

# **Hearing help-seeking and rehabilitation: Perspectives of adults with hearing impairment**

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**Title**

Hearing help-seeking and rehabilitation: Perspectives of adults with hearing impairment

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## **Abstract**

*Objective:* This study investigated the perspectives of adults with hearing impairment on hearing help-seeking and rehabilitation. *Design:* Individual semi-structured interviews were completed. *Study Sample:* In total, 34 adults with hearing impairment in four countries (Australia, Denmark, UK, and USA) participated. Participants had a range of experience with hearing help-seeking and rehabilitation, from never having sought help to being satisfied hearing-aid users. *Results:* Qualitative content analysis identified four main categories (“perceiving my hearing impairment”, “seeking hearing help”, “using my hearing aids”, and “perspectives and knowledge”) and, at the next level, 25 categories. This article reports on the densest categories: they are described, exemplified with interview quotes, and discussed. *Conclusions:* People largely described hearing help-seeking and rehabilitation in the context of their daily lives. Adults with hearing impairment rarely described clinical encounters towards hearing help-seeking and rehabilitation as a connected process. They portrayed interactions with clinicians as isolated events rather than chronologically-ordered steps relating to a common goal. Clinical implications of the findings are discussed.

Hearing impairment is a prevalent health condition (Mathers et al, 2003) and is associated with poorer quality of life (Chia et al, 2007). However, hearing-aid uptake is low and up to 40% of hearing aids dispensed are not used regularly (Smeeth et al, 2002). Despite decades of research, the reasons for these findings are still not fully understood.

A recent systematic review of the literature (Vestergaard Knudsen et al, 2010) identified 24 factors influencing hearing help-seeking, hearing-aid uptake, hearing-aid use, and hearing-aid satisfaction. Demographic factors (e.g., age, gender), personal factors (e.g., expectations, attitudes), and external factors (e.g., cost, counselling) were included. However, self-reported hearing impairment was the only robust predictor of hearing help-seeking, hearing-aid uptake, hearing-aid use, and hearing-aid satisfaction.

Whereas previous research yielded valuable information, there are still many aspects of hearing rehabilitation which have yet to be investigated. For example, it would be interesting to better understand how help-seeking may lead to hearing-aid uptake, use, and satisfaction. Adults with hearing impairment take many steps in the process of seeking help for their hearing impairment and obtaining and using hearing aids, but many of them have not been examined. For example, informal support and previous experiences and knowledge (e.g., hearing-aid experiences reported by peers) may significantly influence help-seeking behavior and outcomes. Also, little is known about how personal interactions with clinicians affect hearing rehabilitation.

Several qualitative studies have focused on hearing disability as experienced both by adults with hearing impairment and by their communication partners (e.g., Barcham & Stephens, 1980; Hallberg & Carlsson, 1991, 1993; Hétu et al, 1988; Kerr & Stephens, 1997; Scarinci et al, 2008; Tye-Murray et al, 2009). Some qualitative studies also have investigated the steps leading to and following hearing help-seeking and rehabilitation. For example, Carson (2005) found that older women iteratively move towards and away from help-seeking and that self-assessment plays an important role in this phenomenon. Lockey and colleagues (2010) investigated hearing-aid use in a qualitative study and found that use and non-use of hearing aids depends on meaningful participation in life situations. Unfortunately, qualitative research focusing on the hearing rehabilitation process itself is scarce, except for a few exceptions such as how adults with hearing impairment make intervention decisions (Laplante-Lévesque et al, 2010a; 2010b). Furthermore, the perspectives of adults with hearing impairment on their help-seeking and rehabilitation have received little research attention so far. As it is common for researchers and clinicians to define hearing help-seeking and rehabilitation as a pathway, a process, a timeline, or a series of steps (e.g., Kiessling et al, 2003), we wished to better understand the perspectives of adults with hearing impairment regarding hearing help-seeking and rehabilitation as a process.

### *Aim*

The aim of this study was to explore and describe hearing help-seeking and rehabilitation from the perspective of adults with hearing impairment.

## **Methods**

### *Study design*

This descriptive qualitative interview study was planned in 2008 and conducted in 2009-2010. The ten authors, with expertise in audiology, engineering, ethnology, health sociology, psychology, and speech pathology, used an interdisciplinary approach in all phases of the research. Four sites located in four different countries participated in the data collection: University of Queensland in Australia (AUS), Eriksholm Research Centre at Oticon in Denmark (DK), Hull York Medical School in the United Kingdom (UK), and University of Louisville in the United States of America (USA). The sites were selected for their dissimilar hearing services: DK and UK have predominantly public hearing services, whilst in AUS only some people are eligible for public hearing services. In the USA, the main public hearing service provider is the Department of Veterans Affairs, but the vast majority of the population is ineligible for public hearing services. In all countries, some people obtain private health insurance, which sometimes reimburses a part or the total cost of hearing services. Sampling participants from four different sites allowed for the collection of perspectives regarding dissimilar hearing services. However, the assessment of cultural differences between the four different sites was not the primary aim of this study. Sites obtained ethical clearance from their relevant ethical review committee.

