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The elderly population's experience with hearing rehabilitation services

Anne Munkejord

Master thesis in special need education,
specialization educational audiology
40 credits

Department of Special Needs Education
Faculty of Educational Sciences
University of Oslo

Spring 2021



Abstract

Objective

The purpose of this master thesis is to get an indication on how elderly with hearing loss experience the hearing rehabilitation services in Norway. The thesis also includes an insight in their day-to-day life, hearing barriers and how they cope with it. The issue of this paper is: *What experience do elderly people with hearing loss have with hearing rehabilitation services?*

Methods

Four participants participated in a one-to-one semi structured interview. The participants were over 80 years of age, living at home, and had some sort of hearing loss. The interviews took 40 minutes on average and were conducted in the homes of the participants. The transcriptions were then coded using open codes.

Results

Three out of four did not receive follow-up appointments after the hearing aids were given. Everyone had some problem with their hearing aid and needed treatment to optimize the utility value. All coped with their hearing loss when it mattered to them, but at times things were avoided to some degree. Changes to their activities because of their hearing loss were common.

Conclusion

There are indications that elderly people with hearing loss are lacking experience with hearing rehabilitation services. Individually adapted hearing rehabilitation is needed. Communication between different professions is lacking. A structured hearing rehabilitation service should be a goal looking forward.

Title: The elderly population's experience with hearing rehabilitation services

Journal: Disability and Rehabilitation

URL:

https://www.tandfonline.com/toc/idre20/current?gclid=Cj0KCQjwkZiFBhD9ARIsAGxFX8DJWjMvGMLJuYcnplSV3E_L6lrO1j6DvaotTZ6FS5OipRkfqTbWdhMaApHsEALw_wcB

Preface

A chapter in my life is about to close. This master thesis is marking the end of my studies, which have given me joy, wisdom, and friends for life. First and foremost, I would like to give my thanks to my four informants, who used their personal time to help a stranger. I could not do this without you.

Secondly, I would like to thank to my supervisor Jorunn Solheim. You have pushed me to believe in myself, and your wisdom is very inspiring. Thank you for all your positive and encouraging feedback. I am grateful.

I would also like to give my thanks to my study friend Madeleine for being there for me, both professionally and as a friend. You have pushed me to be better and I have learned so much from you. These past years would not be the same without you.

My family also deserves a thank you. I know I always can come to you for support whenever I need it. Also, a special thank you to my brother-in-law for taking your time to proofread this master thesis.

Lastly, I would like to thank my soon to be husband. You have always supported me and pushed me when I want to give up. You have also given me space to write when I needed that.

Thank you all for five good years at the University of Oslo. Now it is time for me to step into a new chapter, to a line of work I am now prepared for. I look forward to it.

Oslo, June 2021

Anne Munkejord

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Word count for extended summary: 5154

Word count for article manuscript: 4122

1 Introduction

1.1 Background and purpose of the thesis

This master thesis looks at the collaboration in hearing rehabilitation services. What is implied by that is how elderly people experience the services and whether they are experiencing a holistic hearing rehabilitation service. The reason and purpose behind this thesis is to begin a mapping of today's situation in rehabilitation for the elderly in the health care system (The Ministry of Health and Care Services, 2019), here with the focus of hearing rehabilitation from an educational audiology perspective.

Earlier studies have seen a tendency that elderly people do not get as good a follow-up appointments as they should have (Meyer & Hickson, 2012; Wallhagen et al., 2006; Yueh et al., 2003). Studies also indicate that hearing loss, health problems, and quality of life are closely connected (Armstrong, 2016; Dalton et al., 2003; Sivertsen et al., 2015; Solheim et al., 2011). Today's population is growing, and in particular, the elderly population is growing, which will demand more nursing care placements (Keller et al., 1999; Ministry of Health and Care Services, 2019; Tomita et al., 2001). A problem is that the demand probably cannot be met, and more elderly people must live at home longer than previously. With these factors considered, it is reasonable to think that an improvement of the hearing rehabilitation services would benefit society. This field has been described as deficient, fragmented and without any kind of coordination (Ministry of Health and Care Services, 2019; Norwegian Directorate for Health and Social Affairs, 2007; Solheim et al., 2012). There are many different professions and institutions that are involved in hearing rehabilitation (Birkeland, 2016), and with how the system is built up today, it is plausible that each of these just have focus on their specialization and not the whole picture. In order to improve the hearing rehabilitation services, it is necessary to establish the reality of these services currently, and how they are experienced by the users. Therefore, the issue of this thesis is: *What experience do elderly people with hearing loss have with hearing rehabilitation services?*

1.2 How the extended summary and the article manuscript compliments each other

This master thesis consists of an article manuscript along with an extended summary. The article includes theoretical framework, methods about how data was collected, results of the study, and discussion followed by a conclusion. The extended summary includes theory with descriptions that take a more in-depth look at each topic, methods that focus on theoretical concepts, as well as an introduction that among other things explains the reasoning behind the

choice of journal. In other words, the article manuscript has a focus on the practical and concrete part on the study, while the extended summary has a more theoretical aspect. This has been done to allow the two parts complement each other rather than be in conflict.

1.3 Choice of journal

My choice of journal fell on the journal “Disability and Rehabilitation”. This is an international multidisciplinary journal that includes all aspects of disability, rehabilitation, and services for those who are disabled (Disability and Rehabilitation, n.d.-a). Functional disability due to old age is also included, therefore my goal to investigate the experience of age-related hearing loss is well suited.

The aim of this journal is to encourage a better understanding of disability as well as to promote rehabilitation science, practice and policy aspects of the rehabilitation process (Disability and Rehabilitation, n.d.-a). The journal claims to provide an important forum for the dissemination and to exchange ideas amongst global health practitioners and researchers. As rehabilitation is such a big part of the journal, it is reasonable to believe it is of interest in the health and rehabilitation section on a general basis. It is therefore plausible that this thesis has a wide reach in this sector, within Norway. In general, there are not that many researchers in Norway publishing about hearing loss. However, from those who do, several of them have published articles in this journal, as well as some Swedish contributors (Hallberg et al., 2008; Helvik et al., 2007; Öberg et al., 2009; Rosenhall, 1983; Solheim et al., 2011; Svinndal et al., 2020a, 2020b; Turunen-Taheri et al., 2019). This is also an argument for why I should attempt to publish in this journal. If researchers doing similar things are publishing there, the chances are that they are reading it as well, along with others interested in the subject.

The Journal guides the researcher in their paper, and provides peer reviews to all manuscripts (Disability and Rehabilitation, n.d.-b). The journal also encourages Open Access, which typically receives more citation than closed access. This journal also has an acceptable impact factor as it is published online. Finally, they have a quick decision time, with 24 days being the average from submission to first decision, 99 days average from submission to first post-review decision, and 19 days average from acceptance to online publication (Disability and Rehabilitation, n.d.-c). The acceptance rate is 20%.

