

# Adult Children's Perspectives on Their Role in Their Parent's Hearing Healthcare Processes

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## Abstract

**Background:** Communication partners play an important role in the hearing healthcare (HHC) process of the person with hearing impairment (HI). However, present research focuses mainly on the role of the spouse; the role of the adult child is often overlooked or understated.

**Purpose:** The aim of the study was to describe the role of the adult child in the HHC process of a parent with HI.

**Research Design:** Using a qualitative study design, participants described their role in their parents' HHC process and the impact of a parent's HI on their relationship and communication in individual semi-structured interviews.

**Study Sample:** Twelve adult children of ten parents with HI participated; two sets of siblings were included to gain different perspectives on the HHC process within the same family.

**Data Collection and Analysis:** Thematic analysis, a qualitative method to explore participant's perceptions and viewpoints, was used as the method of analysis.

**Results:** The superordinate theme discussed most frequently by participants, communication management, was bolstered by three ideas or pillars: facilitating HHC, communication strategies, and encouraging hearing aid use. Adult children saw themselves as advocates or supporters of their parent's HHC by taking an ongoing and active role in promoting successful communication rather than a role in directing their parent's HHC actions. Within each pillar of communication management, participants' perceptions and actions were modulated by the varying levels of effort and a desire to ask questions to better understand how to help their parent, which in turn influenced their awareness of the HI and HHC options, often resulting in the adult child putting forth new effort.

**Conclusions:** Whereas the patient journey is often presented to the patient as a linear process, the adult children instead viewed the process of communication management as an ongoing and continuous cycle. The audiologist should be encouraged to involve adult children in the HHC process, as adult children play an important role in everyday communication management.

**Key Words:** adult children, auditory rehabilitation, communication partners, HHC, HI

**Abbreviations:** CP = communication partner; HA = hearing aid; HBM = Health Belief Model; HHC = hearing health care; HI = hearing impairment; PHI = person with hearing impairment

## INTRODUCTION

**F**amily-centered care within adult auditory rehabilitation entails a collaborative relationship

between the clinician, the patient, and the family; in such a partnership, there is respect for expertise, open communication, and trust among all participants (Scarinci et al, 2013). In family-centered care, it is incumbent on the

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audiologist to consider individuals with HI (hearing impairment) and his/her family members “as partners in the planning, execution, and monitoring of treatment” (Singh et al, 2016). Spouses and adult children are the typical family members brought to clinical appointments, although sometimes other family members or close friends are included; thus, we typically refer to these individuals as communication partners (CPs). Thus, family-centered care for adults with HI and their CP would include shared acknowledgment of the communication problems, collaborative goal-setting, instructional management counseling, and the development of communication strategies beneficial to parents and adult children (Scarinci et al, 2013; Singh et al, 2016). Care may be tailored to each member of the affected family to maximize involvement. The level of involvement from CPs is central to increasing social support and corresponding HA (hearing aid) uptake on the part of the parent.

Several studies have considered the role of CPs in the uptake, use, and satisfaction of HHC (hearing health care). For the purpose of this article, we define HHC as a holistic approach to management of HI that may include sensory management, instruction, coaching, training, and counseling with the intent to improve communication and quality of life for both the person with HI and frequent CPs (Boothroyd, 2017).

CPs are important advocates for the uptake of HHC services. When asked who was the motivating force in seeking out services at an audiology clinic, many adults reported that it was someone other than themselves that persuaded them to schedule a visit (Mahoney et al, 1996). In fact, 46 of 91 participants reported that a family member convinced them to seek help. In most of the cases, the family member was a spouse ( $n = 29$ ), followed by an adult child ( $n = 14$ ). We can look to health psychology to understand why CPs are important motivating forces in the uptake of HHC and to gain a better understanding of family-centered care.

An important framework for examining health psychology is the Health Belief Model (HBM). The HBM attempts to explain why only some individuals are successful in taking action to manage a chronic health condition (Rosenstock et al, 1988). One of the mechanisms that may lead to the uptake of HHC is a cue to action, which is frequently described as encouragement by a physician or social support by a frequent CP (van den Brink et al, 1996) to either promote behavior change or maintain it. van den Brink et al (1996) developed and administered the Attitude to HAs questionnaire, a questionnaire based on the HBM, to three groups of individuals with HI: those who had not taken action to manage their HI, those who had discussed HI with their physicians, and those who were HA users. Individuals who consulted a physician regarding their HI but did not pursue HAs reported less supportive CPs than

those who wore HAs. In addition, social pressure to wear HAs was reported by most of the HA users. Similarly, Duijvestijn et al (2003) and Meyer et al (2014) reported that social pressure from CPs increased help-seeking behaviors and the decision to consult an audiologist.