### *Recruitment and sampling*

A total of 34 participants were recruited according to maximum variation sampling (Sandelowski, 1995) to capture a broad range of perspectives among adults with hearing

impairment. New participants were recruited until enough variations in the sample were found in terms of experience with hearing help-seeking and rehabilitation, site, age, gender, degree of hearing impairment, self-reported hearing disability, occupational status, living arrangement, education level, and eligibility for subsidized hearing services. In accordance with purposive sampling, five levels of experience with hearing help-seeking and rehabilitation were defined: never sought hearing help; sought hearing help but did not obtain hearing aids; obtained hearing aids but has not used them for at least 3 months; obtained hearing aids, has used them in the past 3 months, but is very dissatisfied, dissatisfied, or neutral with them; and obtained hearing aids, has used them in the past 3 months, and is satisfied or very satisfied with them.

Each site recruited adults with hearing impairment via a variety of sources such as print and electronic media, notice boards, and word-of-mouth (i.e., snowballing; Morse, 1995). Participants either provided a copy of their recent hearing test results performed in the past 6 months or completed a hearing assessment (otoscopy and air-conduction pure-tone audiometry). Sixteen participants provided a copy of their recent hearing test results, 10 participants completed a hearing assessment with the interviewer after the interview was completed, and eight participants completed a hearing assessment with another author at a later date. Eligibility was restricted to people aged at least 18 years with hearing impairment (defined as at least one air-conduction threshold at 0.5, 1, 2, or 4 kHz greater than 25 dB HL in at least one ear). The majority of participants (73%) had mild or moderate hearing impairment in their better ear. People who had received a cochlear implant or who had undergone ear surgery were ineligible. Those who had obtained their current hearing aids

more than 5 years ago also were ineligible as it was deemed important to focus on recent hearing-aid technologies. Table 1 presents an overview of the sample.

[Insert Table 1 about here.]

### *Data collection*

Participants met with one of the authors trained in interviewing techniques (AL-L in AUS, LVK in DK, LJ in the UK, and JP in the USA), at the most convenient location for each participant (i.e., participant home for 25 participants, participant workplace for one participant, and interviewer workplace for eight participants). Participants completed one interview during which they described their experiences with hearing help-seeking and rehabilitation.

Individual in-depth interviews were favored in order to provide rich data on the perspectives of adults with hearing impairment (DiCicco-Bloom & Crabtree, 2006). All interviews were audio-recorded. Interviews lasted approximately one hour and followed a topic guide (see Table 2) which focused on the participants' actions, thoughts, and feelings in relation to their hearing help-seeking and rehabilitation.

[Insert Table 2 about here.]

### *Data analysis*

The qualitative research software NVivo 8 ([www.qsrinternational.com](http://www.qsrinternational.com)) served as a platform for data analysis. Interviews were transcribed verbatim and translated into English if

conducted in Danish. Each interviewer reviewed their interview transcripts for accuracy and expanded them with relevant contextual information. As the study aimed to explore and describe the perspective of adults with hearing impairment, an inductive and qualitative form of content analysis (Elo & Kyngäs, 2007; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Knudsen et al, in press) was adopted. The distinction between inductive (i.e., conventional or explorative) and deductive (i.e., theory-driven or directive) content analysis features prominently in the qualitative literature (Elo & Kyngäs, 2007; Graneheim & Lundman, 2004). In order to approach the data in an explorative rather than directive fashion, inductive content analysis was preferred here.

In accordance with the principles of inductive qualitative content analysis, the research aim informed the definition of three content areas (i.e., explicit areas of relevant content). Identifying content areas facilitates exclusion of interview sections that have no relevance to the research topic (e.g., when a participant discussed another health problem with no connection with their hearing impairment). The three content areas were: 1) actions, thoughts, and feelings participants reported in relation to their hearing impairment; 2) actions, thoughts, and feelings participants reported in relation to their hearing help-seeking and rehabilitation, and; 3) decisive or turning points. All interview sections addressing at least one of the content areas were identified as units of content. The interview sections that were relevant to the content areas were divided into meaning units (i.e., sequences of words related to each other through their content and context). Each meaning unit was coded by one of four of the authors. A code is a label describing the content of the meaning unit. Each code was as concrete and close to the meaning unit as possible. As many different

codes as necessary were created to describe all aspects of the content. If a meaning unit conveyed more than one concept, the same meaning unit was coded as many times as necessary in order to capture all concepts conveyed by the participant. Excerpts of the coded interviews were reviewed by two of the authors who had not been involved in the initial coding step.

The first 31 interviews generated 2435 different codes and captured a broad range of perspectives among adults with hearing impairment. Two of the authors clustered the codes into categories (i.e., groups of content that share a commonality). Using an inductive approach, low-level and concrete categories were initially created according to the research aims and the data. They were later clustered in higher level and more abstract categories. Participants' perspectives on their hearing help-seeking and rehabilitation were always at the forefront of the data analysis. All authors reviewed the categories and discussed conceptual commonalities and divisions between categories. This helped refine the multi-levelled tree structure in which the results were arranged (Morse & Singleton, 2001).

