



Perspectives of Parents of Minority Culture Backgrounds on Pediatric Hearing Loss Services: A Qualitative Inquiry



La perspective de parents issus de minorités culturelles sur les services offerts aux enfants ayant un trouble auditif : une recherche qualitative

KEYWORDS

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Viviane Grandpierre
Elizabeth M. Fitzpatrick
Roanne Thomas
Lindsey Sikora
Beth K. Potter
Ovini Thomas

Viviane Grandpierre and
Elizabeth M. Fitzpatrick

Children's Hospital of Eastern
Ontario Research Institute,
Ottawa, ON, CANADA

Université d'Ottawa, Ottawa,
ON, CANADA

Roanne Thomas, Lindsey
Sikora, Beth K. Potter, and
Ovini Thomas

Université d'Ottawa, Ottawa,
ON, CANADA

Abstract

Increasing diversity in Canada can create challenges for practitioners providing services to children with hearing loss. Culturally competent services are required to ensure appropriate care for our multicultural population; however, there is a scarcity of evidence in audiology to inform practice guidelines. The perspectives of families of minority culture backgrounds on the services their children receive could provide invaluable information for practitioners seeking to provide appropriate care for all their patients. The objective of this study was to explore minority culture families' perspectives on barriers and facilitators to culturally competent early hearing loss services. A qualitative research design with semi-structured interviews was employed. A total of 10 parents (representing nine different children) participated in this study. Three themes emerged from the interview data: experiences with hearing loss, services, and education systems; needs as a minority culture family; and helpful strategies for service provision to minority culture families. This study is one of the first to explore the experiences of minority culture families receiving early hearing loss services. Families who have children with permanent hearing loss often require long-term, ongoing, intervention services. For this reason, it is imperative for practitioners to provide culturally competent services informed by empirical evidence. Insights from this study offer a starting point for knowledge translation into clinical practice.

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Abrégé

L'accroissement de la diversité au Canada peut créer des défis pour les praticiens qui offrent des services aux enfants ayant un trouble auditif. Des services culturellement adaptés sont essentiels afin d'assurer des soins appropriés à une population multiculturelle. Cependant, peu de données probantes sont disponibles dans le domaine de l'audiologie pour orienter les guides de pratique. Les praticiens cherchant à fournir des soins appropriés à tous leurs patients pourraient tirer de précieuses informations sur les services offerts aux enfants issus de minorités culturelles à partir de la perspective des parents de ces enfants. L'objectif de la présente étude était d'explorer la perspective de familles issues de minorités culturelles quant aux obstacles et aux facteurs qui facilitent l'accès à des services précoces adaptés sur le plan culturel. Un devis de recherche qualitatif utilisant des entrevues semi-structurées a été sélectionné. Au total, 10 parents (représentant neuf enfants différents) ont participé à cette étude. Trois thèmes sont ressortis des données des entrevues : (1) l'expérience des parents avec le trouble auditif, les services reçus et le système d'éducation, (2) les besoins des familles issues de minorités culturelles et (3) les stratégies jugées utiles par les parents dans la prestation de services aux familles issues de minorités culturelles. La présente étude est l'une des premières à explorer l'expérience des familles issues de minorités culturelles sur les services précoces qu'ils ont reçus pour le trouble auditif de leur enfant. Considérant que des services d'intervention continus et s'étendant dans le temps sont souvent requis pour les familles qui ont des enfants ayant un trouble auditif permanent, il est essentiel que les praticiens fournissent des services adaptés sur le plan culturel qui sont guidés par des données empiriques. Les résultats de la présente étude offrent un point de départ pour le transfert de connaissances vers la pratique clinique.

Cultural competence in early hearing loss interventions is required to support language development amongst Canada's diverse population. The latest projections from the Canadian census indicate that by 2036, nearly half of the population will be immigrants or children of immigrants (Statistics Canada, 2017). In the United States, minority groups are anticipated to represent the majority of the population by 2044 (United States Census Bureau, 2015). As diversity increases in North America, early hearing loss practitioners face challenges related to the provision of services; specifically, services developed on Western norms limit the ability of practitioners to deliver culturally competent health services to a more diverse clientele (Bonilla & Edwards, 2011; Grandpierre et al., 2018, 2019). Culturally competent health care refers to

understanding the importance of social and cultural influences on patients' health beliefs and behaviors; considering how these factors interact at multiple levels of the health care delivery system; and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003, p. 293).

