

“When that understanding is there, you work much better together”:

The Role of Family in Audiological Rehabilitation for Older Adults

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Abstract

Objective: This study aimed to explore the experiences and perceptions of adults with hearing impairment and family members regarding the role of family in audiological rehabilitation.

Design: A qualitative descriptive methodology was used.

Study Sample: A total of 37 people participated, 24 older adults with hearing impairment and 13 family members (11 spouses and 2 adult children) Four focus group interviews were conducted with the adults with hearing impairment, and 3 with family members.

Results: Five key themes emerged from analysis of the transcripts: (1) knowledge and understanding of hearing impairment and treatment; (2) the role of family members in rehabilitation is complex and multifaceted; (3) audiologists have an influential role in facilitating family member involvement; (4) the role of communication in rehabilitation; and (5) outcomes of family member involvement. Importantly, although perceptions were generally very positive, there was some uncertainty about the role of family.

Conclusions: Audiologists have a key role in facilitating family involvement in audiological rehabilitation that is identified by adults with hearing impairment and their families. Although participants reported limited involvement in audiological rehabilitation currently, they identified potential for involvement in areas such as goal setting and decision-making.

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The Role of Family in Audiological Rehabilitation for Older Adults

Hearing impairment (HI) is one of the most common chronic health conditions experienced by older adults worldwide and fitting of hearing aids is the most common approach to managing HI. The evidence is that if adults with HI accept and wear hearing aids, then they experience improved audibility of sound, fewer communication difficulties, and improved quality of life (see reviews by Ferguson et al, 2017; Humes & Krull, 2012). Despite the benefits of hearing aids, however, a study in Australia showed that only a quarter of older adults with hearing loss own and use hearing aids (McMahon et al, 2013). Research exploring the barriers and facilitators to hearing aid use has highlighted the significant role of family members in the audiological rehabilitation process, including successful hearing aid outcomes. Family members are often the primary reason why adults with HI seek help for their hearing difficulties (e.g., Laplante-Lévesque et al, 2010, 2011; Wallhagen 2010), and older adults are more likely to seek help for hearing difficulties if they perceive their family members are supportive of hearing aids (Meyer et al, 2014a). In addition, older adults with HI who have more positive support from family members are more likely to be successful hearing aid users (Hickson et al, 2014; Meyer et al, 2014b).

In addition to providing support for the adult with HI, it should be recognized that family members may also be affected by the HI, highlighting yet another reason to include family in the rehabilitation process. Due to the two-way process of communication, it has been shown that family members may share in the hearing disability by experiencing “third-party disability” (Kamil & Lin, 2015). Third-party disability occurs when, although the family member does not

have a HI, they experience activity limitations and participation restrictions as a result of their significant other's HI (WHO, 2001). Such disability has been described by spouses of people with HI (Preminger & Meeks, 2012; Scarinci et al, 2012) and by adult children of people with HI (Heacock et al, 2018).

Given that family members are important for successful outcomes in audiological rehabilitation and may experience third-party disability as a result of their significant other's HI, there is a need to address the role of family. Although traditionally applied in pediatric healthcare, family-centred care (FCC) can be readily applied to adult audiological rehabilitation (Scarinci et al, 2013; Hickson, 2019). In FCC, the interrelated nature of family relationships is acknowledged, and therefore, both the needs of the adult with HI and the family are considered in any intervention (Epley et al, 2010; Meyer et al, 2019). The potential benefits of FCC in this context are that it could improve the uptake of interventions such as hearing aids, improve outcomes of device fitting, and address the needs of family, especially through joint goal setting.

Unfortunately, evidence to date suggests that family may have limited involvement in adult audiological rehabilitation and the reasons for this are complex. In an observational study of 63 initial audiology consultations, Grenness et al (2015) reported that family members attended only 27% of appointments. In the 17 consultations where family members were in attendance, family contributed only 13% of the total utterances (51% audiologist; 37% adult with HI) (Ekberg et al, 2015). Conversational analysis of these interactions indicated that this limited participation was a result of audiologists frequently directing conversation back to the adult with HI. It was clear from the analysis, however, that the adults with HI frequently identified their family members as being important participants in clinical interactions. Similarly positive views

about the importance of families have been expressed by hearing care professionals. Meyer et al (2015) reported audiologists' perceptions that by promoting a partnership with both adults with HI and their family members, they could develop a shared understanding and responsibility for managing the HI, and therefore improve rehabilitation outcomes. Audiologists did however identify some barriers to family involvement including clinical time, misconceptions about hearing aids, mismatched needs and priorities, and family dynamics.