The last three interviews were subsequently coded and used to assess category saturation. Saturation occurs when no significant new data emerges (Morse, 1995). Two of the last three interviews were coded by one of the authors who was not familiar with the latest categorization. As the saturation test did not unveil new categories, saturation had been reached and the analysis had adequately identified the perspectives of adults with hearing impairment on hearing help-seeking and rehabilitation.

In total, the 34 interview transcripts generated 3191 meaning units, which were coded and clustered into 151 sub-categories, 25 categories, and 4 main categories. As inductive content analysis was used, the results depict the perspectives of participants regarding hearing help-seeking and rehabilitation rather than how these concepts are typically defined by researchers and clinicians.

## Results

Table 3 shows the four main categories describing the hearing help-seeking and rehabilitation perspectives of 34 adults with hearing impairment. Three main categories refer to actions (“perceiving my hearing impairment”, “seeking hearing help”, and “using my hearing aids”) whilst one is a backdrop, portraying the general attitudes indirectly influencing hearing help-seeking and rehabilitation (“perspectives and knowledge”). Each of the main categories included categories, sub-categories, codes, and meaning units. Figure 1 gives the example of the sub-categories included in the category “hearing test”, which in turn is included in the main category “seeking hearing help” (see Table 3).

Categories were classified according to their density. Dense categories were described by the participants with many sub-categories relating to complementary aspects of the same category. In contrast, less dense categories were described by the participants with fewer sub-categories and included a limited number of category dimensions (e.g., addressing what happened, but not when or who was involved). Category density was identified by means of

consensus during a face-to-face meeting in which all 10 authors took part. Denser categories are in black in Table 3 and are described in the following section. Selected interview excerpts are followed by the participant's age, gender, site acronym, and experience with hearing help-seeking and rehabilitation to illustrate the categories. Categories that were less dense are in grey in Table 3 and, due to limited space, are not discussed further in this article. As a result, the "perspectives and knowledge" main category is also not discussed in this article. The complete list of categories and the interview transcripts are available from the authors.

[Insert Table 3 about here.]

[Insert Figure 1 about here.]

### *Perceiving my hearing impairment*

This main category encompassed participants' recollections of how they perceived their hearing disability. Its two most dense categories, "experiencing my hearing difficulties" and "having a hearing impairment and interacting with other people", are described below.

### Experiencing my hearing difficulties

Participants described how they noticed their hearing impairment and its consequences, with a focus on its social and psychological impact. They either listed specific events that made them realize their hearing impairment or situations in which they generally experienced hearing difficulties:

*About 10 years ago... Certain people I'd have problems hearing them when they're speaking. (43 year old male, USA, sought hearing help but did not obtain hearing aids)*

People commented on the relative importance they gave to their hearing disability, for example when comparing it to other health conditions. They also evaluated their degree of hearing disability by comparing themselves to others:

*A dear friend, I can never hear what she says, but I find a lot of other people don't hear her either. (83 year old female, UK, obtained hearing aids but has not used them for at least 3 months)*

Participants also assessed the relative importance of their hearing difficulties:

*The things I miss I'm not interested in anyway. (86 year old female, AUS, never sought hearing help)*

The consequences of hearing disability were far reaching and included frustration, fatigue, and social isolation. For example, participants identified difficulties joining in humor, becoming tired by the effort of hearing, or withdrawing from social activities. However, hearing impairment also had positive consequences for some participants:

*My silent world, I love it. I go and sit somewhere and just read a book because that's my world. (50 year old female, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

### Having a hearing impairment and interacting with other people

People described how other individuals responded to their hearing impairment. In some instances, close communication partners noticed signs of hearing impairment whilst participants did not:

*I don't think I have got any problems but (the) family do. (86 year old female, AUS, never sought hearing help)*

Interestingly, participants experienced a wide range of reactions from other people as a result of their hearing disability. Some communication partners became impatient and unsupportive:

*My husband used to say: "I'm sick of you, go and get your ears checked!" When people say that to you, you shrink back, you shrink psychologically. (50 year old female, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

In contrast, other communication partners, such as work colleagues, were accepting and supportive:

*My coworkers learned that I couldn't talk on the cell phone. So they wouldn't call me on the cell phone. They would just e-mail me. (44 year old female, USA, sought hearing help but did not obtain hearing aids)*

Participants also described the extent to which they were willing to disclose their hearing impairment to other people, with striking individual and contextual differences. Some people were uncomfortable discussing their hearing while others were very assertive, for example in relation to their needs in the workplace:

*I insist that people communicate with me by email. I say I need an amplifier on my phone. I just check the box, when I apply for jobs and they say: "Are you disabled?"*  
(35 year old female, USA, obtained hearing aids but has not used them for at least 3 months)

### *Seeking hearing help*

This category encompasses the participants' experiences during professional hearing help-seeking. This was described with several dimensions of hearing help-seeking and rehabilitation reported (see Table 3) and the five densest categories are detailed below.

