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Reconnecting to others: grounded theory of social functioning following age-related hearing loss

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Abstract

Age-related hearing loss (ARHL) is common and a known risk factor for social disengagement in later life. This study explored social functioning following a diagnosis of ARHL. Using a constructivist grounded theory approach we developed an interview schedule to advance a grounded theory from data collected from six older adults who used either hearing aids or cochlear implants. Interview questions concerned social functioning as well as focusing on their perspective of the impact of ARHL on cognitive functioning. We describe a grounded theory conceived as 'Reconnecting to Others'. This theory posits that participants faced social challenges in relation to their ARHL, and resolved these challenges partly through the use of hearing aids and cochlear implantation. The theory also emphasises the importance of help from other hearing aid users for new users, and corroborates prior findings about strategies older adults with ARHL use to cope with their hearing impairment in various social situations. Once hearing aids and cochlear implants are used and adapted to with the help of peers, participants completed their journey by helping others who had received diagnoses of ARHL. Additionally, participants spoke of the pleasure of hearing again. Interestingly, no participant felt that their ARHL had impacted their cognitive functioning. Our theory provides a basis for explaining existing quantitative findings as well as creating new hypotheses for future testing.

Keywords: age-related hearing loss; presbycusis; social functioning; constructivist grounded theory; ageing; hearing aid; cochlear implant

Introduction

Age-related hearing loss (ARHL) affects one-third of those aged over 65 worldwide (World Health Organization, 2019) and as many as 45–55 per cent of those aged over 80 (Roth *et al.*, 2011). Comparatively, in the Republic of Ireland, hearing loss is reported by 37 per cent of those aged over 50, and 50 per cent of those

aged over 75 (McGarrigle *et al.*, 2017). Despite this, only 8 per cent of the older population of the Republic of Ireland use hearing aids, which is comparable to rates reported in other countries (Chien and Lin, 2012). This rate is despite the free availability of hearing aids for qualified older persons in Ireland. Other than the statistics provided by the Irish Longitudinal Study on Ageing (McGarrigle *et al.*, 2017), little is known about the experiences of older adults with ARHL in Ireland. Less is known about ARHL in the Northern Irish population, where hearing aids are also freely available from the National Health Service.

Because of its impact on speech perception (Roth *et al.*, 2011), communication and social interaction may present challenges to individuals with ARHL (Dalton *et al.*, 2003; Pronk *et al.*, 2011). ARHL has been linked cross-sectionally to social isolation in women aged 60–69 (Mick *et al.*, 2014), alongside smaller social network size (Kramer *et al.*, 2002) in older adults of both genders. Longitudinally, hearing loss has been shown to be associated with both loneliness and social isolation (Maharani *et al.*, 2019), lower levels of weekly social activity engagement (Loughrey *et al.*, 2021) and may also drive social disengagement (Andrade *et al.*, 2018), in a dose–response manner (Strawbridge *et al.*, 2000).

As such, intervening on ARHL might not only improve hearing but also potentially protect social functioning. Interventions for ARHL typically constitute either the use of hearing aids (for mild to moderate hearing loss) or cochlear implants (Lin *et al.*, 2012). Rates of uptake of both are relatively low, with half of 30,000 older adults with reduced hearing reporting hearing aid ownership, and with those who own hearing aids often underusing them (Smeeth *et al.*, 2002).

With this in mind, we wanted to explore how older adults with ARHL who have received interventions (hearing aids and cochlear implants) navigate their social engagement. Research in the field of health psychology has previously attempted to contextualise the psycho-social impact of hearing loss within the self-regulatory model of health behaviour (Heffernan *et al.*, 2016) which focuses on cognitive representations that might underpin emotional responses to hearing loss. Heffernan's study engaged in deductive qualitative data analysis to show that the self-regulatory model was a useful framework for the emotional and cognitive consequences of hearing loss (although restrictions to social functioning did arise incidentally in the data). However, the focus was not specifically on the individual's social functioning. Additionally, the sample ranged in age from 20 to 91. We focus our investigation on adults aged over 60, since later life is not just the point of highest risk of ARHL, but is also a time of risk for social disengagement more generally, with social isolation higher among those aged over 68 in the older Irish population (Ward *et al.*, 2019). We employed an inductive method, to ascertain and identify better the challenges faced by older adults in terms of their social engagement following a hearing loss and how hearing interventions impacted these challenges.

The aim of our study was to explore social functioning and engagement in older adults with ARHL who used hearing aids or cochlear implants. Since hearing loss has been identified as a key risk factor for dementia (Livingston *et al.*, 2017) and has been shown to be associated with cognitive decline (Maharani *et al.*, 2018), we also wanted to ask participants whether they perceived cognitive functioning issues as a result of their own hearing issues.