There is extensive literature in rehabilitation to inform the development and maintenance of culturally competent services (see Al Busaidy & Borthwick, 2012; Jaggi & Bithell, 1995; Lee, Sullivan, & Lansbury, 2006; Lindsay, Tétrault, Desmaris, King, & Piérart, 2014; Nelson, Allison, & Copley, 2007; Williams & McLeod, 2012), yet a paucity of research in the field of audiology (Ball & Lewis, 2014; Eriks-Brophy, 2014; Grandpierre et al., 2018). Culturally competent health care services must be informed by evidence to ensure the best standards of care. As a family's cultural background can influence beliefs, values, behaviours, and practices, it is important for practitioners to be knowledgeable about cultural differences when providing services to families of minority culture backgrounds.

The diagnosis of a permanent hearing loss in a child is typically a stressful and emotional event for families without history of hearing loss. Yet, families of minority culture backgrounds are likely to encounter additional challenges beyond the hearing loss itself. For example, Canadian Indigenous children are more likely to experience poorer health determinants and living conditions than non-Indigenous children (Ball, 2008; Findlay & Janz, 2012a, 2012b; Statistics Canada, 2008). In addition, disability is stigmatized in some cultures and a diagnosis can bring shame upon family members, leading to relationships being severed (Jackson, Traub, & Turnbull, 2008). As a result, disabilities are often kept hidden.

Given the lack of research to inform best practices for delivering culturally competent care in pediatric hearing loss, the objective of this study was to explore minority culture families' perspectives on barriers and facilitators to culturally competent early hearing loss services. This study is part of a larger program of research seeking to gain insight into barriers and facilitators to culturally competent early hearing loss services from the perspectives of practitioners and minority culture families.

Method

Participants

Families of minority culture background receiving rehabilitation services for children with hearing loss were invited to participate from the Children's Hospital of Eastern Ontario (CHEO), a tertiary care hospital located in Ottawa, Canada, that provides diagnostic care as well as follow up and auditory-verbal intervention services. Clinicians who have previously worked at the Child Hearing Lab at the CHEO Research Institute also assisted with recruitment.

Caregivers were eligible to participate if they had (a) a child/children with permanent hearing loss who received early intervention services within the past 5 years and (b) a minority culture background, defined in this research as "any cultural groups that are not representative of the majority cultures in Canada." For families who did not speak English, a translator was provided. Eligible caregivers were approached by clinicians to inform them of the study. Clinicians determined eligibility with knowledge of the patients' backgrounds. Residency was also used to help identify potential participants as the Audiology Clinic at CHEO also provides services to Indigenous populations in Nunavut.

Abiding by qualitative research practices (Creswell, 2014; Kelly, 2010), a total of 6–10 participants was considered sufficient for gaining relevant insights into a subject that has received minimal attention. The Research Ethics Boards of the CHEO and the Université d'Ottawa approved this study (REB 16/01X).

Procedure

The method of *interpretive description* informed the data collection in this study (Thorne, 2016). Drawing on elements of grounded theory, naturalistic inquiry, and ethnography, interpretive description attempts to capture an account of a clinical phenomenon and make the results accessible to clinicians. Its foundation of qualitative inquiry is on a smaller scale in that it does not attempt to generate new theories, but instead produces a "tentative truth claim"

(Thorne, Kirkham, & O'Flynn-Magee, 2004, p. 6). That is, interpretive description provides a snapshot of a specific context at a specific time. This is typically achieved by drawing on data collected from small samples through methods such as interviews.