### Deciding to seek help

Participants mentioned a large array of reasons for not seeking hearing help, including a lack of resources such as time and money, concerns about the appearance of the hearing aids, beliefs that hearing aids would not address their hearing difficulties, and low self-perceived degree of hearing disability. For example, this participant explained why, even though she mentions several of her children think she should have her hearing tested, she had yet to do so:

*I don't feel like it's bad enough. (77 year old female, USA, never sought hearing help)*

Participants who had decided to seek help reported triggers such as specific events where they experienced difficulties, other people's comments, changing health status, or new life events or roles:

*I had to be able to hear what the kids were saying. I really wanted to know what the teacher was saying about my child at school. (39 year old female, DK, obtained*

hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them)

Perceiving a decrease in hearing ability over time could also prompt hearing help-seeking:

*I had lost more hearing, to a noticeable degree that I thought I can't hear that record any more or I can't hear the TV. (50 year old male, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

### General medical practitioner clinic

Participants commented on the general medical practitioner and their role, which was typically perceived as a first step towards hearing help-seeking:

*I spoke to my own doctor about it, he was well aware that I can't hear. (39 year old female, DK, obtained hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them)*

Those who had not sought help also viewed the general medical practitioner as a likely entry point for hearing services, sometimes because they already knew them well:

*I would first ask my family doctor for a recommendation. (77 year old female, USA, never sought hearing help)*

Several participants described their experiences visiting their general medical practitioner. There was some recollection of their general practitioner performing otoscopy, investigating the etiology of the hearing impairment, suggesting a referral, or promoting hearing rehabilitation. However, the general medical practitioner sometimes minimized hearing complaints, with important consequences in some cases:

*I had trouble with my hearing. I went to the doctor who said “It’ll soon go” and it didn’t. After about a year I still couldn’t hear in one ear and felt dizzy. (59 year old female, UK, obtained hearing aids but has not used them for at least 3 months)*

People assessed the outcomes of their visit to the general medical practitioner. For example, some were recommended specific hearing-aid providers, whilst others were disappointed by a lack of guidance or referral:

*They wouldn’t do anything, they kept saying it wasn’t bad enough. (69 year old female, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

#### Ear, nose, and throat medical specialist clinic

Depending on the hearing profile and on the model of hearing-services delivery, a medical specialist was sometimes involved in hearing help-seeking. Participants described what happened during those visits and whether this was in line with their own motives. Some participants went to the ear, nose, and throat medical specialist because of a hearing-services delivery system having them acting as gate keepers:

*I went to an ear, nose and throat specialist because you need a referral from an ear specialist. I got that. Then he did a hearing test which I could take with me to (the hearing-aid provider clinic). (72 year old female, DK, obtained hearing aids but has not used them for at least 3 months)*

Ear, nose, and throat medical specialists could be involved even though direct access to hearing aid providers was available. They sometimes commented on hearing aid candidacy and several participants discussed instances where a visit to the ear, nose, and throat specialist ended their hearing help-seeking:

*I went to the ENT and he told me that for that type of decibel hearing loss, hearing aids would not help. (45 year old female, USA, sought hearing help but did not obtain hearing aids)*

Ear, nose, and throat medical specialists also ruled out other health conditions. Some participants perceived a separation between hearing impairment and other hearing health conditions:

*He did a complete examination of my ears and he said there was nothing medically wrong with it, it was just I had a hearing problem. (80 year old female, USA, obtained hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them)*

### Hearing test

People discussed at length the hearing tests they had completed. These were carried out in a variety of settings (e.g., at the general medical practitioner, at the ear, nose, and throat medical specialist, or at the hearing-aid provider clinic), but participants sometimes failed to recall the title of the clinician performing the hearing test. Similarly, many of the participants who did receive a hearing test and/or hearing aids did not mention the title of the clinician who provided these services. In some cases, participants were unaware of it, whilst in others they simply did not mention it unless the interviewer prompted them. As a result, clinician titles such as “audiologist” are not included in the category descriptions.

In contrast, descriptions of the test settings, procedures, and outcomes were common.

Participants also expressed their critical assessment of the hearing tests. Tests were sometimes perceived as quick screenings performed in suboptimal conditions:

*I could see her reflection on the glass so I knew when she was pushing buttons. That became auto-suggestion: I can see her pushing the buttons so there must be a sound so I must be able to hear it. (58 year old female, AUS, sought hearing help but did not obtain hearing aids)*

However, some also construed the hearing test as an extensive diagnostic assessment:

*I was fascinated at the detail of all these sounds and different ways to present them. It seemed to last a long time. (64 year old male, USA, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Motives for private clinics offering free hearing tests also were scrutinized:

*There are places around offering free hearing tests so they can flog a very expensive hearing aid. I'm a cynic on these things. (58 year old female, AUS, sought hearing help but did not obtain hearing aids)*

Participants were frequently critical of this practice:

*They give the service to let me know how serious our problem is and then they can sell their products more. (26 year old female, AUS, sought hearing help but did not obtain hearing aids)*

Participants also recalled how their hearing test results were communicated to them, often in relation to hearing-aid candidacy or to the nature of their hearing impairment:

*It was the higher pitches that were missing for me. (60 year old female, DK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Some people reflected on the hearing test results and compared them to their own assessment of their hearing. These two perspectives did not always coincide, for example for this participant with a high-frequency hearing impairment:

*There's a discrepancy between what I perceive as the wavelengths I don't hear versus what (the test) showed. It's the high-pitched sounds I'm told my greatest deficiency was, whereas my difficulty making out what people say is worse with the low-pitched voices. (64 year old male, USA, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