Methods

Design and methodology

A constructivist grounded theory approach was adopted (Charmaz, 2006) because we wanted to understand loss of hearing in a social context for older adults. We specifically wished to create inductively a theory explaining how older adults respond to their hearing loss, and how this response in turn impacts their lives. We undertook to report our qualitative study in accordance with JARS-QUAL, the Journal Article Reporting Standards for Qualitative Research (Levitt *et al.*, 2018).

Sample recruitment strategy

Theoretical sampling was used (Strauss and Corbin, 2015), in which interviews are conducted until no new themes are yielded. In order to recruit participants, purposive sampling was used. Two advocacy organisations were enlisted to aid recruitment – one in Northern Ireland and one in the Republic of Ireland. Individuals linked with these organisations are likely to have received hearing aids or cochlear implants, a focus in the current study since their use may impact social and cognitive functioning. Sampling inclusion criteria were: self-report of ARHL; aged over 60. Exclusion criteria were: having a hearing impairment other than ARHL; self-report receipt of a diagnosis of dementia, memory impairment or Alzheimer's disease. The advocacy organisations acted as recruitment partners and advertised the study to their members. Thus, participants were self-selecting, and were those who were actively engaged in the organisations, meaning that their social engagement levels may have been higher than those in the population with ARHL. Interviews with seven participants were initially conducted but data pertaining to one individual were excluded because during the interview it transpired that she had a hearing impairment due to trauma rather than age. Thus, the data of six participants are analysed as described below – until thematic saturation was deemed to have occurred (*i.e.* no new themes emerged from the data). Of these, three participants were from Belfast in Northern Ireland and three were from the greater Dublin area in the Republic of Ireland. Participants were aged between 64 and 85 (mean age 75) and 50 per cent were males.

Analytical strategy

We used the coding paradigm described by Strauss and Corbin (2015), with three main features: conditions, actions–interactions, and consequences or outcomes. Analysis was conducted following the transcription of each interview. First, initial coding was conducted on the transcribed interviews. Then focused coding was conducted, followed by the use of the coding paradigm framework – looking for conditions, actions and consequences of each category in the data. Finally, theoretical coding was used. The coder was the last author, and the first author was the second rater. Following analysis, the second rater then reviewed the codes, categories and emerging theory, and few discrepancies emerged. These discrepancies were discussed and a consensus reached.

Rigour was considered carefully during data analysis. In order to avoid selectivity in the use of data, line-by-line coding was deployed and initial codes were retained

for as long as they were coherent and useful to the emerging theory. The process of coding was iterative to avoid the emergence of incomplete theory. Codes emerging from one transcript were checked against other transcripts and retained only if they were echoed by multiple participants. In most cases, the retained codes emerged from all participants. Inter-rater reliability was assured by having a second rater independently assess the data, emerging codes and theory, and by discussing any discrepancies emerging. Finally, the researcher's own positions were carefully considered (*see* the Discussion).

Procedure

Individuals who were linked with the two advocacy organisations were invited to participate in interviews, which were conducted by the lead author. All interviews took place between November 2018 and January 2019. Interviews were held in the advocacy organisations' offices. Interviews all took between 55 and 65 minutes and followed a semi-structured interview schedule which, as per constructivist grounded theory guidelines, was edited in minor ways between interviews to focus better on the emerging theory. The initial interview schedule was developed through a series of three pilot interviews (*see* the supplementary material online). Participants were first brought through the informed consent process and gave their written consent prior to the interview, which was recorded on a Dictaphone and transcribed verbatim afterwards. Participants' hearing loss did not unduly impact their engagement with the interviews (likely because of the use of hearing aids and a quiet interview room). During the informed consent process, participants were given an information sheet to read, and reminded that their involvement or withdrawal would have no bearing on their receipt of services from the advocacy organisation in which they were involved. Participants were told that the study was being conducted in order to learn more about the impact that ARHL has on socialising and cognitive functioning. The study was approved by the Queen's University Belfast School of Medicine, Dentistry, & Biomedical Sciences Research Ethics Committee.

Prior to submitting a description of the study to the Ethics Committee, the research team underwent careful consideration of best practice in relation to ethics, as informed by the British Psychological Society's Code of Human Research Ethics (www.bps.org.uk). In conducting interviews with a population affected by an issue that may makes them vulnerable, we carefully considered the risk–benefit ratio and made the deduction that to explore the experience of ARHL via one-to-one interview would confer a justifiable and minimal risk to individuals (potentially, that they would feel upset reflecting on the experience of ARHL in relation to their functioning). This risk is justifiable because (a) learning about the impact of ARHL is likely to help us to develop necessary interventions, and support those in place, and (b) vulnerable participants engaging in research into sensitive topics report that participation is more of a positive than a negative experience (Alexander *et al.*, 2018). The one-to-one nature of the interviews, with a trained interviewer, minimised further any social risk and commitment to confidentiality of the data, including the protection of identity in any research outputs, aimed to protect further the dignity and rights of participants. During study briefing, participants were informed of their right to participate or withdraw at their wish, for any reason.