Although this series of studies has provided insights into the role of family and the perceptions of hearing care professionals, the views of adults with HI and family members have yet to be explored. Therefore, in this study we aimed to investigate the experiences and perceptions of adults with HI and family members regarding the role of family in audiological rehabilitation.

Materials and Methods

This study employed a qualitative descriptive methodology utilising focus group interviews with older adults with HI and family members (Patton, 2002). Focus group interviews were selected as the most suitable method for the participants to discuss a topic about which very little is known, and to generate new ideas and insights in an interactive group situation (Kitzinger, 1994).

Participants

Participants were recruited through the Communication Research Registry, The University of Queensland, and through newspaper and online advertising. To be eligible for inclusion, adults with HI were required to be 50 years of age or older and have a HI greater than

25dB HTL (better ear frequency average at 500, 1000, 2000 and 4000 Hz). A total of 37 participants were interviewed, consisting of two participant groups: (1) 24 older adults with HI; and (2) 13 family members of older adults with HI.

Older adults with hearing impairment (n = 24). Participants with HI ranged in age from 63 to 85 years ($M = 74$, $SD = 6.67$), and consisted of 16 males (66.66%) and 8 females (33.33%), with the majority ($n = 19$; 80%) living with a spouse or partner. Adults with hearing impairment had on average a mild-moderate hearing loss, ranging from 27.50 to 62.50 better ear HTL ($M = 40.73$, $SD = 10.19$). Seventeen adults with hearing impairment (71%) wore hearing aids, with the most common hearing aids being bilateral behind-the-ear devices which were typically worn more than 4 hours per day (15 of the 17 participants).

Family members of older adults with hearing impairment (n = 13). The 13 family members were 11 spouses, one adult child, and one flatmate, and consisted of 11 females and 2 males, who ranged in age from 34 to 77 years ($M = 63.46$, $SD = 11.86$). All family members had normal hearing, with better ear HTL ranging from 5.00 to 31.25dB HTL ($M = 14.90$, $SD = 6.54$). See Table 1 and Table 2 for a summary of individual participant demographics.

[Insert Table 1 near here]

[Insert Table 2 near here]

Procedure

Permission for this study was obtained from The University of Queensland's Behavioural and Social Sciences Ethics Review Committee (2011000857) and written informed consent was obtained from each participant. Separate focus group interviews were conducted with each participant group. Older adults with HI participated in 1 of 4 focus groups; and family members participated in 1 of 3 focus groups. Focus group interviews were conducted in community locations, lasted between 82-110 minutes (mean = 94.14; SD = 9.71), and were moderated by the first author (NS) with assistance from the second author (CM). During the focus groups, participants were asked to discuss: (a) their prior experiences with hearing services; (b) the current role of family members in rehabilitation; (c) the potential role of family members in rehabilitation; and (d) potential strategies for involving family in rehabilitation. The same interview guide was used for both the client and family member focus groups to ensure consistent data was collected, and that relevant topics were addressed in each focus group in a neutral manner to avoid biasing responses (see supplementary material). Open-ended questions were adapted depending on the individual focus groups in order to encourage a conversation-style interview (Patton, 2002). The researchers concluded interviews when all relevant information on the topic had been expressed and the participants verified that they had nothing further to add.

Data Analysis

Focus group interviews were audio and videorecorded, and transcribed verbatim by a professional transcription service. Information that might potentially identify participants or service providers was subsequently removed from the transcript; general labels (e.g., person with hearing impairment [PHI], family member [FM], hearing service, audiologist) were used to

replace the names of people, service providers, and places. The interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006). An inductive approach identified and analysed patterns within the data such that themes were sourced directly from the interviews (Patton 2002). Firstly, the first and second authors (NS and CM) read each transcript several times to familiarise themselves with the data and to gain a general sense of participants' experiences. An open coding approach (Strauss & Corbin 1998) was then adopted to systematically examine the data set and generate initial codes. Related codes were then collated into categories and potential themes, with each theme and category reviewed against the entire data set to ensure they reflected an accurate interpretation of participants' experiences. To ensure rigor and agreement in the data, all investigators reviewed and refined the codes, categories, and themes at regular research meetings, with data collection continuing until saturation of the data occurred (Braun & Clarke 2006; Patton 2002). On the basis of these discussions, a written summary was sent to participants for verification (Krueger & Casey 2000). Participants were invited to add, change, or remove information, and to confirm that the summary reflected their discussions and perceptions of family member involvement in hearing rehabilitation. Eleven adults with HI and eight family members returned the verification summary (51% response rate), with all participants indicating overall agreement with the summary.