It is also important to consider that whereas supportive CPs may increase uptake of audiology services, unsupportive CPs (with stigmatizing beliefs about HAs) may actually reduce the uptake of these services (Wallhagen, 2010; Meyer et al, 2014). Wallhagen explored this in a large qualitative study of more than 80 dyads, in which one member was a person with hearing impairment (PHI) aged 60 years and older and the other member was a communication partner. They found that perceived stigma drove many decisions regarding the uptake (or lack of uptake) of HHC. For example, some CPs noted that HI was associated with disability and handicap and that wearing a HA would label their partner as such. Most recently, Schulz et al (2016), using the hearing beliefs questionnaire (Saunders et al, 2013) as a measure of communication burden in a CP, were able to improve prediction of HA uptake. When communication burden that arises from a PHI is measured in a family member, this is also known as third-party disability (Scarinci et al, 2012).

When reviewing social psychology literature, it becomes apparent that caregiving experiences differ depending on the relationship between the caregiver and recipient. In a marital relationship, there may be assumption of providing care. However, there is not necessarily an expectation of caregiving for adult children. Conde-Sala et al (2010) examined caregiver burden in spouses and adult children caring for a spouse or parent with Alzheimer's disease. Caregiver burden was found to be greater in adult children than in spouses and more disruptive of the adult children's lifestyle, especially in adult children living in the same household as the parent. However, high levels of guilt were noted in adult children who did not live in the same household as their parent. This could be due to the differences of the role of the relationship or due to the feeling of obligation to their parent (Conde-Sala et al, 2010). In contrast to considering perceived burden, other studies have looked at the rewarding experiences felt by caregivers. Raschick and Ingersoll-Dayton (2004) found that adult children reported more rewarding experiences associated with caregiving than did spouse caregivers. Lin et al (2012) noted that it is also interesting to consider the gender of the caregiver. Female caregivers reported more positive experiences from caregiving than male caregivers (Lin et al, 2012).

Hickson et al (2014) investigated the influence of social support on the use and reported benefit of HAs in adults older than the age of 60 years using a modified version of the Attitude to HAs questionnaire as

described in an earlier paragraph. The strongest predictor of successful HA use was the positive support from significant others (Hickson et al, 2014). Similar findings were measured in a large retrospective study with the aim to determine whether perceived social support was related to HA satisfaction (Singh et al, 2015). Here, social support was measured with a nondisease-specific scale, the Duke-University of North Carolina Functional Social Support Questionnaire, which includes items such as "I get useful advice about important things in life" (Broadhead et al, 1988). Again, perceived social support was the best predictor of satisfaction with HAs.

Models of health behavior change, such as the HBM, point to the value of social influence in promoting and maintaining successful behavior change. In terms of HI, most research has focused on the role of spouses in promoting the uptake of, use of, and satisfaction with HAs. There is reason to believe that the role of the adult child may be different from that of the spouse. This may occur because of the different nature in relationships among spouses versus adult children (Bengtson, 2001); alternatively, this may occur because most adult children do not live with their parents (Taylor et al, 2010). Nevertheless, no previous research has queried adult children about their perceptions of their role in their parent's HHC. In the present study, we used qualitative methodology to learn about the role of the adult child in their parent's HHC process, with special attention given to the uptake and use of HAs.

## METHODS

The current report discusses findings from a qualitative interview study that included a set of predetermined questions in four general areas (see Appendix). Because of the complexity of the interviews, results are discussed in two parts: the social and relational implications of the HI were published previously (Preminger et al, 2015), and issues related to HHC are discussed in the current report. The methods reported here are equivalent to those reported in Preminger et al, except for the Data Analysis section.

### Participants

Twelve adult children of ten parents with HI participated in the study; two sets of siblings were included to gain different perspectives on the HHC process within the same family. Participants were recruited from electronic "flyers" ( $n = 7$ ), clinic patients ( $n = 3$ ), and word of mouth ( $n = 2$ ). The initial intent was to recruit adults older than the age of 21 years who had a parent with a confirmed HI that was acquired during adulthood; in this way, all parents would have at least some experience with the HHC system. As it happened, all participants

had at least one parent who was a HA owner. The parent of participant six wore a single HA, the remaining parents had binaural amplification. Purposeful sampling was used (Knudsen et al, 2012) so that participants varied in terms of age (22–58 years), gender, and frequency with which they communicated with their parent in person. All participants saw or spoke with their parent at least once per week. No participants with confirmed dementia were included in the study. There was no attempt to vary the sample in terms of education, race (all were white), or income. No data regarding perceived HA benefit, satisfaction, or use from the parents' (HA owner) point of view were collected. Five of the participants were from the NY metropolitan area and the remaining seven were from Louisville or Lexington, KY. See Table 1 for the demographic characteristics of the participants and their parents. Four frequency pure tone averages are included in the table; these are interesting to consider when the adult child discusses his/her parent's HA use (or nonuse).