Contact details of the research team were given to all participants upon debriefing. Care pathways were identified and provided in case participants became distressed as a function of their study involvement (although no participants reported having become distressed).

Results

We present a grounded theory entitled ‘Reconnecting to Others’. We describe the journey taken by participants from first learning of their ARHL, towards acceptance and motivation to contribute to the ARHL community. Participants were situated in a societal context that was intolerant of those with ARHL, although they received help and support from family members and others with ARHL. Impacts due to ARHL were felt on several aspects of participants’ lives: occupational, emotional and social functioning. Following a realisation of hearing loss, participants described their journey through the flawed health-care systems and subsequent reliance on other hearing aid users. Through the processes of acceptance of the diagnosis, and educating themselves about potential interventions, all participants spoke about reaching a point at which they could enjoy sound again and start to help others with hearing loss.

Ultimately, other hearing aid users helped participants to regain and enjoy their hearing, and as a result they were motivated to help others to use their hearing aids correctly. In this way, the ARHL community appeared to have a functional feedback mechanism through which those who had received help with hearing aids would go on to return this help to others who needed it. ARHL was seen as promoting social withdrawal. However, help using hearing aids (and thus recovering hearing) was only seen as being available from others with ARHL, and to avoid social withdrawal, participants needed to reach out and connect, mostly via advocacy groups. The themes described were built into two categories within the grounded theory: ‘learning about hearing loss’ and ‘connecting to the world’ (see Table 1).

Category 1: Learning about [one’s] hearing loss

Most participants had spent some time reflecting on what *caused* their own ARHL, or hearing loss generally. ARHL was linked, in the course of their lives, to accrued risks:

When I was young, we used to go every week to very, very loud rock concerts ... And you’d come out and you literally couldn’t hear. That’s probably what caused it... (P3)

I blame it on possibly wearing headphones and a Walkman with the music at full blast. (P4)

Learning about one’s hearing loss occurred in a *family context*. Participants compared their hearing to that of family members. Sometimes, family members were the first to notice participants’ hearing loss.

My father was also deaf, so part of it would be hereditary, you know. (P6)

Table 1. Presentation of categories, sub-categories and sample text from six presented interviews

Category and sub-category	Sample text
Learning about one's hearing loss:	
Reflecting on causes of hearing loss	Now, I was a policeman for 30 years. And the part of the job I was in, we did a lot of shooting. Or shooting practice, without ear protectors, unfortunately. Well, I put a lot of it down to that. (P6)
Family context	I probably had an awareness of it brought on by family comments ... there was this, sort of, comment that at times I couldn't follow conversations. (P1)
Broader societal stigma	That's another thing too, when ... people, when you say you're hard of hearing or you're deaf, they kind of regard ... like, if you're deaf, they presume that you're stupid. (P4)
Impact (jobs, emotions, social, cognitive)	What you have to bear in mind is, the nature of hearing loss quite often impacts on people's confidence. To the extent that they tend to retreat into their shell, they tend to opt out of stuff, and then tend not to be sufficiently assertive ... depression and despair are regular partners to the isolation of hearing loss. (P1)
Avoiding social engagements	You think you're doing alright, but if you're not interacting with people ... Because it's too much like hard work. Or you tend to stay in more than you would, because it's too much like, you know ... Too many hurdles to get over every time you go out. I can understand why people do get socially very withdrawn. (P3)
Connecting to the world:	
Gradual progression/realisation	OK, it's going. It's going, going, going. And to me it's not really perceptible. (P5)
Feeling rushed through	I would analyse them, looking back, I would say extremely poor ... And, OK, I understand the reasons for that; they're under tremendous pressure, they have to concentrate on, to some extent, on children ... children's needs - that's vital, obviously, for a very young child. But yeah, there's a hell of a lot that could be done to improve audiology services. (P1)
Getting help from users	So we know all the problems that you get, and all the annoyances and frustrations you get. You do, 'cause you can say to them, 'I know exactly how you feel, because I've got one.' (P3)
Lack of accommodations	There's not a lot of tolerance for people with hearing loss, it's very difficult to get across the difficulties you're having ... I don't want sympathy, just a bit of understanding. (P6)
Family advocates	N, N, N, the rest of them, they're aware and I think, they will have made adjustments. N - his family are very good. Say, for example, I hate Sky television with a passion. And so, if there's something big, a sports thing I want to see, I'll go up to N's and watch it. And I'm conscious that he always says, 'That OK, can you hear that OK?' (P1)
Acceptance and staying positive	I accepted it as part of ageing. Yeah, I kind of accept those things: 'OK, I don't see as good as I did. I don't hear as good as I did. I don't run as fast as I did.' (P5)

(Continued)

Table 1. (Continued.)