Data were collected via semi-structured individual interviews (see Appendix). Interview questions were informed by findings stemming from our scoping review on barriers and facilitators to cultural competence in rehabilitation services (Grandpierre et al., 2018). The interview consisted of basic sociodemographic questions (e.g., cultural and linguistic background, education, income, child's audiological information) as well as open-ended questions to help explore participant perspectives. Interviews were conducted by the lead author who has expertise in rehabilitation sciences and extensive experience in qualitative research. Medical records were used to supplement information on hearing loss (e.g., diagnosis, age of diagnosis, cause and degree of loss, amplification recommendations, and intervention information).

Field notes were taken by the lead author during and after interviews to record any overall impressions or general thoughts. Interviews were audio recorded and transcribed verbatim by two independent researchers. Field notes were consulted during analysis. Data were entered into NVivo (version 10.1.2), a qualitative software program used for coding. Demographic information was entered into SPSS (version 24), a statistics software program.

Analysis

Consistent with qualitative methods, analysis occurred concurrently with data collection (DiCicco-Bloom & Crabtree, 2006). Inductive data analysis techniques were used to identify themes and commonalities (Thorne, 2016). The lead author analyzed the transcripts using constant comparative method, a coding process based on Corbin and Strauss's (1998) open, axial, and selective coding methods that is consistent with interpretive description methodology (Thorne et al., 2004). During open coding, each passage in the transcripts was assigned a label. In axial coding, characteristics of each label were then compared between interviews to facilitate consistency and eliminate redundancy. Finally, similar labels were categorized and then collapsed into major themes during selective coding.

Trustworthiness (Krefting, 1991) was established to ensure transparency and quality. Trustworthiness consists of four components: credibility, transferability, dependability, and confirmability. Credibility was

achieved by consulting coauthors regarding analysis and interpretation. The provision of in-depth details in the data, along with numerous supporting quotes, ensures transferability. Clear and detailed steps documenting the research process help to ensure dependability. Finally, recording and consulting field notes as well as consulting coauthors with expertise in pediatric hearing loss, health sciences, medical research, and qualitative research help to ensure confirmability.

Results

Context

The study took place in a setting where newborn hearing screening has been implemented province wide. In Ontario, Canada, infants receive screening for hearing loss after birth. Children with results that indicate the need for referral are then sent for diagnostic audiological assessments. Following a diagnosis, audiologists will discuss hearing technology options with families. Discussions of language intervention approaches (e.g., spoken language approaches, visual approaches, and total communication approaches) and financial resources are typically provided by a family support worker. The intensity of language interventions can vary. Children are typically seen weekly for listening and spoken language intervention during the preschool years. During the school years, they are generally seen once to several times weekly based on their needs as determined by the specialist in language intervention.

Description of Participants

A total of 10 parents (representing nine different children) were interviewed. The mother and father of one child chose to be interviewed separately. Half of the interviews were conducted on the phone as per parent requests with the remainder conducted in person. The average interview length was 27.55 minutes (range = 17.01–47.47 minutes).

Table 1 provides a description of child characteristics. Three children did not receive screening due to the lack of a screening program in their country of origin. Median age of hearing loss confirmation was 5.1 months (interquartile range = 4.8–12.5). All children had bilateral hearing loss, were aided with hearing technology (e.g., hearing aids, cochlear implants), and received auditory-verbal therapy. Etiology was known for six of the nine children. All children were receiving or had received auditory verbal therapy. The children had a mean age of 4.8 years (standard deviation = 2.6) at the time of the interviews, and, as such, parents had over three years of experience with hearing loss.

Table 2 provides characteristics of the caregiver participants. Three families had immigrated to Canada within the past 3 years; two had lived in Canada between 10–17 years, and the remaining, over 20 years. Most of the caregivers had university and post-graduate degrees ($n = 7$). Just over half ($n = 5$) reported an annual family income of \$60,000 or over; for context, the median household income in Canada is approximately just above \$80,000 (Statistics Canada, 2019). One family chose not to disclose their income.

Thematic Results

The goal of the interview was to gain some insight into minority culture caregivers' experience receiving early hearing loss services in Ontario, Canada. Three themes emerged from the interview data: experiences with hearing loss, services, and education systems; needs as a minority culture family; and helpful strategies for service provision to minority culture families.