Results

Five themes emerged which captured the experiences and perspectives of older adults with HI and family members regarding family member involvement in audiological rehabilitation. Tables 1 to 5 in the supplementary material provide a summary of each theme and subthemes, as well as additional example participant quotes.

Theme 1: Knowledge and understanding of hearing impairment and treatment

Devaluing the impact of hearing disability. It was apparent from the focus group interviews that in some cases, both parties devalued the impact of the hearing disability. Adults with HI reported that their family members did not take their hearing disability seriously, especially in comparison to other medical conditions: *“If I had a physical disability or say I lost my sight, you’d be all over me helping me. With a hearing disability, it’s ‘you silly old goat’”* [PHI07]. The family participants confirmed this observation: *“I don’t think hearing is something to particularly be worried about. If you say you can’t hear it, it’s not life threatening”* [FM01]. Other family members, however, identified that hearing disability should not be valued any less than other health conditions: *“It’s a lot like if my Dad had cancer, I’d be there straight away and say ‘I want information on what’s going on.’ It’s very similar”* [FM13].

Hearing disability is a shared responsibility. Both participant groups discussed the need for a shared responsibility in managing the hearing disability and subsequent communication difficulties. One adult with HI shared his frustration over family members not taking responsibility for communicative exchanges: *“The frustration for the people that you really care about ... when you feel they’re not taking the extra step expected they would”* [PHI21]. Some family members acknowledged that they had not taken enough responsibility for managing the HI: *“I’m probably not as helpful as I might be at home. I know I shouldn’t speak to him from another room, but I will sometimes, and he gets up and comes to hear what I’m saying”* [FM06]. On the other hand, some family members expressed concern that they were the ones taking all the responsibility for managing the HI: *“He had the problem and therefore I had to do everything towards fixing that problem and helping with that problem. Whereas, there is*

responsibility on the person themselves to be coming part way with that. It should be a partnership. If I'm helping you, you help me situation" [FM01]. This concept of shared responsibility extended to the need to jointly seek help for the hearing disability: *"It wasn't 'There's something wrong with you. Get your butt down there and get some hearing aids and get on with your life.' It was, we're doing this together"* [PHI02].

Desire for empathy and understanding. Both participant groups expressed a desire for increased empathy and understanding about the impact of the HI: *"I've been telling them for years I've got poor hearing ... but the real thing we're looking for is empathy from them [FMs] ... so they understand"* [PHI07]. Adults with HI emphasized that *"you don't want pity"* [PHI23] and *"you want empathy, not sympathy"* [PHI21]. Importantly, family members also expressed a desire for increased empathy and understanding because *"we all have problems with them too ... them not being able to hear us"* [FM01].

Family members are technology-focused. It was clear from both participant groups that family members are technology-focused, and strongly encourage the use of hearing aids. Adults with HI commented on the constant reinforcement they received from their family in regard to use of hearing aids: *"Do you have your hearing aids in yet?"* [PHI16]. This focus was confirmed by the family participants who reported they often "encouraged" the adult with HI to wear their hearing aids: *"I say to him if he's doing something 'Have you got your ears in?' ... I need to teach him to persevere"* [FM03]. Family members not only encouraged the regular use of hearing aids, but also encouraged the adult with HI to attend regular audiology appointments to ensure the technology was functioning effectively: *"Look you're not hearing too well. Go and get those things adjusted"* [PHI17]. One family member reported that she regularly verified the

effectiveness of the hearing aid with her husband: *“Are you happy with these hearing aids? And he says ‘Probably not’, and I say ‘Well let’s go back, righto, I’ll make an appointment”* [FM07].

It was also clear that family members had an expectation that hearing aids would resolve all communication difficulties, and therefore often blamed the technology for any ongoing communication breakdowns. Family members also expressed a belief that hearing aids were a simple solution and they did not understand why the adult with HI did not feel the same: *“I can’t conceive of not having an ability that could be fixed with something fairly small that would encourage me to be able to enjoy life a bit better and communicate, and not taking up that opportunity”* [FM01].

In addition to hearing aids, participants discussed the role of other forms of technology, including assistive listening devices. Family members described how they encouraged the adult with HI to use all available technologies, including captions for the television, headphones, and hearing loops: *“You’d have to nudge him into trying some of the things that were on offer in the theatre ... ‘That one’s much better’ and swapping it into the loop and that kind of thing”* [FM12].

