they experience it to help them in dealing with the diagnosis and decreases misinterpretation. Uncertainty for the parents about the upcoming events can make the system less credible.

> *“this follow up isn’t declared in this, you know, when we should come”, “I feel that maybe that is what I’m worried about today… that there is some phase that is missing” (Interview person #F)*

> *“I don’t know if there was some misunderstanding with us or we just weren’t listening/…/I don’t know if I misunderstood this with the appointment or if sh… if she issued that it could, come this, but I just would have wanted to get it from her, clear, you know, what comes now” (Interview person #E)*

There are even parents who experience information being held back from them at times. This frustrates the parents. On the other hand, they feel it is better to get the information as it comes, which may not always be fully analyzed. This makes it possible to get the results of the hearing tests in steps as they are being diagnosed more thoroughly. Although the information is not what they would like to hear, they want to receive it as soon as it is known.

There are parents who feel that there are things which could make it easier to learn about their child’s hearing loss. Parents mention the way they are told and about the facilities. Parents experienced part of the facilities as inappropriate and missing its warmth. Parents also mention the disturbance they experience with the child is in the room with them. They experience having a hard time concentrating on what is being said to them about the diagnosis and future options. They feel that they would prefer to come back for an appointment to discuss the condition under a calmer situation. This could be a solution that various parents might prefer.

> *“I can just say first of all that the facilities are pitiful… where the doctor is telling us the news… we are being told in a little room used for examination” (Interview person #C)*

> *“Our child was with us there and everything was so small… [my child] was so young so [my child] was running around and all, this wasn’t quiet… it would be… I don’t know” (Interview person #D)*

Parents’ experience when being told the news about the hearing loss does not always meet their expectations, and they do not understand what they are being told. While for some, the interest for understanding the diagnosis is not great. Other parents want to understand the hearing loss, but experience a hard time understanding the audiological terms. There are parents who experience themselves not knowing how to ask when they do not understand the information and even feel that their questions are not intelligent.

> *"it [the information] is maybe enough but, you know, I don't understand quite everything that is being told, because I don't know what it is all called, don't understand quiet the medical terms" (Interview person #A)*

> *"I just think it [the information about hearing loss] is enough, we got a booklet, we got this banana there with the sounds and we got an intense explanation with [the doctor] and we got also explanation with the one that measured his hearing" (Interview person #E)*

There are parents who experience the diagnosis as emotionally hard and they feel that they would like to talk to someone about their experience. In this meaning, there are parents who mention the need for a psychologist or just someone to talk to about what they are going through. There are also parents who do not experience the need to talk to a psychologist. The need for speaking to a psychologist is connected to the degree or nature of the hearing loss. Parents of children with milder hearing loss need less help from a psychologist than parents of children with greater a hearing loss.

> *"We don't need psychological support" (Interview person #E)*

> *"I also put a question mark on that there isn't any social worker or psychologist working at the institute" (Interview person #C)*

Naturally parents feel that they want what is best for their child and sometimes they need help from professionals to make their child's life the simplest as possible based on the hearing loss. Parents feel their child should be healthy and happy despite their hearing loss.

> *"Everyone feels that they are special, I think, that have their children there", "everything concerning the child is 100%" (Interview person #C)*

DISCUSSION

This study was completed to understand the experience parents go through when their child is diagnosed with hearing loss at the National Hearing and Speech Institute in Iceland with a focus on service and treatment they received. This project becomes the first part of a quality control study at the institute. This outcome will become the framework for a quantitative questionnaire to be sent to all parents of children with hearing loss. The questionnaire will provide a good tool to get to all parents of children with hearing loss to see how they experience the service provided. The small population in Iceland gives chance to send a questionnaire to all parents, without having too big material, however the amount of material can be limited. A questionnaire helps receiving a greater image of parents' experience of service and what is needed to be done to improve the service and treatment offered to parents of children with hearing loss.

In Iceland, the research in audiology is limited, especially qualitative research. It is also limited when it comes to parents of children with hearing loss all over the world. Previous studies have been completed in large societies with many various resources available. In Iceland, the society is smaller which results in more limited resources and cannot always be compared with larger societies. A cultural difference between larger and smaller societies can result in different outcomes. Therefore, it is important to be able to understand the situation in the country the research has been completed.

