



Early Information and Clear Recommendations to Parents Positively Influence the Use of Bone Anchored Hearing Systems for Young Children With Unilateral Microtia/Atresia



Fournir des informations aux parents tôt dans la séquence développementale et leur formuler des recommandations claires influencent positivement l'utilisation des systèmes auditifs à ancrage osseux chez les jeunes enfants atteints de microtie ou d'atrésie unilatérale

KEYWORDS

- UNILATERAL
- MICROTIA
- ATRESIA
- BONE ANCHORED HEARING SYSTEM
- DECISION-MAKING

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Abstract

Hearing with two ears is better than one. That said, consensus is lacking on recommendations around hearing devices for children with unilateral hearing loss. This study explores factors influencing parents' decision making around bone anchored hearing systems for young children with microtia/atresia to help inform standardized, evidence-based recommendations for those with unilateral hearing loss. An online survey completed by 16 parents of children (6 years old and younger) with unilateral ($n = 13$) or bilateral ($n = 3$) microtia/atresia explored how information about amplification was offered to parents and how this may have affected their decision-making process to get a hearing device and use it full-time. Qualitative and descriptive analyses showed that parents of children with unilateral microtia/atresia reported varied experiences with their audiologists, including when information was shared, who initiated the conversation, the extent to which a hearing device was recommended, and the degree to which their audiologist influenced their decision. The majority of children with unilateral microtia/atresia had not achieved full-time use, but earlier information sharing and stronger recommendations were linked to earlier trial of a bone anchored hearing system and greater ongoing usage. These findings contrast with those from children with bilateral microtia/atresia, where quicker achievement of full-time use was reported. These results suggest that audiologists and other professionals have important roles to play in helping parents of children with unilateral microtia/atresia understand the long-term risks and benefits related to amplification. There is a need for greater consistency in what, when, and how these parents receive information and recommendations.

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Pour bien entendre, deux oreilles valent mieux qu'une. Cela dit, il n'existe actuellement pas de consensus quant aux recommandations entourant les appareils auditifs à ancrage osseux pour les enfants atteints d'une perte auditive unilatérale. La présente étude a exploré les facteurs qui ont influencé les parents à accepter et à utiliser un système auditif à ancrage osseux pour leur enfant atteint de microtie ou d'atrésie, et ce, afin de développer des recommandations standardisées s'appuyant sur des données probantes pour les personnes atteintes de perte auditive unilatérale. Seize parents d'enfants âgés de six ans et plus et atteints de microtie ou d'atrésie unilatérale ($n = 13$) ou bilatérale ($n = 3$) ont répondu à un questionnaire portant sur la façon dont les informations au sujet de l'amplification leur avaient été communiquées et sur la façon dont celles-ci avaient influencé leur décision à procurer un appareil auditif à ancrage osseux à leur enfant et à l'utiliser à temps plein. Les résultats des analyses qualitatives et descriptives réalisées montrent que les parents d'enfants atteints de microtie et d'atrésie unilatérale ont eu des expériences variées avec les audiologistes. Cela inclut le moment où des informations sur les systèmes auditifs à ancrage osseux leur ont été transmises, la première personne qui a amorcé la conversation à propos des systèmes auditifs à ancrage osseux, la mesure dans laquelle l'appareil auditif à ancrage osseux leur a été recommandé et le degré d'influence de l'audiologiste sur leur décision. La majorité des enfants atteints de microtie ou d'atrésie unilatérale n'utilisait pas encore leur appareil auditif à ancrage osseux à temps plein. Cependant, le fait d'avoir fourni des informations aux parents plus tôt dans la séquence développementale et de leur avoir fait des recommandations plus fortes étaient associés à l'essayage d'un appareil auditif à ancrage osseux chez l'enfant plus tôt dans la séquence développementale et à une utilisation plus importante de ce dernier au moment de remplir le questionnaire. Ces résultats contrastent avec ceux des enfants atteints de microtie ou d'atrésie bilatérale, pour qui les parents ont rapporté avoir adopté une utilisation à plein temps plus rapidement. Les résultats de la présente étude suggèrent que les audiologistes et les autres professionnels ont un rôle important à jouer pour aider les parents d'enfants atteints de microtie ou d'atrésie unilatérale à comprendre les risques à long terme liés à la condition de leur enfant et les avantages associés à l'amplification. Une plus grande cohérence est nécessaire en ce qui concerne le contenu, le moment et la manière dont les parents d'enfants ayant une microtie ou atrésie unilatérale reçoivent des informations et des recommandations au sujet des systèmes auditifs à ancrage osseux.

There is substantial evidence that binaural hearing improves speech perception in noise as well as the ability to localize sounds and to hear in the presence of background noise (Bronkhorst & Plomp, 1990; Lieu et al., 2012; Van Wanrooij & Van Opstal, 2007). Research indicates that children with unilateral hearing loss (UHL), who do not have access to typical binaural cues, may show a higher proportion of language delays and/or speech difficulties than their typically hearing peers (Anne et al., 2017; Lieu, 2004) and have more difficulty listening in the presence of background noise (Griffin et al., 2019) or in school situations that require focused attention (Cañete et al., 2021). Furthermore, children with UHL tend to have greater academic difficulties (Kesser et al., 2013; Lieu et al., 2012; Smit et al., 2021), greater need for educational assistance, and more perceived behavioural problems (Lieu, 2004; Lieu et al., 2010; Tharpe, 2008) than their typically hearing cohort.

Although the benefits of binaural hearing have been known for some time, this has not historically resulted in consistent recommendations for amplification for children with UHL. Children with typical hearing in one ear have often been considered to have sufficient access to develop speech and language normally, and thus amplification has not always, or not consistently, been recommended (Fitzpatrick et al., 2016; Lieu, 2004). Although newborn hearing screening programs have become more widespread, resulting in the early identification of UHL, clear consensus on how children with UHL should be managed audiologically has been slow to emerge (Briggs et al., 2011; Liu et al., 2013).

More recently, the growing body of research on the academic, social, and other impacts on children with UHL (Appachi et al., 2017; Bagatto et al., 2019; Griffin et al., 2019; Kesser et al., 2013; Lieu, 2004; Lieu et al., 2010, 2012) is leading to changes in the audiological management recommendations for these children, with some now being fit with amplification as infants (Bagatto et al., 2018; McCreery et al., 2013, 2017/2019; Rohlf et al., 2017). Nevertheless, the heterogeneity within the population of children with UHL presents a complex management challenge, as different amplification options are available depending on the type and degree of hearing loss (Bagatto et al., 2018). This can lead to confusion in parents' understanding of the impact of UHL on their children's overall development due to a lack of clarity in the information and counselling provided by professionals regarding recommendations for the management of UHL (Fitzpatrick et al., 2016).

To examine this predicament, we focused on a group of children with similar audiological profiles: those with unilateral microtia/atresia (m/a) in British Columbia (BC), Canada. Microtia describes malformations of the external ear, and atresia refers to the absence or closure of the external ear canal (van Hövell Tot Westflieer et al., 2018). These conditions usually occur together (90%; van Hövell Tot Westflieer et al., 2018) and most often affect one side, with 77%–93% of cases being unilateral (Luquetti et al., 2012). Prevalence of microtia is estimated at 2.0–2.9 per 10,000 (Luquetti et al., 2011), based on population-based studies in the contiguous United States. Given the reported numbers of births in BC in 2013–2019 (Government of BC, 2020), there are an estimated 9–13 children born with m/a each year in BC.