Category and sub-category	Sample text
Arming oneself	I think it's my knowledge of it ... as my interest has increased, my own reading on it ... So it's sort of an awareness has developed. But, had I not joined [the group], I'd probably be still living in the dark. Now that I have a high level of knowledge, I'm able to deal with it. (P1)
Enjoying sound	For the first time I realised that, in the past, I didn't hear birds singing. That was really good. There were trees at the back of my house, in the park in Scotland. I could hear the blackbirds and stuff like that. It was really good. (P6)
Helping others	This is my way of paying back. (P4)
Seeking others with hearing loss	Because I found it a complete change when I found the hard of hearing group: social group. It was a real eye-opener for me. People who knew how ... how I felt. It was great. And to meet people who understood about deafness. (P6)

Then I went and had my hearing tested. And it seems to be that this could be hereditary hearing loss. (P2)

Participants had to negotiate ARHL in the context of *broader societal stigma* about hearing loss. Many participants reported that they had implicitly believed these stigmatising ideas about people with hearing loss themselves, until they received their own diagnoses. Participants described two major beliefs about hearing loss: that it implied intellectual inferiority and that it was something that happened to older people:

And particularly with older people, I think they say, 'ah your man is "dawny"', in other words, dumb, 'ah there's no point in talking to him, he's as deaf as a post'. (P5)

But I always thought of it as old person's disease, and I can remember people had these great big hearing aids, and they had the thing in the pocket, and the last thing I wanted ... you know, 'Oh, I don't want to wear a hearing aid.' You just ... you just sort of think no, it makes you look really impaired. It's got kind of a social stigma to it. (P3)

Others argued, however, that the stigma of hearing loss had reduced in recent times:

I don't think nowadays there is anything like a stigma about it because there's a different attitude ... to anybody who's got a disability of any sort. It's a much healthier attitude nowadays. (P3)

I think it's maybe ... familiarity perhaps. As people become more familiar, and as more people wear hearing aids. Yeah, I think the stigma is lessening. (P1)

Participants spoke about the impact that hearing loss had on various aspects of their lives. Two individuals mentioned that it had begun to *impact on their jobs*, which had spurred them to seek diagnosis:

I didn't pay too much attention until I started to work for myself, eventually ... taking orders over the phone, making mistakes. That was when I really began to understand that I had a hearing loss. (P6)

I was working in an open-plan office. And people were getting frustrated because I couldn't ... I just didn't hear what they were saying. Because you had to speak fairly softly because you were in a big, open-plan area. (P3)

Some participants described the *emotional consequences* of losing their hearing. In many cases, these consequences were described as being somewhat transitional:

But it can also lead to being socially depressive, you know? It can be very isolating when you can't hear. (P3)

I was kind of very selfish. Or kind of being ... feeling very sorry for myself. And depressed, lonely. And just possibly miserable (laughs). It puts up a barrier – you just put up a wall. (P4)

One potential consequence of ARHL was *cognitive functioning*. When asked whether their hearing loss seemed to have led to cognitive decline, most participants disagreed, while accounting for the fact that hearing loss can reduce the amount of incoming information, and that coping with hearing loss can tax attention:

I can't see any connection or reason. (P2)

It doesn't immediately strike me that it has. I'm probably unaware of stuff that I don't hear. I can't say that it comes across to me that it has been detrimental. (P1)

Participants also spoke about the *social impact* of their hearing loss. This seems to have been the most critical impact identified in the lives of each of the participants. Most participants referred to communication difficulties, specifically experienced in a more public socialising context, as opposed to in the home. Most participants reported that conversational difficulty in these settings was one of the main frustrations that arose because of hearing loss:

As my hearing deteriorated, my social life kind of declined. But, I mean, I'll go out. But I hate to go out because it's embarrassing to ask people what did they say, you know. And it's, 'I'll tell you later.' (P4)

Restaurants, yeah: problem. Groups of eight in a noisy restaurant ... I could hear, I could talk to somebody opposite me. (P5)

As a result of frustrations experienced because of conversational difficulty, participants reported that they became *demotivated to engage socially*, and in some cases, actively avoided social occasions:

I just can't be arsed ... I can't be bothered going out to a lot of stuff now. (P1)

So, sometimes it just ... it felt like too much effort to ... to engage with things. Yeah, it wasn't worth it, you know. (P4)

Group settings were described as being a challenge because of the 'cross-talk' occurring between group members:

I would tend never to go to a pub on a Saturday night. (P4)

I don't socialise. I liked, many years ago, I'd love to go for a drink, but now it's impossible, in pubs or clubs, they're too noisy ... I don't meet them [friends] anymore. (P6)

Participants were learning about their ARHL in a series of concentric contexts – within their family, taking into account their family history and genetic risk, and more broadly, within their health service and within a society which stigmatised hearing loss as being associated only with later life, and with intellectual inferiority. The family context in which participants found themselves appeared to be a precipitant factor in determining whether they sought a diagnosis. Broadly speaking, learning about hearing loss was described as a negative experience with negative consequences, like social disengagement, occupational difficulties, emotional pain and a reduced sense of safety in the world.