2 Methods

2.1 Data collection with a qualitative approach

This master thesis uses a qualitative approach. That implies that data collection is not as structured and findings cannot be significant, therefore it will only give indication about how something may be (Cohen et al., 2017). This study has used semi-structured interviews to collect data. That means that I conducted the interviews using an interview guide but followed the natural flow of the conversation without steering too far away from the interview guide. The reason why interviews were the source of data collection was so that the subjects were to be seen as individuals and to get a deeper understanding of their experience (Cohen et al., 2017). The aim for this study was to get an indicator on how the hearing rehabilitation services are experienced by the elderly. Therefore, this study had participants over the age of 80, whom had a hearing loss, lived at home, and received municipal care services. This study excluded people with diagnosed cognitive deficit. In total there were four informants qualified and willing to participate in study of those asked, two from a rural area and two from an urban area. The participants were selected from two municipalities, from the urban area, those attending a hearing group were invited to participate, and from the rural area it was the hearing contact in the municipally that contacted relevant candidates.

The interview guide consisted of twelve questions, ranging from the participants daily life, social life, barriers and coping of hearing loss and their experience with hearing rehabilitation services. Almost every question had one or more underlying question to gain a greater description from the participants. Whilst conducting the interviews, I became aware that some of the questions were too advanced to be understood easily by someone without a prior knowledge of the subject. I tried to accommodate this by explaining what I meant or rephrasing the question. The interviews were conducted in the homes of the participants, part of the reason for this was that Covid-19 made it difficult to meet at a neutral place. There are positives of conducting interviews at someone's home. People may be more relaxed in their own home, which can give a better flow in the conversation. The length of the interviews averaged around 40 minutes, which corresponds to the estimated length of 30 to 45 minutes.

The interviews were audio recorded and were transcribed immediately afterwards. A reason to transcribe straight away is to aid me in remembering situations from the interviews that aren't as easy to transcribe, because for instance it is inaudible, but can be remembered from the interviews (Cohen et al., 2017). These situations or non-verbal responses are difficult and sometimes impossible to transcribe, but may hold great significant, nonetheless. All the audio

recording was transcribed, that was possible because the sample size was so small. After transcribing, the transcriptions were anonymized. The anonymized transcripts were then analyzed.

The analysis was performed using five codes. The codes were made up on the spot when there was something important in the transcription. The five codes were “Activity and interests”, “Hearing barriers”, “Coping with hearing loss”, “Hearing aids and assistive hearing devices”, and “Hearing support and services”. These codes allowed me to systemize the transcripts. This type of coding is somewhat an open coding (Cohen et al., 2017). Meaning that they are broad reaching codes. I chose not to get any narrower because of the small sample size, and making it narrower would mean a greater amount of work for the same results. This study also just looks at a broad aspect, as a narrower aspect would make the study less valid.

2.2 Quality of the study

Validity generally is defined as a measure of what you actually intended to measure (Cohen et al., 2017). Validity varies from quantitative research and qualitative research. In qualitative research, the focus is on broad description, social and cultural aspects, holism, descriptive data, and concern for the process not the outcome (Cohen et al., 2017). I have tried to consider these aspects whilst conducting the study. When creating the questions, I did not just ask about hearing rehabilitation services, although that was what I was really interested in. For example, I asked about their life situation today and their interests. I did that to gain a greater description of the persons participating, making them individuals rather than strictly data. Since this study is supposed to represent all of Norway and not just big cities, it was logical to have participants from both rural and urban areas. Doing that made it possible to see differences in experiences across the different environments. The life of the participants can differ both socially and culturally in these different areas and the choice of having representatives from both areas was done to get a more complete picture. With all my data I have tried to be descriptive. Considering that it is a small sample size with only four participants, it is not possible to say that how they are experiencing it is how everyone else in a similar situation is experiencing it. The only way then to get a sense of the data is not to put any numbers to it, but to describe what each person thinks to the questions being asked. This study is mostly intended to highlight how hearing rehabilitation services are experienced today, not to change it. To change it you need to have a larger study and to implement

interventions on a greater scale. Therefore, the process is more important than the outcome because the outcome just points in a direction to go to next.

Reliability is defined as dependability, consistency and replicability over time, methods and samples (Cohen et al., 2017). This term is mostly used in quantitative research but can to some degree be used in qualitative research as well. To simplify this term can we ask three questions (Cohen et al., 2017).

Question one: Would the same answers and interpretations have been made if the interviews had been conducted at different times? The answer to that question is probably not. The reason for that is that at the time of the interviews the world was in the middle of a pandemic, and a lot of the answers given were based around that. For example, the participants did not do the things that interested them, because they were not allowed to do it. This weakens this study slightly, and it is possible that other answers would be given at another time when a world event was not consuming everyone's life.

Question two: Would the same answers and interpretations have been made if other interviewers had been conducted at the time? The answer to this is two-parted. Firstly, during the interviews I did realize that some of the questions were too difficult to understand, therefore I did need to simplify or exemplify some of them on the spot. I did that to ensure that meaning did not get lost, but another interviewer might phrase them differently, and thereby receive a slightly different answer. On the other hand, I did for the most part follow the interview guide, and I believe that someone else with the same interview guide would have acquired similar answers from the sample.

Question three: Would another interviewer, working in the same theoretical framework, have made the same interpretations? The answer is to some extent yes. Should another researcher receive the same answers to the same questions as I did, the transcript would look quite similar. Considering that my interpretations come from the transcript, it is likely that they would match. However, what I see as important might differ from what others see as important, and in that way the interpretations would be different.

2.3 Methodological strengths and limitations

Interviews have their limitations due to being time consuming, and not being able to reach out to as many people. This of course varies in relation to resources available, but a master thesis using interviews can be limited by this. This study went for an interview guide approach. The strengths of this are that the outline increases the comprehensiveness of the

data, as well as data collection becoming somewhat systematic for each participant (Cohen et al., 2017). Logical gaps in data can also be anticipated and closed, and interviews remain relatively conversational and situational. The weaknesses are that important and salient topics may be inadvertently omitted (Cohen et al., 2017). It is possible that interviewer flexibility in sequencing and wording questions can result in substantially different responses, and therefore reducing the comparability of responses.

The timing of this study was not ideal either, since the participant had lived with the restrictions of a pandemic for over a year. Normal habits were changed, and they had spent more time by themselves, so it is difficult to pinpoint if the answers were influenced by the pandemic or strictly because of hearing loss.