Although there is strong support and recommendations for the use of bone anchored hearing systems (BAHS) for those individuals with bilateral m/a (Hol et al., 2005; Verhagen et al., 2008; Wang et al., 2018), there has not historically been the same consensus in support for individuals with unilateral m/a (McDermott & Sheehan, 2009; Snik et al., 2008; Tietze & Papsin, 2001). Despite a growing base of research into this topic (Alexander et al., 2020; Graham et al., 2015; Kunst et al., 2008), and evidence that some individuals with UHL can receive significant benefit from use of a BAHS (Appachi et al., 2017; Banga et al., 2013; Hol et al., 2005; Snik et al., 2002; Wazen et al., 2001), there appears to be great variability in the type of support, information, and recommendations parents of children with unilateral m/a receive regarding their child's use of a hearing aid device (Bagatto et al., 2018, 2019; Liu et al., 2013, 2017).

For example, the BC Early Hearing Program follows the early hearing detection and intervention best practice guidelines commonly referred to as the 1-3-6 model, meaning screen by age 1 month, identify by age 3 months, and fit with amplification and enroll in intervention services by age 6 months (Joint Committee on Infant Hearing, American Academy of Pediatrics, 2007). Although the BC Early Hearing Program established full implementation of their early hearing detection and intervention program by 2010 (BC Early Hearing Program, 2010) consistent recommendations and guidelines on how to support amplification trials for children with unilateral m/a have only recently emerged (McCreery et al., 2017/2019).

Prior to 2017, amplification for children in BC with UHL (including those with unilateral m/a) was left to the individual audiologist's discretion. These children were not routinely referred to early intervention services but were monitored by speech-language pathologists through the

BC Early Hearing Program at 9–12, 18, and 24 months of age using the Communication & Symbolic Behaviour Scales Developmental Profile Infant-Toddler Checklist (Wetherby & Prizant, 2002) during a phone interview with a parent. Children under 2 years of age were referred by the BC Early Hearing Program for early intervention services if any concerns were identified (as reported by the parent or based on results of the Infant-Toddler Checklist), if there was a change in hearing, or if the family decided to trial a hearing aid (L. Bell, personal communication, December 15, 2021).

The revised amplification and early intervention guidelines in BC, developed in 2017 and updated in 2019 (McCreery et al., 2017/2019), recommend a BAHS for infants with permanent UHL due to m/a as soon as the child can sit without assistance, which is typically around 6–9 months of age (Government of BC, 2019). This is in contrast with the guidelines for those with permanent bilateral hearing loss due to m/a (as well as those requiring behind-the-ear hearing aids for other types of unilateral or bilateral hearing loss), where amplification is recommended as soon as feasible following confirmation of hearing loss, ideally between 3 and 6 months of age.

This difference in recommended age of fit is due to the unique challenge of having a baby wear a softband device; it is difficult to keep the device positioned correctly on the mastoid while still allowing it to vibrate freely when a child spends most of the time lying down. Through anecdotal experiences of individuals, we are aware that the BAHS must vibrate freely to work properly; when it is touched, the vibration is impeded and the sound is altered, resulting in decreased clarity, sound distortion, and/or acoustic feedback.

For children with bilateral m/a, the recommendation for early amplification supersedes placement concerns because without it the child does not have adequate access to spoken language. For a child with typical hearing on one side, the potential benefit of the BAHS is more directly linked to correct placement of the device, given that the child already has auditory access on one side, and the goal is to add binaural information. Thus, we could expect a child with bilateral m/a to be fit with a BAHS a few months earlier than a child with unilateral m/a. It is also worth noting that the BC guidelines recommend fitting only a single BAHS for children with bilateral m/a, and do not fund a second BAHS (McCreery et al., 2017/2019). This recommendation is based on the assumption that one device will stimulate both cochleae. Although the guidelines acknowledge the impact of head shadow effect and transcranial attenuation, they do not recommend bilateral BAHS as the standard of care due

to limited evidence of the benefit of bilateral systems for this population (McCreery et al., 2017/2019).

Given that recommendations for children with unilateral m/a have historically differed from other groups (bilateral m/a, other types of hearing loss) and have changed over time, it is not surprising that we have observed and received anecdotal parent reports suggesting that families are given differing information and recommendations regarding the benefits of hearing device use for children with unilateral m/a. In our clinical practice working with children who are deaf¹ and hard-of-hearing in BC (birth to 5 years old), we have observed that although many families of children with bilateral hearing loss are able to achieve full-time hearing aid use at a young age, families of children with UHL are more varied in their ability to reach this level of use, a trend also observed by Fitzpatrick et al. (2016). On the one hand, parents of children with unilateral m/a have often reported being advised that a BAHS could be considered as an option when their child grows older. On the other hand, we have also observed older children with unilateral m/a who were less receptive to using a BAHS than younger babies and their parents were, as was also noted by McDermott and Sheehan (2009). We have also encountered many parents struggling to make the decision to trial or obtain a nonsurgical option of a BAHS to use for their child. This aligns with research finding that parents can be overwhelmed with hearing loss diagnosis, including when mild or unilateral in nature, and these feelings can be exacerbated when faced with having to decide about hearing technology (Fitzpatrick et al., 2016). Even when families make the decision to use a BAHS, many struggle with attaining full-time use – they can be less determined to keep the hearing aid on at all times when their child still has some access to sound without it.

With the objective of understanding these variations in the level of BAHS use in infants and children with unilateral m/a, this study explored various factors that may influence a family's decision to accept and use a BAHS for their child. Specifically, we explored how families reacted to the information they received early in their journey (as well as when and how that information was shared), and how this information affected decisions about getting and using a device. We hypothesized that the experiences of parents of children with unilateral m/a were inconsistent with respect to (a) receiving clear information and recommendations about the need for and the benefits of a BAHS for their child as an intervention option, (b) choosing to use a BAHS for their child, and (c) attaining full-time use of the BAHS. We further hypothesized that those parents who received clearer, more consistent information and recommendations earlier about the need for and the benefits of a BAHS for their children

¹We use the terminology deaf rather than Deaf when referring to children because they have not yet had an opportunity to identify with a particular cultural group.

would be more likely to trial a BAHS earlier and achieve full-time BAHS use for their children.

Method

This research was approved by and conducted in accordance with the requirements of the University of British Columbia Behavioural Research Ethics Board (#H17-03354) on March 13, 2019.

Online Survey

We developed an online survey of 66 questions for primary caregivers of children with m/a (available on request). After rigorous question development, the language level of the content was reviewed to ensure it was appropriate for families not familiar with the research study, free from technical terms, and was at a level that was accessible to caregivers with at least a high-school level of education and fluency in written English. Some questions were conditional on responses given to previous questions, thus, not all participants were required to respond to all questions. Questions included a combination of response options (Likert scales, yes/no, and open-ended).

