

Psychosocial Experiences of Parents of Young Children who Use Hearing Devices: A Scoping Review

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Abstract

Objective: The purpose of this scoping review was to provide information about the research base related to psychosocial experiences of parents of young children who are deaf or hard of hearing (DHH) and use hearing devices. A scoping review identifies trends and gaps in available evidence. This information can be used to inform practice and identify areas in need of further research.

Design: A scoping review was conducted in June 2020 to identify English-language peer-reviewed journal articles published through May 31, 2020.

Study sample: Nine articles were found that investigated psychosocial factors of parents of children birth through five years who are DHH and use a hearing device.

Results: Four psychosocial areas were explored in the identified studies: stress ($n = 5$), self-efficacy ($n = 2$), depression ($n = 1$), and depression/psychological flexibility ($n = 1$). None of the studies investigated an intervention to address parent psychosocial factors interfering with treatment adherence.

Conclusions: There is a scarcity of research related to psychosocial barriers experienced by parents of young children who use hearing devices. Research is needed to identify effective interventions and to demonstrate the effect of addressing parent psychosocial barriers on spoken language outcomes for children. Providers have opportunities to use validated screening tools to assess for parent barriers and to individualize support for parents within the care plan for children identified with hearing loss.

Keywords: psychosocial, parents, pediatric, hearing device

Acronyms: AAQ = Acceptance and Action Questionnaire; DHH = deaf or hard of hearing; PHQ = Patient Health Questionnaire; PSI = Parenting Stress Inventory; SPISE = Scale of Parental Involvement and Maternal Self-Efficacy

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Hearing loss is a common condition affecting approximately 34 million children worldwide (World Health Organization, 2020). For many children, their hearing loss is identified during the first few months of life through objective newborn hearing screening measures. This early identification provides children with the opportunity to receive early intervention critical for supporting developmental milestones and school readiness (Joint Committee on Infant Hearing, 2013). Consistent use of well-functioning hearing devices is a foundational aspect of the intervention process for spoken language development—better language outcomes have been found for children who wear their hearing aids 10 or more hours per day (Tomblin et al., 2015). Parents have a central role in intervention; however, it can be difficult for parents to be consistent in integrating evidence-based intervention

routines (e.g., hearing aid listening checks) in their daily lives (Muñoz et al., 2019) and this can interfere with meeting intervention goals.

It is understandable that parents encounter challenges with daily intervention routines, such as having their child wear the devices consistently, checking function of the device regularly, and incorporating language strategies to provide a language-rich environment. For many parents, their child's diagnosis is their first experience with hearing loss, as most parents have normal hearing themselves (Mitchell & Karchmer, 2004). Hearing loss degree varies among children (White, 2018), and parents may struggle with perceptions of what it means for their child to have a hearing loss and use a hearing device (Ambrose et al., 2020). Parents are faced with learning new information, new systems of care, and new skills

that can feel overwhelming to navigate. Every family is unique and support needs may differ based on various factors including their beliefs, how they learn, their support network, and their psychosocial experiences. Family dynamics and parental coping strategies can influence engagement in the intervention process, and it is reasonable to expect support be provided differently based on individual parents' strengths and needs.

Partnering with parents requires professionals to comprehensively consider factors, including parent thoughts, feelings, and behaviors, that are influencing parent engagement. Various psychosocial factors (e.g., depression) may influence how effectively parents cope with the addition of intervention demands in their daily lives as a result of the identification of their child's hearing loss. This can signal the need for different or additional support. Considering and incorporating parent needs within the intervention process can provide protective factors to support progress toward intervention goals. For example, Cross et al. (2018), in a systematic review, found that person-centered care to promote caregiver well-being within the care plan is needed when working with dementia patients. In another systematic review, Borghi et al. (2019) found that psychosocial factors were important for parent adjustment to and treatment of phenylketonuria.

Psychosocial factors can influence intervention whether or not they are recognized by the audiologist and early intervention providers and considered in the overall care plan. Therefore, the purpose of this scoping review was to provide information about the research on psychosocial experiences of parents of young children who are deaf or hard of hearing (DHH) and use hearing devices. A scoping review identifies trends and gaps in available evidence and this information can be used to inform practice and identify areas in need of further research.