Category 2: Connecting to the world

Participants spoke about the next stage of their journey as involving an adjustment to ARHL and receipt of aids and services. This was done following mostly gradual realisations of the existence of hearing problems. Some participants reflected on the *gradual progression* of ARHL, which seemed to make it difficult to notice:

Hearing loss is so gradual, imperceptible, incremental that it's not as if you're waking up one morning and, oh God, everything is different. It was so slow, the whole process. (P1)

You know, people don't realise, when hearing loss is very gradual, you really don't ... unless something happens where you have an accident and boom, you've lost hearing in one ear or something, it can be very gradual, and you honestly don't realise that it's going. (P3)

Participants reported having felt '*rushed*' through the diagnostic process, and a general sentiment that services were under-resourced and that audiologists had limited time to spend with patients:

I went to the audiologist. That was ... it was ... kind of full on ... I had about an hour at the hospital. I went to see an audiologist who put you in a booth and tested your hearing. And then, once you've had that done – that was probably 20 minutes – you went to see a doctor, who looked at the printout and said, 'Yes, you need a hearing aid.' So, I took this along to the audiology ... the technician audiologist. And it was programmed, fitted. But that bit was quite confusing because

there's a lot going on, and you've got this strange object in your ear, and you find it ... it's ... and then suddenly things are clearer, and you feel like you've ... almost like you've been assaulted really. (P3)

Participants reported feeling frustrated at the lack of knowledge about hearing aid use and maintenance on the part of professionals. They felt that professionals lacked insight into hearing aid use and often did not have the right information to give to new hearing aid users. Instead, they preferred to get *help from other hearing aid users*, framing the user as expert:

I have a very clear recollection of the only time that someone actually sat down with me and explained the hearing aid in more detail, how it worked ... And it was he who explained to me the way your brain has to adapt to the new type of sound. (P1)

Now, audiologists can be excellent or mediocre. They don't wear hearing aids normally so they aren't aware of the problems that can arise ... It's great if you get somebody who wears hearing aids. Because they can ... they're on your wave track. And they can say, 'Oh yes', as I said, when somebody said about something, I said, 'Oh yes, I've experienced that and it was water in my ... the tubes.' (P2)

Participants spoke about *the lack of accommodations* made by others in public such as businesses or services, describing a society unwilling to understand or cater for hearing loss:

I had a cold, one time I went to a doctor's surgery. And I just said ... he kind of was mumbling ... So I said, 'Excuse me, doctor. Would you mind looking at me, so I can see what you're saying?' 'Because I'm hard of hearing.' And he looks up at me, and he roars at the top of his voice, 'What is wrong with you?' (P4)

And we never hear public announcements – train stations, airports, anywhere. Well, you have to go and find a noticeboard or something like that, you know. Most places have monitors now, with times and directions on them. Well, you're always last to leave the boat (laughs). You're watch ... you're watching other people moving, and then you decide it's time to get up. (P6)

This broader socialising context was contrasted with the social interactions with closer loved ones and family members. Many participants reported that they had specific loved ones who *acted as advocates* for them, and made special accommodations for their hearing loss:

Yeah, the hearing – I suppose, in the family, yeah it's accepted ... to me, they act normally. (P5)

My daughter in particular, she's very good. She looks after me. (P6)

As participants learned about their ARHL, they reacted in similar ways. *Acceptance and staying positive* was described by some, and maintaining a positive attitude by others, as being crucial for wellbeing:

It's just a practical thing. You just accept it. It's just part of me ... You see, on an intellectual level, yeah it would be great, you know, flip a switch and my hearing's perfect. That would be great. But that's not the reality, I mean. It's like, you know, wishful thinking. Let's be realistic! Don't hide it. Accept it. You can't change it; you can't turn a magic switch. There's no good wishing it away. (P1)

I'm very adaptable, and I have a wicked sense of humour. I make fun of it ... And I'll say, 'You just have to fight, fight, fight, or else I'm not going to beat the hell out of this.' If you have a positive outlook it really does help you survive. (P4)