### Interviews

Semi-structured interviews were conducted by either the second or third author and followed the Interview Guide shown in Appendix. The questions posed to the participants focused on three areas of interest: (a) awareness of the HI, (b) seeking hearing HHC, and (c) the social and relational implications of the HI. The questions relating to the first two topics are the focus of the current report. The findings from the third topic have been published previously (Preminger et al, 2015). Interviews were held at the participant's home ( $n = 3$ ), the participant's workplace ( $n = 5$ ), or the interviewer's workplace ( $n = 4$ ). The interviewers followed the techniques described by Smith and Osborn (2008), in which interviewers initially established rapport, asked questions in an order that flowed naturally from the conversation, and explored pertinent concepts and perceptions raised by the participant with follow-up questions. Interview length ranged from 25 to 75 minutes (mean = 40.8). Interviews were recorded with Roland Edirol R-09HR digital recorders and transcribed verbatim; all transcriptions were verified by the interviewer for accuracy.

### Data Analysis

The original analysis of the transcripts (Preminger et al, 2015) used a double hermeneutic approach in which the researchers try to comprehend the participant's reported perceptions, whereas at the same time, the researchers acknowledge that the participant's perceptions are an attempt to make sense of their lived experience (Smith and Osborn, 2008). In other words,

**Table 1. Demographic Characteristics of Adult Children and Their Parent with Hearing Impairment**

Subject Number	Participant					Parent				
	Age (years)	Gender	Education	Occupation	Driving Distance to Parent	Times Per Month See Parent	Age (years)	Gender	Age HI Acquired (years)	Hearing aid Owner?
1	56	Female	Postgraduate	University librarian	5 min	9	81	Male	50s/60s	Binaural
2	58	Female	Postgraduate	Audiologist	45 min	2.5	82	Female	60s	Binaural
3	40	Male	College degree	Information technology	90 min	2	77	Male	50s	Binaural
4	25	Female	Postgraduate	Medical student	10 min	7	58	Female	40s	Binaural
5	47	Male	Some college	Caregiver (formerly hospitality)	Lives with parent	30.5	79	Female	60s/70s	Binaural
6	22	Female	College degree	Graduate student	6 hours	0.5	58	Male	40s	Left ear
7*	57	Female	College degree	Dental hygienist	1 hour	2	89	Male	60s	Binaural
8*	61	Female	College degree	Retired (former art educator)	15 min	4.5				
9*	58	Female	College degree	Teacher's aide	30 min	13	86	Female	80s	Binaural
10*	56	Male	College degree	Business	45 min	13				
11	28	Male	College degree	Business	30 min	11	60	Female	50s	Binaural
12	42	Female	College degree	Administration	2 hours	2	78	Male	20s	Binaural

Note: \*Subjects seven and eight are siblings, subjects nine and ten are siblings; min. = minutes; RE = right ear, LE = left ear.

this approach uses a two-stage analysis process. In the first-stage, the participants try to make sense of the interviewer's questions (see Appendix); participants are the "experts" of their own lived experience; however, figuring out their perceptions and beliefs is truly a process as many adult children have not considered these perceptions. For example, at the end of the interview with participant four the interviewer asked, "Anything else that we didn't discuss that comes to mind?" The participant responded, "Talking to you brought up more than I realized." In the second stage, the researchers begin to organize and categorize the transcript experts, with the knowledge that the researchers are experts in the associated literature and this can influence the results.

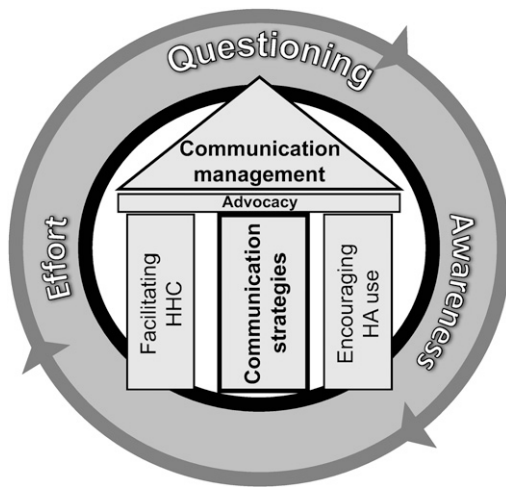
Interpretative phenomenological analysis, as described by Smith et al (1999), was used to discover the themes in the data. Themes are perceptions and concepts that occurred across the transcripts (Braun and Clarke, 2006). Using nVivo 10, QSR International, Melbourne, Australia, <http://www.qsrinternational.com/>, an iterative process was used, in which the authors read the transcripts, assigned codes to transcript excerpts, organized codes into themes and subthemes, and discussed their findings. The authors continually returned to the transcripts to insure that the themes were consistent with the participants' perceptions (Smith et al, 1999). The analysis started after the 2nd transcript was completed and was continuously updated and modified with each subsequent transcript over a 7-month period. This analysis occurred during conference calls and an in-person meeting (Preminger et al, 2015). With each new transcript, new themes were added and the thematic structure was modified. No new themes emerged following the 9th transcript, indicating that saturation had been reached (Guest et al, 2006).

As shown in Appendix, four broad questions were asked. Transcript excerpts related to questions three and four ("social and relational implications of hearing loss" and "hearing loss and other family members") are described in the 2015 article. For the purpose of the present article, techniques described in the previous paragraph (Smith et al, 1999; Braun and Clarke, 2006) were used to reanalyze all transcripts and meaning units related to HI and HHC (transcript excerpts related to questions one and two "first noticing hearing loss" and "seeking rehabilitation for hearing loss"). Then, themes and subthemes were diagrammed and re-diagrammed to visualize and understand their relationships (Miles and Huberman, 1994).

## RESULTS

The primary aim of this analysis was to learn how adult children perceived their role in their parents' HHC, specifically in the uptake and use of HAs. Questions of this nature were included in the interview guide and discussed with all participants (see Appendix). However, analysis of the data provided very little insight into this research question. Whereas the HHC process is typically portrayed in a linear fashion to HHC professionals, beginning with awareness of HI and ending with successful HA use (e.g., Gregory, 2012), this was not the view of the participants. The adult children viewed their role in HHC primarily as communication management, the superordinate theme in the final diagram (as shown in Figure 1).

Further elucidation of communication management can be seen in Figure 1; the three pillars of communication management include practicing effective communication strategies, considering the facilitation



**Figure 1.** A visual representation of the three pillars of communication management and the three modulating factors.

of HHC services (e.g., accompanying a parent during an audiologist visit), and encouraging HA use. A common embedded theme within all three of the pillars of communication management was consistent with the adult child's own advocacy, or purposeful support of their parent's communication management. In the diagram, communication management is enclosed in a circular arrow to indicate that management was viewed as an ongoing process that did not end after obtaining HAs. Visiting the audiologist played only a minor role in this view; instead, the adult children considered the day-to-day steps they took to enable their parent's successful communication.

Communication management is encircled by three additional modulating factors: varying levels of effort, leading to questioning whether the employed communication management was working, and the associated (re)awareness of the HI and HHC options which often led to additional effort. Each of these factors modified or influenced attempts to manage communication and seemed to recur over time. Illustrative meaning units (quotes from the participant transcripts) are displayed in Tables 2–4 and illustrate the relationship between the pillars of communication management and the modulating factors. Of the three-pronged approach to communication management, the approach noted most frequently was the use of communication strategies.

#### **Pillar I—Communication Strategies: “Mom, do you hear what I’m saying?” (Participant 9)**

Recognizing the need for communication strategies, or a plan to improve the exchange of information between a sender and a receiver, was a notable step and an important pillar of the three-pronged approach to communication management. In the above quote,

participant 9 implemented a strategy of ensuring that her parent is following the conversation before moving on to her next point. A review of the transcripts revealed that every participant mentioned at least one communication strategy. Most strategies were discovered by the participants themselves, none of whom mentioned that these strategies were described to them by their parent's audiologist or another family member. The participants did not report attempting to teach his/her parent or other family members specific communication strategies, but rather expressed a desire to intervene and suggest strategies to guests of the parent with HI when there was a noticeable difficulty communicating, such as during a party or gathering. In the following three sections, communication strategies are discussed within the context of the three modifying factors as shown in Figure 1.

#### **Effort**

Participants described the effort, or focused attempt to improve communication, involved in using effective communication strategies, in encouraging consistent HA use and in facilitating HHC. Several participants reported using multiple strategies to improve communication at home (see Table 2, row 1). Participants noted a variety of effortful strategies including repeating information when needed, ensuring that the parent was included in the conversation, and checking to make sure the parent understood what was taking place. Many participants expressed not only the desire to fill in the missed conversation but also a desire to advocate for the parent by thinking of strategies to suggest to those communicating with the parent. For example, participant 3 tried to intervene when guests were over to promote successful communication. She noted that her father wouldn't speak up for himself, so at times she would suggest a communication strategy to the guest: “I want people to be comfortable, so if two people are going to talk, [I] say, ‘look he can't hear very well.’” (Words in brackets were not spoken by participants; they were interpreted by the researchers from context within the transcript.)

#### **Questioning**

Participants noted that much time was spent trying to understand what exactly would be the best way to help the parent understand. In Table 2 row 2, participant 9 discussed her uncertainty in determining whether her mother understood her. Through questioning, or seeking insight or more information about parent's decisions and communication needs, participants were constantly seeking to understand if the parent understood what was being said or whether the communication strategies implemented by the adult child were

Table 2. Representative Meaning Units for the First Pillar of Communication Management, Communication Strategies

Pillar I: Communication Strategies		
1	Effort	So if she's by the sink and the water's running, I'll get really close or tap her on the shoulder to talk to her instead of yelling from another room or trying to talk over. Or I'll lower the TV first before I try to talk to her while she's watching it (Participant 11).
2	Questioning	I'll start off very slowly and repeat, and have her repeat to me because sometimes she just says, "Yes, I understand. I understand," but I'm not quite sure that she has (Participant 9).
3	Awareness	Acceptance of True HI I knew there was something not right. . .she was guessing words that we were saying and I started having to repeat myself again and again and again, and then, it was like, yes, now we've really got to try to do something here (Participant 5).
	Minimizing	We keep the TV lower in the background. If that's on, we'll turn it down low. It's not much of an issue, but that's pretty much it (Participant 4).

Note: \*When participant 10 refers to "we" and "us," he is referring to his sister who is participant 11.

effective. In addition, participant nine continually tried to verify her mother's comprehension (as noted in the section heading) as a means to verify her communication strategies.

Awareness

According to most participants, awareness or the adult children's evolving perceptions of the impact of the HI increased with time. Some participants were not sure if their parent really had a HI or if there was another reason why they had difficulty communicating; this is noted in Table 2, row 3 in the sub-theme acceptance of true HI. In the meaning unit, participant 5 noticed the need for repeated communication strategies that initiated HHC seeking. Some families blamed the TV rather than accepting that their parent truly had a HI. A second subtheme (within evolving attitudes) is minimizing. After accepting that there was a true HI, some participants and family members tried to minimize the HI and the need for HHC. As shown in Table 2, row 3, participant 4 explained that how over an extended period of time (before her father obtained HAs), her family tried to minimize the communication problems that they experienced. Several participants

stated that the family knew that there was a problem, but thought that the severity of the HI did not require professional HHC. In addition, some participants noted that their negative attitudes involving the HI evolved into a discovery of rewarding circumstances after advocating for HA or communication strategy use. Participant 2 describes that she found positive meaning in the emphasis on communication: "The speaker has to focus on the needs of the listener as opposed to just throwing information out there for someone to grab. It truly becomes interactive, as any other educational situation. It's a message being received from the teacher to the student. The teacher's responsibility is to make sure the message is received."

Pillar II—Facilitating HHC: "I don't think it was one necessary event, it was a culmination" (Participant 11)

Most participant's comments related to facilitating HHC addressed their role in helping their parent to recognize the HI and their role in encouraging initial and subsequent visits to the audiologist. In rarer cases, participants discussed attending audiology appointments as

Table 3. Representative Meaning Units for the Second Pillar of Communication Management, Facilitating Hearing Healthcare

Pillar II: Facilitating Hearing Healthcare		
1	Effort	I think the last year and a half, what prompted us to come in and get the hearing aids is we realized that it was getting difficult communicating. She wasn't following us or really wasn't participating (Participant 10).
2	Questioning	I don't think it was one necessary event, it was a culmination. . . I think just after a while I think my dad and brother both suggested it to her several times and it got to a point where, I don't know, maybe she realized that there was something that she should do about it (Participant 11).
3	Awareness	Acceptance of True HI Honestly, I think it started as early as middle school for me, but. . .it didn't seem like true hearing loss, but I would say I probably was 17 or 18 and we tried to get his attention and he wouldn't even notice that, so that's when I think we really encouraged him to go back to the doctor (Participant 6).
	Minimizing	Because, I just don't think it's that bad yet [the hearing loss] (Participant 4).

**Table 4. Representative Meaning Units for the Third Pillar of Communication Management, Encouraging Hearing Aid Use**

Pillar III: Encouraging Hearing Aid Use		
1	Effort	I try to get on him, reminding him to put his hearing aids in if we were going to be in a crowd, or to not have the TV so loud when we're in the room too (Subject 1).
2	Questioning	I need to really extract what the issues are... I really want to understand exactly why she doesn't wear them all the time (Participant 11).
3	Awareness	Hearing Aid Satisfaction Even just the few weeks after him getting the hearing aid, I was calling to check in. How's it going? Are you liking it? What aren't you liking? And it was just easier (Participant 12). Hearing Aid Dissatisfaction It's not what I thought they would be. But, now as understanding them, they are what they are. They are not a replacement to hearing, they are just a, you know, her crutch and, you know, some crutches do better than others (Participant 1).

an active participant or helping their parent to use their HA or practice effective communication strategies.