Method discussion

In this study, a qualitative method was chosen since the aim was to explore parents' experience. When looking at qualitative methods, IPA is the method was most appropriated for this study. IPA explores the experience a person has of certain situations or events. When analyzing with IPA, the researcher transcribes the interviews word for word and then read through the transcription. Words or phrases which interested or significant to the researcher where written down. Then the words or phrases where transformed to summarize the main ideas were clustered into groups. These groups were clustered a few times until themes were found. The themes were clustered to get superior themes and subthemes (23). The interviews were not compared with each other. They were analyzed on their own, making them independent from each other. With a quantitative method, the participants would have been controlled in answering the questions, which does not give as broad of answers as a qualitative method. In this study participants are able to discuss what is important for them.

The researcher is aware of the narrow sampling of participant. Participants could have been less homogenous. For example; they could have lived outside the capital area or had children with greater difference in hearing loss. Limited time and interest to participate were the main limitation for the homogenous group of participants. With more time for doing the research, there would have been more possibility to reach out to parents living outside of the capital area. Getting their experience might have been interesting for the reason that they have further to travel to get service and have less possibilities of getting specialized service. There are always parents who are not willing to participate in studies, especially when it involves emotions. There are a number of reasons for why parents did not return to researcher with a positive answer of participation. For example they forgot, they don’t like to discuss their experience, they were afraid of the connection the researcher had with the hearing central and thought it could affect their child's (re)habilitation. Furthermore the researcher is aware of that those who participate can have something in common which those who did not participate might not have had which could have been important for the study. Wonderings about, if those who participated in the study were those who best fitted, can always be mate. There is no reason to doubt the capability of the participants in this study.

Result discussion

Difficult at first

According to the literature, diagnosis of a hearing loss is a difficult experience for parents and many mentions “sorrow”, or a similar word when describing their feelings at time of diagnosis. Sadly, there does not seem to be an agreement between feelings audiologists have for the parents’ experience and what parents say they feel. The first reaction when their child is diagnosed with a hearing loss parents label as “sorrow”; however, audiologists label it as “denial“ (13). Professionals need to be open to parents’ different ways of expressing their feelings and need to be certain they are not misinterpreted. According to the parents in this study, they feel sorrow when they learn about the hearing loss and this feeling is regardless of the hearing loss degree. As said in the background, getting a child diagnosed with hearing loss can be compared to the symbolic death of that child (3, 4).

Participants in the study vary in their acceptance to the hearing loss and in their cases the degree of hearing loss does not seem to be a great effect, which correlates with the literature (4). However, participants' background experience with hearing loss does have more effect. Like also expressed in the literature, a child's hearing loss affect parents in many ways. Although it does not have to take long time for parents to accept their child's hearing loss, it can be hard to cope with the emotional aspect of the hearing loss (18). As for the feeling of "sorrows", there is not always an agreement; between the audiologists understanding of the parents' feelings and the parents own feeling of how long it takes for them to "accept" the child's hearing loss. The audiologist might think it takes the parents up to a month to "accept" the hearing loss, but the parents feel they immediately accept their child's hearing loss. This shows the difference in the understanding of feelings between parents and professionals (13). Therefore it is hard, or almost impossible, to make any generalizations of whether the participating parents have fully accepted the hearing loss or not. Kurtzer-White & Luterman (4) talk about grief, as a cycle and that it is nonfinite through the child's developmental life. Sorrow, anger, confusion and guilt are all feelings that parents go through in this cycle, but there is no rule in which order they appear or how many feelings at a time. With time parents get more sense of hope, but often the developmental milestones trigger the cycle and parents go through a feeling of loss again.

Harrison and Roush (18) said coping with the hearing loss is important for parents, especially for those of children with severe to profound hearing loss; however, how parents cope does not have to be affected by the degree of the child's hearing loss. The participating parents are in different stages of coping with the hearing loss; however, they seem to be able to cope better when they have better understand the situation. Yet, some might require more help to better cope with their child's hearing loss. A family intervention program that covers medical, social, educational and caring aspects for children with disabilities is mentioned in the literature to be able to help families to change their coping strategies from being passive to being more observant and active. At the start of such a program many parents seem to already be optimistic and have life satisfaction which may be the reason for the programs not to increase the optimism and life satisfaction (19).