Table 1	
Child Characteristics	
Characteristics	Children ($n = 9$)
Sex, n (%)	
Female	3 (33.3%)
Route to confirmation of hearing loss, n (%)	
Screened	6 (66.6%)
Passed	1 (11.1%)
Referred	5 (55.5%)
Age at confirmation, (months), median (IQR)	5.1 (4.8, 12.5)
Onset of hearing loss, n (%)	
Congenital	3 (33.3%)
Early onset	2 (22.2%)
Late onset	1 (11.1%)
Unknown	3 (33.3%)
Hearing loss description, n (%)	
Bilateral	9 (100%)
Degree of hearing loss, n (%)	
Moderate	3 (33.3%)
Mod-severe	2 (22.2%)
Severe	1 (11.1%)
Profound	3 (33.3%)
Amplification, n (%)	
Hearing aids	3 (33.3%)
Cochlear implants	6 (66.6%)
Etiology, n (%)	
Known	
NICU graduate*	2 (22.2%)
Hereditary/genetic	2 (22.2%)
ENT malformation	2 (22.2%)
Unknown	3 (33.3%)
Age at interview (years), mean (SD)	4.8 (2.6)

Note. *NICU does not include children with syndromic hearing loss or ENT anomaly.

ENT = Ear, nose, and throat; IQR = interquartile range; NICU = Neonatal Intensive Care Unit; SD = Standard deviation.

Table 2	
Parent Characteristics	
Characteristics	Participants (n = 10)
Interviewee, n (%)	
Mother only	9 (90%)
Father only	1 (10%)
Languages spoken at home, n (%)	
English	9 (90%)
French	3 (30%)
Chinese	1 (10%)
Arabic	4 (40%)
Somali	1 (10%)
Russian	2 (20%)
Creole	1 (10%)
Countries of origin, n (%)	
Lebanon	2 (20%)
France	1 (10%)
Philippines	1 (10%)
Cambodia	1 (10%)
Somalia	1 (10%)
Syria	1 (10%)
Haiti	1 (10%)
Iraq	1 (10%)
Africa	1 (10%)
Ukraine	2 (20%)
Highest level of education in household, n (%)	
None	1 (10%)
College/university	9 (90%)
Family income, n (%)	
Below \$20,000	2 (20%)
\$20,000 to less than \$40,000	2 (20%)
\$60,000 to less than \$80,000	2 (20%)
More than \$80,000	3 (30%)
Did not disclose	1 (10%)

Experiences with hearing loss, services, and education systems.

Perception of hearing loss. When asked about how their cultures perceive hearing loss and disability, many of the parents described how it is stigmatized, taboo, and often hidden. For some, this stigmatization resulted in them not disclosing the hearing loss to close friends or family.

Disability back at home...it's like you put [a disabled person] into an institution and lock the door. No

one sees them, no one hears about them, nothing... When (child's name) first started to wear her hearing aids, we couldn't take her [out]...like when we went to certain places, we couldn't put the hearing aids on. Our Lebanese culture...they don't understand the fact that you know, I need glasses to see. It is like "oh my god, she is disabled!" So, there was a little bit of a struggle with some of our family members - but at the end, (husband's name) and I, were like whatever, this is our kid. If she needs it [hearing aids], she is going to wear it.

We don't care if they don't like it, you don't have to see us. (Participant 1)

We don't share a lot. We are very private. I mean private - like not even my friends are supposed to know [about disabilities or disease]. So, it is something you are not able to control...hearing loss, autism, all of this is taboo. (Participant 7)

When exploring reasons for why hearing loss is stigmatized, some parents described a lack of knowledge surrounding hearing loss and the need for hearing technology interventions.

There is no one with hearing loss [where participant grew up].... Ones that do have hearing loss, it's not like in Canada, they are always put in to this separate little category.... So, when we say he has hearing loss, they [family] are like oh are you sure? Have you tried this and that? Like it is hearing loss, he can't hear us properly! (Participant 3)

Because there are not a lot of children hearing aids in our home country.... They wanted to put all the children in the special schools, so in real life there is no children with hearing aids here [Ukraine] at all. (Participant 10)

All parents reported experiencing a wide range of emotions when learning of their child's diagnosis, from relief to having the loss finally confirmed, to shock, devastation, denial, and even seeing it as a divine gift.