### **Effort**

Only one of the 12 participants, the son of a widowed mother (participant 10), discussed taking a role in either recommending or scheduling a HHC appointment; see Table 3 row 1. However, several did note the importance of joining their parent at appointments for other health-care conditions to ease communication and provide advocacy. For example, participant 5 described the need for her to be present at her mother's appointments: "[Interviewer] Can she communicate with her caregiver, the physicians, or audiologists on her own? [Subject] I let her talk to her [audiologists and physicians]. I let her converse with them until there's a discrepancy of some sort and then I'll chime in . . . the child has become the parent and the parent has become the child. I'm living it! I hate to say it, I mean she's still Mom, she's still my mom, but I still do everything for her, do all of her appointments and everything."

### **Questioning**

Some participants were unclear as to who initiated the decision to seek HHC (see Table 3 row 2). There was also uncertainty about the benefit of HHC (as noted in Table 2 row 3—both meaning units); however, attending a HHC appointment may have been an important factor in participants' taking the step to facilitating HHC. Participant 10 attended the HA fitting appointment with his mother. His experience allowed him to gain an understanding of the benefits of HA use: "I was here [at the audiology clinic] when we got her examined. I know it [the HA] worked, I mean I saw it, I saw you ask her questions and I knew it was working for her."

### **Awareness**

As participant 11 stated in Table 3 row 3, most participants described a gradual period during which the

family and the participant began to understand and accept that troubles understanding and communicating were truly due to a HI. Participant four also describes a similar experience in Table 3 row 3.

### **Pillar III—Encouraging HA Use: "I need to really extract what the issues are" (Participant 11)**

As noted previously, all parents were HA owners; however, almost every participant commented on the fact that their parent did not wear their HAs at all times. Several participants appeared to struggle with defining their role in encouraging HA use.

### **Effort**

Several participants noted the effort that they made to encourage their parents to wear their HAs by promoting regular use to benefit communication. The example shown in Table 4 row 1 demonstrates an adult child advocating for HA use. None of the participants explained that they felt that they pestered their parent to wear the HAs; some felt that this was more appropriate when coming from the parent's spouse, "but mom will badger him a little bit" (participant 3).

### **Questioning**

Participant 11 explains in Table 4 row 2 (and this section's heading) his concern as to why his parent is not wearing his HAs and would like to understand more to better manage his parent's communication. There are many examples of participants looking for answers throughout the interviews. Another participant believed she was figuring out the reason why her mother did not wear her HAs, and at the same time, she was trying to come to terms with what to do about it. "She doesn't want to lose them. I just kind of give up. I just don't want to battle with her about it, I figure if she doesn't want to wear them it is her choice" (participant 9). Some participants had questions related to stigma and their parent's HA use and others related HA

nonuse to negative attitudes toward HAs. Participant two related her mother's nonuse to stigma and the fear of losing the HAs: "She gets into the church and swish. They came out of her ear because she's afraid to lose them. Then they go into her pocket book. Yet, they were fine in the car; they were fine walking from the home to the car. So, it's probably a little bit of vanity there."

### **Awareness**

There were evolving attitudes about encouraging HA use related to HA satisfaction and dissatisfaction. Some participants noted that both their parents' and their own attitudes toward HA technology grew to be more positive over time. Participants commented that HAs are now smaller, more discreet, less of a nuisance, and that wearing them in social situations is easier and less conspicuous. Perhaps, because of these features, some participants became satisfied with the parent's HAs over time. If the parents are satisfied with their HAs, this also means that less encouragement and facilitation are required from the adult child as noted by participant 12 in Table 4 row 3. Attitudes toward HAs were not without their shortcomings, however. Participant 1 described the limitations of HAs during her interview as shown in Table 4 row 3. Others described an acceptance of the limited benefit provided by HAs, and thus the need for continued communication strategies.

## **DISCUSSION**

Through analysis of the interviews, it was determined that adult children saw themselves as supporters of their parent's HHC by taking an ongoing and active role in promoting successful communication rather than that of a role in participating in or directing their parent's HHC actions. Throughout each of the pillars of communication management, participants' perceptions and actions were modulated by the varying levels of effort that they were willing to take, a desire to understand how to better help and understand their parent's experience, and their increased awareness regarding HHC management. These findings provide a significant level of insight into the motives and mindset behind the roles and beliefs of adult children. In the following sections, we elaborate on the findings described here as they relate to social support and HA uptake, social support and satisfaction and HA use, and the ongoing cycle of communication management.

### **Social Support and HA Uptake**

Social support has been shown to influence successful management of a chronic healthcare condition. As addressed in the introduction, the HBM attempts to ex-

plain the successful management of a chronic health condition (Rosenstock et al, 1988) with a cue to action as an important facilitator to the uptake of health services. As noted in the introduction, other studies have shown that spouses are an important cue to the uptake of HHC (Mahoney et al, 1996; van den Brink et al, 1996).