Method

Procedure

A scoping literature review was completed in June 2020 using the PRISMA extension (Tricco et al., 2018). Scoping reviews follow a systematic process to examine a broad area and can be used to identify main concepts and gaps in research. The purpose of a scoping review is to identify what kind of evidence is available, not necessarily to provide a critical appraisal of the evidence. The Joanna Briggs Institute provides a detailed description of the purpose and process for conducting scoping reviews (Aromataris & Munn, 2017).

For inclusion in the review, the articles needed to address psychosocial factors of parents of children birth to five years who are DHH and use hearing devices within their research question. This age range was selected because young children require help from their parents to access sound consistently through their hearing devices, and parent challenges can interfere with amplification management adherence. Peer-reviewed journal articles published prior to May 31, 2020 were included. Research articles were excluded if child age could not be

determined, if the children did not have hearing devices, if no data were collected related to parent psychosocial factors, or if they were not in English.

To identify potentially relevant articles, three databases were searched by the authors (MEDLINE, CINAHL Complete, PsycINFO via EBSCOhost) using the following key words ([hearing loss OR deaf OR hearing impairment OR hearing disorder] AND [hearing aid OR cochlear implant] AND [adaptation OR psychological OR psychosocial OR coping OR quality of life OR mental health] AND [parent OR caregiver OR mother OR father]).

Two of the authors jointly developed a data charting form prior to completing the search and calibrated the search by working together before continuing the search independently. First, article titles and abstracts were reviewed. Second, a full text review was completed, followed by discussion to finalize article selection. Finally, reference lists of included articles were reviewed to identify further articles for consideration. Nine articles met the inclusion criteria (see Figure 1 for article inclusion flowchart). The primary reason for article exclusion was age of the child. Included articles were analyzed to identify psychosocial factors and findings were synthesized to provide a narrative overview.

Results

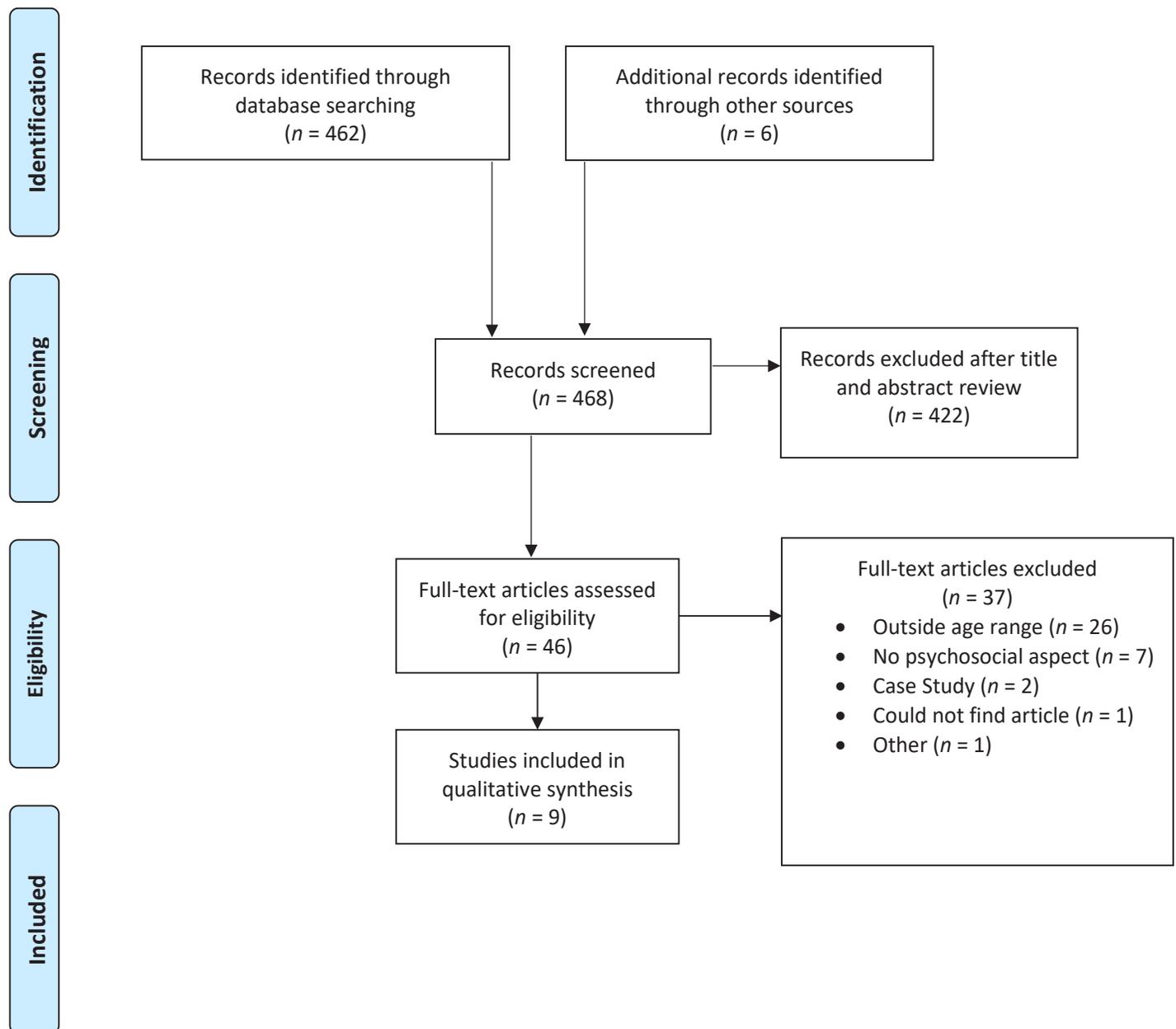
The scoping review identified nine peer-reviewed research articles, published through May 2020, that investigated psychosocial factors of parents of children birth through five years who are DHH and use a hearing device. Of these, four psychosocial areas were explored (see Table 1 for study details): stress ($n = 5$), self-efficacy ($n = 2$), depression ($n = 1$), and depression/psychological flexibility ($n = 1$).