Effect on life

As shown above the hearing loss has a large effect on participants, both physical and emotional. This can also be seen in the literature; however parents are affected in different ways. For some the hearing loss is only an obstacle but for other life turns upside down (1). This affect differs by degree of hearing loss. The parents of the children with CIs are more affected than the parents of the children with hearing aids. There are even parents who do not initially realize the changes in their life due to the hearing loss. It seems that for those parents, they realized the hearing loss has affected them more than they thought. By learning about and handling a new technique, the parent is changing his/her life-course as it is also it is needed to find a solution to best live life with a hearing loss. As said in Jacksons article (15), parents need be able to meet the needs of the child with a hearing loss as any other family members and need to have enough information to be able to make important decisions. Parents can even feel they do not have enough skills to parent a child with a hearing loss. It is a new role parents have to take when parenting a child with hearing loss. The participants in the study did also experience this by not being able to use the parenting strategies they decided in the beginning. Being flexible and needing to adapt to different circumstances is probably the way parents are mostly affected.

Future and development

The participating parents worry about their child's future and development, because of the hearing loss, in different ways. This is not dependent on the child's degree of hearing loss. Will the child learn to speak, correctly or at all, and when will it happen? Another way participants are affected is the increase in child's sound awareness. These parents worry more about the sound around the child. They wonder what can be done to make their child hear better and how the sound environment is at home or at school.

These worries about the future and the sound environment seem to be something parents do not think about as much when it comes to children with normal hearing. Since this is not a common concern for parents of children with normal hearing, it is even more important for parents of children with hearing loss. They do not know what's acceptable in development and sound environment for children with hearing loss. Parents also understand a child with a hearing loss might have some more difficulties learning to speak than other children with normal hearing. According to Harrison and Roush (18) child language development is important for parents irrespective of the degree of hearing. Parents often turn to their audiologist for information about language development when a specialized team is not available. Therefore it is important that the audiologist is familiar to material about development.

Need for knowledge

Unfortunately the knowledge about hearing loss in the society is not great. Not only do parents of children with hearing loss need more information, but professionals working with children with hearing loss also need more information about hearing loss and its consequences on the child development and behavior. Parents need to be able to trust professionals, like daycare personnel and physicians, to see if anything is out of the norm in the child's development. If all professions help each other, it can result in children being diagnosed earlier. This is especially needed in Iceland where the mean diagnostic age, for children diagnosed between 2002 and 2006, was over 6 years of age (22). This age is too high and needs to be changed. Hopefully, the age has decreased since the introduction of newborn hearing screening in 2007.

Although participants have varying needs for understanding their child's hearing loss, the understanding is less than what is wanted. This can also can be seen in the literature, and is talked about in the background, parents differ in their wishes for information (18) Parents need to be able to have access to the information they want and not to feel stupid when asking for more information. The information provided needs to be given on the level the parent understands and be as clear as possible. There can always be medical results or technical information that is not understood or known by the professionals. In those cases, it needs to be explained for parents what is not known. If they want to search for themselves, it can also be positive to let parents know where, and how, they can look for good information. As the literature in the background shows parents appreciate professionals' helpful and honest approach although they are not able to answer all questions. By helping parents to access up-to-date information, professionals are helping parents finding recourses that might help them in their decision making (8, 13).

Support

The participating parents got support through the information they receive form professionals. This informational support is appreciated. However, there are parents that need more support and the psychological support seems to be the support that is needed the most. As mentioned in the background, parents go through emotional turbulence and that needs to be recognized by the audiologist (13). The need for the psychological support differs with degree of hearing loss. Parents with children with greater losses and children with CIs require more than parents of children with milder losses. Even though not explicitly mentioned by the participants, the need for psychological support or counseling seems to be great. Although there are parents who do not feel there is a need for psychological support, they seem to have the need to talk to someone about their feelings and experiences. In these cases a social worker might be helpful. As mentioned in the background parents, who have received an appropriate service from a social worker, value it greatly (8). It is hard for parents to get the news their child is not like the one they thought he/she was going to be irrespective of the degree of the hearing loss, this should not be forgotten. According to literature, it is more common parents of children who get CIs meet with a psychologist than parents of children with conventional hearing aids. The parents of children with milder hearing losses more often meet with a social worker. The parents' view of the need for social service support differs. Since this service is often not a part of the audiology program, parents can work with a social worker who does not know much about hearing loss. This is not the case for all parents, as some speak very positively about the social service support they receive. Parents seem not to express negative experience about social support. It is either positive or neutral (8).