Theme 2: The role of family members in rehabilitation is complex and multifaceted

Family members play a significant role in help-seeking. Both participant groups spoke about the significant role of family in the help-seeking process, with one adult with HI reporting that *“the reason I have hearing aids is because of my wife, because of her prodding, encouragement, however you might to phrase it”* [PHI02]. Family members verified this important role and related their help-seeking to relationship satisfaction: *“We just had to get*

them sorted or else I'll be out of here. I'm not staying married to you when you can't be part of this" [FM12]. Participants also reported that adult children played a role in prompting them to initiate hearing services: *"I was in denial probably, but my younger daughter, she hammered it home"* [PHI01].

There is uncertainty about family member involvement. It became clear that there was a level of uncertainty about the notion of family member involvement in rehabilitation. Before participating in the study, a surprising number of adults with HI had not previously considered involving their family in hearing rehabilitation, with participants reflecting during the study about how to best approach this situation. This especially applied to participants who did not have a partner and whose closest family member was an adult child: *"I think that maybe because I'm on my own (I didn't consider involving family) but my son and daughter and partner and daughter-in-law, they like to be involved"* [PHI14]. For those adults with HI whose family members had been involved in rehabilitation, they reported some initial reservations about whether or not their family would be willing to play a role in the rehabilitation process. The majority of adults with HI, however, expressed a positive attitude towards family member involvement. One adult said: *"When it was suggested that [FM] get involved, I didn't think she'd be terribly interested. I wasn't aware that she wanted to participate and she said 'Yeah I do'. I thought 'Righto, well why not?'"* [PHI02].

Family member involvement requires an individualized approach. Importantly, participants emphasized the importance of taking an individualized approach to family member involvement, with the decision to involve family being made in consultation with the adult with HI: *"I think that just goes back to the husband as to whether he wants or will let you be involved.*

He either wants you to be involved or he doesn't want you to be involved ... If he doesn't think you need to be involved, it's his problem" [FM01]. Some participants had the perception that involvement of family had the potential to undermine the autonomy of the adult with HI. One participant expressed a clear preference for independently managing his own hearing healthcare: *"There was nothing that she could add. I could understand the results. There's no point in having someone there holding my hand"* [PHI13].

There is inconsistency in family member involvement. For those participants who had experience with family members attending audiology appointments, there were varied reports regarding the level of family involvement. Some reported that family members were actively involved in all aspects of the rehabilitation: *"We're very happy with the one we go to ... she involves us. I always go and have my two little cents worth"* [FM07] and *"It included both of us. When I asked the question, he [audiologist] spoke to both of us because we were sitting beside him"* [FM12]. The majority of participants however reported that family involvement was minimal: *"Probably not terribly [involved]. I was there, but just observing I guess"* [FM09]. One family member reported that *"They [audiologist] were a little surprized that I was there in the first place, and secondly, that I had a question to ask about it"* [FM12].

Family members play a significant role in decision-making. In addition to expressing a general preference for family involvement in audiological rehabilitation, participants also referred to the significant role of family in the decision-making process: *"They (adult children) are involved in my life decisions and I'm involved in theirs too"* [PHI14]. A number of participants also discussed the importance of family member input given the financial cost of hearing aids: *"I felt weak at the knees at the price of them (hearing aids) ... so we talked about it"*

and I said to him 'Look, I want to tell you straight away that if we pay \$5000 for two hearing aids, you're wearing them' and that's what he did" [FM12]. Other participants referred to the support of family in financing hearing aid purchase: *"She is totally supportive ... I said to her '\$8000', she said 'Mum, I'll pay for that' and that's the truth. I don't need her to [pay], to be honest, but there is that support in that"* [PHI14]. Importantly, however, not all participants saw the need for family input in decision-making, especially those participants who independently managed their own healthcare decisions: *"I mean I'm an independent person. I don't need input from anyone else"* [PHI13].

Theme 3: Audiologists have an influential role in facilitating family member involvement

Central to discussion about the role of family was the role of audiologists in involving family members in audiological rehabilitation. Adults with HI expressed the belief that family members sometimes *"listen to every other person out there, good and bad ... so the audiologist has a very commanding opportunity"* [PHI24] to involve family members in all aspects of rehabilitation.