Another action that participants reported taking in response to learning about their hearing loss was to *arm themselves* to cope with the loss. Partly this was accomplished by engaging with advocacy and support groups. Many observed that learning more about hearing loss increased their sense of confidence:

It's given me more confidence, if anything. (P3)

My confidence has gone up 100 per cent. So, I would never have made phone calls. So, N [group contact] was here. So, she said, 'I'm going to try and phone you now ... So I wouldn't hear it, you know. I said, 'Try it, try it, try it.' So it's ... So then she phoned me. And she said, 'OK', she said. 'What did you have for breakfast this morning?' And I said, 'Porridge' (laughs). So, that ... I had quite a start getting more confident at making phone calls. (P4)

Other participants spoke about the changes they made in social situations in order to cope with their hearing loss. Some participants described their attempts to advocate for themselves in social situations to avoid social withdrawal:

But, again, you have to take responsibility. And say this: 'I'm sorry, I haven't heard that.' Make a nuisance of yourself if necessary. (P2)

I do make certain adaptations like, again, talking about in the pub, getting into the corner. And I would, maybe, say to people, jokingly [?], 'Oh, let's move over here. I don't want to get stabbed in the back', or something, and get in against the wall. But that's, again, to help me cope with the conditions. (P5)

As a result of processes including acceptance of the diagnosis, advocacy from self and the family, and educating oneself about available resources, many participants reported positive outcomes. These outcomes commonly related to the *pure enjoyment* of hearing sounds, for many:

This is fantastic. I can actually hear detail. I can hear the car radio. (P3)

I have been transformed. My life has been transformed ... I'm adjusting to the sound of the real world outside. But right after I left, on the first day, I went

outside and I just had to sit down with my sister ... And I was saying, 'I can hear a sound', and I described it, and said, and they were looking around and said, 'Oh, it's the rain on the window.' You know, so it was just ... it's just mesmerising. (P4)

Ultimately, the attempt to connect with others, in many participants, appeared to have led to a desire to *help* others similarly affected by hearing loss, specifically those who have recently been diagnosed with hearing loss. This sentiment was echoed in multiple interviews:

[I've become] the hearing aid man! I just do my wee bit. (P1)

And I just had time. And I thought, well, if I can repay, you know, somebody, and help somebody else. (P2)

Some participants mentioned that instead of engaging socially with others who were not always sympathetic or understanding of their hearing loss, they sometimes specifically sought out social engagement with *other people with hearing loss*, anticipating some empathy and understanding around the issue:

I actually went to a support group. So, that's been a lifeline as well. Because you meet more people ... and, of similar problems and feelings. Because it can be very isolating when you can't hear. (P4)

Connecting with the world was problematic for individuals with ARHL, and different situations were more problematic than others. Broadly, participants reported that they tended to avoid loud places and busy social occasions involving a lot of people where 'cross-talk' was difficult to understand. Family and close friends were described as being, for the most part, solicitous and accommodating of their hearing loss. Participants reported several actions that they engaged in to offset their communication difficulties, including specific conversational strategies like leaning in to the speaker, using technology, lip-reading classes, and engaging purposefully with others with hearing loss to gain understanding and empathy. Having received support and help in using hearing aids to recover some of their hearing, most participants wanted to give back to the hearing-loss community by helping others to manage their own hearing aids.

Discussion

We present a grounded theory describing how older adults with ARHL who used hearing aids or a cochlear implant experienced their social engagement. We entitled this theory 'Reconnecting to Others', since participants detail a process through which, with the help of hearing aids and cochlear implants, they moved from acceptance of an ARHL diagnosis to be able to reconnect with other people in their lives and contribute to the community, in the context of help from family, consideration of causal factors and broader societal stigma.

Findings are broadly concordant with prior findings linking hearing loss with communication difficulties, social interaction challenges and social isolation (Strawbridge *et al.*, 2000; Dalton *et al.*, 2003; Pronk *et al.*, 2011; Mick *et al.*, 2014; Andrade *et al.*, 2018; Maharani *et al.*, 2019; Loughrey *et al.*, 2021).

Our findings extend these findings by suggesting potential mechanisms through which hearing loss might impact social interaction: participants describe their difficulties in following *conversations* (particularly in group settings), *lack of accommodations* they experienced from others, a decline in *motivation* to engage socially and active *avoidance of social occasions*. Participants also described their efforts in the face of reduced motivation to engage (*see arming oneself*). These themes echo the concepts of disengaged and engaged coping reported previously (Heffernan *et al.*, 2016). In discussing these themes, Heffernan *et al.* draw the distinction between valuable social interaction time, in which the participant is engaged and communicating successfully, and less-valuable social interaction time in which the participant is withdrawn. Our theme of arming oneself was approximated by multiple other themes (controlling the environment, instructing others, asking for repetition) established from analysis of data in a Swedish sample (Hallberg and Carlsson, 1991). The impact of hearing loss on one's *job* was also identified as a key concept in Hallberg's theory (described as 'career hindrance').