#### Hearing aid provider clinic

Depending on the model of hearing-services delivery, hearing aid providers with various titles and from different settings dispensed the hearing aids. Participants reported being influenced by a range of factors including recommendations, marketing, location, and costs when choosing a hearing-aid provider:

*How did I find him? It was through somebody at a golf club. (85 year old female, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Those who could choose between a public and a private hearing-aid provider described the differences they perceived between them. For example, public services were depicted as having a longer wait for an initial appointment but being more affordable:

*That would be the difference between the National Health and private, that you'd get an appointment much more easily (with a private provider). (85 year old female, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

For others, the cost of private services was prohibitive:

*I wouldn't go private at £2000, too much. (96 year old male, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Some participants made choices based on the quality of service they thought they would receive:

*At the VA [Department of Veterans Affairs] they seemed more friendly, like they cared. Whereas Army doctors it's like McDonald's: get the bag out the window and next car. (43 year old male, US, sought hearing help but did not obtain hearing aids)*

Some people talked about their experiences at the hearing aid provider clinic in terms of hearing aid selection, fitting, and maintenance. They reflected on the hearing aid selection in terms of how options were presented and how choices were made. Not everyone however actively took part in decisions:

*I have thought about whether it was necessary to have two (hearing aids). But I don't think I asked about it, I let (the hearing-aid provider) decide what should happen. (70 year old male, DK, obtained hearing aids but has not used them for at least 3 months)*

Among factors such as styles, appearance, and hearing-aid types available for subsidy, cost also influenced hearing aid selection. The range of hearing aid costs was a surprise to some participants and they commented on their difficulty understanding the differences between hearing aid prices:

*I was surprised at the price, because that friend of mine, his was a different price. But he showed me his and they were identical. (80 year old female, USA, obtained*

hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them)

Participants emphasized the guidance (or lack of) from the hearing aid provider, using both descriptive and evaluative terms:

*More time should have been spent in making sure I could fit (the hearing aid) in and make sure that I could adjust the control. That wasn't as clearly and firmly done as it should have been. (83 year old female, UK, obtained hearing aids but has not used them for at least 3 months)*

Participants assessed the services they received from their hearing aid provider through elements such as good interpersonal skills, a genuine interest in the participant, and availability for follow-up services. These qualities were valued and noticed when they were not available:

*(The hearing aid provider) doesn't care whether you use (the hearing aids) or not, once you have bought them there is no follow-up. It was difficult to get an appointment with them, not when you wanted to get the hearing aids, but once you had bought them and needed an appointment to have them adjusted. Suddenly no one was free, you had to wait. (72 year old female, DK, obtained hearing aids but has not used them for at least 3 months)*

Participants described when and why they visited the hearing aid practitioner after a hearing aid fitting. Ongoing services were rarely reported as central to successful hearing aid use, but some people felt it was up to them to ask for support from the hearing aid provider:

*It's a big, long process of getting used to them and I don't think you should be scared to say: "This isn't good enough. You need to adjust them differently." Go in there straight away and say: "You need to get rid of this screeching tone. You need to*

*program it differently.”(39 year old female, DK, obtained hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them)*

### *Using my hearing aids*

This main category encompasses people’s interactions with their hearing aids in their daily lives; the three densest related categories are described below.

#### Deciding to use hearing aids

People talked about how they used their hearing aids and, for some, why they stopped wearing them. Participants described their hearing-aid use patterns, which varied very much from one participant to the other:

*For me it is when I get up in the morning. It is not the first thing, it is not until I have had breakfast, read the paper, etc. Then I insert my hearing aids. It is not the first thing I do. (60 year old female, DK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Interestingly, hearing-aid use as measured in terms of number of hours per day was not always directly related to other determinants of success such as satisfaction with hearing aids. This satisfied hearing-aid user describes how he did not use his hearing aid most waking hours:

*I wear it when we go out, always. But when I'm home on my own, I don't wear it. I don't see the point of wasting the batteries!* (76 year old male, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)

Those who stopped using their hearing aids reported perceiving little benefit from their hearing aids:

*There was no real recognizable difference in my daily life quality. So I would leave them out. They were not particularly important to me at that point because they were not a vital part of my existence.* (35 year old female, USA, obtained hearing aids but has not used them for at least 3 months)

Alternatively, they experienced problems with their hearing aids and help was unsuccessful or too complex to access:

*(My hearing aid) fell off. I tried to see somebody about that, but that was very complicated. So I actually gave up that hearing aid and couldn't really get assistance for it.* (59 year old female, UK, obtained hearing aids but has not used them for at least 3 months)

Despite some participants having clear reasons for stopping to use their hearing aids, they often reported feeling disappointed, embarrassed, or guilty as a result.