Encouraging family member attendance. Adults with HI suggested that audiologists should *"Tell them (family members) to come along where possible and that would be a big step forward"* [PHI24] and *"make it part of a session just like normal ... but it was one where family came along"* [PHI]. Participants also discussed ways in which their current audiologist facilitated family involvement, including organising the appointment and physical space: *"We organized it. She (audiologist) always called us in together. There was always a chair for each of us"* [PHI15]. Interestingly, however, one participant identified time as a potential barrier for audiologists in the implementation of family involvement: *"Commercially, I don't think*

audiologists would have the time. They're out there with their shops paying big rent, you know, that shoppingtown. I don't think they've got the time to be involving family" [PHI17].

Building understanding and empathy in family members. Both participant groups agreed that audiologists help build understanding and empathy in family members: *"I'm thinking they should be like a good GP (general practitioner). They should be maybe coming from a point where they're looking at me [FM] and saying 'She knows absolutely nothing about this. She isn't suffering it. She's not hearing impaired. Maybe I should tell her roughly how it is"* [FM12].

Adults with HI expressed the importance of facilitating this understanding: *"She (family member) should understand what the problem is and then when that understanding is there, you work much better together"* [PHI04]. Educating family about the impacts of HI was also deemed a very strong motivator for family to become involved: *"You said to me, 'How do we get ... our spouses, partners here [at appointments]'. You've got to give them a reason and the reason is, you'll understand him or her better"* [PHI24].

Providing education. Both participant groups identified the important role of audiologists in educating family: *"It would be good to be there to hear the unbiased professional opinion"* [FM13]. Adults with HI and family members discussed the various aspects of education that could be provided, including information about hearing aids *"There's too much money at stake ... you have to prove to me it's going to make a difference"* [FM12] and education about the specific nature of the HI: *"I'm wondering what he hears and why it seems to be sliding a little"* [FM12]. Education was identified as one way of encouraging family members to engage as partners in rehabilitation: *'If they're (audiologists) going to issue one set of rules to one (client with HI) then they need to send it to the other (family member). In writing is a good*

idea because it's like a doctor's appointment. You go outside and you think 'Oh, what did he say about that?' ... And you can always go back to that set of rules" [FM01].

Involving family members in goal setting. Firstly, participants discussed the importance of audiologists gathering information from family members: *"I guess I'd be hoping that I'd be asked what impact actually is on the people around her and the things that I've observed that she can't hear even if she doesn't want to admit it" [FM11].* After identification of the difficulties experienced by both the adult with HI and the family, participants commented on the subsequent involvement of family in goal setting: *"It's not just a little mechanical thing. It's about improving your quality of life and that includes other people around you. It's about educating ... and then saying 'Have a think about how you might improve things at home'" [FM11].*

Theme 4: The role of communication in rehabilitation

Communication strategies: They just don't know. The need to address communication in hearing rehabilitation was identified by both participant groups. Although some adults with HI made reference to their family member's effective use of communication strategies, the majority noted that their family had limited knowledge of strategies that could be used to facilitate communication. Interestingly, the majority of strategies used by family were reportedly used without any formal education or training: *"My wife always answers the phone, and if we're in a group, she knows when I've missed something, she just knows" [PHI13].* The need for communication training was linked to the notion that family members may not understand what it is like to have a HI, and therefore, may not understand the importance of using communication strategies: *"She's (family member) concentrating on what she's doing and she loses the fact*

because with the education, without the experience, she doesn't understand that I'm missing it" [PHI24].

The role of communication training. Participants identified the important role of communication training in the form of both group education and simulated hearing loss sessions: *"A session on communication that dealt with the coping mechanisms, both for the person with the hearing loss and for the members of the family so it's a two-way thing"* [PHI07]. Both participant groups discussed the potential of group education sessions: *"They [audiologist] could have something like this (group discussion) couldn't they ... With the men, well perhaps separately and then together"* [FM08]. Participants also suggested that audiologists consider the use of simulated HI with family members to increase understanding and empathy: *"Say if there was a simulated thing, if they had ear-muffs on and they could only hear 50% and that empathy ... that's what it's like for me normally having a conversation. How do you feel?"* [PHI16] and *"The one question I had to ask of this is 'Can somebody let me hear what the person with hearing loss hears?' because that's where I find it difficult"* [FM11].