Stigma also arose as a contextual factor in learning about one's hearing loss. Stigma was previously shown to be a key factor influencing decision-making in adults with hearing loss (Wallhagen, 2010) and cognitive representations akin to stigma were previously reported (Heffernan *et al.*, 2016). Participants all made reference to potential causes of hearing loss, and one expert participant in Heffernan's study suggested that individuals with hearing loss may be 'fixated' on the cause of their hearing loss, in an unhelpful manner (Heffernan *et al.*, 2016). The gradual nature of hearing loss reported in this study was also reflected in a theme in Heffernan's study (Heffernan *et al.*, 2016). While participants in Heffernan's study reported that their hearing loss had a negative effect on their close interpersonal relationships, participants in the current study mostly reported that while hearing loss affected their broader social engagement levels, they were for the most part reliant on, and happy with, their family relationships (*see family advocates*). Close relationships appeared to offer our participants a context in which they could develop strategies for coping with hearing loss in social situations. Beyond family and close friends, our participants found that the help they needed was seldom offered or to be found from society more generally (*see lack of accommodations*).

Participants were users of hearing aids (or cochlear implants, in the case of one woman). As stated, it is relatively unusual for an older adult to receive a cochlear implant, although it seems to be becoming more common (Lin *et al.*, 2012). Participants had a lot to say about the use and misuse of hearing aids. For instance, participants indicated that health-care professionals often did not adequately explain the use of hearing aids (*see feeling rushed*) and all recommended that new users be trained to use their hearing aids by existing users of hearing aids (*see getting help from users*). Such a process (*helping others*), they suggested, could create a virtuous feedback cycle that would improve life for new hearing aid users in the future (*see helping others*). This informal support system is a critical community resource that needs to be evaluated in other populations and supported formally if required.

One participant had a cochlear implant. This was not established until she had already begun her interview. Her data were compared with the data of the other participants and considerable overlaps were established, leading to the decision

to retain her data. However, it is possible that other cochlear implant users face unique challenges that are not captured by the current theory. This is also suggested by previous research which showed that cochlear implant but not hearing aid use led to reduced levels of loneliness in adults aged over 50 (Contrera *et al.*, 2017).

Since *cognitive functioning* is a critical consequence associated with ARHL, we specifically asked participants about their insight into this link. Interestingly, none of the participants reported that they felt their cognitive functioning was affected by ARHL. However, participants did suggest that indirect pathways might exist between ARHL and cognitive functioning: via inattention, via frustration and via failure to encode information ('missing things'). These pathways warrant further study. We have found elsewhere that ARHL exerts an indirect effect on cognitive outcomes via social activity engagement (Loughrey *et al.*, 2021). Results of this quantitative analysis revealed no direct effect of subjective ARHL on episodic memory, but indicated that some indirect effect was driven by social activity engagement. While our results may not be generalisable, the findings of (a) no direct association between subjective ARHL and memory and (b) the discovery of an indirect effect via social engagement in our previous publication (which was based on data obtained from a nationally representative cohort) are compatible with our current findings.

We used an inductive approach to yield a theory grounded in data, in order to explain how older adults with ARHL cope with social functioning challenges. Against the background of contextual factors (family context, stigma and thoughts about causes of hearing loss), the theory presents a linear process whereby participants gradually become aware of their hearing loss, receive a diagnosis from a stressed health-care system (feeling rushed) and feel the impact of their hearing loss in many ways (occupationally, emotionally, socially, psychologically but not cognitively). Having experienced these impacts, participants arm themselves with information to help cope with their ARHL, as well as utilising support from others with hearing aids and from family (and in some cases, receiving a lack of support from society more broadly). Ultimately, most participants accepted ARHL, often sought out others with hearing loss for support and felt motivated to help new hearing aid users. This theory is a broadly positive description of coping with ARHL, and participants were for the most part positive about their situations and about their ability to cope with the challenges that their hearing loss presented for their social functioning. However, qualitative research is not typically aimed at generalisability, and as a result we cannot extrapolate from our findings to the broader hearing loss population. Indeed, we acknowledge that social context can shape and alter social mechanisms (Hedström and Ylikoski, 2010). It is possible that those with no links to advocacy organisations did not receive the level of help with their hearing aids typical of our participants. This organisational context may thus have spawned the positive narrative presented in the current analysis. Further research could attempt to replicate this theory with older adults who either do not use hearing aids, or with those who use hearing aids without the support of others with hearing aids. We could suggest, based on our findings, that those who do not receive support from advocacy organisations or who cannot advocate for themselves may be at risk of failing to move towards a stage of reconnecting to others, since they would be less likely to receive help from other users of hearing aids and have fewer opportunities to give this help to others in the future. It is

critical, therefore, for advocacy organisations to consider what they can do to reach out to older adults with hearing loss who may not be in a position to advocate for themselves or to receive social support in other ways.