Stress

Meadow-Orlans and colleagues published three articles (Meadow-Orlans, 1994, 1995; Meadow-Orlans & Steinberg, 1993) from one study that explored parental stress. The results were part of a larger longitudinal study (MacTurk et al., 1993) that investigated the development of infants that had moderate to profound hearing loss and used hearing aids at four time points (i.e., 9, 12, 15, and 18 months). No differences on the Parenting Stress Inventory (PSI) were found between mothers of infants who were DHH and mothers of infants with typical hearing. The PSI score at nine months, however, was strongly correlated with the mother's behavior at 18 months for mothers of infants who were DHH, and social support had a significant positive effect on mothers' behavior with their children who were DHH (Meadow-Orlans & Steinberg, 1993). The authors suggested that when mothers received support closer to the time of hearing loss identification, it had a greater impact on their behaviors at 18 months. Meadow-Orlans (1994) found that there were no difference in stress levels between mothers and fathers. They also found that PSI scores were significantly related to the Life Stress Index for mothers, but not the fathers. PSI sub-scales revealed fathers of children who

Figure 1
Literature Review Flow Chart

PRISMA Extension Flow Diagram



were DHH felt less attached to their children compared to their wives, whereas mothers were more depressed than their husbands (Meadow-Orlans, 1995). The authors encouraged professionals to include family support within their services, with particular attention to fathers, stating that families vary and individualization of services for each family member is critical.

Dirks and colleagues (2016) found that mothers of toddlers with bilateral hearing loss had comparable levels of stress compared to mothers of children with typical hearing on the Nijmegen Parenting Stress Index. Children of parents with higher stress levels had poorer social-emotional functioning and language ability, and parents who received

less social support reported higher levels of stress. The authors indicated that professionals have a role in being aware of signs of parental stress and should pay attention to social support and social networks of parents.

