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Engaging Parents of Children with Mild Bilateral or Unilateral Hearing Loss: Counseling Considerations

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Abstract

A notable percentage of children identified with hearing loss through newborn hearing screening have mild bilateral or unilateral hearing loss (MB/UHL). Caregivers' appropriately strong emotions, fears, and personal struggles may inadvertently interfere with their engagement with audiologists and other professionals, as well as adherence to jointly determined intervention protocols. Researchers have shown variable outcomes for children with MB/UHL; inclusion of counseling that addresses emotional and cognitive factors is an essential component for effectively engaging parents. The aim of this article is to describe counseling attributes and strategies that providers can incorporate when working with parents of children with MB/UHL to improve parent engagement in the intervention process. Implementation of Motivational Interviewing, and evidence-based counseling techniques when working with parents of children who have MB/UHL can provide a supportive foundation to help parents and benefit children. When service providers are purposeful in their approach to communication, they can help parents accept the hearing loss, support them in making informed decisions about intervention, and overcome barriers. Ultimately, the objective of incorporating counseling methods in audiological sessions with parents is to improve greater adherence to jointly agreed upon intervention plans and improve quality of life.

Key Words: counseling, pediatric hearing loss, parent engagement

Acronyms: CDC = Centers for Disease Control and Prevention; EHDI = Early Hearing Detection and Intervention; MB/UHL = mild bilateral or unilateral hearing loss; MI = Motivational Interviewing

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A significant percentage of children identified with hearing loss through newborn hearing screening have mild bilateral or unilateral hearing loss (MB/UHL). According to data reported for 2012-2014 by state Early Hearing Detection and Intervention (EHDI) programs to the Centers for Disease Control and Prevention (CDC), children who have MB/UHL represented 53% of all children with hearing loss identified during that time period (White, 2018). When children are identified with MB/UHL, parents often experience uncertainty about the effect of the hearing loss on their child and have doubts about the benefits of intervention, including use of hearing aids. Children with MB/UHL are at risk for delays in development, and parent uncertainty can interfere with their engagement in intervention. Counseling parents of children with MB/ UHL is essential for supporting intervention engagement. Parents need help identifying and addressing barriers that interfere with their ability to act on intervention recommendations. The aim of this article is to describe counseling attributes and strategies that providers can incorporate when working with parents of children with MB/ UHL to improve parent engagement in the intervention process.

Partnering with parents after hearing loss diagnosis requires providers to interact intentionally by arranging conversations to support parents where they are and to help them take needed actions to help their children. Providing services that are individualized and reflect person-centered care necessitates providers' use of evidence-based counseling skills that support behavior change. There are various counseling theories that can inform practice (e.g., Health Belief Model [Rosenstock, 1974], Self-efficacy Theory [Bandura, 1977], Acceptance and Commitment Therapy [Hayes, Strosahl, & Wilson, 2011]); however, an in-depth discussion of these theories is beyond the scope of this paper. Motivational Interviewing (MI) is another evidence-based approach and is commonly used in health care to support health-related behavior change (Rollnick, Miller, & Butler, 2008). MI is applicable to this population because it can be used to help parents of children with MB/UHL address barriers to intervention including feelings of ambivalence they may be experiencing. MI is a style of communication that can be woven into provider-parent/patient interactions and is based on the conceptualization that people go through stages of change (i.e., pre-contemplative, contemplative,

preparation, action, maintenance) when faced with chronic health concerns. A core feature of MI is tailoring intervention to stage of change. MI is a process and typically occurs over a period of months.