In the present study, it appeared that the adult children did not consider themselves important cues to action; however, several noted that their parent's spouse did take on that role. Many of the adult children appeared reluctant to encourage entry into the HHC system outright, perhaps because they believe their role is secondary as compared with a spouse in this regard. It should be noted that two of the parents in the study were widowed, and in both of those cases, one of their adult children did serve as a cue to take up HHC. However, we cannot say with certainty that spouses did take a role in promotion uptake of HHC in the other families. In a recent qualitative study, Kanstrup et al (2017) analyzed the views of PHI and CPs about the patient journey toward HA uptake and use. When asked to consider the stages of the journey, some of the PHI noted that the "prepare" phase (acknowledging HI and seeking HHC) was a stage where they would have liked to have more support, whereas none of the CPs noted this as an important stage where more support was needed. In this study, of the ten CPs, eight were spouses and one was an adult child.

### **Social Support and HA Satisfaction and Use**

Although the present study did not measure HA benefit or satisfaction, some participants reported that their parent was satisfied with his or her HA. Several participants noted that they received "benefits" when their parent obtained HAs. They described increased intimacy of the relationship between the parent with HI and the adult child and improved communication ability. These findings are corroborated by several studies: when an adult begins to wear a HA or cochlear implant, CPs have reported decreased communication burden, reduced frustration (related to high television volumes and to HI in general), decreased annoyance related to the need to repeat oneself, less of a need to repeat, increased participation in social activities, and improved communication (Brooks et al, 2001; Stark and Hickson, 2004; Kennedy et al, 2008). The positive experiences described by the adult children in the present study suggest decreased third-party disability following successful HA use by their parent (Scarinci et al, 2012). Whether the experience of the caregiver is a positive one can often depend on the relationship between the caregiver and the parent with HI. Raschick and Ingersoll-Dayton (2004) found that the adult children reported more rewarding experiences associated with



caregiving than did spouse caregivers, although these positive experiences do not come without hard work.

Many study participants reported that despite the benefit provided by HAs, effective communication still requires effort from all parties involved. Participants described the effort involved in using effective communication strategies, in encouraging consistent HA use, and in facilitating HHC. Participants noted a variety of effortful strategies including repeating information when needed, ensuring that the parent was included in the conversation, and checking to make sure the parent was understanding what was taking place. This social support not only helped the parent with HI to communicate better and to feel included but also the adult child reported an increased ability to connect with their parent and gain satisfaction from improving their parent's hearing health. Stephens et al (Stephens et al, 2004) noted that when CPs were asked to report any positive experiences of communicating with a person they knew very well with HI, the most frequently cited response category included the development of patience and tolerance as well as having an understanding and awareness of hearing problems. It is interesting to consider whether adult children experience more positive experiences than spouses related to supporting their parent with HI because in the caregiving literature adult children report more rewards associated with caregiving than spouses (Raschick and Ingersoll-Dayton, 2004). It has been speculated that this may be due to social norms wherein spouses are expected to care for each other; however, when an adult child cares for his or her parent, he or she is exceeding expectations (Raschick and Ingersoll-Dayton, 2004).

Despite some enthusiasm for their parent's HHC experience, some participants reported dissatisfaction, primarily because of lack of consistent HA use. Encouraging HA use was an important theme found in this study; however, some participants left this task to their parent's spouse. Similarly, Scarinci et al (2008) have also noted that spouses can be reluctant to badger their partners regarding HA use. According to Scarinci et al, spouses were reluctant to act from fatigue, whereas in the present study, some adult children were reluctant because of perceived lack of authority or role. In other words, children felt that this was the responsibility of their parent's spouse, rather than their own.

It is interesting to consider whether the limited role that the adult child took in their parents' HA use was related to the limited role that they took in their parents' audiologic appointments. In the present study, the few participants who reported being present at appointments or meetings with the audiologist reported specific benefits of HA use. It is possible that these participants were better able to promote successful HA use as compared with those who did not attend HHC appointments. The presence at appointments could also

give adult children a more accurate view of requirements for successful communication. Adults with HI have reported a desire for increased support and motivation from their CPs in the HHC process (Kanstrup et al, 2017). It is interesting to consider if HA outcomes would improve if CPs were routinely invited to audiologic appointments and included in rehabilitation planning discussions (Singh et al, 2016). The adult children in the present study who did attend HHC appointments found their attendance to be useful; it does not appear that importance of CP involvement in HHC should differ for different types of CPs.

In our small sample of 12 participants, only one lived with his parent with HI and only two of the parents (one of whom had two adult children participating in the study) were unmarried. In those cases, the adult children were more involved in their parent's HHC seeking than for the remaining nine participants. In general, the nine adult children whose parents with HI had spouses perceived that the spouse had more of a role in encouraging and participating in HA adoption and use, as compared with their own. It would be useful to learn if increased involvement by adult children in their parent's HHC improves outcomes for both the adult child and the parent, even when the parent is married.