Jean and colleagues (2018) interviewed mothers of children with severe-to-profound hearing loss to explore their experience with parenting stress and two themes emerged: contextual stressors and stress-reducing resources. Contextual stressors included distress related to hearing devices and intervention services that often contributed to delays in intervention and a lack of commitment to the intervention program. Parents described that the process of having to gain new

Table 1
Included Articles

First Author	Year	Sample Size	Demographics	Psychosocial Aspect	Hearing Device
Meadow-Orlans	1993; 1994; 1995	40	Mothers and fathers; primarily white	Stress	Hearing aid
Desjardin	2005	54	Mothers; 63% white	Self-efficacy	Hearing aid; cochlear implant
Muñoz	2014	55	Mothers and fathers; 91% white	Psychological flexibility; depression	Hearing aid
Dirks	2016	30	Not reported	Stress	Hearing aid
Caballero	2017	42	80% mothers; Hispanic	Depression	Hearing aid
Jean	2018	15	Mothers; Malaysian	Stress	Hearing aid
Ambrose	2020	72	80% mothers; 92% white	Self-efficacy	Hearing aid; cochlear implant

knowledge and apply new learning was stressful. Parents expressed distress from not meeting their own personal expectations, concerns about their child's future, and experiencing negative social attitudes from others about their child's hearing; including from family, friends, and strangers. Maternal coherence was the core social process that emerged from the interviews and it appeared to influence how mothers view and experience their parenting stress and their overall sense of wellbeing and parenting control. Mothers who perceived that they had control over the context stressors indicated that they felt more confident and motivated to engage in the intervention process.

Self-efficacy

Self-efficacy is broadly described as perceived estimations of an individual's competence and confidence to perform a task. Desjardin (2005) created the Scale of Parental Involvement and Maternal Self-Efficacy (SPISE) and used it to assess maternal self-efficacy for mothers of young children with profound hearing loss who use hearing aids or cochlear implants. The findings revealed mothers of children with cochlear implants had higher self-efficacy than mothers of children with hearing aids. Furthermore, mothers of children with cochlear implants perceived themselves to be more involved in their child's device use (i.e., checking device function on a daily basis and supporting speech-language development). The author described technical training and support needs critical for parents to learn new information and skills.

Ambrose and colleagues (2020) used a revised version of the SPISE (SPISE-R) to explore self-efficacy for parents of children birth to 36 months who use cochlear implants or hearing aids. Findings revealed that parents of

children with cochlear implants reported higher knowledge scores than parents of children with hearing aids, and that mothers reported higher confidence than fathers. Furthermore, scores on knowledge and confidence were significantly correlated with parent action and hearing device use, and confidence scores were significantly related to language scores. The authors concluded that to provide comprehensive support for families it is important to assess parents' perceptions, knowledge, confidence, and actions; as this information will help early intervention professionals identify parents' strengths and areas in which they may need additional support and guidance.

Psychological Flexibility

Psychological flexibility describes a thought process used to respond effectively to difficult internal experiences by being open and nonjudgmental of these experiences in the present moment and able to successfully take personally meaningful action (Hayes et al., 2006). Muñoz and colleagues (2014) explored hearing aid management challenges for mothers and fathers of children birth to three years. Using a general instrument, Acceptance and Action Questionnaire (AAQ-II; Bond et al., 2011), Muñoz et al. surveyed psychological flexibility and depression (described in the next section) on hearing aid management. Ninety-six percent of the parents had low scores on the AAQ-II, indicating that psychological inflexibility was not a factor. A limitation was that this instrument was not specific to parents of children who are DHH, and challenges with psychological flexibility in the context of hearing aid management may have been missed by using the general AAQ-II questionnaire.

Depression

In a study done by Muñoz et al. (2014), depression was explored using the Patient Health Questionnaire (PHQ-9; Pfizer, 1999). Twenty-two percent of the parents were experiencing mild to severe symptoms of depression, and of those, 40% indicated the depression was influencing their ability to manage. The authors stated that comprehensive care includes addressing needs of mothers and fathers. In a similar study, Caballero and colleagues (2017) explored hearing aid management, including symptoms of depression, for mothers using the Spanish version of the PHQ-9. Forty-four percent of the participants reported minimal to moderately severe symptoms of depression.