### Describing my hearing aids

People explained how their hearing aids worked. Hearing aid styles and features were often compared. For example, this participant described the three listening programs of his hearing aids:

*They've given me a couple of (hearing aids), it's got three modes that you can switch between. One is everyday normal use, another one is suggested for noisy environments, so (it) concentrates the hearing towards the person I'm speaking to and cuts out a bit of the background noise, cos obviously they're behind me ears so it's picking up all the stuff behind me. That's on number two, and if I go in to a bank or something that's got one of the loop induction systems then that's number three. But I don't think I'm going to use that much unless the cinema's got one. (50 year old male, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Their accounts ranged from describing the sound of the hearing aids to appraising their comfort, appearance, and maintenance:

*They were like ear plugs, I was shut off from the world. (72 year old female, DK, obtained hearing aids but has not used them for at least 3 months)*

For others, the appearance of hearing aids was central:

*I like that (the hearing aids) are not very visible. These blend in with my hair real well. (64 year old male, USA, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Some people offered very specific hearing aid descriptions, for example when recollecting their first experiences with their hearing aids or when listing situations where their hearing aids were helpful or unhelpful. Some participants also described the broader impact of hearing aids on their lives:

*Since I've had these, it's made such a difference. This is a life changing experience. (50 year old female, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

### Using hearing aids and interacting with other people

Participants reflected on how using hearing aids influenced their interactions with people around them. They reported the help they received from others but also whether others noticed their hearing aids or their hearing aids' impact on their hearing. A few participants received help from family and friends in relation to their hearing aids. For example, this person asked a family member, a young adult, for help to insert her hearing aid:

*I got hold of my grandchild. I thought we could have a go together. She helped me put it in. (83 year old female, UK, obtained hearing aids but has not used them for at least 3 months)*

Some participants reported that any hearing aid benefit went unnoticed to their family and friends. Others had communication partners who remarked on the change, for example this participant's wife:

*She's very pleased. She notices that I don't ask: "Can you speak up?", "Can you repeat it?" (61 year old male, UK, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Some individuals felt pressured by other people to wear their hearing aids. One participant felt strongly excluded when his wife reacted to his communication difficulties by telling him he should wear his hearing aids, although he already had them on:

*That was an unmistakable tension point. It was her tone of voice when she said: "You haven't got your hearing aids on." There was a line in the sand. I said: "That's it. You go and live in your world over there!" (80 year old male, AUS, obtained hearing aids but has not used them for at least 3 months)*

Several participants appeared to seek opportunities to exchange experiences with other hearing-aid users and to appreciate this new companionship:

*The little girl the other day with the two pink (hearing aids)... I showed her (my hearing aids) and I said: "I'm the same as you. I've got these as well." And she said: "Same as me, same as me." It made her feel like you're not the odd one out. (50 year old female, AUS, obtained hearing aids, has used them in the past 3 months, and is satisfied with them)*

Overall, the results show that participants largely made sense of hearing help-seeking and rehabilitation in the context of their daily lives. They rarely described their clinical encounters as a connected process and they seldom portrayed interactions with clinicians as events chronologically-ordered and relating to a common goal.

### **Discussion and conclusion**

This study explored hearing help-seeking and rehabilitation from the perspectives of adults with hearing impairment. More specifically, four main categories ("perceiving my hearing impairment", "seeking hearing help", "using my hearing aids", and "perspectives and knowledge") emerged from interviews with 34 adults with hearing impairment held in four different countries. This is the first known international and interdisciplinary qualitative study conducted in audiology. The interdisciplinary approach benefited by expanding the inquiry scope of this study. As data collection occurred in four different countries, findings have greater transferability than if they had been collected in only one country (Guba, 1981). This article described the findings across the countries as the results showed more similarities than dissimilarities in the experiences of adults with hearing impairment from different

countries, despite dissimilar hearing services. For example, most sub-categories contained perspectives of participants from all four countries. Nonetheless, as data was only collected in industrialized Western countries, it would be premature to apply this study's findings to other parts of the world where culture and hearing services are different.

Some of this study's results corroborate previous qualitative research results conducted with adults with hearing impairment. The study's findings confirm how self-assessment is an important aspect towards help-seeking (Carson, 2005) and decision making (Laplante-Lévesque et al, 2010b) in people with hearing impairment. The participants in the previous studies had recently sought help or made rehabilitation decisions and therefore were sharing their recent experiences. In contrast, some of the participants in the present study had no experience with help-seeking and decision making. Therefore this study extends the previous findings as it highlights how self-assessment is central to adults with hearing impairment when sharing both their experiences but also their expectations. Lockey et al (2010) identified the central role of participation in determining hearing-aid use in four older Canadian women and the present study depicts similar concepts in a sample of 34 men and women of various ages and countries. Finally, the importance of a client-centered approach reported in this study, for example with participants valuing clinicians who have a genuine interest in them, echoes previous qualitative research (Laplante-Lévesque et al, 2010a).

How participants described hearing-aid use was a new finding of this study. Many different patterns of selective hearing-aid use and satisfaction emerged. It is common for clinicians to equate high levels of hearing-aid use with hearing-aid satisfaction, however this relationship

can be questioned based on the findings obtained here. Some participants wore their hearing aids very infrequently, for example only to access the audio loop at church when attending funerals, but still described themselves as satisfied hearing aid users. In contrast, some participants wore their hearing aids for all waking hours but described themselves as dissatisfied hearing aid users. Although it is well known that hearing-aid use correlates with hearing-aid satisfaction (Wong et al, 2003), such findings represent group-based trends. For example, Kochkin (1997) found that, although they measured a positive association between hearing-aid use and hearing-aid satisfaction, 33% of very dissatisfied hearing-aid owners and 60% of dissatisfied hearing-aid owners wore them at least four hours per day. Qualitative research allows for a better understanding of individual variability and this study highlights how drivers of hearing-aid use (e.g., pressure from communication partners) can be different from drivers of hearing-aid satisfaction (e.g., hearing-aid ability to reduce activity limitations and participation restrictions that initially prompted help-seeking), at least in some people.

Thematic analysis is another way to explore qualitative data. Themes are the essence or the common thread across participants' narratives (Graneheim & Lundman, 2004). Themes will be discussed in future articles. Furthermore, data analyses according to differences in the sample could generate important results. For example, future research could contrast the experiences of participants who had sought hearing help with those who had not, as this could yield new meaningful information for clinical practice.

When asked open-ended questions, participants recollected their experiences according to three dimensions: description (e.g., what happened, what was said), intention (e.g., why

seeking help, what are expected outcomes), and evaluation (e.g., was it good or bad).

Mentions of their intentions and of their evaluations were more frequent than factual descriptions. For example, participants listed impressions (either based on personal experience or on general knowledge if they had no experience seeking hearing help) rather than descriptions when discussing hearing-aid providers and their services.

Hearing help-seeking was described with the most dimensions but overall it accounted for only one of the four main participants' perspectives on their hearing. Contrary to what one might expect, participants did not describe the initial hearing-aid fitting as an important episode, rather putting emphasis on aspects of relevance to their daily lives such as the guidance they received on hearing-aid use and care. Few participants recollected this technical task performed by the hearing-aid provider, most likely as it is of no direct significance in their rehabilitation from their point of view. Rather, they emphasized aspects of the clinical encounter which they considered to have direct relevance to their daily life, for example guidance regarding hearing-aid management. This study's participants also stressed the events surrounding and influencing hearing help-seeking and rehabilitation. The three other main categories ("perceiving my hearing impairment", "using my hearing aids", and "perspectives and knowledge") do not focus on hearing help-seeking and rehabilitation as typically defined from the researcher or clinician's perspective but rather on participants' own dealings with their hearing outside of clinical settings. A recent study used a "patient journey model" to prompt hearing aid users regarding their experiences and processes during the course of hearing impairment and its rehabilitation (Manchaiah et al, Accepted for publication). Although Manchaiah and colleagues used a more directive approach to data

collection, they also reported that "... the emphasis of the patients' responses was more on both the early and the late phases of the journey with less emphasis on the middle phases, especially on what happens during diagnostic testing." They concluded that considering the perspectives of both clients and clinicians would provide a better understanding of the process. Our findings also support how participants largely use their daily life experiences rather than interactions with hearing services when constructing the meaning of their hearing help-seeking and rehabilitation. Therefore it stresses that clinicians must consider the effects of hearing impairment, help-seeking, and rehabilitation on everyday life. This calls for client-centered hearing services which acknowledge the client's point of view.

Importantly, participants rarely described clinical encounters towards hearing help-seeking and rehabilitation as a connected process. They portrayed interactions with clinicians as isolated events rather than chronologically-ordered steps spanning over time and relating to a common goal. As it is common for researchers and clinicians to define hearing help-seeking and rehabilitation as a pathway, a process, a timeline, or a series of steps (e.g., Kiessling et al, 2003) and as we deliberately included in our topic guide prompts targeting this concept, we initially expected this study to provide an understanding of how adults with hearing impairment understand and experience clinical pathways. However, participants generally viewed hearing help-seeking and rehabilitation as a series of isolated events. In other words, most participants were unaware of the steps involved in hearing help-seeking and rehabilitation. This could be due to the overall lack of continuity in the hearing clinical pathways, especially at junctures between the different professionals involved in the provision of hearing services. The participants who reported awareness of steps in hearing

help-seeking and rehabilitation usually did so when considering chronological personal events such as gradual awareness of hearing difficulties or self-adaptation to hearing aids. Participants also sometimes referred to their clinicians as not being aware of such a process. For example, participants either did not recognize as important (or felt their clinicians did not recognize as important) ongoing appointments with the hearing-aid practitioner. This points to a mismatch between the views of adults with hearing impairment and their clinicians when approaching hearing help-seeking and rehabilitation. According to our findings, it is common for either the client or the clinician to view hearing rehabilitation as a “quick fix” and for the other party to view hearing rehabilitation as a pathway, a process, a timeline, or a series of events spanning over time and relating to a common goal. We suggest that a better match between how clients and clinicians approach hearing help-seeking and rehabilitation is required. By adopting a client-centered perspective to hearing rehabilitation, clinicians can begin to foster better communication with people with hearing impairment.