2.4 Ethics

Ethical considerations are important when doing a research study. Throughout the whole research process there are ethical dilemmas to consider (The Norwegian National Research Ethics Committees, 2019). Before conducting the interviews, I made sure that the participants consented to the study. I did that by giving them a letter of information in writing explaining the study, what it means for them to participate, how privacy will be protected, and their rights. Unfortunately, it was not possible to give this information to the participants before I was present in their homes, as the participants were relatively old and none of them had access to e-mail. After reading the letter of information, I did provide a sheet where they could give their written consent. Before conducting the interviews, I received consent and left the letter of information for them so that they could read it afterwards. In the letter it explicitly said that the participant could withdraw their consent at any time without giving any reason, so I believe that informed consent was maintained.

Confidentiality means that information about the informant is not shared in a way that makes it possible to identify the informant (The Norwegian National Research Ethics Committees, 2019). In other words, the participant should be anonymous. That is why all the participants are given pseudonyms and the transcriptions anonymized. To be able to connect the anonymized data to the personal data, you must have a connection key. It is important not to have that saved together with the anonymized data. This is so that no one unauthorized can identify who the informants are. All personal data must be saved in an appropriate locked place.

Identifiable personal data is not supposed to be used in any research studies other than it is first intended for. (The Norwegian National Research Ethics Committees, 2019). However, anonymized data is allowed to be used elsewhere. It is important to note that this does not include de-identified data, to which personal data still can be connected as the researcher has both the anonymized data and the connection key.

Every research from the University of Oslo that processes personal data must gain approval from Norwegian center for research data (NSD) (University of Oslo, 2018). The project must be sent in at least 30 days before beginning the data collection, for the NSD to have time to approve. I received that approval before I contacted potential participants. To ask for approval you need to send in a form consisting of as many details about your research study as possible. Along with the form, you must attach, in my case, the interview guide, the letter of information and statement of consent.

3 Theory

When finding theory for this master study, a search on PubMed was made. The phrases that were used were: ("hearing loss" OR "hearing impairment") AND (elderly) AND ("care services" OR nursing home). This resulted in 51 articles with publication dates in the last five years, which were scanned for interest. Along with these articles, there are also other articles of interest that have been used, but those have different origins. In this thesis, both the word hearing loss and hearing impairment are used and mean the same thing.

3.1 Hearing loss

Hearing loss is defined by decibel levels. The American Speech-Language-Hearing Association have these definitions: normal (10-25 dB), slight (16-25 dB), mild (26-40 dB), moderate (41-55 dB), moderately severe (56-70 dB), severe (71-90 dB) and profound hearing loss (≥ 91 dB) (Petrovsky et al., 2019). The most common type of hearing loss is presbycusis (Sacco et al., 2016), which is age-related hearing loss.

A study conducted in Singapore found that a frequency of 35.7% of the participants over 80 years old had a hearing loss greater than 40 dB (Lee et al., 2017). A study in Norway found that greater than 90 % of the population over 80 years of age had some sort of hearing loss, half of them saying that their hearing was a problem (Tambs, 1998). Having a hearing loss as an elderly person can cause decreased communication performance and poor psychosocial functioning (Heine & Browning, 2002; Meyer & Hickson, 2020).

3.2 Quality of life

World Health Organization defines quality of life as:

individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment. (The Whoqol Group, 1998, p. 1570)

A systematic review that looked at the correlation between hearing impairment, visual impairment and dual sensory impairment with quality of life, found that sensory impairment was significantly associated with quality of life (Tseng et al., 2018). An increase in sensory loss resulted in a decrease of quality of life, and having both senses impaired gave a worse

result than having just one of them affected. Meyer & Hickson (2020) found that hearing impairment has negative consequences on an individual level such as decreased quality of life, psychosocial health, and mortality. Solheim et al. (2011) found in their study that perceived participation restriction is associated with general life satisfaction. The findings are that general life satisfaction is lower for people that are experiencing participation restrictions than those who do not.

3.3 Cognitive function

Dementia is one possible reason for cognitive deficit. I will therefore use that description to explain decrease in cognitive function. However, it is important to note that this thesis includes all form of cognitive deficit and the following is just an example. Dementia is a brain syndrome which is characterized by a decline in cognitive function (World Health Organization, 2018). The cognitive impairments can affect memory, executive functions, attention, language, social cognition and judgement, psychomotor speed, visuoperceptual or visuospatial abilities.

Decrease in cognitive function, such as dementia, is increasing in the elderly population (Höbler et al., 2018). Within this population it is also common to have sensory loss, for example, over 90% of people over 80 years of age have some sort of hearing loss (Tamb, 1998). With these two factors having a big prevalence, it is not surprising that several studies have looked for the relationship between them. Acar et al. (2011) found an increase in cognitive function after using hearing aids. Wittich et al. (2018) had nurses report several facilitators and barriers for screening hearing and vision loss in those with dementia. And Amieva et al. (2015) found that hearing loss is independently associated with a decrease of cognitive function in community-dwelling older adults. In other words, it is plausible that cognitive deficit and untreated hearing loss are closely related.

3.4 Comorbidity

Along with every diagnosis it is possible to have other diagnoses as well. The technical term is comorbidity, and means that two or more diseases or medical conditions are present at the same time in one person (NOAB - The Norwegian academic dictionary, n.d.). This is relevant as people with comorbidities along with hearing loss have greater difficulties in life (Solheim et al., 2011).

Depression is an umbrella term for different depressive disorders. It is characterized by depressive mood or loss of pleasure, where other cognitive, behavioral or neurovegetative

symptoms are affected as well (World Health Organization, 2018). This is the criteria for getting diagnosed, but there are people with depressive signs that do not have a diagnosed depressive disorder. In studies that look at the comorbidity of depression and hearing loss or dual sensory loss, both diagnosed and depressive signs are included. Armstrong (2016) found that individuals with sensory loss reported higher rates of depression, and Acar et al. (2011) found a decrease of depressive signs after using hearing aids.

As people get older, it is often both hearing and vision that decline. When both senses are declining, it is called dual sensory loss. Where some studies just focus on one sensory loss, there are also studies that include dual sensory loss. It is important to consider dual sensory loss in the elderly, because it can affect communication and psychosocial performance (Heine & Browning, 2002). Guthrie et al. (2018) found that elderly people in nursing homes or receiving home care were particularly vulnerable with unique needs and challenges. And Yamada et al. (2016) found an association between dual sensory loss and increased mortality in nursing homes when combined with no involvement in activities. However, Petrovsky et al. (2019) found no association between social engagement and sensory impairment in nursing home residents with sensory loss. Haanes et al. (2019) explored how elderly people with both hearing and vision impairments manage their every day. The result was that hearing impairments were problematic in social gatherings, and vision impairments were problematic in simple daily activities such as reading and changing light bulbs. We can see that with dual sensory loss, there are more barriers and challenges experienced than with having only one sensory loss.