Written health information. Participants indicated an overwhelming preference for any communication training to be augmented with written material so they could provide it to other family members who may not be able to attend appointments: *"I'd like to see something in writing to give to my friends and my nieces"* [PHI09] and *"It's more than just telling them. Maybe like with a little sheet, 'Hey listen, these are some tips'"* [PHI07]. Multimedia was also suggested as a means of providing education: *"Maybe if a DVD could be compiled that you could buy or give to your new customer, that he can then say to the family 'Please take this home and read it or watch it and digest it'"* [PHI10]. Participants with HI agreed that their family

members would be open to receiving such material: *“I think it could be helpful. I could imagine my son and daughter and daughter-in-law and grandchildren ... I think they’d be happy to hear it because they’d want to know how can we best help”* [PHI14].

Theme 5: Outcomes of family member involvement

Sharing concerns. A primary benefit of involving family was reported to be that it created a safe forum for voicing shared concerns: *“I think it (family member involvement) allows us to probably verbalise some of the concerns we may have”* [PHI06] and *“Sometimes you’re going along so as that you can have your questions answered ... and maybe reduce the frustration you’re feeling about dealing with it”* [FM13]. Family also discussed the benefits of sharing concerns with the audiologist: *“He wants me to go with him (to the audiologist) and then I just sit and listen, but I ask, I have a store of questions ... we discuss things as a threesome”* [FM08].

Family relationships. Both participant groups agreed that increased family involvement had the potential to improve family relationships. Given the identified tensions that may exist in the context of communication and hearing problems, adults with HI believed that if family were involved, and had an increased knowledge and understanding of hearing disability, there would be *“less frustration in their (family member’s) life, more comfort at home, less clashing ... and for her to understand my frustrations and to satisfy her frustrations, is a very powerful motivation”* [PHI24].

Family support. Participants also discussed the importance of family member participation as a means of facilitating ongoing positive family support: *“If they are involved in*

some way, they could make your coping and handling it so much easier” [PHI10]. Family members discussed how, as a result of being involved in the process, they were able to express a positive attitude towards rehabilitation: “I guess you could certainly give him positive feedback. You know straight away that he’s got hearing aids and then you go ‘Hey, these hearing aids are really good Dad. You should have got these a long time ago’” [FM11].

Sharing the emotional journey. Another identified positive outcome of family involvement was the opportunity it provided to share the emotional journey of rehabilitation. In the context of an uncertain outcome, adults with HI described feeling more committed to rehabilitation if their family members were involved: *“It wasn’t so much to do or not to do [get hearing aids], it was whether in fact I would get them and just put them aside, and I think by having her (family member) involved in that method, I felt more – not comfortable, that’s the wrong word – just more committed” [PHI02].* Participants also reflected on the emotional aspects of hearing aid fitting and the benefits of having their family involved in the process: *When he [audiologist] fitted the hearing aid and my husband was sitting there, and I heard him (husband) for the first time, I cried, I honestly cried. I was so happy that I could hear him” [PHI19].* Family members also acknowledged the emotional process of rehabilitation: *“You’re certainly happy that he did hear what was going on ... his emotions that he was going through. He was pretty happy” [FM11].*

Family member involvement benefits everyone. From the perspective of adults with HI, involving family had a number of benefits. Of importance, however, was the notion that *“Getting her (family member) involved was both a wise move politically and a wise move practically” [PHI02].* Family participants discussed a number of benefits of their involvement,

with trust in the process being a key issue: *“I like to go to the appointment with her just to make sure that she’s being completely honest about it as well because she does do that thing where she guesses what’s being said to her”* [FM13]. It also became clear that educating and involving family made the decision-making process and subsequent rehabilitation easier as all parties were “on board”. One family member said: *“He (audiologist) was explaining in a visual way what his hearing loss was ... It didn’t show me where it was gone but it showed me ... what he was missing and I could visualise what it would be like if I couldn’t hear that. So it made it much easier to proceed”* [FM12].

Discussion

Adults with HI and family members identified five themes that encompassed their experiences and perceptions around the role of family in audiological rehabilitation. Overall, both groups of participants acknowledged the potential benefits and positive outcomes associated with greater involvement of family in audiological rehabilitation. However, there were some reservations expressed about exactly what that involvement should be. Further, adults with HI and family identified ways in which audiological rehabilitation can be enhanced by the inclusion of family. In this section, benefits of family involvement, complexities of that involvement and the clinical implications for audiological rehabilitation are discussed.