Grounded theory is a methodology aimed at developing theories of behaviour, particularly in social contexts (Glaser and Strauss, 2009). We have described a theory that explains how older adults respond, in social contexts, to loss of hearing and subsequent use of interventions for that loss. Theory development is critical for population health to progress but theories must be evaluated, *e.g.* by criteria previously set out (Carpiano and Daley, 2006). Using these criteria, our theory is logical, contains statements about causality, is falsifiable and stipulates clear implications. However, its scope is limited to a relatively small phenomenon: those experiencing ARHL who seek interventions. As such, as a theory it has limitations, and may require further refinement. The theory described here might better be termed an identification of possible causal mechanisms or feedback/feedforward processes with contexts (Westhorp, 2018), linking the event of experiencing ARHL to the possible outcomes of acceptance, seeking to help others and enjoyment of sound (in the context of societal stigma, family support and causes). Although qualitative and quantitative triangulation is always helpful, modern case-based qualitative designs, such as causal process tracing (George and Bennett, 2005), might offer a tractable approach to test our theory deductively.

Study limitations

The study is not without limitations. Grounded theory methodology specifies that data are collected until theoretical saturation is achieved. Almost every theme we report had data from all six of our participants. No new themes were emerging from our data by the time that we stopped data collection. However, we acknowledge that our sample size is, compared to other (mostly deductive) studies, quite small, at six participants. Additionally, we base our evaluation of saturation on potentially redundant principles, given more recent developments in quantification of sampling in qualitative research (Lowe *et al.*, 2018).

Furthermore, participants were recruited via advocacy organisations. Both organisations offer additional services (such as community support services, befriending services, hearing aid support services, social support groups, aural rehabilitation classes and hearing loss workshops). Thus, they had a relatively high level of social engagement and, consequently, results should not be taken as generalisable to the broader hearing loss population. In any event, this is not the intention of small-sample, qualitative studies. The theory developed from the data needs further confirmatory deductive research.

The team lead and research assistant were both psychologists, with an interest in social isolation and loneliness in the ageing population. It is possible that bias arose in the data interpretation because of their experience in this area. For instance, the lead researcher (JMCHP) had conducted previous qualitative explorations into loneliness in later life, in which ARHL was mentioned by participants as a cause of loneliness, and some degree of loneliness was expected in the current sample as a result. Furthermore, because of the team's prior work establishing a link between hearing loss and cognitive functioning (Loughrey *et al.*, 2021), it was anticipated

that this link would be borne out in the qualitative findings too, although this was not found. It may be important to note that two of the authors have either personal or immediate familial experience of deafness (rather than ARHL), which in part drove their interest in the topic.

In offering a theory or set of processes through which ARHL can impact important outcomes for older adults, the current study yields many suggestions for future research. We propose that many testable hypotheses can be derived from our theory, and that approaches like causal process tracing can help to test our theory further. Deductive qualitative approaches (Gilgun, 2014) can also help to refine the existing theory in broader hearing loss populations and extend the theory's scope in this manner, to satisfy further the criteria set out by Carpiano and Daley (2006). Service delivery implications can also be drawn from the current findings. As above, services aimed at helping older adults with hearing loss should consider those who are less able to engage with such services, including potentially older adults with cognitive impairment or non-native English speakers, and make special attempts to reach these people to help them manage their hearing loss. Employers should be cognisant of the negative impact that hearing loss can have on job performance, and make efforts to support employees experiencing these issues to help them to avoid premature (unwanted) departure from the workforce. Staff in audiology clinics should be aware that patients may feel rushed through the process of a diagnosis of hearing loss, and make efforts within the usual resource constraints to give patients as much time as possible. Advocacy organisations offer services to older adults with hearing loss in a hospital context, such as an appointment liaison who can attend hospital appointments with the older adult. It is likely that such services are used by individuals already linked in with such services and thus past the point of diagnosis. As such, advocacy organisations could make special efforts to advertise such services for individuals before the point of diagnosis.

Since helping others with their hearing loss and hearing aid use was described as a source of accomplishment and joy to participants, advocacy organisations should make efforts too to encourage their members to help new members.

In conclusion, we describe a grounded theory of the process of reconnecting to others following diagnosis of ARHL and subsequent uptake of interventions (hearing aids or cochlear implant). No link between hearing loss and cognitive decline was experienced by participants, but significant impacts on social and emotional functioning were reported. The theory yields testable hypotheses to be evaluated in future confirmatory research.

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