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### **Declaration of interest**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

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**Table 1.** Summary of sample characteristics (n=34).

| <b>Characteristics</b>   | <b>Number of participants<br/>% (n)</b> |
|--|---|
| <b>Experience with hearing help-seeking and rehabilitation</b>                                       |   |
| Never sought hearing help  | 15% (5)                                 |
| Sought hearing help but did not obtain hearing aids  | 18% (6)                                 |
| Obtained hearing aids but has not used them for at least 3 months                                    | 18% (6)                                 |
| Obtained hearing aids, has used them in the past 3 months, but is dissatisfied or neutral with them* | 18% (6)                                 |
| Obtained hearing aids, has used them in the past 3 months, and is satisfied with them*               | 31% (11)                                |
| <b>Site</b>  |   |
| Australia  | 24% (8)                                 |
| Denmark  | 26% (9)                                 |
| United Kingdom   | 24% (8)                                 |
| United States of America   | 26% (9)                                 |
| <b>Age</b>   |   |
| < 50   | 21% (7)                                 |
| 50-65  | 32% (11)                                |
| > 65 and ≤ 80  | 26% (9)                                 |
| > 80   | 21% (7)                                 |
| <b>Gender</b>  |   |
| Female   | 56% (19)                                |
| Male   | 44% (15)                                |
| <b>Hearing impairment in better ear (average hearing thresholds at 0.5, 1, 2, &amp; 4 kHz)</b>       |   |
| Normal (≤ 25 dB HL)  | 21% (7)                                 |
| Mild (> 25 and ≤ 40 dB HL)   | 38% (13)                                |
| Moderate (> 40 and ≤ 60 dB HL)   | 35% (12)                                |
| Severe (> 60 and ≤ 80 dB HL)   | 6% (2)                                  |
| <b>Occupational status</b>   |   |
| Employment or study (full or part time)  | 44% (15)                                |
| Retirement or unemployment   | 56% (19)                                |
| <b>Living situation</b>  |   |
| Alone  | 32% (11)                                |
| With other(s)  | 68% (23)                                |
| <b>Education level</b>   |   |
| Less than secondary school   | 6% (2)                                  |
| Secondary school   | 62% (21)                                |
| More than secondary school   | 32% (11)                                |

|  |          |
|--|----------|
| <b>Eligibility for public payment of hearing aids</b>          |          |
| Eligible   | 68% (23) |
| Not eligible   | 32% (11) |
| <b>Self-reported hearing disability (without hearing aids)</b> |          |
| None   | 3% (1)   |
| Mild   | 21% (7)  |
| Moderate   | 35% (12) |
| Severe   | 29% (10) |
| Profound   | 12% (4)  |

\*Participants were asked to rank their satisfaction with their hearing aids on a scale from 1 to 5: Responses from 1 to 3 were defined as dissatisfied or neutral and responses from 4 to 5 were defined as satisfied.

**Table 2.** Topic guide excerpts.

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**Initial prompt**

- Tell me the story of your hearing.

**Other prompts**

- Experiences with hearing and hearing services (e.g., What have you done or not done about your hearing?)
  - Time path (e.g., When did this occur? What happened next?)
  - Sources of help, nature of help, and evaluation of this help (e.g., Tell me about your hearing aids. Tell me about any other help you use for your hearing. What happened? What was it like?)
  - Referrals (e.g., How did you get from there to here?)
  - Professionals (e.g., What was their role? How were they?)
  - Family and friends (e.g., What was their role? How were they?)
  - Other people with hearing impairment and hearing aids (e.g., Who do you know?)
  - Reflection (e.g., What was the most important thing that happened to you? How could things have been better for you? If an acquaintance told you they had hearing difficulties, what would you recommend they do?)
  - Future (e.g., What do you think will happen next?)
-

**Table 3.** Main categories (n=4) and categories (n=25). More dense categories (discussed in the text) are in black and less dense categories (not discussed in the text) are in grey. The category with a \* is shown in Figure 1.

| <b>Main category</b>                    | <b>Category</b>   |
|---|---|
| <b>Perceiving my hearing impairment</b> | Experiencing my hearing difficulties                          |
|   | Having a hearing impairment and interacting with other people |
|   | Identifying the cause of my hearing difficulties              |
|   | Perceiving other people with hearing impairment               |
|   | Seeking information about hearing impairment                  |
| <b>Seeking hearing help</b>             | Deciding to seek help   |
|   | General medical practitioner clinic                           |
|   | Ear, nose, and throat medical specialist clinic               |
|   | Hearing test*   |
|   | Hearing aid provider clinic                                   |
|   | Delay between initial help-seeking and getting help           |
|   | Evaluating my help-seeking                                    |
|   | Experiencing difficulties hearing the professional            |
|   | Giving recommendations to other people about help-seeking     |
|   | Hearing services other than hearing aids                      |
|   | Other people giving me recommendations about help-seeking     |
|   | Seeking information about help-seeking                        |
| <b>Using my hearing aids</b>            | Deciding to use hearing aids                                  |
|   | Describing my hearing aids                                    |
|   | Using hearing aids and interacting with other people          |
|   | Giving recommendations to other people about hearing aid use  |

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**Perspectives and knowledge**

Wearing hearing aids

Describing my approach to hearing impairment, help-seeking and hearing aid use

Describing my general approach to health

Explaining hearing impairment, help-seeking and hearing aid use

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**Figure 1.** Example of main category “Seeking hearing help”, category “Hearing test”, and relevant sub-categories.

→ ○ = codes