## Communication Management

A third topic included the perception of the HHC "journey." Although audiologists may see it as such, the HHC process was not found to be a journey with a beginning, middle, and end from the point of view of the adult child. Although adult children could recall a time when their parent had HI, they did not seem to explicitly associate it with a starting or awareness point. This is counter to what has been described in the literature in which the patient journey begins with pre-awareness (e.g., noticing hearing difficulty and managing problems without realizing the HI) and ends with resolution (e.g., Manchaiah et al, 2011). In some cases, resolution indicated an end to the process (e.g., problems satisfactorily resolved), but in other cases, it indicated the beginning of a new process (e.g., identification of new problems). When the journey was investigated from the CP point of view, there was even less of a resolution (Manchaiah et al, 2013). Here, resolution was described as continued difficulties in communication during social situations (Manchaiah et al, 2013). Importantly, a new stage was added to the patient journey model: adaptation, which occurs immediately before resolution. Adaptation included examples such as "exploring new ways of dealing with PHI's communication difficulties" (Manchaiah et al, 2013). In the present study, the adult children described a gradual, ongoing cycle of communication management. This is

similar to the findings of Kanstrup et al (2017), who noted that PHI and CPs viewed the process of HHC to be “more dynamic and complex” (page 1161) than that described in the typical patient journey. Alone, the patient may view their journey as linear and become disheartened when they are dissatisfied with the “resolution.” However, if the clinician takes time to include the adult children in the journey, patients may gain a better understanding of the management cycle process, and with this support, they may have a better outlook on their ongoing journey.

There were limitations in this study that should be noted. All participants in this study had parents who were HA owners and this is not representative of all adults with HI. All of the participants were white and 11 participants had obtained at least a college degree. As with most qualitative research, the sample size was small, so transferability may be limited. Additional studies to examine the transferability of these findings would be useful.

## CONCLUSIONS

Adult children have an important impact in the HHC process of their parents with HI. Adult children did not view the HHC process as one with a beginning, middle, and end; rather, they viewed it as an ongoing process. Their substantial focus was on effective communication management in which they advocated for specific communication strategies, assisted with the facilitation of HHC, and encouraged HA use. These pillars of communication management were modulated by effort, questioning, and awareness.

Although HA satisfaction was not measured or specifically discussed in the present study, many of the participants did feel that the HAs were useful and effective. Participants in this study had limited involvement in the HHC process, and thus, this may have limited the support that they could give their parents in regard to HA use. Encouraging involvement of adult children in the uptake process would add another point of connection between the adult child and their parent, and help to expand their role, lessening the burden on their parent and other CPs.

It is important to consider the audiologist's involvement of family members, not only during the HA fitting but also in the entire audiologic process. Audiologists should be encouraged to provide family-centered care that allows for support to the patient throughout the entire HHC process and beyond. Based on research regarding spouse support, better outcomes in terms of satisfaction and benefit can be achieved with the involvement of CPs that comes with family-centered care. The present research suggests that adult children are not as involved with the HHC process as are spouses. To fully encompass

and reap the benefit from family-centered care, adult children should be included in appointments and the HHC process whenever possible. Providing information to adult children CPs about HI and treatments, along with encouraging them directly to attend all appointments, is essential for including them in the HHC process. Future research can investigate whether or not the involvement of adult children improves outcomes. An approach that can further differentiate between adult children and spouses when investigating involvement of CPs in audiologic appointments could also be useful. This research topic could be addressed using a more quantitative method to see if these conclusions apply to a larger population.

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## APPENDIX: Interview Guide

This is a guide to the topics that should be covered in the interview. These particular questions don't need to be asked, nor do they need to be asked in this order.

Let the interview be as open as possible, but at the end, make sure that each of the issues are covered...

- First Noticing the HI

- When did you begin to think or notice that your parent had a problem with hearing?
- Can you describe a situation (or situations) during which you became aware that something was wrong with your parent's hearing?
- What did you do or say when you first noticed your parent's hearing loss?

- Seeking Rehabilitation for HI

- Who took action after your parent decided to seek help for his/her hearing problem?

- Who decided that your parent should seek help for his/her hearing loss? Did you have a role in this decision? What was it?
- What was your role in your parent's hearing help seeking? Did you accompany your parent to clinic visits? Did you discuss the visits with your parent?
- What was this experience like for you?
- What is your role with your parent as a hearing aid or cochlear implant user? Do you have to help with it? Do you have to remind your parent to wear it?
- How is the situation now?
- What has been the greatest challenge in dealing with ... (your parent's hearing loss, your parent's hearing aid)
- Have there been any other challenges (conflicts)?