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REVIEW ARTICLE



Parent challenges, perspectives and experiences caring for children who are deaf or hard-of-hearing with other disabilities: a comprehensive review

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ABSTRACT

Objective: The purpose of this literature review was to explore parent challenges in caring for children who are deaf or hard of hearing with other disabilities and discuss implications for audiologists related to supporting families.

Design: A comprehensive literature review was conducted, and through qualitative analysis, emergent themes were identified, and a narrative summary generated.

Study sample: Nine research studies were included in this review. Combined, these studies reflect a sample of 111 children, 23 families and 41 parents.

Results: Three broad themes were identified, and include parent-reported challenges related to family, professional and child variables. Sub-themes were identified within each broad theme to further describe parent experiences, such as challenges related to decision-making and planning, interprofessional collaboration, and child communication and behaviours.

Conclusions: Parents of children with hearing loss and additional disabilities face unique challenges related to family, professional and child variables that could impact how they manage their child's hearing care.

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KEYWORDS

Paediatric; additional disabilities; parent challenges; review

Introduction

The World Health Organisation (WHO) estimates that nearly 9% of hearing loss in the world occurs in children (WHO 2016), and in the United States, permanent hearing loss is diagnosed in 1 to 3 of every 1000 births (CDC 2016). Incidence reports related to children with hearing loss who also have other disabilities have been variable (NDCS 2012); however, general estimates indicate 25–40% of children with hearing loss have one or more comorbid disabilities (Cupples et al. 2014; Wakil et al. 2014). Understanding the multiple underlying challenges of parents who care for children who are deaf or hard of hearing with other disabilities (D/HH Plus) can aid the paediatric audiologist in providing quality services for this population. How audiologists understand and partner with parents of children who are D/HH Plus could influence how they manage hearing care, and in turn, produce positive intervention outcomes.

The challenge of accepting, adapting and managing hearing loss has been shown to impact individuals and their families emotionally across the lifespan (Luterman 1997; Hintermair 2006; Quittner et al. 2010). When additional disabilities are involved, the needs of both parents and children may extend beyond the needs of parents and children with hearing loss alone. This extension of needs could compound burnout for parents or caregivers. Burnout is the result of physical, emotional and cognitive exhaustion (Melamed et al. 2006). For parents of children who are D/HH Plus, this burnout could impact how they manage their child's hearing care.

Hintermair (2000) found that parents of children who are D/HH Plus experience a significantly increased amount of stress compared to parents of children with hearing loss alone. Furthermore, families of children who are D/HH Plus may experience chronic guilt (e.g. self-blame for their child's multiple disabilities), and this may affect parental behaviours and interactions with their children (Luterman 2004). For example, Klein (1977) described a continuum of parent interactions, ranging from a "helicopter parent" approach to care (e.g. parents allow for the needs and wants of their child who are D/HH Plus to dictate all family functioning), to an alienation approach to care (e.g. parents exclude the child who are D/HH Plus from family activities).

Both Klein (1977) and Luterman (2004) concluded that parents of children who are D/HH Plus may require different approaches for communication from providers, as parents may not be emotionally or physically able to adhere to standard treatment recommendations. Thus, understanding the range of challenges of parents caring for children who are D/HH Plus may aid paediatric audiologists in establishing shared goals, and partnering with parents in decision-making and action-planning on behalf of children who are D/HH Plus. Therefore, the purpose of this study was two-fold: (1) to comprehensively review research that has explored parent-reported challenges in caring for children who are D/HH Plus to describe the various aspects of parental burden and (2) suggest implications for audiologist communication to support the additional needs of these patients and families.

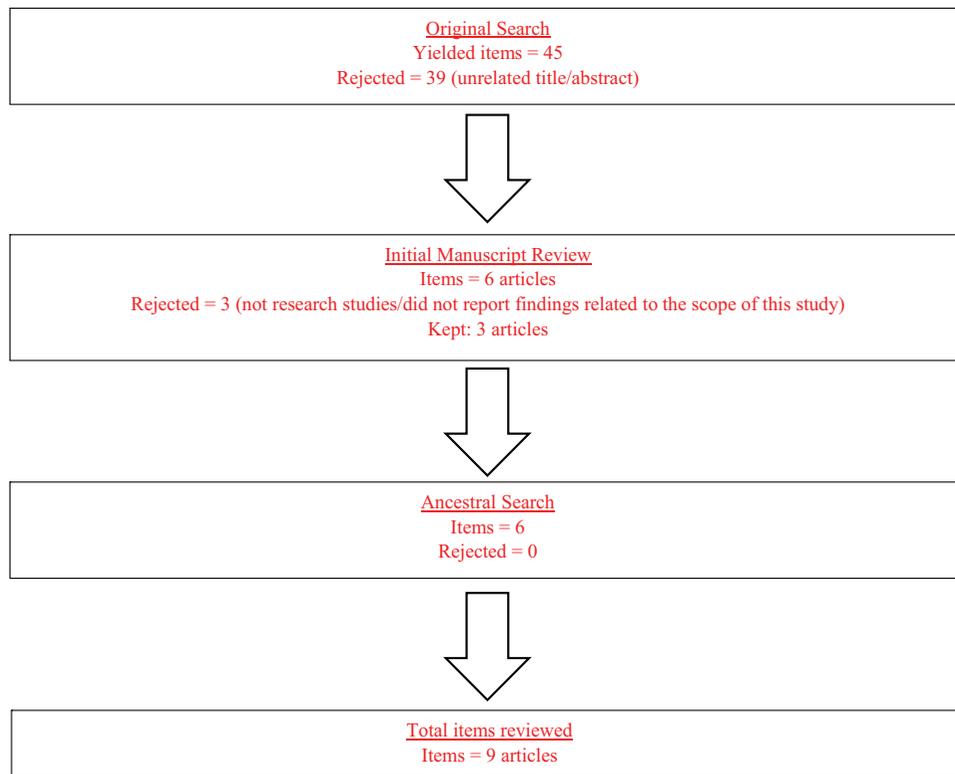


Figure 1. Manuscript search and selection.

Methods

Procedure

A comprehensive literature review was completed in September–October 2017 to identify journal articles related to parent challenges caring for children who are D/HH Plus. The following databases were used: ERIC, MEDLINE, Psychology and Behavioral Sciences Collection, and PsycINFO. Key terms for this literature search were: (children OR adolescents OR youth OR child OR teenager) AND (multiple disabilities OR additional disabilities) AND (parent challenges OR parent coping OR parent experiences OR parent perspectives OR parent needs).

The first author identified articles by first screening by title and/or abstract. If articles appeared to meet the inclusion criteria, a full-text review was completed. Inclusion criteria were that the article was (1) published in English, (2) published in a peer-reviewed or editor-reviewed journal between 1976 and 2017, (3) reported findings which included parent challenges, perspectives or experiences caring for children with hearing loss and an additional, specified disability and (4) a research study (e.g. not a position paper).

The database search yielded 45 articles after duplicates were removed. Thirty-nine were eliminated based on an irrelevant title and/or abstract. Full text was reviewed for the remaining six articles. At this stage, three articles were excluded for the following reasons: two were not research studies, and one did not report on findings related to the challenges, perspectives and experiences caring for children who are D/HH Plus. The remaining three articles were considered relevant, and included in the review. To ensure that all relevant articles were identified, an ancestry search of the references cited in the three eligible articles was completed, and following the same process as before, six additional articles were found and considered eligible for

inclusion. A total of nine articles qualified for this comprehensive review (see Figure 1).

Analysis

The nine articles were reviewed, and a thematic qualitative analysis was completed. Emergent subthemes were identified and recorded in a spreadsheet. These subthemes were then coded for the type of insight that was provided (e.g. working with professionals), and categorised into broad themes. As this review was exploratory in nature, broad themes were not predetermined, but emerged from the subthemes. These themes and subthemes were reviewed and in agreement with the second author of this study. Following agreement, the themes and subthemes were narratively summarised to describe parent challenges, perspectives and experiences caring for children who are D/HH Plus.