3.5 Activities and social life

Hearing loss can affect activities and social function in daily life (Solheim et al., 2011). For instance, hearing loss can make it difficult for the person follow a conversation to the fullest, and some see themselves as poor conversationalists. Helvik et al. (2007) found that people with hearing loss use coping strategies to overcome the communication barriers they meet. Guthrie et al. (2018) found that those with dual sensory loss along with cognitive impairment had the most trouble with communication. However, those with only hearing loss also had difficulties to comprehend and join in on social activities to some degree. In contrast, Petrovsky et al. (2019) found no association between social engagement and sensory loss in nursing home residents.

It would benefit every elderly person to have at least one hour of daily activity which should include activities that they have an interest for and wish to do (Ministry of Health and Care Services, 2019). These activities are supposed to give good experiences, stimulate senses and memories and the feeling of being in a social community. As every person has the right to do the activities they want to do, this will result in that on some occasions, people with hearing loss choose not to participate in activities they wish to do. Some of the reason for this might be that the hearing loss hinders the person taking part to the extent they would like to. These activities might be going to a café with friends, or watching a sports event. Solheim et al., (2011) found that hearing loss has been shown to give a limitation on activity which again has decreased general life satisfaction.

3.6 Audiological rehabilitation

Audiological rehabilitation is a natural part of hearing rehabilitation services given. However, giving ordinary audiological rehabilitation alone will probably not increase social participation nor life satisfaction, but with adequate efforts it could, to some extent, reduce or prevent several negative effects of hearing loss, such as perceived participation restriction (Solheim et al., 2011). Turunen-Taheri et al. (2019) found that nine out of ten patients were satisfied with the hearing rehabilitation that they were offered, but those who got group rehabilitation were the most satisfied.

Audiological rehabilitation should differ when dealing with different age groups. One of the reasons for this is keeping up with technology. Smartphones and tablets make it easier to have access to the internet and social media and broadband and wireless networks have also been getting faster and easier to use. However, a lot of elderly people will have problems keeping up with technology when it is changing so fast. This is not just a sad story that elderly people cannot connect with technology, but it is relevant as elderly people with hearing loss and poor mobility may find it beneficial to use communication through text based social media (Ministry of Health and Care Services, 2019).

Solheim et al. (2011) concluded that general life satisfaction, daily life consequences of hearing loss and health conditions are closely related. That's why it is reasonable to think that an audiological rehabilitation that does not only focus on the hearing loss itself might be beneficial for the elderly. Their findings also indicated that health factors and psychosocial aspects should be a natural part of audiological rehabilitation.

3.7 How the hearing rehabilitation services is organized in Norway

In Norway you can divide hearing rehabilitation services into three groups of organizations, the state, the municipalities, and the user organizations (Birkeland, 2016).

The state can then again be divided into three directions: health, education and labor/social. The role that the state has in the matter of health is that they own the hospitals. A deal made between the state and the Norwegian Labor and Welfare Administration made sure that users with the need for hearing aid and other assistive listening devices would get fair service resulting in equality in the society and workplaces (Birkeland, 2016). The deal makes sure that wherever you may live you have the right to get the service that you need, whether that is a service in cooperation with the municipalities, private ear, nose and throat doctors or other established services. In the matter of education, the state owns Statped which is an advisory service specialized in different special needs education under groups, hearing being one of them. The last one is labor/social, the primary part being the Norwegian Labor and Welfare Administration through the assistive technology centers which are established in every county, giving out the right assistive listening devices for the right users.

The municipalities on the other hand have the formal responsibility of providing rehabilitation for the person with a hearing loss (Birkeland, 2016). Every municipality must have a so-called hearing contact, which serves as a connection between all the hearing rehabilitation services and the user. Though the quality differs in different municipalities, the job of the hearing contact is to follow up the user and guide them in all available hearing rehabilitation services. Economics and population density are some of the causes blamed for the big difference in the quality throughout the municipalities (Birkeland, 2016). The bigger cities have an additional counseling office for the hearing impaired to strengthen the services offered. The municipalities also have a responsibility through their General Practitioner, who is supposed to refer the users to specialists. Lastly, the municipalities have something called an Educational-psychological service, which do follow ups in schools and kindergartens. When the relevant expertise is missing from the Educational-psychological service, they obtain the expertise from Statped. (Birkeland, 2016).

Finally, we have the user organizations. There are two organizations worth mentioning, National Association of the Hearing Impaired (HLF) and Norwegian Association of the Deaf (NDF). These organizations have something in common, that is that they operate with something called Peer Support. This involves users getting in contact with another person

with a similar disability, who has taken a course to become a Peer Support (Birkeland, 2016). One of the main things HLF does is to run a high school for pupils with hearing loss that uses speech as their first language. They also run a center where they offer courses in various hearing impairments, such as Ménière and tinnitus (Birkeland, 2016). NDF on the other hand offers a folk high school for people who are deaf and a center with courses that offers teaching in sign language (Birkeland, 2016).

The first point of contact for a person with potential hearing loss is with their GP, in most cases (Soerlandet hospital, 2020). The GP then refers the patient to specialists. There the patient meets an ear, nose and throat doctor and an audiologist. While the doctor examines the ears, the audiologist does hearing measurements. If there is a hearing loss, the audiologist will fit hearing aids. Then follows a period where the hearing aids will be tested and adjusted if needed. If the hearing aid itself is not satisfying, there is a possibility to change to some other hearing aids during this time. How long this period is, does vary, but on average it takes two to three months (Solheim et al., 2018). After the fitting period is over, the patients usually need to contact the audiologist themselves if something is wrong with the hearing aids or adjustments are needed (Soerlandet hospital, 2020). It is also possible to contact a private audiologist or other specialists, but then the patient needs to contact them themselves.

4 Conclusion and further implications

In order to improve rehabilitation better suited for elderly people, the service has to have continuity and interaction between professions. Today, a lot of elderly and their relatives experience a discontinuity and loss of predictability in meeting with the rehabilitation services (The Ministry of Health and Care Services, 2019).

The result of this master thesis can be used to improve the hearing rehabilitation services. By mapping experiences for the elderly, this could contribute to the possibility of creating a model for hearing rehabilitation services that benefits the elderly, and not being as unstructured as it is today.