My reaction was the same as my family's in the beginning, I was just shocked. But at the end of the day, we're people that are spiritual - so we do understand that God creates people differently. And it's a gift that was given to her, only to her, and we accept it. (Participant 5)

Perception of services. Following the diagnosis, almost all parents (90%) reported they felt happy with the services their children received. The majority felt that practitioners were sensitive to their cultural needs. Practitioners were able to fully address their concerns and gaps in knowledge regarding hearing loss and technology, while also ensuring they understood intervention options.

You have no idea how lucky I feel to have that kind of team.... Like the team were absolutely amazing. Like they gave us everything, they explained everything. We came out of our few meetings, very aware of the situation and they were always there to help us out if we had any questions.... Honestly, I would not have been able to keep going without our team. I would tell our speech therapist, "I can't have [child's name] wear the hearing aids all time

because of the people [from her country]" and then she also gave me some therapy, she made me feel so much better coming out of it. (Participant 1)

Another parent noted, "They are extremely happy with the services at CHEO because it is better than they ever expected" (Translator for Participant 8).

However, a few families emphasized their wish to raise their child multilingually and felt that those needs were not met. They stated how it was a struggle to decide on which language to focus on (e.g., service language vs. home language). Some also expressed the desire for more multilingual practitioners.

The first thing the audiologist told us was to concentrate on one language and one language only because he had hearing loss. To us, that is important to our family because we speak Arabic at home.... Because had we not stuck to it, and he would only have spoke English and he wouldn't have a way to communicate with his grandparents or great-grandparents. (Participant 3)

It was this whole question of how to integrate the whole family...so I don't see [how] you can pick one [language] or the other. And so, they actually got us to meet a bilingual therapist.... She was really realistic that it may be a challenge for a child with hearing loss, but she was able to help us to actually try to teach him two languages. And I think this is because we are in Ottawa. I just talked recently with someone saying that the family who has a little boy who is only 5, they were told that they should pick one language and they should actually pick English. (Participant 2)

Perception of education systems. Finally, several parents expressed an appreciation for the option to include their children in the general education system. They explained that, in their home country, children with disabilities reside in institutions. Parents even experienced challenges when registering their children into weekend schools where their home language is taught: "When a child has something that is out of the norm, they are usually institutionalized. They are usually put in to a special center. So a child like mine would definitely be in a special school" (Participant 2).

In Ukraine, it was horrible, yes. Every half a year, we had the medical commission [medical examination]. Every time they told they need to put him to special school [institution]. So every time I refused.... Here [Canada], nobody told me to send my child to a prison for children (laughs, referring to special school). Everyone just wants

to help him, speak and understand. And everyone wants to help me as well and it is really great!! (Participant 3)

I was looking to register them [her children] for Arabic school on Saturday, because they can speak fluently but I want them to read and write it and I filled out the online registration form and then the person from registration called me...cultural differences sometimes, they are brutal. [Child's name] has two cochlear implants. I said the teacher would have to wear a mini-mic so her voice would go directly to his processors so he is able to hear her clearly. And she goes, "oh! Well I have never had such a...something as hard and different as your son's case!" And I am like, hard and different? Are you saying strange? You speak as you haven't come across it.... It is not as hard as you make it sound. He is fully functional, learning three languages! I think that's when cultural differences lead to restrictions. (Participant 3)

Needs as a minority culture family. The majority of the parents described how vital it was to have access to a translator when language barriers were present. Parents who recently immigrated to Canada, did not know the service languages, and had a child that required ongoing medical attention emphasized the need to have the same translator at each appointment.