Results

Of the nine articles reviewed, five were studies related to parents of children with cochlear implants and a variety of additional disabilities (McCracken and Turner 2012; Mulla et al. 2013; Isarin et al. 2015; Zaidman-Zait et al. 2015; Turan 2016), three were related to parents of children with hearing loss and Autism Spectrum Disorder (ASD; Myck-Wayne, Robinson, and Henson 2011; Wiley, Gustafson, and Rozniak 2014; Zaidman-Zait and Curle 2016), and one study was related to parents of children with dual sensory impairments (hearing loss and visual impairment) (Giangreco et al. 1991). Eight of the studies used a qualitative research design, and one study used a mixed methods design. Combined, these studies reflect a sample of 111 children, 23 families and 41 parents. A summary of the studies included in this review, including their individual sample sizes, can be

Table 1. Table of studies.

References	N ^a	Disabilities included	Instrument
Giangreco et al. (1991)	28C	Vision impairment	Semi-structured interviews
Myck-Wayne, Robinson, and Henson (2011)	4C	ASD	In-depth interviews
McCracken and Turner (2012)	12C	Learning disability; lung disease; tracheotomy; kidney disease; tube fed; Cerebral Palsy; hypotonia; hypertonia; blind/visually impaired; ASD; Vacterl syndrome; Mitochondrial cytopathy; lp36 deletion	Unstructured interviews
Mulla et al. (2013)	10C	Down syndrome; ASD; cerebral palsy; CHARGE syndrome; visual impairment; severe learning disability; ^b severe/chronic epilepsy	Semi-structured interviews
Wiley, Gustafson, and Rozniak (2014)	4P; 3C	ASD	Focus group/Structured interviews
Isarin et al. (2015)	23F	Cytomegalovirus; CHARGE syndrome; cerebral palsy; meningitis; Down syndrome; twin-twin transfusion syndrome; Noonan syndrome	In-depth interviews
Zaidman-Zait et al. (2015)	45C; 23P	Learning disability; language disorder; cognitive delay; vision impairment cerebral palsy; ASD; Down syndrome; foetal alcohol syndrome	Questionnaire
Turan (2016)	5M	ASD; mental/motor disability; Williams syndrome; cytomegalovirus	Semi-structured interviews
Zaidman-Zait and Curle (2016)	9M; 9C	ASD	Semi-structured interviews

^aASD: autism spectrum disorder; C: children; F: families; P: parents; M: mothers

^bSevere learning disability in European literature is indicative of an intellectual disability.

seen in Table 1. Three broad themes were identified from the review regarding parental challenges, perspectives and experiences caring for children who are D/HH Plus: (1) *Family variables*, (2) *Professional variables* and (3) *Child variables*. For a brief overview, see Table 2.

Family variables

Eight of the nine studies identified family variables which presented as challenges in caring for children who are D/HH Plus. The family variables reported included challenges related to (1) decision making and planning on behalf of children who are D/HH Plus, (2) extended family reaction, (3) funding and (4) the emotional and physical drain of caring for children who are D/HH Plus.

Decision-making/planning

Five studies reported findings related to parent challenges and experiences in decision-making or planning on behalf of their child. Giangreco et al. (1991) found that parents felt uncomfortable thinking about the future of their child, for fear of the unknown. Some parents avoided planning for the future as a way of coping with the stress of caring for their child. For some of the parents in this study, thinking of the future sparked feelings of depression – feelings which were compounded when contemplating the care their child would require for a lifetime.

Both Myck-Wayne, Robinson, and Henson (2011) and Zaidman-Zait and Curle (2016) reported parent challenges regarding selection of services for their child with hearing loss and ASD. In these studies parents described taking a “trial-and-error” approach to selecting types of services for both the hearing loss and ASD, basing those selections only on the degree of their child’s improvement in behavioural and communication skills. Parents from Myck-Wayne, Robinson, and Henson’s (2011) study described how they prioritised hearing care differently; for example, some of parents valued an emphasis on treating the child’s behavioural issues related to the ASD before attending to the hearing-related issues.

Selecting a mode of communication was a challenging decision for the parents in both McCracken and Turner’s (2012) and Zaidman-Zait and Curle’s (2016) studies. For these parents, it was unclear as to which method for developing language they

should adhere, given their children’s complex needs. Some parents felt that spoken language was not possible for their child, whereas other parents chose to employ a combination of sign or gestures with spoken language.

Finally, Isarin et al. (2015) found that parents of children who are D/HH Plus, who received cochlear implants, reported difficulty deliberating whether cochlear implantation was right for their child before implantation, given the invasiveness of the surgery, and the lack of guarantee for success. Other parents found this decision difficult, because they considered sign language and Deaf culture as important aspects of their child’s identity.

Extended family reaction

One study reported findings related to extended family members, and it explored family member reactions to the dual diagnosis of hearing loss and ASD (Wiley, Gustafson, and Rozniak 2014). Some extended family showed interest and demonstrated a willingness to learn how to effectively communicate with the child; however, other extended family members were in denial, and had difficulty in accepting the needs of the child. Some even advised the parents in ways to manage the child’s behaviour, without considering the challenges that both hearing loss and ASD present for behaviour. Parents reported that these negative reactions changed over time, or as more information (e.g. evaluation reports) was shared to explain the child’s condition.

Funding

Three studies reported parent challenges related to funding for the needs of children who are D/HH Plus. McCracken and Turner (2012) found that some parents struggled paying for hearing care (e.g. hearing aids and cochlear implants), because of the already burdensome finances related to their child’s other medical needs. Zaidman-Zait et al. (2015) found that, even though the medical needs of each study participant were funded by the government, parents were charged with the task of managing these funds and completing a significant amount of paperwork.

Zaidman-Zait and Curle (2016) found that many families of children with hearing loss and ASD faced structural changes in their family that impacted their financial stability. For example, several mothers gave up their careers to care for their child full-

Table 2. Themes and subthemes.

Themes	Subthemes	Studies
Family variables	Decision-making/planning	Giangreco et al. (1991) Myck-Wayne, Robinson, and Henson (2011) McCracken and Turner (2012) Isarin et al. (2015) Zaidman-Zait and Curle (2016)
	Extended family reaction funding	Wiley, Gustafson, and Rozniak (2014) McCracken and Turner (2012) Zaidman-Zait et al. (2015)
	Emotional and physical drain	Zaidman-Zait and Curle (2016) McCracken and Turner (2012) Wiley, Gustafson, and Rozniak (2014) Turan (2016) Zaidman-Zait and Curle (2016)
Professional variables	Interprofessional collaboration	Giangreco et al. (1991) Isarin et al. (2015) Zaidman-Zait et al. (2015)
	Attitudinal barriers to support	Giangreco et al. (1991) McCracken and Turner (2012) Turan (2016)
	Educational placement and school support	Giangreco et al. (1991) Myck-Wayne, Robinson, and Henson (2011) Mulla et al. (2013) Zaidman-Zait et al. (2015) Turan (2016) Zaidman-Zait and Curle (2016)
Child variables	Child communication	Wiley, Gustafson, and Rozniak (2014) Zaidman-Zait et al. (2015) Zaidman-Zait and Curle (2016)
	Behaviour management	Mulla et al. (2013) Wiley, Gustafson, and Rozniak (2014) Isarin et al. (2015) Zaidman-Zait et al. (2015)

time. Many families had to relocate to access the specialised services their child needed. Some families even split up to access specialised services (e.g. the mother and child with hearing loss and ASD would live in a different city for the week to attend the child's interventions services, while the father remained in the family's home community to take care of typical family needs, such as caring for the other children).

Emotional and physical drain

Four studies reported parent experiences related to the emotional and physical drain in caring for children who are D/HH Plus. Turan (2016) found that five mothers of children with cochlear implants and additional disabilities reported the first year of their child's life as "exhausting" emotionally and physically. For example, one of the mothers described the first year of her child's life in terms of travelling back and forth between hospitals and home multiple times a week for testing, which was complicated due to the child not sleeping. This mother reported sleeping, herself, for only two to three hours most nights to care for her child.

Zaidman-Zait and Curle (2016) found that mothers of children with cochlear implants and ASD experienced emotional drain by taking on multiple roles in the care of their child. Roles, as perceived by one mother, included speech therapist, behaviour therapist, teacher, case manager and service coordinator. One mother stated: "I have to be everything and I'm only one person" (page 5). These burdens led many mothers to express feelings of overwhelm, depression, isolation and loneliness.

Both McCracken and Turner (2012) and Wiley, Gustafson, and Rozniak (2014) reported on parents' emotional strain as it related to their children's diagnostic process. In McCracken and

Turner (2012), some parents of children with cochlear implants and additional needs reported that it took years for them to get a referral for cochlear implant evaluation, and to find a cochlear implant centre that would consider cochlear implantation for their child. Some parents from this study obtained a referral and evaluation for cochlear implantation; however, near the end of the time-consuming assessment process the parents were informed that their children did not meet cochlear implant candidacy criteria, which impacted parents' already sensitive emotions.

Wiley, Gustafson, and Rozniak (2014) found that parents of children with hearing loss experienced varied emotional responses to the additional diagnosis of ASD. One family felt left out of the diagnostic process for ASD and were frustrated at the difficult tasks being given to their child as part of the diagnostic assessment, knowing that the child would not perform well because of the hearing loss, and not necessarily due to the suspected ASD. Parents reported feeling that the assessment batteries did not account for their child's hearing loss-related needs.

Professional variables

All nine articles identified professional variables that challenge parents of children who are D/HH Plus. The professional variables reported included challenges related to (1) interprofessional collaboration, (2) attitudinal barriers to support and (3) educational placement and school support.

Interprofessional collaboration

Three studies reported parent challenges related to interprofessional collaboration. Giangreco et al. (1991) found parents of

children with dual sensory impairments were frustrated with the lack of communication between the number of professionals caring for the several aspects of their children's needs. One parent expressed that each professional seemed to have a different idea about what was right for the child. Parents reported perceiving specialists as professionals with minimal expertise beyond a small area of knowledge. Parents felt they were answering the same questions multiple times to different professionals. Families with a case manager to liaise between professionals experienced greater satisfaction.

Isarin et al. (2015) found that the greatest cause of parental dissatisfaction in services was related to a lack of coordination among the different professionals, or even within teams of professionals. One parent stated: "There were so many doctors and all of them did their own thing" (page 226). Similar to Giangreco et al.'s (1991) findings, Isarin et al. reported that when a case manager was used to coordinate information and monitor progress, parents felt more confident they could ask a question, and then be directed to the appropriate professional.

Zaidman-Zait et al. (2015) found that the parents of children with cochlear implants and additional needs in their study were stressed in managing the multiple appointments and services their child needed to attend and felt overwhelmed at the number of recommendations made to them from varying professionals. One parent reported being in meetings with 20 different professionals, each representing the various aspects of the child's care. Parents expressed that it would be helpful for professionals to communicate, coordinate and combine services.

Attitudinal barriers to support

Three studies provided insight into the attitudinal barriers of professionals, and the extent to which professionals provided support to families. Giangreco et al. (1991) found that parents of children with dual sensory impairment noted hesitancy from the vision and hearing professionals, respectively. They reported feeling that itinerant visual and hearing specialists were minimally involved with their children when it made sense that they should have been more involved, and the more complex the children's handicaps, the less likely any visual or hearing professional was involved at all. Parents perceived this lack of involvement as being due to the professionals' fear of not knowing something, or coming across as inexperienced; thus, parents supposed, the coping mechanism for professionals was to not work with the child altogether or pretend to know something which they did not.

For both McCracken and Turner (2012) and Turan (2016), parents reported a negative attitude that professionals (mostly physicians or audiologists) displayed related to whether the child with hearing loss and other disabilities should receive a cochlear implant, which impeded parents' efforts in pursuing cochlear implantation for their child, some for years. For example, one of the mothers from Turan's (2016) study reported that a neurologist continually ignored the urgings from both a child's mother and his interventionists to implant him at an early age. By the time the neurologist finally consented, the child had turned 4.

Educational placement and school support

Six of the nine articles reported findings regarding parent challenges and experiences navigating their child's educational needs. Giangreco et al. (1991) found parents reported feeling uninvolved in educational planning, which often leads to decisions being made by educators that did not meet the child's or family's

needs. Similarly, the parents in Zaidman-Zait et al. (2015) study also felt uninvolved or uninformed regarding their child's school life and expressed that effective communication between the school and the family is important to parents. Furthermore, parents of this study expressed concern that extracurricular activities were hard to find for their child with complex needs; when they were found, such programmes were expensive.

Mulla et al. (2013) reported parents had difficulty finding schools that they perceived to meet the unique needs of their children. Only one of the seven children in this study was placed in a deaf education classroom; the rest were placed in classrooms designed for children with severe learning difficulties. According to the parents in this study, these classrooms did not provide an appropriate listening environment for the children, and therefore the children's hearing needs were not met. Similarly, only one of the four children with ASD and hearing loss in Myck-Wayne, Robinson, and Henson's (2011) study was placed in an educational setting that had other children with hearing loss. To obtain this placement, the parents had to file for due process.

Both Myck-Wayne, Robinson, and Henson (2011) and Zaidman-Zait and Curle (2016) found that many of the parents of children with hearing loss and ASD experienced little coordination between deaf education services and ASD services. In these cases, Zaidman-Zait and Curle (2016) reported that some mothers attempted to help educators integrate the child's hearing needs and needs related to ASD. However, some mothers felt that the educators were not responsive to these attempts, causing frustration for parents.

Finally, the mothers in Turan's (2016) study reported difficulty getting their children the services they need in school. One mother had to write to her government's ministry to get her child a teacher of the deaf to help in his regular education classroom. Another mother reported that her child's teacher did not want her child who was D/HH Plus in her classroom and worked to minimise the child's hours in class. The same school required the mother to stay at school with the child in case there was "any trouble".

Child variables

Five articles identified child variables that challenged parents of children who are D/HH Plus. The child variables reported in this review were challenges related to (1) child communication and (2) behaviour management.

Child communication

Three studies reported parent challenges in developing meaningful communication with their child. Wiley, Gustafson, and Rozniak (2014) found parents of children with hearing loss and ASD were challenged in transferring communication strategies used at school (usually the picture exchange communication system [PECS]) into the home. Some parents reported they felt their child was better able to communicate in diverse ways (e.g. writing, total communication, etc.), so they would not "force" PECS, which went against the school's recommendations.

Zaidman-Zait and Curle (2016) found that mothers of children with ASD who were cochlear-implanted were challenged in interpreting their child's wants and needs based from the child's behaviours (e.g. crying, facial expressions, actions, etc.), which "mystified" some mothers, and was the source of considerable frustration. Similarly, Zaidman-Zait et al. (2015) found that more than half of the parents they surveyed (60.9%), who had children

with cochlear implants and additional needs, reported communication difficulties related to both the child's general language skills, and the parent-child interactions.

Behaviour management

Four studies reported findings related to parent challenges managing their child's behaviour. In three of these studies, the children had cochlear implants, and the challenges were related to device wear-time. Mulla et al. (2013) reported some parents found that having their child wear their device was much harder than they thought it would be, leading to feelings of failure. Both Isarin et al. (2015) and Zaidman-Zait et al. (2015) reported parents' feelings of frustration and even desperation as they learned to manage behaviours such as chewing, throwing or losing processors, and aggressively resisting processor placement.

One study (Wiley, Gustafson, and Rozniak 2014) found parents of children with hearing loss and ASD faced general challenges to behaviour management. Because routines were important to many of the children in this study, tasks such as changing hearing aid batteries required a detailed plan to minimise disruption and child break-downs. Behaviour challenges in public settings were especially difficult for these parents, which caused a shift in some of the parents' priorities for help to focus on functional and social skills, and not on academic achievement.

Discussion

The purpose of this comprehensive review was to explore and describe challenges parents experience when a child has hearing loss and other disabilities, and to discuss implications for paediatric audiologic practice to effectively meet the unique needs of these families. The comprehensive review of the literature identified nine articles that conducted research in this area. The small number of articles found suggests that this topic area is under-investigated; however, most of the studies were published recently (eight of the nine within the last six years), indicating an increased recognition of the importance of understanding issues to better support families of children who are D/HH Plus. Although a wide variety of medical, developmental and intellectual disorders are represented in the combined sample of individuals included in these studies, not all disabilities are represented (e.g. social-emotional disorder, mood disorders, etc.).