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Appendix A

Vil du delta i forskningsprosjektet "Samhandling i hørselsrehabiliteringstjenester"?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å finne ut hvordan samhandlingen i hørselsrehabiliteringstjenestene fungerer. I dette skrevet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Formålet med dette prosjektet er å finne ut av hvordan samhandlingen i hørselsrehabiliteringstjenestene fungerer. I dette prosjektet vil dette bli gjort ved å få innsikt i eldre sine erfaringer med hørselsrehabiliteringen. Problemstillingen for prosjektet er følgende: Hvilke erfaringer har eldre med nedsatt hørsel med mottatte hørselsrehabiliteringstjenester? Dette er en masteroppgave, hvor innlevering av oppgaven er i juni 2021.

Dette prosjektet er i samarbeid med et større prosjekt, men de vil kun ha tilgang til anonymiserte transkripsjoner og ingen form for personopplysninger. Dette prosjektet kalt «Samhandling om kommunal hørselsomsorg» har som hovedformål å utvikle en tverrfaglig samhandlingsmodell for hørselsrehabiliteringstjenester tilrettelagt eldre med nedsatt mobilitet.

Hvem er ansvarlig for forskningsprosjektet?

Universitetet i Oslo er ansvarlig for prosjektet. Prosjektet vil bli gjennomført av masterstudent Anne Munkejord som studerer spesialpedagogikk med fordypning i audiopedagogikk.

Hvorfor får du spørsmål om å delta?

Du har blitt spurt om å delta på dette forskningsprosjektet fordi

- Du bor hjemme
- Du får kommunale omsorgstjenester
- Du er over 80 år
- Du har et hørselstap

Hva innebærer det for deg å delta?

Hvis du velger å delta, innebærer det at du stiller til et intervju. Intervjuet er estimert til å ta mellom 30 og 45 minutter, men dette vil kunne variere fra person til person. I intervjuet vil du få spørsmål om din livssituasjon og opplevelsen din med et hørselstap samt spørsmål knyttet til din erfaring med hørselsrehabiliteringstjenester. Dine svar vil bli tatt opp på lydopptak som senere vil bli anonymisert i en transkripsjon, i tillegg vil jeg ta notater fra intervjuet.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet.

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Det vil kun være Anne Munkejord og Jorunn Solheim som vil ha tilgang på din

kontaktinformasjon, men det er Anne som kommer til å behandle de

personvernsopplysningene som kommer frem i intervjuet og som skal anonymisere

disse. Dette vil blant annet gjøres ved at navnet og kontaktopplysningene dine vil

erstattes med en kode som lagres på en egen navneliste adskilt fra øvrige data. All

data som kan identifisere deg vil oppbevart innelåst slik at det ikke blir tilgjengelig for

uvedkommende. For å transkribere og analyser intervjuet, vil det bli brukt et

dataprogram kalt NVivo, som sikrer for at ikke dataene dine kommer på avveie.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Opplysningene anonymiseres når masteroppgaven er godkjent, noe som etter

planen er 30.06.2021. Da vil lydopptakene og navnelisten slettes, slik at ingenting

kan tilbakeføres til deg. De anonymiserte transkripsjonene vil likevel kunne bli brukt

videre i det prosjektet som dette prosjektet er i samarbeid med, men det vil ikke

kunne spores tilbake til deg.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitet i Oslo har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Jorunn Solheim. *Telefon:* 976 59 680. *E-post:* jorunn.solheim@lds.no
- Anne Munkejord. *Telefon:* 900 15 468. *E-post:* anne.munkejord@live.no
- Vårt personvernombud: Roger Markgraf-Bye. *E-post:* personvernombud@uio.no

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Jorunn Solheim
(Forsker/veileder)

Anne Munkejord

Appendix B

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *Samhandling i hørselsrehabiliteringstjenester*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- å delta i *intervju*
- at informasjon om min mottatte hørselsrehabilitering brukes i prosjektet*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

(Signert av prosjektdeltaker, dato)

Appendix C

Behandlingen av personopplysninger er vurdert av NSD. Vurderingen er:

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 15.01.2021 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:

nsd.no/personverntjenester/fyll-ut-meldeskjema-for-personopplysninger/melde-endringer-i-meldeskjema Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet behandler særlige kategorier av personopplysninger om helse og alminnelige kategorier av personopplysninger frem til 30.06.2021.

LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen er dermed den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Nettskjema-diktafon er databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29. For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET

NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!

Kontaktperson hos NSD: Simon Gogl Tlf.

Personverntjenester: 55 58 21 17 (tast 1)

Appendix D

Intervjuguide

1. Kan du fortelle litt om din livssituasjon slik den er i dag?
2. Har du aktiviteter og interesser du er opptatt av?
 - a. Hva da, kan du fortelle litt om dem?
3. Opplever du å ha et hørselsproblem?
Hvis ja:
 - a. I hvilke situasjoner?
4. Fører hørselstapet til begrensninger i ditt sosiale eller private liv?
 - a. På hvilken måte? Gi eksempler.
5. Hva gjør du for å mestre de situasjoner hvor hørselen ikke strekker til?
 - a. Kan du gi eksempler med utgangspunkt i konkrete situasjoner?
6. Opplever du å fungere bedre hørselsmessig i noen situasjoner enn andre?
 - a. Kan du gi noen eksempler?
7. Er det noe omgivelsene kan bidra med for at du selv skal fungere bedre, og hva kan du selv gjøre?

8. Har du mottatt hørselstekniske hjelpemidler? (F.eks. høreapparat, HTH for varsling, t.v., brann, telefon og kommunikasjon)

Hvis ja:

- a. Hvilke?
- b. Bruker du disse daglig?
- c. Er du fornøyd med disse?
- d. Hvem sørger for at du fikk hjelpemidlene?

9. Har du mottatt andre hørselsrelaterte rehabiliteringstjenester? (f.eks. kurs, praktisk-pedagogisk oppfølging, likepersontjenester, annet)

Hvis ja:

- a. Hvilke?
- b. Av hvem fikk du tjenestene? (f.eks. hørselssentral, hjelpemiddelsentral, hørselskontakt/ergoterapeut, audiopedagoger, HLF likepersoner, rådgivningskontor, andre)

10. Har du behov for (flere) hørselsrelaterte tjenester og tiltak?

(f.eks. høreapparat, hørselstekniske hjelpemidler, likepersontjenester, kurs. NB. forklar ulike tilbud/tiltak) Hvis ja:

- a. Hvilke?

11. Hvilken erfaring har du med oppfølging av hørselsrelaterte rehabiliteringstjenester? (Inkl: hørselstekniske hjelpemidler)

- a. Har hjelpen vært nyttig og tilstrekkelig?
- b. Har det vært lett å komme i kontakt med tjenesteytere?

c. Blir du fulgt opp rutinemessig?

d. Opplever du å få oppdaterte informasjon om nye løsninger/produkter?

12. Hvilke erfaringer har du med samhandling mellom aktører innen ulike hørselsrelaterte rehabiliteringstjenester? (f.eks. er informasjon delt mellom hørselssentral og/eller hjelpemiddelsentral, og hørselskontakt i kommunen, hjemme-/omsorgstjenester, likepersoner etc?)

a. Har dine pårørende/familie fått informasjon knyttet til hørselsrelaterte rehabiliteringstjenester? (Inkl: Hørselstekniske hjelpemidler)

The elderly population's experiences with hearing rehabilitation services

Anne Munkejord

Department of Special Needs Education, University of Oslo, Oslo, Norway

Disability and Rehabilitation

https://www.tandfonline.com/toc/idre20/current?gclid=Cj0KCQjwkZiFBhD9ARIsAGxFX8DJWjMvGMLJuYcnplSV3E_L6lrO1j6DvaotTZ6FS5OipRkfqTbWdhMaApHsEALw_wcB

Abstract

Objective

The purpose of this master thesis is to get an indication on how the elderly with hearing loss experience the hearing rehabilitation services in Norway. This thesis also includes an insight in their day-to-day life, hearing barriers and how they cope with it. The issue of this paper is: *What experience do elderly people with hearing loss have with hearing rehabilitation services?*

Methods

Four participants participated in a one-to-one semi structured interview. The participants were over 80 years of age, living at home, and had some sort of hearing loss. The transcriptions then were coded using open codes.

Results

Three out of four did not receive follow-up appointments after the hearing aids were given. Everyone had some problem with their hearing aid and needed treatment to optimize the utility value. All coped with their hearing loss when it mattered to them, but less important things were avoided to some degree. Changes to their activities because of their hearing loss were common.

Conclusion

There are indications that elderly people with hearing loss are lacking experience with hearing rehabilitation services. The participants of this study do not know how the communication between different professions is in these services.

Keywords

hearing loss; hearing impairment; elderly; care services; rehabilitation; hearing rehabilitation

Introduction

With a growing population of elderly people and the average age of the population increasing, it is likely that there will be an increasing demand for hearing rehabilitation services. In an attempt to improve rehabilitation for elderly people, there needs to be an offer of a service that has continuity and interaction between professions. Today, a lot of elderly and their relatives experience a discontinuity and loss of predictability when encountering the rehabilitation services [1].

A study conducted in Singapore found that a frequency of 35.7% of the participants over 80 years old had a hearing loss greater than 40 dB [2]. Whilst a study in Norway found that greater than 90 % of the population over 80 years of age had some sort of hearing loss, half of them saying that their hearing was a problem [3]. One study showed that 30 to 48 % of an elderly population benefit from hearing aids, but only 70 to 80 % of them are satisfied with them [4]. Bertoli et al. [5] found that dissatisfaction was associated with dialects, how much the hearing aids were used, problems with managing the hearing aid, and non-regular use.

Consequences of hearing loss, and care services

With a hearing loss you have to make an effort to listen when others can easily hear, make a guess when other people know, be on guard, and ask others to repeat themselves [6]. Hearing loss can cause people to have poor self-rated health, difficulties with daily activities, difficulties with memory, they may fall more often, higher rates of limited communication, fatigue, balance problems, decreased cognitive function, decreased quality of life, and lower overall well-being [7–9]. Hearing loss can affect activities and social function in daily life [10]. People living in rural areas might face problems with access to care [11]. For instance, it can be a long way to specialized care services, such as an audiologist, and transportation there might not be optimal.

Guthrie et al. [7] studied older adults living in nursing homes or receiving home care. They looked at combined sensory loss due to the fact that older adults often experience a decline in more than one sensory function as they age further. This study found that communication deteriorated with more than one sensory function being impaired. Armstrong et al. [11] reported higher rates of depression and lower quality of life in people with dual sensory loss. Some of the risk factors for depression are older age, cognition deficit, and physical deficits [12]. However, Acar et al. [13] reported a decrease of depressive signs as well as an increase of cognitive function as a result of using hearing aids. The reason why depression is a problem is that it is associated with poorer quality of life, poorer physical condition and earlier death [12].

Petrovsky et al. [9] found in their study, that with greater social engagement, people with sensory impairments would have fewer occurrences of depression and stronger cognition. However, Solheim et al. [14] found that 78 % of the employees at nursing homes reported a lack of social interactions by the residents of nursing homes. Another study also support vulnerability to social isolation [15]. Meyer and Hickson [8] recommend three stages of intervention for people working in nursing homes to help the residents with hearing loss; the first one is to manage build-up of earwax, laying the foundation for the hearing aid to work properly. The second recommendation is to support to the residents using hearing aids or hearing devices, and third is to make communication strategies designed for the residents with hearing loss. In contrast, studies have shown indications that only a minority of the staff in nursing homes have received training in use and care of hearing aids, and employers feel the need for more information about hearing loss in general [14,16]. Lack of screening measures and training programs can also be a factor for poor support on hearing loss [17,18].

Grue [6] believes that motivating elderly people to seek out specialized care and use their hearing aids and hearing devices is an important job that can lead to a common culture in

different places such as hospitals, nursing homes and in home care. Today, Norway has divided hearing rehabilitation services into three groups of organizations, the state, the municipalities, and the user organizations [19]. Each organization has responsibility for different areas. The state has responsibility for the hospitals, and to provide economical resources for hearing aids and hearing devices. The municipalities have the formal responsibility of providing rehabilitation for the person with hearing loss. The user organizations offer courses and rehabilitation programs for people with hearing loss. This indicates that it can be a challenge to give a holistic service throughout the whole hearing rehabilitation sector, but it is plausible to facilitate for this through good communication between professions.

There have been several studies about hearing loss in nursing homes [9,15,17,18,20]. But with the elderly population increasing rapidly, we need to know more about how to give hearing rehabilitation to the elderly still living at home. For this reason, this study seeks to discover what experiences that the elderly with hearing loss and living at home, have with hearing rehabilitation services currently. Therefore, the issue of this paper is: *What experience do elderly people with hearing loss have with hearing rehabilitation services?*

Methods

Participants

Four people participated in this master thesis, three women and one man. All given a pseudonym: Tina, Amelia, Jenifer, and Simon. Two of the participants (Jenifer and Simon) lived in a rural municipality and two (Tina and Amelia) lived in a big city. All the participants were between 85 and 95 years of age and living at home. The participants all lived alone.

The criteria for participation were being over 80 years of age, living at home, have some sort of hearing loss, and receive municipal care services. As an exclusion criterion, the participants could not have a diagnosed cognitive deficit.

The interviews

Semi-structured interviews were conducted. The interviews had twelve questions with some follow-up questions within them. The length of the interviews averaged around 40 minutes. The questions have had some different theme-based background, including life situation, experiences with hearing loss, hearing services received, and experiences with collaboration in hearing rehabilitation services. The interviews were conducted in the participants' homes, one-to-one.

Analyzes

The interviews were analyzed using five codes: "Activity and interests", "Hearing aids and assistive hearing devices", "Coping with hearing loss", "Hearing barriers" and "Hearing support and services".

Results

Activity and interests related to the experience of hearing loss

Three of the participants (Tina, Amelia and Simon) are alone often and watch television quite a lot. The male participant explicitly said that he was lonely. In contrast, Jenifer said that she is outgoing and has a lot of friends that she speaks with regularly. Tina likes to exercise by walking, but thinks it is too much hassle now in her old age. She also liked to knit, paint, and read, but with a stiff neck she only has reading left that she can do. When Amelia was younger, she attended concerts, talks and the theater, but because of her hearing she cannot attend any more. However, once a week, she attends a social evening with a quiz, music, and conversations. Simon is politically interested and has been his whole life, he has even been politically active and participated in debates. Now that he cannot hear that well, he has taken

a step back, only receiving the reports of important meetings. Jenifer likes to go to group exercises but because of her hearing she is more and more reluctant to go.

Three out of the four participants (Tina, Amelia, and Simon) mentioned their family often, and being with them seems important to them, although their hearing loss created some barriers for this. Tina cannot follow a group conversation that well and gets overwhelmed by her great grandchildren running and screaming indoors. Simon feels he is too much of a bother to his family and does not see himself as interesting because he is not connected to the outside world that much anymore. For Jenifer, the last of all four, she is more reliant on her friends rather than her family and she mentioned one friend especially that helps her out, by for example telling everyone in the room to speak one at a time so that Jenifer can be a part of the conversation. The two participants from an urban area (Tina and Amelia) both wished they had a friend to talk to, who could understand their situation. Their problem is that all their friends have passed away. Simon does not feel he can contact his old network of friends that he has lost due to moving, because his hearing is so poor, and he feels that he would be intrusive.

Hearing Barriers

During Covid-19, Jenifer and Tina both found hearing more difficult. Jenifer did not realize how much she lip-read until people started wearing face masks that covered their mouths. Tina said that she hears less with people wearing face masks. When asked about in what situation the hearing loss becomes a problem (question 3), Jenifer first said that she has the same problem with hearing no matter the situation, but later she said that with more than five people she can just give up trying to hear and will mimic the others. Simon said that whatever he does, the hearing is always the troubling part, and that makes him inactive. Tina finds it more difficult to hear when there are more than two people, than if she is having a conversation with just one other person. This also requires that they be sitting opposite of

each other in quiet surroundings. She also has trouble with dialects and when watching television, she finds music and background noises troublesome. When someone calls her, she needs to put her phone on speaker to be able to hear. Family dinner is something that she is not very comfortable with, due to the fact that she can only pick-up parts of the conversation and feels that if she is asked something directly, she will not be able to answer. Amelia feels that every situation is troublesome with the hearing loss and that she becomes an outsider after getting tired of asking what people said.

Coping with hearing loss

When asked about how they manage their hearing loss (question 5), Simon said that he does not do anything and tries to avoid situations that requires good hearing abilities. He said he does not contact old friends because he does not want to bother them with his bad hearing, but he did contact the secretary at his local political party to receive a report of the yearly members meeting. The three others said that they ask people they speak with to speak higher or repeat themselves. All the women have people close to them that help them in difficult communicative situations. Two of them have brought relatives to appointments to be sure that they understood everything. Tina is tired of always reminding people that she hears poorly and feels that she is always the burden.

Hearing aids and assistive hearing devices

All the participants used hearing aids. Everyone also has some sort of assistive hearing device provided for the television. Three of the participants (Jenifer, Simon, and Tina) have a hearing loop and Amelia has a headset. For the telephone, Jenifer has an alarm that goes off if her telephone rings, the alarm is quite loud and can be heard through her whole house. The same alarm also sounds if someone rings her doorbell or there is a fire. Simon has a headset for his telephone, this assistive hearing device helps him hear the person on the other end of the line properly. Additionally, Jenifer has a vibrating bed in case of fire and Amelia has an

advanced wireless microphone that helps those with hearing loss get the sound of the conversation directly to their hearing aids [21].

All the participants used their hearing aids on daily basis (question 8). However, their assistive hearing devices were not always that frequently used. Two participants (Simon and Tina) confirmed that they found it useful when watching television, which is a daily activity for them, the male participant also uses his assistive hearing devices for his telephone daily. One participant (Amelia) does not use her assistive hearing devices that frequently. Jenifer's devices are mostly some sort of alarm, which indicates that she uses it whenever it sounds, though she did not specify.

In the question regarding whether they are happy with their hearing aids and assistive hearing devices (question 8) the participants had mixed thoughts. Two of the participants (Tina and Amelia) recently got their new hearing aids. Tina is happy with hers to some degree but has a problem with the fitting done to one ear. Amelia is generally happy with it, but it does not work properly on the day of the interview. The two other participants are both eager to change their hearing aids, and will do so this year, they both feel the hearing aid is not working optimally anymore. Every participant mentioned the rule that the government provides support for a new hearing aid every sixth year [22], and most of them think that is too long to wait. In assessment of their assistive hearing devices, Tina is happy with her hearing loop to the television, Amelia does not specify other than her hearing aids, Jenifer is generally happy with her assistive hearing devices, and Simon is not that pleased with his headset to the telephone and thinks his hearing loop to the television also needs an upgrade.

At the point of the interviews, no one felt the need for other hearing devices (question 10). Jenifer said that if she feels the need, she knows where to go, to the hearing contact in the municipality where she has received all her other assistive hearing devices. Simon has bought

his hearing devices himself and does not feel the need to get anything else due to his old age.

Tina is certain that if she receives another assistive hearing device, she will not use it and will just lay it aside, due to not being comfortable with new technology. Amelia does not specify.

Hearing support and services

Three of the four participants (Jenifer, Tina, and Amelia) all have one person in the system that they rely on. For Jenifer, it is the hearing contact in the municipality, Tina has the audiologist at the hospital, and Amelia has the audiologist at the hearing aid company that she uses. The last one (Simon) does not get any help from the system other than fitting hearing aids every sixth year and does not seem to have a personal connection to whoever that does that job. He feels neglected by the hospital no matter how bad his hearing is between his six-year appointments. Amelia also does not get appointments between the six-year appointments but does not seem bothered by it. Jenifer is very happy with the help she gets but she does not receive follow-ups automatically and it is up to Jenifer herself to make contact herself if needed. Tina likes the fact that all her health-related appointments are at the same hospital, but she gets her hearing related aids from a different place than the hospital. When asked about the communication between those two places (question 12), she said it does not seem like they communicate with each other but that they do know about each other's existence. Jenifer has a similar experience, her old audiologist has retired, and she has not been to the new place yet, but she said that her hearing contact and the old audiologist did not seem to talk to each other but knew about each other. Those two participants both receive updated information about new products, but both said that they did not bother with it too much. None of the participants have had any courses learning about hearing loss or any other hearing-related rehabilitation services that they know of, and only one (Tina) is willing to attend a course if it fits her needs. Every participant said that all information regarding their hearing

loss which their next of kin and family knew about, was conveyed through themselves and not through the system.

Discussion

Activities and interests

Elderly people as a group have a lot of difficulties that may accrue over time, such as: vision loss, decreased mobility, cognitive deficits, and physical health issues that need medication and support. Despite hearing problems being the most common issue in an older population, these are seemingly not prioritized by health care workers [23,24]. Three of the participants reported hearing loss to be the main reason not to do the activities they like. The fourth one reporting another reason: a stiff neck. But it is possible that a stiff neck comes from hearing loss without the participant knowing. Stiff neck can develop with hearing loss if you need to concentrate so much that your neck and shoulders gets put in an unnatural position. Some of the activities did not require good hearing abilities, such as knitting and painting, and with proper information and training, those activities might be possible. For activities needing good hearing ability, better information, and guidance from for instance an educational audiologist, might be helpful. This educational audiological rehabilitation might include information about life in general with a hearing loss, finding the right hearing devices for that exact person in that exact situation, and general follow-ups. Only one participant mentioned anything about seeing an educational audiologist, and the one that had, did not seem to have any contact with her in years. There may be different reasons for all of them not seeing an educational audiologist, for instance lack of follow-up, not knowing this service exists, or lack of communication between different hearing rehabilitation services. One point of note is that the only person with a connection to an educational audiologist lived in an urban area. Educational audiologists do tend to work in urban areas, and for people living in rural areas this service might not be as available and they may not have even heard of it. This is

consistent with Armstrong [11] detecting that where you live might affect what services you are offered.

Hearing barriers and coping with hearing loss

To be a part of a group conversation seemed to be troublesome for all the participants. Not being able to look directly at someone or seeing the mouth of the other conversationalists also created some hearing barriers. This is consistent with other studies [10,25,26], which found people with hearing loss often seeing themselves as poor conversationalists.

There seems to be two ways of handling the difficulties with not being able to hear. One is to avoid; the other is to act. All the participants acted when it really mattered. The male participant was the most reluctant and still avoided situations that demanded good hearing abilities. Findings indicate that some of the things people do to cope with hearing loss are: asking others to repeat themselves, ask people to speak louder, make sure they see the person talking, and keep people they are very familiar with close to help out in difficult situation.

Hearing aid and assistive devices

None of the participants were fully satisfied with their hearing aid. This finding does support other studies finding that not everyone is satisfied with their hearing aid [4,5,27]. Having an assistive hearing device for the television and the telephone seems to be common for all the participants. That is not surprising, since everyone said that the television and their telephone was their most used communication to the outside world. What is more surprising is that not everyone has an assistive hearing device for regular conversations, not included hearing aids. If we are to believe Petrovsky et al. [9], social engagement is important to have a lower chance of depression and a better quality of life. The fact that all the participants did find conversations difficult, we can see that something is missing for them. Whether it is another assistive hearing device or listening training or another audiological rehabilitation, is not easy to say. None of the participants wanted a new assistive hearing device, so perhaps

audiological rehabilitation is the solution that will make conversations easier for the elderly with hearing loss.

Hearing rehabilitation services

Three out of the four people in this study do not get follow-up appointments automatically. However, one of the three is not afraid to make contact if needed, but that is usually regarding assistive hearing devices and not the hearing aid itself. There is only one person getting follow-up appointments annually for her hearing aids, the others wait six years, which is when new hearing aids are offered [22]. However, according to this regulation, the six-year rule is not an absolute. If a new hearing aid will give significantly better hearing function, it is possible to get a new hearing aid before six years have passed. Hearing ability can worsen over time, and if people do not get a follow-up in six years, nobody would know if it is necessary to provide a new hearing aid, or to regulate it to match the actual hearing loss. Approximately 70% of the sample in a study reported one or more issues with the hearing aid just six months after fitting [27]. Without a follow-up, these issues might not be resolved.

One interesting finding is that none of the participants seemed to think that different professions speak to each other. This challenges the aspect of a holistic rehabilitation service. If communication improves between different hearing rehabilitation services, it would become easier to identify when different services are needed. For instance, if an educational audiologist was responsible for the follow-ups in the municipalities, they would be able to notice when an audiologist would be needed and refer the person to one, instead of that pressure being on the elderly. Meyer and Hickson [23] concluded that not every elderly person with a hearing loss seeks help, some of the reasons can be mild hearing loss, not having self-reported activity limitations and not seeing the benefits over the barriers. For the participants in this thesis, some of the reasons were not wanting to be a bother to people or not seeing it as an option. There is reason to believe that having a profession specialized on

hearing close to the users, that can communicate with other professions is important to offer an optimal hearing rehabilitation service. Lastly, with closer follow-up appointments, it would also be easier to engage relatives of the users, which would benefit everyone long term. For instance, two of the participants did say that new technology was difficult, and if for example, a son or a daughter learned how a hearing device works, they would be able to help before the user has to call someone that they are not familiar with.

Study limitation

Due to the lower number of participants, this study cannot claim that this is statistically significant, as it could be coincidence. Interviews are limited by them not being able to not include a representative sample. With only four participants, nothing can be significantly proven, and the result may be random. Replication is difficult because of the inclusion criteria, to some degree because they had to be over 80 years of age, and with Covid-19 being a risk of serious illness for elderly people, candidates were skeptical of being close to a stranger. The study followed an interview guide approach, which has its weaknesses in the interviewer's flexibility in sequencing and wording of questions which can result in substantially different responses [28].

Conclusion

The participants of this study all felt like they lacked experience with hearing rehabilitation services. They did not know of the whole system, and therefore did not know of every service that is offered. Communication between professions does not seem to be noticed by the user themselves. If there is in fact a lack of communication or whether the communication simply does not include the user, this study cannot answer. For that to be answered, another study is needed that looks directly at the services.

There were indications that the participants of this study did not get the follow-up appointments they needed and had to wait too long to get help. How to help them best to

fulfill their need of treatment is another thing this study cannot conclude. Here there is also the potential for a study which investigates new ways of providing treatment to elderly people with hearing loss.

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Appendix A

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 - Reconstructive surgery is a technique available to this group.
 - In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

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