Discussion

Parents of children who are DHH experience treatment adherence challenges for hearing device management. This is a critical issue as auditory access is essential for spoken language development. The model of cumulative auditory experience includes consistent use of well-functioning hearing aids and states that intervention for malleable factors are needed to reduce barriers that interfere with auditory access (McCreery & Walker, 2017). Parent psychosocial experiences can interfere with auditory access and it is important to recognize that psychosocial issues can be positively influenced with appropriate support. The purpose of this scoping review was to provide information about the research on psychosocial experiences of parents of young children who are DHH and use hearing devices. This scoping review revealed research gaps and opportunities to expand services to include identifying and addressing the needs of parents when children are identified with hearing loss—parents are essential intervention partners and their engagement is critical for optimizing child outcomes.

Parents can experience both practical and emotional barriers related to hearing aid management; however, there is a scarcity of research on parent psychosocial factors that interfere with and/or facilitate engagement in hearing device management for parents of children birth to five years of age. All of the studies identified in this review voiced the importance of and the need for parents to receive support that is individualized to their specific needs. This support may help them address challenges that interfere with effective engagement in the intervention process.

The gaps in the research conducted to date present limitations. The study samples represent a narrow demographic—primarily English-speaking, white mothers with a college education. Relatively little research has been done related to the psychosocial considerations for fathers and other caregivers. No intervention studies have been done to address parent psychosocial challenges. Research is needed to understand the needs of a broader demographic of parents, including those that do not speak English, and to provide more depth of understanding of the work parents must engage in to successfully implement

treatment recommendations. Additionally, research is needed to identify effective approaches for addressing parent psychosocial barriers to treatment adherence within the intervention process, including interprofessional collaboration.

There are important clinical implications to consider when a child is identified with hearing loss. Current practice guidelines address parent adjustment (American Academy of Audiology [AAA], 2013); however, specific implementation guidance is lacking. There are validated screening tools clinicians can include as part of routine practice to assist them in determining when parents are struggling with internal distress (e.g., depression) that is interfering with treatment adherence. To address parental struggles, providers need to understand the extent of parent struggles, the intervention options available within their scope of practice, and how to recognize when referrals are indicated for professional counseling. Without practice guidelines that address the issue of how to support parents, the extent and scope of services provided will likely be insufficient and widely variable.

Informational counseling has received more attention in guidance documents (AAA, 2013) and clinicians have reported being more comfortable with providing information than addressing parent emotional barriers (Meibos et al., 2017). Providing parents with information is important; however, it is not sufficient to support the behavior change parents must engage in to become proficient in their role. Support for health behavior change, which includes addressing parent psychosocial challenges, is a component of service delivery that is largely missing from pediatric audiology practice and is understudied as it relates to pediatric hearing loss. Partnering with parents requires a responsiveness to the practical and emotional work they must navigate to fulfill their role, and this includes individualized support. Parents are their child's most important teacher and are the people most invested in their child's future.

This scoping review revealed a scarcity of research related to psychosocial barriers that parents of young children who use hearing devices experience. Research is needed to identify effective interventions to support parents in reducing barriers to auditory access for children, and to demonstrate the effect of addressing parent psychosocial barriers on spoken language outcomes for children. This review brought to light important opportunities. Providers can use validated screening tools to assess for parent barriers, and providers can incorporate individualized support for parents within the care plan for children identified with hearing loss when parents are struggling.

References

- Ambrose, S. E., Appenzeller, M., Mai, A., & DesJardin, J. L. (2020). Beliefs and self-efficacy of parents of young children with hearing loss. *Journal of Early Hearing Detection and Intervention*, 5(1), 73–85.
<https://doi.org/10.26077/kkhh-vj55>