Participants perceived that family member involvement in audiological rehabilitation would be beneficial because it allowed families to gain knowledge and understanding about the impact of HI and to develop a shared responsibility for managing that impact. The fact that this was identified as necessary may reflect the devaluing of the impact of the HI for both the adult with HI and the family unit. For example, participants in a study investigating hearing help-

seeking by Laplante-Lévesque et al (2011), talked about playing down the effect of their HI on themselves and their families. Evidence from studies on the psychosocial experiences of people with HI and their communication partners indicate that HI has many negative consequences for both parties (see review by Barker, Leighton & Ferguson, 2017) and this supports the need for family to have a role in understanding HI and its impact. Audiologists have also acknowledged the need to address the shared communication impacts of HI and the importance of educating family about HI and its effects (Meyer et al, 2015).

Additional benefits of family member involvement identified in the current study were the support they can provide in help-seeking, decision-making, goal setting, communication training, and hearing aid use. These benefits are in line with the growing body of literature on FCC in adult audiological rehabilitation that has demonstrated associations between family support and taking action about HI and obtaining optimal outcomes as a result of those actions (Laplante-Lévesque et al., 2010; Preminger & Lind, 2012; Meyer et al., 2014a, 2014b; Hickson et al, 2014; Singh & Launer, 2016).

In terms of rehabilitation for HI, family members tended to have a strong focus on the technology, which is not surprising given that hearing aids are the most common form of intervention for HI. In the Manchaiah et al (2013) study of the journey of communication partners through the hearing rehabilitation process, family members also focused their support of the person with HI on the use of hearing aids; however, the family also quickly realized that hearing aids did not necessarily solve all the communication problems. It was encouraging therefore to hear participants in the current study reflect on the importance of communication training within the audiological rehabilitation process, including the provision of written health

information about communication strategies. This is consistent with the emphasis placed on communication management by adult children whose parents had HI in the study by Heacock et al (2019). The implication for clinical practice is that meaningful inclusion of family in audiological rehabilitation goes beyond them merely attending appointments; they should be active participants in communication education. Group rehabilitation programs are likely to be particularly useful in supporting family member involvement (Hickson et al, 2007; Preminger & Meeks 2010).

Another key finding of this study was the uncertainty expressed by adults with HI and their family members about the specific nature of their role in audiological rehabilitation and how family involvement could be implemented. This may, of course, have been because family members have had low levels of involvement in the past (e.g., Ekberg et al, 2015; Grenness et al, 2015) and therefore were not aware of how they might engage. Despite the numerous clinical tools that have been developed to facilitate family involvement in audiological rehabilitation (see examples at www.idainstitute.org; Meyer et al, 2019) and widespread education regarding the use of these tools in audiology training programs, conferences, and professional development events, participants in the present study did not report any instances of such involvement.

Both participant groups discussed the influential role of audiologists in facilitating family member participation throughout the rehabilitation process. A number of recent publications have outlined a range of recommendations for audiologists to maximise family member involvement throughout the audiological process and to manage potential complexities associated with their involvement (e.g., Scarinci, 2020; Singh et al., 2016). Such approaches include encouraging family member attendance at the time of making the appointment,

reinforcing the importance of family members involvement to both clients and family members prior to and during audiology appointments, building understanding and empathy in family, providing education, and involving family in joint goal setting and decision making. Strategies such as discussing the impact of the hearing loss on the family unit, the use of communication strategies around the home, group education programs, and providing written information were all suggestions made by participants in this study. In addition, the concept of jointly setting treatment goals and then sharing decision-making is a fundamental tenet of FCC. Again there are examples of tools that can be used for this purpose, such as the Ida Institute's Goal Sharing for Partners (GPS; Preminger & Lind, 2012), decision aids for adults with HI and their families (Hickson et al, 2016) and the Family Oriented Communication Assessment and Solutions (FOCAS; Crowhen & Turnbull, 2018).

A complexity in the delivery of FCC in adult audiological rehabilitation is the fact that not every participant in the study expressed a desire for family member participation. This is not unexpected and supports the need for an individualized approach to hearing rehabilitation which is consistent with principles of patient- and family-centred care, wherein it is encouraged that intervention planning considers the needs and resources of each patient and family member (Grenness et al, 2014; Hughes et al, 2008). Of further consideration in the context of adult hearing rehabilitation is acknowledgement of patient autonomy and choice (Hughes et al, 2008; Law et al, 1995), specifically with respect to decision-making (Wolff & Roter 2012). It is important that audiologists are aware of the potential conflict that may arise to patient autonomy if the adult with HI and their family members disagree on treatment decisions, something which has been observed during some initial hearing assessment appointments (Ekberg et al, 2014). Therefore, before involving family members in audiological rehabilitation, it is important to

consult with the client to determine their preferences for family member involvement. In addition, at any stage of the rehabilitation process, clients with HI should have the freedom to make their own decisions, supporting the important principles of self-determination and independence (Hughes et al, 2008).

Conclusion

This study has added to our knowledge of the role of family in hearing rehabilitation, from the perspectives of adults with HI and their family members. Findings suggest that there is enormous potential to increase family member participation - a change that is likely to improve outcomes of rehabilitation for people with HI. There is, however, not a 'one-size-fits-all' approach and hearing care professionals should explicitly discuss family involvement with their clients with HI and their families. Although the use of separate focus groups for people with HI and their family members allowed participants to openly share issues relevant to them, future research could integrate their perspectives in joint interviews in order to develop a shared understanding and perspective on family involvement in audiological care.

Acknowledgements:

The authors would like to thank the participants for their invaluable contribution to the study. We would also like to thank Dr Heidi Ham and Mr Paul Bunn for their assistance with participant recruitment. This research was supported by participants from the Communication Research Registry, School of Health and Rehabilitation Sciences, The University of Queensland. This research was funded by the HEARing CRC, established under the Australian Government's Cooperative Research Centers (CRC) Program. The CRC Program supports industry-led collaborations between industry, researchers, and the community.

Declaration of Interest Statement:

The authors declare no conflicts of interest.

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Table 1.

Individual Participant Demographic Information: Adults with Hearing Impairment

Participant ID	Gender	Age (years)	Better ear pure-tone average* (dB HTL)	Hearing aid #	How often hearing aids are worn
HIP01	Male	79	46.25	Unilateral BTE	Sometimes
HIP02	Male	66	33.75	Bilateral BTE	Often (4-8 hours/day)
HIP03	Female	68	32.50	None	N/A
HIP04	Male	74	58.75	Bilateral BTE	Never
HIP05	Male	66	35.00	None	N/A
HIP06	Male	68	35.00	None	N/A
HIP07	Male	63	42.50	Bilateral BTE	Always (> 8 hrs/day)
HIP08	Female	75	31.25	Bilateral BTE	Always (> 8 hrs/day)
HIP09	Female	85	38.75	Bilateral BTE	Often (4-8 hrs/day)
HIP10	Male	76	41.25	Bilateral BTE	Always (> 8 hrs/day)
HIP11	Male	82	40.00	Bilateral BTE	Sometimes (1-4 hrs/day)
HIP12	Female	79	37.50	None	N/A
HIP13	Male	72	53.75	Bilateral BTE	Always (> 8 hrs/day)
HIP14	Female	73	30.00	None	N/A
HIP15	Female	84	51.25	Bilateral BTE	Always (> 8 hrs/day)
HIP16	Male	85	62.50	Bilateral BTE	Always (> 8 hrs/day)
HIP17	Male	80	57.50	Bilateral BTE	Always (> 8 hrs/day)
HIP18	Female	80	31.25	Bilateral BTE	Always (> 8 hrs/day)
HIP19	Female	73	31.25	Unilateral BTE	Always (> 8 hrs/day)
HIP20	Male	70	27.50	Unilateral ITC	Never
HIP21	Male	63	42.50	Unilateral BTE	Often (4-8 hrs/day)
HIP22	Male	74	28.75	None	N/A
HIP23	Female	70	50.00	Bilateral BTE	Seldom (< 1 hr/week)
HIP24	Male	71	38.75	Bilateral BTE	Often (4-8 hrs/day)

Note. * Average from test frequencies .5, 1, 2, and 4 kHz

BTE = behind the ear, ITC = in the canal

Table 2.

Individual Participant Demographic Information: Family Members of Adults with Hearing Impairment

Participant ID	Gender	Age (years)	Better ear pure-tone average* (dB HTL)	Family member role
SO01	Female	66	15.00	Spouse
SO02	Male	68	13.75	Spouse
SO03	Female	77	31.25	Spouse
SO04	Female	65	13.75	Spouse
SO05	Female	57	11.25	Spouse
SO06	Female	66	16.25	Spouse
SO07	Female	72	16.25	Spouse
SO08	Female	70	15.00	Spouse
SO09	Female	72	13.75	Spouse
SO10	Female	69	18.75	Spouse
SO11	Male	45	5.00	Flatmate
SO12	Female	64	18.75	Spouse
SO13	Female	34	5.00	Daughter

*Note.** Average from test frequencies .5, 1, 2, and 4 kHz