Professionals may underestimate information and adjustment needs of parents when children who have MB/UHL are identified, and inadvertently minimize the importance of issues parents need to consider (Fitzpatrick et al., 2016) including those that can negatively impact their child's psychosocial well-being (Wake, Hughes, Collins, & Poulakis, 2004). For example, at the time of diagnosis, parents have reported not remembering information presented, and wanting professionals to be compassionate as they experience shock and grieving, similar to parents of children with more significant degrees of hearing loss (Borton, Mauze, & Lieu, 2010). This is not surprising, as 90% of parents have typical hearing themselves (Mitchell & Karchmer, 2004) and did not consider their child may have a hearing loss. Parents need support as they adjust to the diagnosis, learn what it means for their child to have a MB/UHL, and receive information to make informed decisions. MI includes strategies specific to information sharing, such as elicitprovide-elicit. First, the provider asks the parent what they already know or would like to know (elicit), then shares relevant information (provide), and then asks the parent what additional information or clarification they need (elicit), and so on until the parent's immediate information needs are met.

It is important for providers to keep in mind that parents of children with MB/UHL may have questions that are different than those of children with a greater degree of hearing loss, and this can influence the type of information they need. For example, they may wonder why they need to be concerned if their child can hear well out of one ear. They may not understand why hearing aids are needed if their child can hear conversational speech without amplification. At the same time, they may wonder if their child's hearing will get better or worry their child's hearing will get worse. Parents often have difficulty reconciling their observations at home, noticing their child's response to sounds, with the diagnosis, and this can delay acceptance of the hearing loss and interfere with their ability to take action on recommended intervention.

Parents' conflicting thoughts and doubts about the benefits of intervention can influence their ability to acknowledge risks of not adhering to intervention and to appreciate the urgency of acting on recommendations. According to the Health Belief Model (Rosenstock, 1974), individuals' perceptions about the seriousness of a condition, susceptibility to negative outcomes, benefits of intervention, and barriers can influence their actions. These emotional and cognitive factors (feelings, thoughts) can interfere with how parents respond to their child's hearing loss diagnosis and how parents support their child in daily life. When parents' expectations are not aligned with their child's abilities, it can be detrimental to the child's development, including the child's social-emotional

well-being. Addressing parents' challenges (e.g., worries, fears, insecurities) at the beginning creates a long-term benefit as parents continue to help their child with MB/UHL navigate transitions to different listening environments and social situations. Because MI is an approach that guides parents based on what they value, their perceptions of importance and motivation are explored to help them identify barriers that are interfering with their ability to achieve their intervention goals.

Counseling that entails addressing emotional and cognitive factors experienced by parents of children with MB/ UHL is critical for developing a foundation for effective engagement. The use of MI can facilitate the development of a therapeutic relationship that provides a safe space to explore internal barriers (e.g., fears, doubts) without judgement and determine how to move forward. Voicing thoughts (e.g., ambivalence about intervention) helps people feel heard and when information is provided in a supportive environment, they are better able to engage in a process of shared decision-making on important issues. Conversely, when providers focus on their agenda, they may dominate the conversation (Muñoz et al., 2017) or provide technical information in response to emotionbased concerns (Ekberg, Grenness, & Hickson, 2014). In doing so, providers may inadequately address parent/child priorities, interfering with their patients' engagement in the process. On the other hand, fully addressing emotional or cognitive variables may greatly increase engagement and result in stronger outcomes.

Counseling to Engage Parents

Family-centered care is central to the EHDI process (Joint Committee on Infant Hearing, 2013) and the relationship professionals develop with parents provides the basis for parent engagement. This therapeutic working alliance is positively influenced by provider attributes (e.g., being honest, respectful, confident, interested), and communicated through counseling techniques incorporated in MI (e.g., reflecting, validating, attending to the patient's experience) within a conscious and active collaboration (Ackerman & Hilsenroth, 2003). Within this collaborative relationship, providers can help parents work through acceptance by reflecting their concerns about their child's future, validating their pain of having a child with hearing loss, or exploring their doubts about intervention effectiveness. Simply listening and allowing a parent to express their struggles can reduce that emotional barrier. Failure to do so can leave emotional or cognitive variables in the way for the duration of the intervention process.

Using behavioral counseling interventions such as MI in a primary care setting is not new and healthcare providers have the unique opportunity to facilitate adaptive behavioral change associated with improved outcomes (Whitlock, Orleans, Pender, & Allen, 2002). Audiologists, for example, should see themselves as playing a key role in motivating patients to adhere to intervention plans (e.g., addressing low hours of hearing aid use or non-use), intervening on internal barriers parents are experiencing (e.g., fear, doubts about benefit of amplification), and

providing feedback and support when appropriate. In other words, audiologists need to recognize the scope of their job is not confined to merely teaching parents skills related to hearing devices or sharing technical information. Audiologists should be interested in all variables that may affect parent engagement. Conceptualizing their role in this broader way will likely result in greater behavioral outcomes as it addresses variables that are likely interfering with parent engagement and provide more holistic care for their patients.

The first step toward initiating behavior change is assessment of variables affecting parent motivation and ability to practice new behaviors (Whitlock et al., 2002). Providers need to have a solid understanding of the factors influencing the patient (e.g., family dynamics, personal goals, access to resources) to formulate, with the parent, an intervention plan that matches their needs and current skill level. Part of this assessment entails identifying the function of parent behaviors. The same behavior likely requires different interventions depending on the purpose it serves for the individual. For instance, if Parent A cancels appointments regularly because they are concerned about people finding out about their child's mild hearing loss and Parent B misses appointments because they hold two jobs and often encounter scheduling issues, the provider should take different approaches to remedy the same intervention-interfering behavior. Making assumptions without knowledge of the parent's context can easily lead to intervention attempts that may be perceived as invalidating or that obstruct progress.

Once providers have implemented an appropriate intervention, it is imperative they monitor the results of the intervention and make changes to the intervention plan where necessary (Whitlock et al., 2002). The two main reasons for this are: (1) the intervention may not have the intended positive effect and (2) parent/child variables may have shifted since the last assessment, warranting an adjustment in the intervention. The ultimate barometer of progress is alignment with parent/child goals and needs. That is, a successful intervention should result in the parents engaging in behaviors that are important to them. Providers also need to be cognizant of their own agenda and evaluate whether they are acting based on their agenda rather than parent goals. Provider bias has the potential to derail the intervention agenda and limit parent autonomy in intervention decision making. Furthermore, providers should be sensitive to parent/child variables that influence where parents/children are along the intervention process and adjust intervention plans accordingly. For instance, a parent lacking in resources may not be able to initiate intensive behavior change and a more gradual approach may be warranted.

At the same time, enhancing motivation, providing emotional support, and collaborating on behavior change plans is not straightforward or even intuitive for audiologists and other providers (Meibos et al., 2017; Muñoz et al., 2017). To accomplish these tasks, providers need to understand how behavior works and how to

effectively apply behavior change strategies, such as those included in MI. Without this foundation, providers may find themselves engaging in unhelpful communication with parents that only serves to strengthen resistance to change. For example, when a parent does not follow through with intervention recommendations, a common way audiologists respond is to highlight the benefits of adhering to audiologist advice and consequences of failing to do so (Coleman et al., 2018). In MI, this tendency is called the Righting Reflex, and from an MI perspective, it can be more effective to elicit - rather than provide - such reasoning from patients (Miller & Rollnick, 2002). For example, saying "Help me understand what is getting in the way to wearing the hearing aids during all waking hours," will likely get at the true variables in the way and lead to greater engagement than reminding parents about the importance of adhering to the protocol. Indeed, intuitive responses that do not address the actual variables that are interfering with wear time could actually do more harm than good. Thus, providing more comprehensive care requires knowledge and skills to address all facets of parent concerns.

Counseling Examples

The following audiology encounter examples help illustrate how conversations look different when audiologists use MI counseling techniques in an intentional way during appointments. Contrasting examples of how it may look when audiologists follow their intuitive response to the situation are also provided.

Counseling at the time of diagnosis. Table 1 shows an example of sharing the news of the hearing loss diagnosis with the parent following completion of testing. Notice the difference in parent engagement. In the example on the left, the audiologist dominates the conversation and the audiologist's agenda is followed. In the example on the right, the audiologist engages the parent using MI counseling techniques: asking permission before sharing information respects parent autonomy and helps the audiologist know the parent is ready to hear the information. Silence after sharing the difficult news gives the parent space to process the news. Validation of the parent's feelings and pausing gives the parent room to respond about how they are feeling and expand on what they are thinking. Reflecting how the parent is feeling helps the parent feel understood, opening up the parent for further discussion. Asking open-ended questions helps the audiologist know what the parent needs, and this supports a shared process for how to move forward.

Counseling hearing aid use. Table 2 shows an example of sharing hearing aid data logging results at the first follow-up appointment after the fitting. Notice the difference in parent engagement. In the example on the left, the audiologist dominates the conversation and tells the parent why it is important to wear the hearing aids. In the example on the right, the audiologist engages the parent using MI counseling techniques, in addition to asking permission, asking open-ended questions, and validating and reflecting

Table 1

Counseling Example for Sharing Diagnosis of a Mild Table I

Intuitive Response

"Mrs. Jones, we're done with the hearing test and I'd like to go over the results with you. The results show that Emma has a mild hearing loss in both ears. I've mapped it out on what we call an audiogram." (shows parent audiogram).

[mother looks at the audiogram]

"As you look at this chart, you see low pitched sounds on this side (pointing to the left) and the pitches get higher as you go to the right. This side shows how loud the sounds are. The softest sounds are at the top (pointing to 0 dB) and they get louder as you go down towards the bottom of the audiogram. The marks I've added (pointing) show where Emma is hearing, you can see she can hear a lot of sounds. This is good, she can use hearing aids and should have no trouble learning to talk."

[mother looks at you and nods her head]

"There are some things we need to do next."

"OK.

"You'll need to go to the doctor to get medical clearance for hearing aids."

[recommendations continue]

Counseling Response

"Mrs. Jones, we're done with the hearing test and I'd like to talk over the results, does that sound OK to you?" [asks permission] [mother hesitates, then nods] "Yes."

"The results show that Emma has a hearing loss in both ears." [silence]

[mother looks at Emma and tears up]

[Silence] "This is hard news." [validation]

[mother wipes her eyes] "I don't know what to think."

[audiologist nods] [encourager for parent to continue talking]

"Last night I made noises to see what she would do, and she heard them."

"It feels confusing to see her respond to sounds and have the test results show a hearing loss." [reflection]

[mother nods]

"I would like to tell you some specific information about what she can hear and what is harder for her to hear, would that be OK?" [asks permission]

"Yes, that would help."

"Emma has a hearing loss that is classified as mild, that means she can hear many sounds including people talking, but it is softer for her, and she can't hear softer speech sounds, like "s" or "f" and this will make it harder for her to understand what is said, especially when there is noise. What questions do you have?" [open-ended question]

"Will her hearing get better?"

[conversation continues to explore parent needs]

parent feelings, the audiologist uses additional techniques from MI to support behavior change. MI can help parents identify reasons or motivations for seeking intervention, explore feelings of ambivalence (e.g., recognizing the need for hearing aids but not wanting to wear them), and change behavior (Rollnick et al., 2008). Audiologists can use MI within a purposeful dialogue with parents to help them work through barriers they are experiencing. Note that these examples do not represent a comprehensive description of all facets of MI.

Other areas of healthcare have successfully used MI to support desired behavior change to increase adherence to jointly agreed upon interventions (Rubak, Sandbæk, Lauritzen, & Christensen, 2005). Audiologists can incorporate MI within their interactions with parents of children with MB/UHL as it is a style of communication

rather than a service component that must be added to the appointment. It is important to understand that behavior change takes time. By implementing MI over time, audiologists can partner with parents to explore their ambivalence, collaborate with them, elicit change talk from parents, and in the process, reduce resistance, build trust, and increase self-efficacy (Hettema, Steele, & Miller, 2005). MI provides audiologists with a purposeful approach to guide - rather than direct - parents through a process of problem solving and behavior change at a pace set by the parent. While MI is a solid empirically derived choice, there are other counseling choices that can be helpful with patient engagement. If learning MI feels overwhelming, start by adding basic counseling techniques such as listening, and asking open-ended questions about the client's experience, and validating emotional struggles.