The parents of newly diagnosed children need follow-up and guidance from the hearing clinic. This is regardless of the child's degree of hearing loss. For some parents it is not enough to tell them to contact the clinic if they wonder about anything or are worried. Structure is needed for parents of children with greater and milder hearing losses. Parents experience the structure clearer when the child has a greater hearing loss. There can be a number of reasons why parents do not seem to contact the clinic themselves. In this study parents do not want to look needy; parents rather want to be told to come. As mentioned in the background parent feel it difficult to admit that they need help and to have the contact themselves, however they would be open to talk to someone who had been sent to them (20). One can wonder if a meeting with a psychologist would change anything for parents in this situation. At least it is clear, parents feel that there is a need for more structure which gives them some idea about what is about to happen and how things will be in the future. As mentioned in the background, it is important to build up trust and good connection between the parents and the audiologist (7).

Parents need to talk to other parents, although they do not seem to do as much about it as perhaps wanted. It seems that parents need help to get in contact with each other to be able to have each other's support. As mentioned in the background this could be done for example by having list of parents at the audiological clinic with parents willing to help others (12). This need to talk to other parents of children with hearing loss is greater for parents of children with greater losses. This is evident when parents of children with greater hearing loss have more need for support in general. According to the literature, parents of children with disabilities in general have the need to meet other people in the same in situation. The way they come in contact with each other can be through various ways, including the clinical list, aid organization or others that come in contact with the children. Parents feel this, contact with others and the knowledge others have the same worries for their child helps (26).

One can even wonder if parents get the support they need from other parents is it possible they might then need less help from professionals. For parents it would probably be best if both professional support and support from other parents were in balance. The impression has been given these two supports balance each other. While the professionals do not have the lived experience parents of children with hearing loss have, they have the technical and medical information and explanation which the other parents do not have.

Support from friends and family is also important for parents when going through difficult times, as it can be when a child is diagnosed with a hearing loss. However, not everyone get this support in the amount needed and as mentioned in the background; not having the support from family and friends can make everything much harder for the parents (16). These parents who do not get this support are, possibly, in more need for professional support and even support from other parents. According to literature, it is important for parents that their extended family members understand and acknowledge raising a child with a hearing loss is more challenging than raising a child with normal hearing. Parents are thankful for when others around them show interest and help seeking information, for example, right after diagnosis and before making decisions about the future (14).

Overall good experience

It is positive to know participants in this study were overall positive towards the service and treatment at the hearing clinic. Furthermore, with more clarity and structure the experience of the clinic can be even better. As with everything, there can always be improvements. It is important for parents that professionals speak openly about the child's situation. It can be frustrating for parents when not having the access to all information available, as mentioned in the background it is important for parents to hear the information, although it is not pleasant, to build up a trust between the parents and the audiologist (7). This means that parents would rather get the information in small portions, even though not fully analyzed, than having to wait until all the information has been gathered and analyzed. Of course, this can vary between parents. No one wants to get the feeling of being held back on important information, although it is uncomfortable knowledge. As can be seen in an article by Fitzpatrick (8), parents are highly satisfied with the service provided, once they have passed the difficult stage of diagnosis. However, parents can experience a complication of the service, which can lead to distrust in the service providers. A co-location of professionals or good communication between the professionals working with the child can help parents experiencing the service to be simpler.

When parents are being told about their child's hearing loss the surroundings are important. Parents need to feel comfortable and not disturbed when discussing the child’s hearing loss and future. When circumstances are not comfortable for parents, they feel more pressured and have a harder time concentrating on what is being said to them. Parents prefer to come back later to discuss the child’s situation and the future in calmer surroundings, if not possible in the beginning, than feeling pressured. They might even prefer the child not being present as it easily distracts them.

When talking about the service given at the hearing clinic, parents are satisfied with the service the child receives. In a study by Rahi et al. (26) it was shown being treated with respect and getting supportive care where they felt treated as individuals and equal to other is a high priority for parents of children with disabilities. It is important for professionals to remember when working with children there are always parents who also need attention, which may even be more than the attention the child requires.

Further research

This project is a part of a bigger quality control study of the National Hearing- and Speech institute in Iceland. The next step of the quality control is to make a questionnaire which will be sent to all parents of children with hearing loss in Iceland. From this study a few interesting subjects appeared to investigate further among the parents, and those are:

- Prior to diagnosis – This part is to understand parents’ knowledge of hearing loss prior to diagnosis. Do parents have any suspicion about the child’s hearing loss? Did any of the professionals meeting the child (eg. physician or daycare personnel) realize or should have realized sooner that there is something not “normal” about the child. It would be interesting to see and can give an idea of the other professionals’ knowledge about hearing loss in children.

- The service –This is a part where the parents experience for the provided service is checked, but there are few things that would be interesting to observe. Parents’ satisfaction of the information given about the hearing loss, hearing aids and their child’s future, is one of the things that would be interesting to observe. It would be interesting to check parents’ experience for the support they received, whether it is from professionals around the child, other parents of children with hearing loss or their own family or friends.

Parents' experience of the process around diagnosis and (re)habilitation is another thing that would be interesting to see. Knowing how parents are satisfied with different parts of the process, for example, the time between diagnosis and hearing aids and clarity of the next steps in the process, could be important and interesting for further development of the hearing clinic. Another area to investigate would be if the parent' own view of hearing loss and hearing aids has changed with this experience.

- Comfort – This part would be checking parents' level of comfort when receiving information about their child's hearing loss. This would cover the surroundings where parents receive the information and the vocabulary used. Understanding parents' level of comfort in asking questions when not understanding the information or wanting to get further information is interesting knowledge.
- Effect – This part would cover the effect the hearing loss has on the parents, which can be interesting to see. Parents' view on life can change with their child's hearing loss, as could parents' up bringing strategies change. Both of these could be in relation to the degree of hearing loss. Another thing that could be interesting is if parents feel they behave differently towards the environment or other people around because of the child's hearing loss. These behavioral change could both been seen positive and/or negative. At last it would be interesting to see if parents feel emotionally affected by the hearing loss and if they feel they need any help to manage those emotions.

Doing this research with a qualitative method gave some new angles which might not have been discovered with a quantitative method. This is because parents can explain their answers to the questions they are asked. It would be interesting to do more research in the future around these new angles. Angles which came up during this research are: parents' feelings of how the professionals around the children have let them down. It would be interesting to study more parents' experience towards those professionals and also the knowledge these professionals have. It was also interesting to see how parents want to be more controlled by the professionals dealing with their child's hearing loss. They want to come more often for visits and to be told what to do. They feel insecure about the situation, which is not strange since they are entering an unknown world. Another thing that would be interesting to research further is their limited interest about meeting other parents in similar situations. There is not enough available research.

This research has opened up many interesting angles to research in the future and hopefully it can help with the development in the audiological field in Iceland.

CONCLUSION

- In the beginning parents experience their child hearing loss as a terrible thing but later on they focus more on what they can do to make life as easy as possible for the child.
- Overall, parents are positive towards the provided service. However when closely examined parents feel there is some service missing.
- Parents do not always realize they are receiving support and it differs how much support is wanted. Some parents would appreciate more apparent support.
- Parents often feel there is a shortage of information about the hearing loss and the hearing aids and would often like more information with easier access.

The participating parents in this study give an idea about how their child’s hearing loss can affect parents’ lives; however, the hearing loss becomes more positive in the view of the parents as they learn more about it. In the beginning at the diagnosis, the news is difficult for parents, but with time it becomes easier with which to live. The hearing loss has positive and negative effects on the parent’s life. They start seeing the world from a different point of view and become more open-minded. At the same time, life becomes more complicated and parents, in a way, feel the loss of the normal child. For parents it is important that they get the knowledge about the child’s future and development. Although, they understand this sometimes is uncertain. Parents’ experience of treatment and service around hearing loss and hearing aids could be improved with more support and more solid information. There is a need for more information about hearing loss and hearing aids with parents of children with hearing loss. There is a need for more knowledge about hearing loss and hearing aids in the society, for example, for professionals working with children. For parents of children with hearing loss support is important; however, not everyone is able to get all the support they need, whether it is from professional, from other parents of children with hearing loss or family and friends. Overall, the experience parents have of the provided service and treatment is good, but there are always parts which could be improved.

REFERENCES

1. Corcoran JA, Stewart M, Glynn M, Woodman D. Stories of Parents of Children with Hearing Loss: A Qualitative Analysis of Interview Narratives. In: Seewald RC, editor. A sound foundation through early amplification: Proceedings of an international conference. Switzerland: Phonak; 2000. p. 167-74.

2. Meinzen-Derr J, Lim LH, Choo DI, Buyniski S, Wiley S. Pediatric hearing impairment caregiver experience: Impact of duration of hearing loss on parental stress. Int J Pediatr Otorhinolaryngol. 2008 Nov;72(11):1693-703.

3. Luterman D. Emotional aspects of hearing loss. Volta Review. 1997;99(5):75-83.

4. Kurtzer-White E, Luterman D. Families and children with hearing loss: grief and coping. Ment Retard Dev Disabil Res Rev. 2003;9(4):232-5.

5. Fitzpatrick E, Graham ID, Durieux-Smith A, Angus D, Coyle D. Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. Int J Audiol. 2007 Feb;46(2):97-106.

6. Magnuson M, Hergils L. Late diagnosis of congenital hearing impairment in children: the parents' experiences and opinions. Patient Educ Couns. 2000 Oct-Nov;41(3):285-94.

7. Tattersall H, Young A. Deaf children identified through newborn hearing screening: parents' experiences of the diagnostic process. Child Care Health Dev. 2006 Jan;32(1):33-45.

8. Fitzpatrick E, Angus D, Durieux-Smith A, Graham ID, Coyle D. Parents' needs following identification of childhood hearing loss. Am J Audiol. 2008 Jun;17(1):38-49.

9. McCracken W, Young A, Tattersall H. Universal newborn hearing screening: parental reflections on very early audiological management. Ear Hear. 2008 Jan;29(1):54-64.

10. Fitzpatrick E, Coyle DE, Durieux-Smith A, Graham ID, Angus DE, Gaboury I. Parents' preferences for services for children with hearing loss: a conjoint analysis study. Ear Hear. 2007 Dec;28(6):842-9.

11. Minchom S, Shepherd M, White N, Hill J, Lund P. Service needs of hearing-impaired children and their families: Report of a survey of parental attitudes. Deafness and Education International. 2003;5(2):93-107.

12. Luterman D, Kurtzer-White E. Identifying hearing loss: parents' needs. Am J Audiol. 1999 Jun;8(1):13-8.

13. Roush J. Implementing Parent-Infant Services: Advice from Families. In: Seewald RC, editor. A sound foundation through early amplification: Proceedings of an international conference. Switzerland: Phonak AG; 2000. p. 159-65.

14. Zaidman-Zait A. Parenting a child with a cochlear implant: a critical incident study. J Deaf Stud Deaf Educ. 2007 Spring;12(2):221-41.

15. Jackson CW, Turnbull A. Impact of Deafness on Family Life: A Review of the Literature. Topics in Early Childhood Special Education. 2004;24(15):15-29.

16. Sach TH, Whynes DK. Paediatric cochlear implantation: the views of parents. Int J Audiol. 2005 Jul;44(7):400-7.

17. DesGeorges J. Family perceptions of early hearing, detection, and intervention systems: listening to and learning from families. Ment Retard Dev Disabil Res Rev. 2003;9(2):89-93.

18. Harrison M, Roush J. Information for Families with Young Deaf and Hard of Hearing Children: Reports from Parents and Pediatric Audiologists. In: Seewald RC, editor. A sound foundation through early amplification: Proceedings of an international conference. Switzerland: Phonak; 2002. p. 233 - 49.

19. Dellve L, Samuelsson L, Tallborn A, Fasth A, Hallberg LR. Stress and well-being among parents of children with rare diseases: a prospective intervention study. J Adv Nurs. 2006 Feb;53(4):392-402.

20. Magnusdottir A, Sandholt I. Velkomin í hópinn: upplifun foreldra af þjónustu þegar fyrirséð er um frávik hjá barni þeirra. Reykjavik: Iceland University of Education 2007.

21. Information register at the National Hearing- and Speech Institution in Iceland. (2009).

22. Pálsdóttir K. Diagnostiseringålder på barn med hörselnedsättning under åren 2002 till 2006 på Island. Examensarbete. Gothenburg University 2007.

23. Smith JA, Osborn M. Interpretative Phenomenological Analysis. In: Smith JA, editor. Qualitative Psychology: a practical guide to research methods. London: SAGE; 2007. p. 53-80.

24. Kvale S. Den kvalitative forskningsintervjun. Lund: Studentlitterature; 1997.

25. Giorgi AP, Giorgi B.M. The Descriptive Phenomenological Psychological Method. In: Camic P.M. RJE, Yardley, L., editor. Qualitative Research in Psychology. Washington, DC.: American Psychological Association; 2003. p. 243-73.

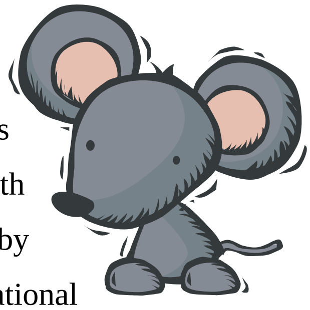
26. Rahi JS, Manaras I, Tuomainen H, Hundt GL. Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. Pediatrics. 2004 Oct;114(4):e477-82.

APPENDIX #1

Heyrnar- og talmeinastöð Íslands

[5]Research: Parents experience when their child is diagnosed with hearing loss

Dear parents/legal guardian,



Planed is a research about parents experience when their child is diagnosed with hearing loss. The study is based on a work with parents/legal guardian of children with hearing and will be done by Kristbjörg Pálsdóttir, audiologist in cooperation with the Icelandic National Hearing- and Speech Institute in.

Kristbjörg is working on her Masters degree in audiology in Sweden and will the study be her final theses.

The study result will later be used in quality improvement in the children’s department of the Icelandic National Hearing- and Speech Institute, to see what is positive and what can be done better.

The responsible for the research is Ingibjörg Hinriksdóttir, senior physician at the Icelandic National Hearing- and Speech Institute, Háaleitisbraut 1, 105 Reykjavík telephone: 581-3855, e-mail: ingibjorg@hti.is

We wish for your participation in the research. Participation with be completed by an interview that will take about an hour and will be sound recorded. One parent will be spoken to at a time. The interviews till be completed at the participants home unless something else is wished. Kristbjörg is bound to secrecy and will the interlocutor and the content be unidentifiable. All research material will be destroyed at the end of the research, while the research is on will the research material be in save keepings of the

---

[5] Originaly in Icelandic, translated of researcher

responsible one and will only the responsible one and the researcher have access to the material.

Materials that will be provided from the child’s journals are: sex, age at diagnosis, severity of hearing loss and the stage in (re)habilitation.

Participants are free to quite participation at any time, without explanation and without effects of future service in the future for the child.

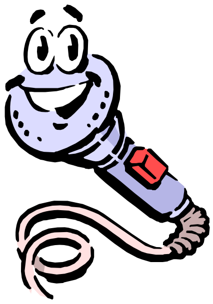
If any discomfort in association with the research comes up, participants are offered to contact

Bryndís Guðmundsdóttir, audiologist at the Icelandic Hearing- and Speech Institute, telephone 581-3855.

The research has been reported to the Icelandic Data Protection Authority and approved of the National Bioethics Committee in Iceland.

If you want to participate or wish for more information please contact Kristbjörg Pálsdóttir as soon as possible, through e-mail krissap@simnet.is or telephone 897-4494

With best regards and sincere wish of your participation,



Ingibjörg Hinriksdóttir, chief physician

If you have any question about your rights as a participant in scientific research or want to quit your participation in this research you can contact the National Bioethics Committee, Vegmúli 3, 108 Reykjavík. Telephone: 551-7100, fax: 551-1444.

APPENDIX #2

<u>Questions for interview with parents of children with hearing loss</u>

#1 - Experience of the child's hearing loss

- Can you describe your experience of your child's hearing loss?
    - What went through your mind when you heard about the hearing loss?
    - In what way has your child's hearing loss affected you?
    - What are your feelings towards the hearing loss?

#2 - Treatment/service

- What went through your mind when your child got hearing aids?
    - Can you describe your experience with professionals
        - How is the treatment?
        - How is the service?
            - Around diagnosis
            - Around hearing aids

#3 - Support

- Can you describe the support you have gotten?
    - From professionals?
    - From other parents to children with hearing loss?
    - From other people around you?
        - In what way do you feel they've helped
        - In what way do you feel they've not helped

#4 - Information

- How do you experience the information that you have been given?
    - About the hearing loss?
    - About hearing aids?
    - About the child's future development?
        - for all: too much, too little, clear or unclear

Last question

- Has your child's hearing impairment had any positive effects on your life?
    - How? (1)