Findings from the review suggested one overarching implication for audiologists' consideration regarding the potential impact of additional disabilities on parent burnout, and ultimately how parents of children who are D/HH Plus manage their child's hearing care. Although parent burnout is commonly experienced by many, including parents of children with hearing loss alone, this review identified the extent of challenges that may substantially perpetuate the level of burnout for parents of children who are D/HH Plus. This was made clear in the way several of the parents in these studies attributed their physical, emotional and cognitive exhaustion to navigating the multiple roles required to meet the considerable number of recommendations and expectations of many different healthcare and educational professionals. Burnout could lead to feelings of anxiety or depression. Audiologists can screen for these and make appropriate referrals to ensure that parents are receiving the support they need (Muñoz et al. 2017).

Audiologists should recognise that, for parents of children who are D/HH Plus, challenges may be more complex and take

more time to work through than for children with hearing loss alone. Furthermore, these parents may have pressing concerns that extend beyond their child's hearing needs. Through counselling to elicit these pressing concerns, audiologists can engage in a shared decision-making process to ensure that audiologists' actions are congruent with the families' goals related to caring for children who are D/HH Plus. By engaging in shared decision-making, audiologists may better address many concerns pointed out in this study related to deciding a communication modality for the child, determining the parents' financial priorities, or understanding the child's behaviours and strategies that can be incorporated to handle poor behaviour. In this way parents may be more empowered to act, thus increasing likelihood of positive outcomes for their child who are D/HH Plus.

Many of the challenges reported in this review are similar to the challenges reported by parents of children with special healthcare needs (CSHN). For example, Kuo et al. (2011) found in a national survey of parents caring for CSHN that more than half experienced health-care related financial burdens (56.8% $n = 184,043$) and/or required a caregiver to stop working to care for the child (54.1%, $n = 175,294$). Additionally, one-third of the parents (33.1%, $n = 107,350$) reported difficulty accessing non-medical services (e.g. education services).

Understanding the multiple challenges parents face in caring for children who are D/HH Plus can inform audiologists regarding how to better collaborate and communicate with parents and other professionals. Based from this review's findings, how audiologists share information with parents and with other professionals may influence parents' perceptions on quality of care that, in turn, may influence how much parents respect and trust their child's audiologist. Audiologists should consider developing a system to ensure that quality resources are provided to parents (e.g. handouts, online learning, etc.). Additionally, audiologists (including educational audiologists) should ask parents how they would like information streamlined to other professionals in a way that avoids confusion among parties (e.g. through a case manager or care coordinator). For audiologists working in hospital settings, taking the time to coordinate appointments to line up with the child's other medical or rehabilitative appointments may help relieve some burden to parents.

Furthermore, how audiologists assess for hearing loss in children with disabilities can play a role in parents' confidence in test results. Children with multiple disabilities may not condition well to behavioural testing, thus impeding the reliability of traditional audiometric testing. Poor communication and poor testing can result in parents attempting to manage their child's needs on their own. When parents attempt to manage their child's need alone, they may introduce other challenges associated with delayed or suboptimal service delivery, given that the child is not receiving specialised early intervention or other services in a timely manner.

Further research is needed in this area to understand how parents of children who are D/HH Plus prioritise hearing care differently from parents of children with hearing loss alone. From this review, minimal information was found regarding parent challenges related to child communication development, which is a crucial aspect of hearing loss; thus, further research to explore communication development in children who are D/HH Plus, and related parent challenges, is warranted. Additionally, further research is needed to explore audiologists' perspectives in working with children who are D/HH Plus, and to understand what educational supports (e.g. graduate training, continuing

education, etc.) audiologists need to effectively address parent challenges.

Conclusion

Parents of children who are D/HH Plus face multiple underlying challenges that are not all related to hearing. These challenges include factors related to family, professional and child variables, and could impact how much, or how effectively parents manage their child's hearing care.

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Disclosure statement

The authors have no conflicts of interest.

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