Following an initial statement of information, instructions, and consent, the 66 questions of the main survey content were divided into five sections. The first 12 questions collected demographic information about the primary caregiver and the child, and the following eight questions focused on the child's hearing (e.g., type and level of loss, presence of m/a in each ear). The next 11 questions asked how the primary caregiver first learned about options for amplification for their child (when and how they received information from the audiologist, who initiated the discussion, and the degree to which a BAHS was recommended). Participants were also asked in this section about the extent to which others informed their learning as well as their perception of the risks and benefits of amplification and options for owning their own device (e.g., whether it was provided for free or they had to purchase the device privately). The fourth section of the survey consisted of 27 questions about the child's experience with a BAHS or other hearing equipment: if they tried/owned a BAHS, at what age, for how long; whether the child had used a conventional hearing aid or a second BAHS if bilateral; type of BAHS, perceived benefit; methods of wearing the BAHS (e.g., headband, abutment); and level of use. Last, the survey asked eight questions about factors (appearance, acceptance, benefit, risk, cost, other) and people (audiologist, Deaf or hard-of-hearing adult, ear nose and throat doctor, early interventionist/therapist, family doctor, family/friend, parent of child with m/a, parent of child with different type of hearing loss) and other sources

(internet resources, social media, other) influencing the primary caregiver's decision to try, keep and/or stop using a BAHS for their child.

The finalized survey was entered into the University of British Columbia Survey Tool provided by Qualtrics, an online survey tool platform that complies with the BC Freedom of Information and Protection of Privacy Act, keeping survey data secure, stored, and backed up in Canada. It was accessible using a smartphone, computer, or tablet, and pilot testing by three parents of older children with m/a indicated that the full survey took less than 30 minutes to complete (with participants able to pause and come back to complete the survey). Feedback from these parents led to minor changes in wording only. The survey was advertised in written English, and the survey was offered only in written English.

Participants

Eligible participants were primary caregivers of a child aged 6 years or younger with bilateral or unilateral m/a, who self-selected to complete the survey. Caregivers of children with bilateral m/a were included in this study, despite the expectation that the much lower incidence of bilateral m/a would result in a small sample size that would prevent quantitative comparison with the unilateral group. Responses from this smaller cohort were gathered to provide context and additional information.

Participants were offered a \$10 Amazon gift card in return for their participation. The study targeted such families in BC, with a flyer advertising the study distributed by email to the province's three early intervention agencies that specialize in supporting families with young deaf and hard of hearing children, a parent-driven, nonprofit organization dedicated to supporting families with children who are deaf or hard-of-hearing in BC (BC Hands & Voices), and three Facebook groups that support families of children who are deaf and hard-of-hearing in BC.

Data Analyses

The survey was available for completion between May 15 and September 18, 2019. During this 4-month period, we received 709 responses (648 completed surveys and 61 partially completed ones). A qualitative and descriptive analysis was done on the 16 genuine responses to the survey. The high number ($n = 693$) of fraudulent responses detected were eliminated from further consideration.

The incentive behind these fraudulent responses was most likely the offer of a \$10 Amazon gift card in return for completion. The antifraud tools available from Qualtrics

are testament to the problem online surveys face from fraudulent responses. However, fraudulent attempts could be readily discriminated from genuine responses using a combination of technology embedded within the Qualtrics software and a series of filter questions designed to cross-check these automated detections. Filter questions included a series of questions about the children's hearing which needed to logically agree and open-ended questions whose written responses needed to make sense and bear some relation to the topic being asked. The data were then sorted independently by two raters into three categories ("fraudulent" to be excluded, "genuine" to be included, and "unsure" to be discussed between the two raters and a co-principal investigator). A response was identified as fraudulent (either from bots or cheaters) and excluded from the data set if it met two or more of these criteria:

- Flagged as a duplicate by the ballot box stuffing feature and/or the relevant ID technology implemented in the survey design or had a duplicated IP address.
- Flagged as a bot response by the Q-RecaptchaScore feature implemented in the survey design.
- Latitudinal and longitudinal coordinates were outside the province of BC.
- Nonsensical responses (e.g., giving contradictory information when describing child's hearing loss, such as indicating bilateral hearing loss but then responding that hearing levels in one ear are typical).

Using these criteria, two raters unanimously identified 660 responses as fraudulent (606 completed surveys; 54 partially completed responses). The remaining responses were further reviewed for validity. Fifteen genuine responses were clearly identified as meeting none of the above criteria (14 completed surveys and one partially complete one). They also exhibited a familiarity of the subject (e.g., naming early intervention agencies or providing logical comments or answers about hearing loss and/or equipment). This left 34 "unsure" responses (28 completed surveys and six partially complete ones), which had one criterion from the fraudulent response list or did not seem genuine in their comments or answers. The two raters reviewed these unsure responses with a co-principal investigator. Of these, one incomplete response was confidently considered to be genuine, bringing the total number of genuine responses to 16 (14 completed and two partially completed surveys). Of the remaining responses, 16 (12 completed and four partially completed surveys) were confidently considered to be fraudulent, and 17 (16 completed and one partially completed surveys) were considered to be likely fraudulent.

Although we went to lengths to protect participants' anonymity and we did not gather identifying information as part of our response validation, we are highly confident that the independent data screening by three people using the criteria described did indeed yield 16 genuine responses.

Results

Demographic information for the participants is summarized in **Table 1**. Briefly, participants were mothers who varied in their country of origin. Eight respondents were born in BC and four were born in other provinces or territories in Canada. The remaining four respondents were from other countries. Twelve respondents use English as their first language, but the other four indicated that it was not their native language. Two participants reported having a high-school education, four a bachelor's degree, and five a graduate degree. Two reported having a diploma in early childhood education and the remaining participant self-identified as a care attendant.

Background information on the participants' children with m/a is summarized in **Table 2**. All respondents indicated that their children were born in BC and that their hearing loss was identified at birth. Thirteen reported having a child with unilateral m/a and three a child with bilateral m/a.

The reported years of birth for the children ranged from 2013 to 2018. Six of the children with unilateral m/a were born in the years 2017 and 2018; the remaining seven and all three of the children with bilateral m/a were born prior to 2017, at a time when recommendations regarding amplification were left to the discretion of the individual audiologist.

Device Use

Fifteen of the 16 participants reported usage of BAHS. For those with unilateral m/a, the age of first fit for trialing the device was between 6 and 33 months ($M = 12.0$, $SD = 8.6$) whereas those with bilateral m/a were first fit for trialing their first device earlier, at 5 weeks, 6 weeks, and 8 weeks ($M = 6.34$, $SD = 1.5$; **Table 2**). The single participant whose child with unilateral m/a had not used a BAHS was the only participant who did not report receiving specialized early intervention services (**Table 2**). All participants who reported having trialed a device used only either a softband headband provided by the company or a homemade/purchased headband.

Of the three parents of children with bilateral m/a, one family reported receiving their second BAHS at 9 months, a second family reported 10 months, and a third family did not indicate when they received a second BAHS. All three families reported being informed that only the first BAHS

Table 1		
Respondent (Parent) Demographic Information		
Variable	Child with unilateral microtia/atresia (n = 13)	Child with bilateral microtia/atresia (n = 3)
Relationship to child		
Mother	13	3
Level of education		
High school/GED	2	0
Bachelor's degree	4	1
Graduate degree	5	1
Other		
ECE diploma	2	0
Care attendant	0	1
Birthplace		
British Columbia	6	2
Other:		
Province/territory		
Manitoba	1	0
Ontario	0	1
Alberta	1	0
Yukon	1	0
Outside Canada		
Switzerland	1	0
Japan	1	0
Hong Kong	1	0
Unspecified	1	0
First language		
English	7	3
Other	4	0

Note. GED = General Educational Development test; ECE = early childhood education

would be provided for free and that they were responsible for purchasing the second themselves or securing funding through an alternate source.

Some parents of children with unilateral m/a reported full-time use of BAHS (*n* = 4), but many of them were still working to achieve full-time use (*n* = 6), were satisfied with part-time use (*n* = 2), or did not use a BAHS (*n* = 1). This was consistent with the number of hours per week of BAHS usage that the parents reported (*M* = 42.0, *SD* = 25.1). There was also a range in the reported use of the BAHS across different environments for children with unilateral m/a

(**Figure 1A**). The three parents of children with bilateral m/a all reported full-time use across almost all environments (**Figure 1B**), with an average of 84 hr per week.

Sources of Information and Influencing Factors

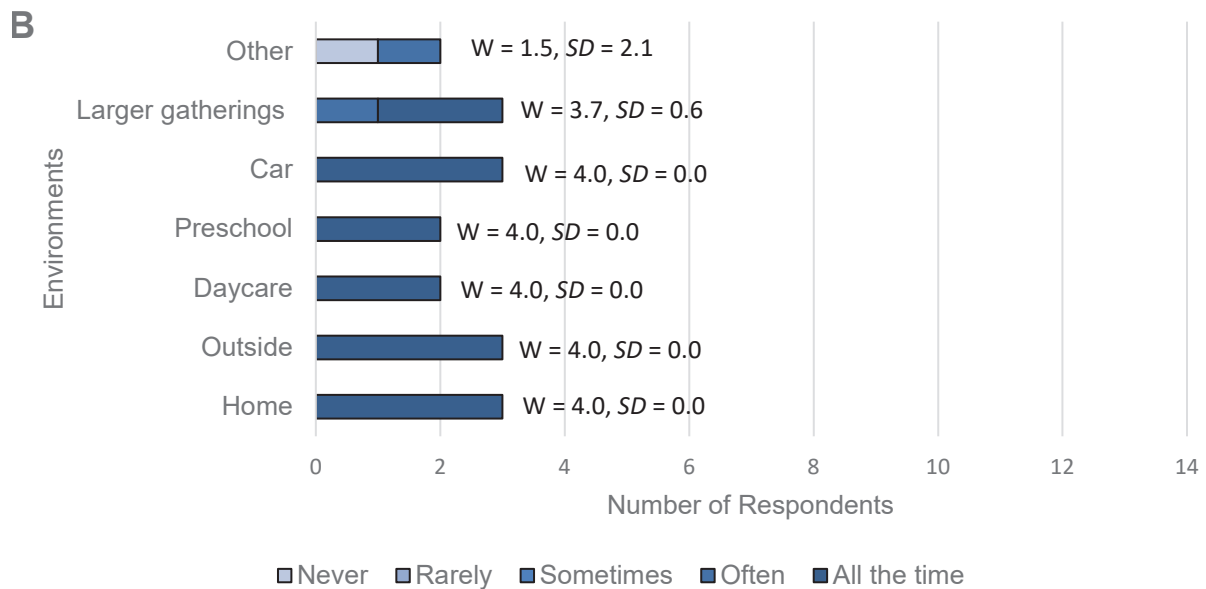
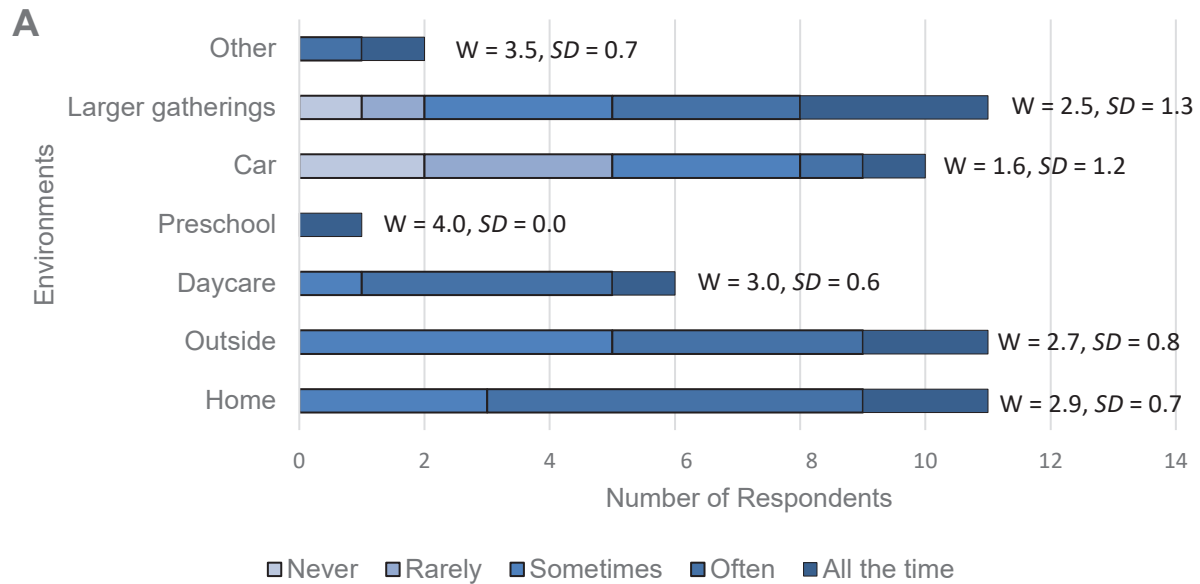
Parents of children with unilateral m/a reported varied experiences in terms of learning about BAHS as an option for their child. This discussion was most commonly initiated by the audiologist (*n* = 7) but for some it was started by the parent or family member (*n* = 2) or by “other” (*n* = 3; where “other” indicated a range of self-initiatives: “myself,” “audiologist of course,” “parents I met at baby groups at

Table 2		
Children's Birth Statistics, Amplification Trial, and Service Enrollment Data		
Variable	Unilateral microtia/atresia (n = 13)	Bilateral microtia/atresia (n = 3)
Birth year		
2019	0	0
2018	5	0
2017	1	0
2016	3	2
2015	2	0
2014	0	1
2013	2	0
Birthplace/residence		
Fraser Valley	6	1
Interior BC	5	0
Northern BC	0	0
Vancouver Coastal	0	1
Vancouver Island	2	1
Additional needs		
Yes	1	1
No	10	2
Unsure	2	0
Service enrollment^a		
Child development centre	4	1
Specialized early intervention agency	12	3
Public health agency	4	0
Other	2	0
None indicated	1	0
Age of identification		
Newborn (at birth)	13	3
Age at which first trialed bone anchored hearing system		
≤6 months	3	3
≤1 year	5	0
≤2 years	3	0
≤3 years	1	0
Never trialed	1	0
Ear(s) affected		
Right	7	3
Left	6	3

Note. BC = British Columbia.

^aParticipants could select more than one service agency because families in BC are able to receive services from more than one agency when the child may benefit from support from other service providers (e.g., occupational therapists, physiotherapists, etc.) or when they receive services from a local service provider as well as from a service provider specialized in working with children who are deaf or hard-of-hearing.

Figure 1



Extent of bone anchored hearing system use in different environments

Note. Panel A shows responses by parents of children with unilateral microtia/atresia (n = 12; one participant with unilateral microtia/atresia did not begin a trial of a bone anchored hearing system). Panel B shows responses by parents of children with bilateral microtia/atresia (n = 3). Average weighted score (W) was calculated where the sum of scores (Never = 0, Rarely = 1, Sometimes = 2, Often = 3, All the time = 4) was divided by the number of responses.

hearing support centers," "people from Hands & Voices," "parent guide," "parents I met at BC Family Resource Center [sic] baby groups," "SLT [Speech Language Therapist] at BCFRC [BC Family Resource Centre]," "joint discussion," "we gathered info on internet prior to appt [appointment] with audiologist." Participants of children with bilateral m/a reported that the discussion about BAHS as an option for their child was initiated by their audiologist ($n = 2$) or was jointly brought up ($n = 1$).

Most of the parents of children with unilateral m/a felt their audiologist had influenced their learning about BAHS for their child to a *moderate* or *great extent* but some felt their audiologist had influenced their learning about BAHS *very little, to some extent, or not at all* (average weighted score = 3.1; see **Figure 2A**). The top three most influential "other" sources of information were early intervention agencies, other parents of children with m/a, and the internet (average weighted scores = 2.8, 2.5, 2.2, respectively). The parents of children with bilateral m/a rated the internet as the most influencing factor (average weighted score = 4.0; see **Figure 2B**), followed by their audiologist, other parents of children with m/a, and their early interventionist (average weighted scores = 3.7, 3.3, 2.7, respectively).

Although the three parents of children with bilateral m/a all reported being informed about BAHS as an option within 6 months and all felt amplification was recommended to a *great extent* by their audiologist, there was variation in when families of children with unilateral m/a were informed and to what degree these parents felt amplification was recommended. The earlier the audiologist informed parents about BAHS being an option for their child, the more likely and earlier they began a BAHS trial; the eight families who were informed about BAHS being an option for their child within 6 months of diagnosis were fit with a BAHS between 6 and 18 months ($M = 8.8$, $SD = 3.9$). This compares to three families who were informed about BAHS being an option for their child between 6 months and 1 year after diagnosis, who were fit with a BAHS between 13 and 33 months ($M = 23.3$, $SD = 10.0$). The one family who was not informed of this option by their audiologist did not begin a trial.

Moreover, parents of children with unilateral m/a who reported the BAHS was recommended to a *moderate* or *great extent* generally trialed the BAHS and did so earlier than families who felt that a BAHS was only recommended to a *very little extent*, or who were not informed about BAHS as an option. Eight families who reported BAHS being recommended to a *great extent* were fit with a BAHS between 6 and 24 months ($M = 11.5$, $SD = 6.5$) and three families who reported BAHS being recommended to a *moderate extent* were fit with a BAHS between 6 and 8

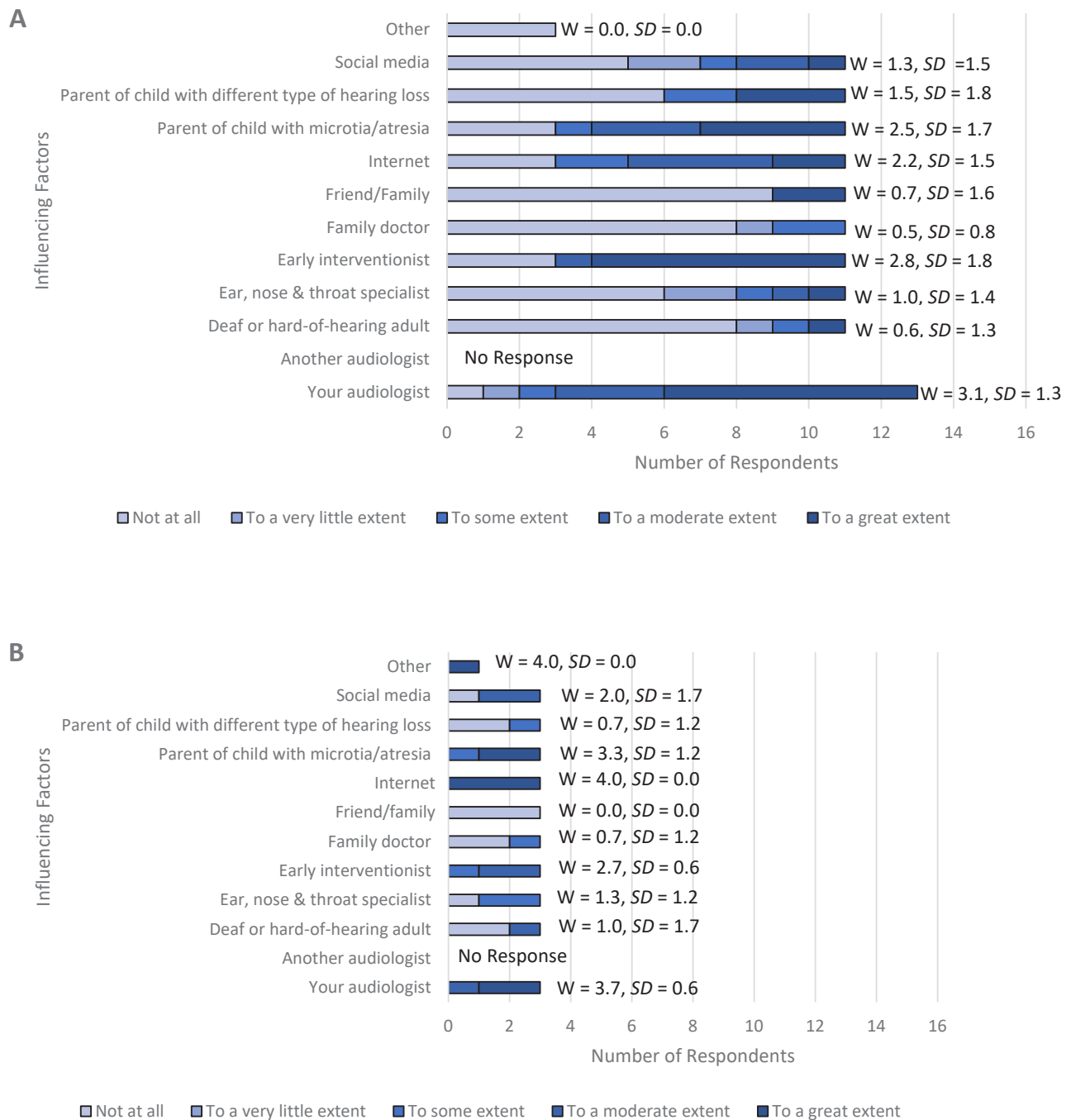
months ($M = 7.2$, $SD = 1.0$). This contrasted with one family who reported the BAHS was recommended to a *very little extent* and the BAHS was fit at 33 months, and the single participant who was not informed of this option by their audiologist and did not begin a trial.

The three parents of children with bilateral m/a all reported achieving full-time use of BAHS. Parents of children with unilateral m/a tended to report greater ongoing usage of the BAHS by their child and more commonly reported full-time use (or working towards full-time use) of BAHS by their child when their child's audiologist informed them about BAHS as an option earlier (**Figure 3A**) and recommended BAHS to a greater extent (**Figure 3B**). The eight families who were informed about BAHS being an option for their child within 6 months of diagnosis reported BAHS use between 11.5 and 84.0 hr per week ($M = 47.4$, $SD = 25.5$). This compares to the three families who were informed about BAHS being an option for their child between 6 months and 1 year after diagnosis, who reported BAHS use between 3.5 and 42.0 hr per week ($M = 28.2$, $SD = 21.4$). The one family who reported being "unsure" when BAHS was recommended reported BAHS use as 0 hr per week.

The eight families who reported BAHS being recommended to a *great extent* reported BAHS use between 3.5 and 84.0 hr per week ($M = 41.3$, $SD = 29.7$); the three families who reported BAHS being recommended to a *moderate extent* reported BAHS use between 0 and 52 hr per week ($M = 31.5$, $SD = 27.7$); one family who reported the BAHS being recommended to a *very little extent* reported BAHS use of 31.5 hr per week; and, one family who was not informed of this option (and thus it was not recommended) by their audiologist reported 0 hr of BAHS use. Overall, the older children with unilateral m/a in our study were less likely to achieve full-time use or the respondents were more satisfied with part-time use compared to the younger children with unilateral m/a (**Figure 3C**).

Parents of children with unilateral m/a reported varying degrees of influence from factors such as cost, risk of not amplifying, benefit, child's acceptance of the device, and appearance on their decision to trial a BAHS (**Figure 4A**). The perceived benefit and the child's acceptance of the BAHS were the two strongest influences overall (average weighted scores = 3.3, 2.6, respectively), followed by risk, cost, and appearance (average weighted scores = 2.3, 1.9, 1.1, respectively). Parents of children with bilateral m/a rated risk and benefit as strong influences (average weighted scores = 4.0, 3.7), while acceptance, appearance and cost were all rated much lower and well below the scores of the parents of children with unilateral m/a (average weighted scores = 0.7, 0.3, 0.0; **Figure 4B**).

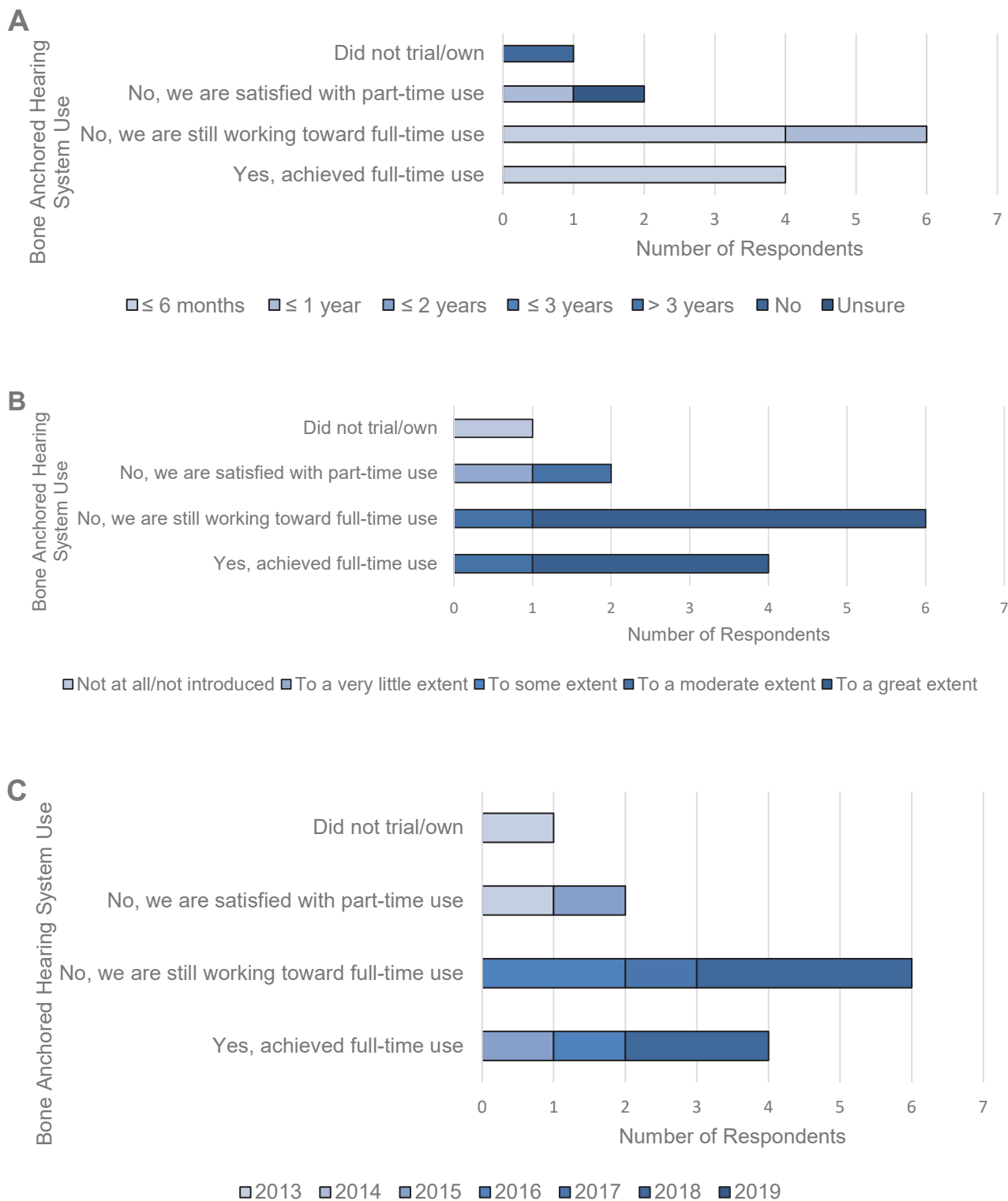
Figure 2



Factors influencing learning about bone anchored hearing systems as an option

Note. Panel A shows responses by parents of children with unilateral microtia/atresia (n = 12; one participant with unilateral microtia/atresia did not begin a trial of a bone anchored hearing system). Panel B shows responses by parents of children with bilateral microtia/atresia (n = 3). Average weighted score (W) was calculated where the sum of scores (Not at all = 0, Very little = 1, Some = 2, Moderate = 3, Great extent = 4) was divided by number of responses.

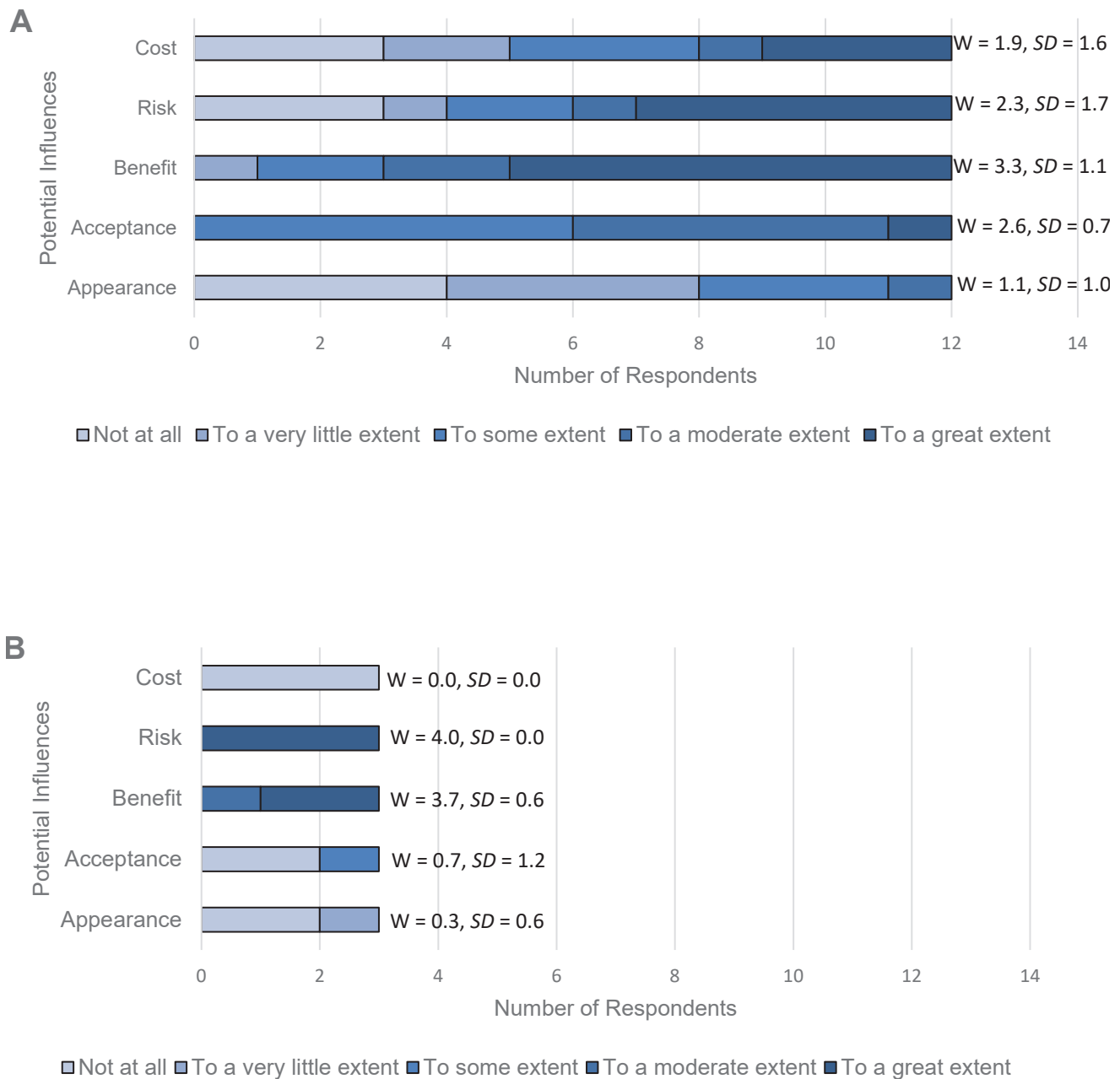
Figure 3



Extent of full-time use of bone anchored hearing systems by children with unilateral microtia/atresia

Note. Panel A shows the timeline parents were informed about bone anchored hearing systems (BAHS) being an option for their children. Panel B shows the extent to which BAHS were recommended to parents by an audiologist. Panel C shows the birth year of the children (n = 13).

Figure 4



Extent that potential risks and benefits influenced parents of children with microtia/atresia to trial bone anchored hearing systems

Note. Panel A shows responses by parents of children with unilateral microtia/atresia (n = 12; one participant with unilateral microtia/atresia did not begin a trial of a bone anchored hearing system). Panel B shows responses by parents of children with bilateral microtia/atresia (n = 3). Average weighted score (W) was calculated where the sum of scores (Not at all = 0, Very little = 1, Some = 2, Moderate = 3, Great extent = 4) was divided by the number of responses.

Responses to Open-Ended Questions and Opportunities for Comment

The survey included opportunities for parents to include comments after several of the questions. Comments were shared related to what options parents were given for owning their own BAHS, how they felt their child benefited from wearing a BAHS, the extent to which various factors and people influenced their decision to first try or not try a BAHS, and any final comments they wanted to share. Two parents of children with unilateral m/a commented about the decision-making process: "I honestly didn't think much. I wanted to offer every possible therapeutic options [sic] for my child. Back in those days, I remember just going to an appointment as if checking off the list of things to do," and, "I would be very interested in knowing more about the impacts of wearing a BAHS on a unilateral m/a child . . . we made our decision mostly based on the fear that she could be impacted negatively if she didn't wear one."

The parent of the child who did not try a BAHS reported that she "didn't like the idea of the headband for the baha," and her "husband and I agreed to just see what happens with his hearing without a baha." However, she also commented, "Now that my son is in school he has trouble hearing with all the different sounds going on."

Other comments from parents of children with unilateral m/a expressed uncertainty about the benefit their child was receiving: "As her hearing is typical in the right ear, it is very difficult to know what the benefits to speech and language are," and, "I'm not sure of the benefit yet. She's a very happy baby to begin with, and vocal as well." In contrast, when asked about benefit of having a BAHS, the three parents of children with bilateral m/a were more confident in their assertion of the benefit: "He has never refused them and always wants them on," and, "Our son wears his BAHS constantly. He is very protective of his 2 Ponto 3 Superpowers. He is very good about telling us when the batteries need changing."

The survey also contained open-ended questions addressed specifically to parents of children with bilateral m/a, asking them to describe their experiences with bilateral BAHS, the benefits of wearing two versus one, and their decision-making process for getting a second BAHS. All three participants reported improved auditory access when their child started wearing a second BAHS: "Improved sound quality," "can hear very quiet sounds/speech much better with 2," and, "My daughter received her second Ponto BAHA when she was around 1 year old. We noticed an improvement with her overall hearing levels."

Two of the three participants commented on the importance of having two BAHS for localization. One parent noted "it is imperative for helping her to locate sounds," and "her sound location ability became apparent." Another parent observed that "directional sound is so much greater with two. He can easily locate where sound is coming from." One participant reported an impact on clarity of speech: "One broke and we were without for a week and actually noticed his speech wasn't as clear. Was quite amazing when he got the second one back."

Two participants commented on the head shadow effect: "There is an argument that 1 BAH [sic] stimulates both Cochlea. But if there is no microphone on one side of the head to pick up any sounds there it becomes what is known as head shadow. Where they miss out on sounds being produced on the non-aided side," and, "Logically there is a shadow effect where sound will not be as easily amplified with one versus 2 aids."

Parents described their child's preference for two BAHS: "He loves wearing both and is sad if one breaks;" "I see a huge change in bilateral boy when he's wearing one vs two or if a battery is running low;" "She also states she can hear better with two;" and "She will let us know when one is not working and wants it fixed, and she is only 3."

Last, all three participants stated their belief that two BAHS should be standard for children with bilateral m/a: "I strongly feel 2 aids should be offered and the norm! I am ready to advocate as we are approaching abutment time and I will be again ensuring my son remains bilaterally aided;" "2 bahs is necessary in my opinion. . . . The cost sadly is outrageous for bahs and it would be great if it was covered fully for two ongoing for kids with bilateral microtia and atresia;" and, "We feel that two is far superior. . . . I feel that both hearing aids should be covered in the BC Early Hearing Program."

Discussion

The present study examined the way information about amplification was offered to parents of children with m/a and how this may have affected both their decision-making process to get a BAHS for their child and their ability to achieve full-time use of the BAHS. By investigating parents' perceptions of what was shared with them by professionals (and others) in their children's early years, this study gives insight into how the process could be improved, so that future parents of children with m/a receive clear and consistent information that allows their children to maximally benefit from early amplification.

Our results demonstrated that the experiences of parents of children with unilateral m/a are inconsistent with respect to receiving clear information and recommendations about the need for and the benefits of a BAHS for their children as an intervention option. These parents reported varied experiences with their audiologists in terms of when information was shared, who initiated the conversation, the degree to which a BAHS was recommended, and the degree to which their audiologist influenced their decision. In contrast, the group of parents of children with bilateral m/a, while small, showed striking consistency in their reports of their early experiences with their audiologists. This is concerning, given Kanzara et al.'s (2020) observation that "it is likely that that parents' decisions are influenced by the suggestions made by the healthcare practitioner they access" (p. 75).

Although 12 of the 13 parents of children with unilateral m/a chose to have their child use a BAHS, three quarters of the children had not achieved full-time use, with their parents reporting they were either still working towards full-time use or were satisfied with part-time use. There are several factors that may contribute to this. First, older children were less likely to have achieved full-time use, or their parents were more satisfied with part-time use compared to the parents of younger children. This may be related to the change in the amplification protocol that was released in BC in 2017, recommending early amplification as the standard for children with unilateral m/a (McCreery et al., 2017/2019). The years of birth for children being reported in this survey spanned the date of release for the changed protocol; the six parents of children with unilateral m/a born after the new guidelines rolled out likely received more consistent recommendations than the seven whose children were born prior to 2017.

Second, the age of the child at the time of survey completion could be a factor, as almost half of the children with UHL were still under 2 years of age. Given that the children with unilateral m/a started trialing equipment at an average age of 12.2 months ($n = 12$), some may not have had sufficient time to achieve full-time use, especially considering the challenge of keeping such a device on children at an age when they spend a considerable amount of time being held, lying in supine, and in car seats (Alexander et al., 2020).

Finally, four of the parents of children with unilateral m/a indicated that English was not their native language. It is possible that these parents did not understand the information and recommendations shared with them as easily as the native English speakers. It is also possible that

cultural influences (e.g., levels of social stigma related to hearing loss and device use) impacted families differently.

Parents of children with unilateral m/a reported varying degrees of influence on their decision to trial a BAHS from factors such as cost, risk of not amplifying, benefit, child's acceptance of the device, and appearance. Although the perceived benefit of the BAHS was rated as the strongest influence on the initial decision, parents' comments indicated they found it difficult to know how much benefit their child was actually getting from the device. In contrast, parents of children with bilateral m/a expressed their views very clearly about the benefits of bilateral hearing using bilateral BAHS. They reported improved auditory access, speech perception, and localization of sounds, and described the need for two BAHS to counteract the head shadow effect. They also noted how their young children clearly showed or expressed a preference to wear both BAHS. These parents advocated for bilateral BAHS being the standard for children with bilateral m/a and advocated that the cost of purchase for a second device should be covered by government funding. It is worth noting that all three of these families acquired a second BAHS for their child even though they had to pay for it themselves or secure funding through an alternate source.

Professionals have previously had less evidence and fewer guidelines on which to base their recommendations for amplification for children with unilateral m/a compared to bilateral m/a and other types of hearing loss, so it logically follows that their messaging to families may be perceived as less strong or urgent. Nevertheless, professionals must be aware that the way in which information is shared can impact parents' understanding of their children's hearing status, as well as their approach towards taking crucial next steps (Fitzpatrick et al., 2016; Kanzara et al., 2020; Porter et al., 2018). As stated in the Speech-Language & Audiology Canada position paper on UHL in children, "The provision of information to families regarding the potential impacts of UHL, including speech, language, academic, and social issues, is an important component of the care process. Families need an understanding of how auditory deprivation and binaural advantages can impact their child's development" (Speech-Language & Audiology Canada, 2020, p. 2). Unfortunately, a possible unintended consequence of inconsistency or uncertainty amongst professionals about the recommendations for amplification for children with UHL is that parents may not view amplification as being critically important for their child (Fitzpatrick et al., 2016). As a result, they may be less motivated to get started with amplification with their baby, and ultimately less likely to achieve full-time use and maximal benefit.

Our results suggest that audiologists and other sources of information such as the internet, other parents of children with m/a, and early intervention agencies have an important role to play in helping parents of children with unilateral m/a understand the long-term risks and benefits related to amplification. Indeed, the influence the audiologist may have on a family's decision to use a BAHS and the extent to which it is used was evident. The earlier the audiologist informed caregivers about BAHS being an option for their child, the more likely and earlier caregivers began a BAHS trial for their child with unilateral m/a. Also, those parents who reported the BAHS was recommended to a great extent generally trialed the BAHS and did so earlier than families who felt they were recommended to a lesser extent or were not informed. Furthermore, parents who were informed earlier and perceived the recommendation from the audiologist as being stronger reported better usage of the BAHS by their child.

There is a need for greater consistency in terms of what information and recommendations parents receive, as well as when and how they receive it. As was suggested by Kanzara et al. (2020), it is important that the variety of professionals involved with these children and their caregivers, not only the audiologist, establish a united multidisciplinary approach so that the messaging they provide to parents is clear and consistent. The BC Early Hearing Program has made efforts to implement a standardized protocol since 2017 (McCreery et al., 2017/2019). Citing McCreery et al. (2013) and Moodie et al. (2017), Speech-Language & Audiology Canada (2020) also shared general guidelines related to fitting amplification for this population, recommending a hearing aid "if the degree of hearing loss on the affected side permits the child to receive appropriate speech audibility from either an air or bone conduction hearing aid" (p. 3). There is still a need, however, for more detailed universal guidelines specific to fitting BAHS for children with unilateral m/a.

Limitations and Confounding Factors

Due to the low incidence of children with m/a and the population of BC, it was anticipated that the sample size of the current study would not be large. Despite the 16 survey responses we obtained representing a significant portion of this population (approximately 17.6%–25.4% based on an estimated 9–13 children born with m/a each year in BC), this sample size precludes statistical analysis and, thus, limits generalizing our findings to a larger population. In particular, the high ratio between bilateral and unilateral m/a groups (a consequence of their relative incidences in the general population) limits comparative quantitative analyses, a challenge that could be addressed in a larger

scale study. This study is, however, intended as preliminary and qualitative in nature. It is hoped that the results will lead to further exploration of recommendations made for amplification with children who have unilateral m/a, as well as parents' perceptions of those recommendations.

The present study is vulnerable to participation bias, as parents were relied upon to self-select. It is possible that parents who were motivated to complete the survey were also more motivated to actively explore intervention and amplification options for their children, and so the present sample may not accurately reflect the range of attitudes and experiences of all caregivers of children with m/a. BC is culturally and linguistically diverse, but the present study was advertised exclusively in written English and the survey was only offered in written English. This likely limited the number of families who were able to participate in the study. There were, however, four respondents who noted that English was not their first language.

Last, the survey collected information about parents' perceptions and recollections of their experiences. Clinical records were not accessed to confirm accuracy, nor were audiologists or other professionals asked for their recollections of what and how information was shared. It is possible that there was information offered by professionals that caregivers could not later recall due to both the passage of time and the stress and emotional upheaval that is commonly experienced by caregivers when making decisions about amplification (Kurtzer-White & Luterman, 2003).

Conclusions and Future Directions

Investigating parents' recollections of what was shared with them by professionals in their children's early years is an important first step in working towards standardized, evidence-based recommendations, so that children who have unilateral m/a will have the opportunity of getting maximal benefit from early amplification. This study suggests that parents of children with unilateral m/a may benefit from early, clear, and consistent information and recommendations about amplification in order to achieve maximum benefit from amplification. Our results also suggest that more research is needed to determine the impact of part-time versus full-time BAHS use for children with unilateral m/a and the optimal timing of fitting of a BAHS for these children. In conclusion, standardized protocols and guidelines on intervention and amplification recommendations for young children with unilateral m/a would benefit from collaborative development between various stakeholders including parents as well as professionals, such as audiologists and early interventionists, in BC and beyond. Furthermore, education

about such protocols and guidelines should be provided across disciplines, including to medical professionals who are often the first contact for families when their baby is born and m/a is diagnosed.

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