Table 2

Counseling Example for Sharing Data Logging Results and Addressing Hearing Aid Use

Intuitive Response

"Mrs. Jones, when you were here last week, we talked about data logging. That is the feature the hearing aid has to track how many hours, on average, the hearing aids are on each day. The data logging results are showing that Emma had her hearing aids on for an average of only 1 hour per day this past week."

[mother looks down]

"I know it can be overwhelming, there is a lot to learn."

[mother looks at audiologist and nods]

"She needs to hear speech consistently because she is learning language. I would like Emma to wear her hearing aids whenever she is awake, every day. Do you think you can try that this week?"

"Yes, I think so."

Counseling Response

"Mrs. Jones, when you were here last week, we talked about data logging. That is the feature the hearing aid has to track how many hours, on average, the hearing aids are on each day. The data logging results are showing that Emma had her hearing aids on for an average of 1 hour per day this past week. How does that compare with your thoughts on how much Emma wore her hearing aids?" [open-ended question] "It sounds about right."

Audiologist nods [encourager for parent to continue talking]

"We had a hard time with it. Emma responded to so many sounds without them."

"It's hard to put the hearing aids on when you see her responding to sounds and you're not sure she really needs hearing aids." [reflection]

"Right, I mean, I know you did the test and it showed hearing loss, but still, it's hard you know. I worry about what will happen as she gets older."

"What are you concerned about as Emma gets older?" [open-ended question]

"Well, I worry she'll get teased and have trouble with making friends. I don't want to make her life harder. If she really needs hearing aids, I want to help her, but I don't know, I'm not sure she really needs them."

"On one hand you want to help her hear by having her wear the hearing aids and on the other hand you worry about how she will fit in. What's important for you as you consider Emma's future?" [motivational interviewing to explore parent ambivalence and elicit parent values]

"I want her to do well in school and to have the opportunity to do whatever she wants to do in her future."

"It's important to you for Emma to have options in her future and you don't want her hearing loss to get in her way." [reflection]

"Right, so I do want to help her, I just feel uncertain about how the hearing aids are really helping her."

"What would help you understand how the hearing aids are benefitting Emma?" [open-ended question]

"I don't know."

"Some parents find it helpful to have a demonstration about how things sound for their child without the hearing aids. Is that something you would like me to do for you?"

"Yes, that would be helpful."

[demonstration]

"I didn't realize just how soft some sounds are for her."

"What are your thoughts on having her wear the hearing aids?" [open-ended question]

"I think I want her to wear them, but I want to learn more about how to know they are helping her."

"All right, that sounds good. So you want her to wear them and you want some ways to observe how she is doing. [summarizing] It can help to have a specific plan. Would it be OK with you if we put a plan in place?" [asks permission to develop an action plan]

"Yes, that sounds good."

"Let's start with how much Emma will wear her hearing aids. What do you think you can do this week?" [elicits specific goal]

"I think she can wear them when she is awake."

"Ok, so you will have her wear them when she is awake. That would be about 10 hours a day. What do you think could get in the way for you?" [explores anticipated challenges]

"I'm home with her, and I want to really have a chance to see how they help her, I can't think of anything."

"Ok, so next time we can check data logging and talk about how the week went for you. [accountability] How does that sound?" [open-ended question]

"That sounds good."

[continue to talk about and develop a specific plan for how to determine benefit]

Implementation of evidence-based counseling techniques when working with parents of children who have MB/ UHL can provide a supportive foundation for parents and benefits for children. When providers are purposeful in their approach to communication, they can help parents accept the hearing loss, support them in making informed decisions about intervention, overcome barriers, learn how to monitor their child's performance, become an effective advocate for their child, and help their child to become an effective self-advocate. Ultimately, the objective of incorporating counseling methods in audiological and early intervention sessions with parents is to improve quality of life and maximize outcomes for children with MB/UHL.

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