They [the parents] can't understand anything that the doctors are saying. So to them, the interpreter is the doctor. From their experience, it's very frustrating [that] they can't understand the medical staff. Extremely frustrating. It should be the same interpreter that follows with the family. Because he says every time they have to bring a different interpreter, they have to say his story all over again. He also said that he wants to have access to the interpreter. He wants access so he can call the interpreter and interpreter can call the hospital and speak to them. (Translator for Participant 8)

Explanations of the health care system were also seen as crucial to culturally competent service delivery as many parents emphasized how different health care is in their home country. Some deeply appreciated explanations from practitioners about what is and is not covered by Canadian health insurance, as well as what supports and services are available. Others felt such explanations need to be routine.

In Ukraine we get nothing from government.... It is absolutely different experience. We bought everything by ourselves, with the help of my family, with the help of my parents.... We had to buy the hearing aids and everything by ourselves. Here, when we arrived here, they [practitioners] explained everything, there are lots

of programs that can help the families with children with the disabilities, there is a social worker. Everybody was so kind, so polite, so friendly, it is great. Really great! It is really wonderful, especially for children and especially for children like [child's name]. (Participant 9)

...what I found was the kid is falling through the cracks. The parents [friends of participant] didn't ask [about support availability] and they were just following the system and the kid had barely any support. And I think it is pretty typical of what could happen with immigrant...they come and trust what is happening...and then if the kid falls through the crack, they won't see it. (Participant 2)

Parents also expressed a desire for practitioners with experience with multicultural families. They felt that practitioners with more experience were better able to provide care that was culturally sensitive and could be tailored to meet the needs and values of their family.

But I think again it goes back to the professional themselves, if they have had the chance to work with different clientele and different cultures, then they are more open to other peoples' ideas. For others who generally dealt with certain clientele - they don't tend to be as open-minded. Some people are not open-minded because it's just black and white. For some, they are set in their ways and they are not as willing to listen to others and see things for what they truly are. (Participant 3)

Another participant noted, "Being sensitive to somebody's needs [when asked what's important for culturally sensitive care]. Just understanding [cultural differences] I guess. Patience and understanding is pretty much all it is" (Participant 6).

Helpful strategies for service provision to minority culture families. Parents described a variety of strategies practitioners used to help them. This included providing reading materials, ongoing support, and visual cues when language barriers arose. For one of the families, the parents did not believe that their child had hearing loss until the practitioner conducted a hearing test and gave them the same test.

He [father] was convinced the second time when he [in a hearing test] actually heard the sound in his own ears and he couldn't take it because it was so loud. Whereas for his son, he wasn't even annoyed by it. He was just playing. So, the father was convinced. (Translator for Participant 8)

Parents also reported how helpful it was to have practitioners that patiently provided clear and thorough

explanations of the hearing loss and what was to be involved in the intervention. Another strategy was repetition, as parents are not just struggling with language barriers but also the emotional trauma of learning how to navigate life with a child with a disability.

They told me about the ABR [auditory brainstem response] tests, and the audiogram and how to read it. That was very helpful. Then they told me that she needs hearing aids and they taught me how to put on and take off these hearing aids and how they work. They taught me how.... I was taught to basically train her to talk and what - to this day, we attend speech therapy tries to help us to...focus more on her and try to teach her how to talk, and different activities and ways to communicate with her and try to encourage her to talk. I found all that helpful. (Participant 5)

Example Case Study

This section provides a case study of one interviewee, with all identifying information changed to ensure confidentiality. This case helps capture a detailed account of experiences families of minority culture background may encounter.

Akram and Amira are Middle Eastern refugees who immigrated to Canada in late 2016 with their daughter, Maya. Maya is two years old and only had her hearing loss discovered upon her first health checkup in Canada. There is no newborn hearing screening in her home country. Her parents had stated they did not believe she had hearing loss for a long time. It was only when their daughter's audiologist showed them pictures of the cochlea, explained the type of loss she had, and pointed out how their daughter's younger brother had more words than her that they began to believe the diagnosis.

With the help of a translator, the audiologist discussed the ways in which their daughter would benefit from bilateral cochlear implant surgery. She also discussed other intervention options, such as sign language, to ensure that they could choose an intervention that aligned with their values. Akram and Amira initially felt afraid of the surgery. They communicated this fear and, in response, the audiologist showed them pictures of the ear and explained the surgical process.

Though access to a translator helped overcome their language barriers, Akram stated that the pictures helped them better understand what was involved in the surgery as they were not familiar with medical terminology in their own language. They expressed extreme gratitude

for this strategy as it enabled them to make an informed decision. Maya now receives weekly auditory verbal therapy, a spoken language approach to language therapy. Her language therapist speaks fluent Arabic and, as a result, she tailors all the therapy to their language and culture, thereby ensuring culturally sensitive services. Akram states that, in this way, everything (e.g., therapy content) is relevant and helpful.

Discussion

The aim of this study was to gain insight into barriers and facilitators to culturally competent early hearing loss services. Specifically, the goal was to explore minority culture caregivers' experiences with services for their children.

A child receiving a permanent hearing loss diagnosis was the beginning of many cultural challenges that families encountered. Discussing the diagnosis and amplification needs with family members and friends was often described as difficult due to cultural stigma. An examination of existing literature suggests perceptions of disability vary across cultures and can impact the way families experience and manage the diagnosis (Jackson et al., 2008; Zhang & Bennett, 2003). Though these views did not influence every parent's experience, it is important for practitioners to be aware of these different perceptions when providing services to newcomers. Minority culture families may have specific cultural and linguistic needs and values that practitioners need to be aware of and address to ensure culturally competent care delivery.

Language barriers also created stressful experiences for families unable to converse in English or French. Access to a translator was seen as beneficial, but having access to the same translator who is familiar with the child's medical history can relieve additional stressors for the parents. Other helpful strategies for facilitating communication include providing thorough explanations with repetition to ensure comprehension. This is consistent with Yeowell's (2010) study in which a participant of minority culture background recommended practitioners talk slowly and conduct comprehension checks by asking the patient to repeat back the information told to them.

Families in the current study also reported experiencing challenges due to practitioner perceptions of multilingualism. Specifically, they voiced a need for practitioners to promote multilingualism. Although many challenges were reported, several families felt appreciative of the services they received and also provided recommendations for improving culturally competent

services. Such recommendations included providing clear explanations of the diagnosis and interventions, and to supplement explanations with additional reading materials and ongoing support. Descriptions of the healthcare system (e.g., coverage, support services) were also seen to be crucial for families who had recently moved to Canada to address the sometimes strong contrasts between what is available in Canada vs. their home countries. The need for explanations of health care systems has also been documented in several other studies, highlighting the need for a change in health care practices when servicing minority culture families (Kummerer & Lopez-Reyna, 2006; Nelson et al., 2007; Yeowell, 2010).

Practitioners experienced in delivering services to multicultural patients were also viewed as valuable assets to culturally competent care. When this is not possible, seeking knowledge on a patient's cultural background, attending workshops on cultural competence, or even attending cultural events can be beneficial to practitioners (Lindsay et al., 2014; Nelson et al., 2007; Stedman & Thomas, 2011). Our recent systematic review (Grandpierre et al., 2018) included additional recommendations, such as communication strategies (using simple language, speaking slowly, using visual aids such as pictures, etc.).

More research is needed to inform culturally competent practices in early hearing loss services. A limitation to our study is that our participants were selected from one setting with a particular service model. In addition, only three of the families were recent newcomers, thereby further limiting insights into experiences of minority culture families. There is also a lack of insight from Canadian Indigenous families and less educated families. However, the limitations in this study provide direction for future research investigating the perspectives of families of minority culture backgrounds receiving hearing loss services for their children.

This study is one of the first to explore the experiences of minority culture families receiving early hearing loss services. Families who have children with permanent hearing loss often require long-term, ongoing, intervention services. For this reason, it is imperative for practitioners to provide culturally competent services informed by empirical evidence. Insights from this study offer a starting point for knowledge translation into clinical practice.

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Authors' Note

Correspondence concerning this article should be addressed to Viviane Grandpierre, Université d'Ottawa, Roger Guindon Hall, 455 Smyth Road, Ottawa, ON, Canada, K1H 8L1. Email: vgran048@uottawa.ca

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Appendix

Interview Protocol

Parent Interview Protocol: Minority culture parents of children with permanent hearing loss

Purpose of Interview

I am meeting with minority culture parents to help me understand what your service needs are.

I would like to hear about your experiences with your child’s hearing loss services. Specifically, I would like to hear about how you learned about your child’s hearing loss, what your experience was like when you were told about the treatments available, and what your experience was like with the language therapy sessions.

Procedure

Before we begin, I’ll ask you some general questions about your child’s hearing loss. Next, I will begin asking you questions to guide our conversation, but feel free to talk about your experiences and to add any information you feel is important. Please don’t hesitate to ask questions. I’m going to start off by asking you some background questions. Next, I’ll ask about how you found out about your child’s hearing loss, and then I’ll ask about your experiences with receiving hearing loss services.

General Information for Interviewer

Location of interview: Home Clinic Other: _____

Informant: Mother Father Other: _____

City of residence: _____

Number of children: _____ Number of children with hearing loss: _____

Age of child/children: _____ Age of diagnosis: _____

Amplification: Hearing aids Left ear Right ear

Hearing aids Left ear Right ear

Age of amplification: _____

Background Questions

Have you always lived in Canada?

Tell me a little bit about your family.

Prompt: Are your kids in school yet?

Tell me about your family’s cultural background.

Prompt:

What is your child’s/children’s cultural heritage?

Do you have any cultural traditions?

Tell me about something about the customs of your culture (e.g., meals).

Are there any differences in the health care system?

What languages do your family speak?

Hearing Loss History

Tell me about how you found out about your child’s hearing loss.

Prompt:

Was your child screened at birth?

Tell me about the process from screening to when your child’s hearing loss was confirmed. How many visits?

How long was it before you got the confirmation that your child had a hearing loss?

What were your needs from the time that you learned your child potentially had a hearing loss to after the diagnosis?

Prompt:

What kind of information did you find helpful in the beginning?

What information or guidance did you need after the diagnosis (e.g., after confirmation)?

What kind of supports did you need, e.g., social worker, therapist, family?

What supports/information did you receive?

Cultural Information

How is hearing loss regarded in your family's culture?

Prompt:

Is hearing loss viewed as a disability? Is it viewed negatively or positively?

How are disabilities viewed/seen in your culture?

What was your reaction to discussing and receiving hearing aids, assistive hearing devices, or cochlear implants for your child?

Prompt:

Did you initially want your child to have hearing aids/assistive technology/cochlear implants? Why/Why not?

Sometimes parents have a hard time with having their child's hearing loss being made visible. Tell me about your experience.

Experiences with Hearing Loss Services

Now I'm going to ask you about what you thought of your child's hearing loss services from diagnosis to the time you received treatments. Would you have wanted information on how Canadian health care works?

How did you feel about using English/French in your hearing loss appointments?

Prompt:

Would you have wanted an interpreter?

Were you encouraged to use your language with your child? How did you feel about that?

How did you feel about how your health care practitioner told you about your child's hearing loss?

Prompt:

Was your doctor/therapist sensitive to your experience?

What would be the best way to be told about your child's hearing loss?

How did you feel about the way your health care practitioner discussed hearing aids, cochlear implants, or assistive hearing technologies with you?

Prompt:

Was your health care practitioner sensitive to your needs?

Was your health care practitioner sensitive to your values?

If you could improve this experience, what would be different?

How do/did you feel about your child's language therapy?

Prompt:

Were the materials used in your child's language therapy items that you are familiar with?

What did you think of the therapy that you needed to continue at home?

What are some recommendations for improvement?

When you've filled out questionnaires that look at your child's hearing and language skills, did you find the content describing your home environment?

Prompt: Did the questions and answers work with you and your child's experiences or did you find some things that didn't work? For example, were some parts discussing things that don't exist in your home environment?

What would you say is the most important thing for good patient care when practitioners and patients don't share the same language?

Is there anything you'd like to discuss that I haven't covered?