- American Academy of Audiology. (2013). *Pediatric amplification: Practice guidelines*. <http://galster.net/wp-content/uploads/2013/07/AAA-2013-Pediatric-Amp-Guidelines.pdf>
- Aromataris, E., & Munn, Z. (Eds). (2017). *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. <https://reviewersmanual.joannabriggs.org/>
- Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., Waltz, T., & Settle, D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire–II: A revised measure of psychological flexibility and experiential avoidance. *Behavior Therapy* 42(4), 676–688. <https://doi.org/10.1016/j.beth.2011.03.007>
- Borghi, L., Salvatici, E., Riva, E., Giovannini, M., & Vegni, E. (2019). Psychological and psychosocial implications for parenting a child with phenylketonuria: A systematic review. *Minerva Pediatrics*, 71(2), 181–195.
- Caballero, A., Muñoz, K., White, K., Nelson, L., Domenech-Rodrigues, M., & Twohig, M. (2017). Pediatric hearing aid management: Challenges among Hispanic families. *Journal of the American Academy of Audiology*, 28(8), 718–730.
- Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: A systematic review and meta-synthesis of qualitative research. *Psychology & Health*, 33(11), 1321–1342.
- Desjardin, J. L. (2005). Maternal perceptions of self-efficacy and involvement in the auditory development of young children with prelingual deafness. *Journal of Early Intervention*, 27(3), 193–209.
- Dirks, E., Uilenburg, N., & Rieffe, C. (2016). Parental stress among parents of toddlers with moderate hearing loss. *Research in Developmental Disabilities*, 55, 27–36.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1–25. <https://doi.org/10.1016/j.brat.2005.06.006>
- Jean, Y. Q., Mazlan, R., Ahmad, M., & Maamor, N. (2018). Parenting stress and maternal coherence: Mothers with deaf or hard-of-hearing children. *American Journal of Audiology*, 27, 260–271.
- Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 Position Statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, 131(4), e1324–e1349.
- MacTurk, R. H., Meadow-Orlans, K. P., Koester, L. S., & Spencer, P. E. (1993). Social support, motivation, language, and interaction: A longitudinal study of mothers and deaf infants. *American Annals of the Deaf*, 138, 19–25.
- McCreery, R. W., & Walker, E. A. (2017). *Pediatric amplification enhancing auditory access*. Plural Publishing.
- Meadow-Orlans, K. P., & Steinberg, A. G. (1993). Effects of infant hearing loss and maternal support on mother-infant interactions at eighteen months. *Journal of Applied Developmental Psychology*, 14, 407–426.
- Meadow-Orlans, K. P. (1994). Stress, support, and deafness: Perceptions of infants' mothers and fathers. *Journal of Early Intervention*, 18, 91–102.
- Meadow-Orlans, K. P. (1995). Sources of stress for mothers and fathers of deaf and hard of hearing infants. *American Annals of the Deaf*, 140(4), 352–357. <https://doi.org/10.1353/aad.2012.0392>
- Meibos, A., Muñoz, K., Schultz, J., Price, T., Whicker, J., Caballero, A., & Graham, L. (2017). Counseling users of hearing technology: A comprehensive literature review. *International Journal of Audiology*, 56(12), 903–908. <https://doi.org/10.1080/14992027.2017.1347291>
- Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4(2), 138–163.
- Muñoz, K., Larsen, M., Nelson, L., Leopold, S., & Twohig, M. (2019). Pediatric amplification management: Parent experiences monitoring children's aided hearing. *Journal of Early Hearing Detection and Intervention*, 4(1), 2–11.
- Muñoz, K., Olson, W. A., Twohig, M. P., Preston, E., Blaiser, K., & White, K. R. (2014). Pediatric hearing aid use: Parent-reported challenges. *Ear & Hearing*, 36(2), 279–287.
- Pfizer. (1999). *Patient health questionnaire (PHQ) screeners*. http://www.phqscreeners.com/pdfs/02_PHQ-9/English.pdf
- Tomblin, J. B., Harrison, M., Ambrose, S. E., Walker, E. A., Oleson, J. J., & Moeller, M. P. (2015). Language outcomes in young children with mild to severe hearing loss. *Ear and Hearing*, 36(1), 76s–91s. <https://doi.org/10.1097/AUD.0000000000000219>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., . . . Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473.
- White, K. R. (2018). Demographic considerations in serving children who are hard of hearing or deaf. *Journal of Early Hearing Detection and Intervention*, 3(2), 14–17. <https://doi.org/10.26077/k8j2-vp95>
- World Health Organization (2020). *Deafness and hearing loss*. <https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss>