

Barriers and Facilitators to Cultural Competence in Early Hearing Loss Services

Viviane Grandpierre

A thesis submitted to the
Office of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for the
Doctorate in Philosophy degree in Rehabilitation Sciences

School of Rehabilitation Sciences
Faculty of Health Sciences
University of Ottawa

© Viviane Grandpierre, Ottawa, Canada, 2018

Dedicated to my mother,
without whom,
none of this
would have been possible

Table of Contents

Dissertation abstract.....	vii
Acknowledgements.....	ix
Chapter 1: Introduction.....	1
Figure 1. Route to early hearing loss intervention.....	3
Theoretical framework.....	8
Figure 2. Circles of influence (Duncan, 2010).....	9
Objectives.....	9
Methodology.....	9
Table 1.....	10
Scoping review (Chapter 2).....	10
Interviews (Chapter 3, 4).....	10
Surveys (Chapter 5).....	11
References.....	11
Chapter 2: Scoping review.....	19
Background.....	19
Methods.....	20
Analysis.....	22
Results.....	22
Table 1.....	23
Table 2.....	25
Table 3.....	25
Table 4.....	26
Table 5.....	28
Discussion.....	33
Conclusion.....	35
References.....	36
Chapter 3: Practitioner interviews.....	41
Background.....	41

Methods.....	42
Table 1	43
Procedure.....	44
Analysis.....	44
Results.....	45
Table 2	50
Discussion	52
Chapter 4: Caregiver Interviews	57
Background	57
Methods.....	58
Procedure.....	58
Analysis.....	59
Results.....	59
Table 1	60
Table 2	61
Discussion	67
References	69
Chapter 5: Practitioner surveys.....	71
Introduction	71
Methods.....	73
Participants	73
Analysis.....	74
Results.....	74
Table 1	75
Table 2	77
Table 3	80
Table 4	81
Table 5	82
Table 6	83
Discussion	83
References	87

Chapter 6: Integrated discussion	91
Background	91
Context	91
Theoretical framework	91
Figure 3. Bronfenbrenner’s bioecological systems theory in a pediatric hearing loss context	92
Method	92
Table 1	93
Dissertation methodology	93
Summary and Interpretation of Findings	93
Inquiry 1 – Scoping Review	93
Inquiry 2 – Interviews with Practitioners	94
Inquiry 3 – Interviews with Caregivers	94
Inquiry 4 – Survey of Practitioners	95
Integration of findings	96
Summary	97
Future research	98
Conclusion	99
References	100
Statement of Contributions	101
Knowledge Translation	102
Appendix A	103
Appendix B	110
Appendix C	111
Appendix D	112
Appendix E	115
Appendix F	118
Appendix G	123
Appendix H	124
Appendix I	129
Appendix J	132

Appendix K	134
Appendix L.....	138
Appendix M.....	141
Appendix N	149
Appendix O	157
Appendix P.....	161
Appendix Q.....	165

Dissertation abstract

BACKGROUND: Cultural competence in early hearing loss interventions, such as Spoken Language Therapy, is required to support language development amongst Canada's diverse population. Every year an estimated 2000 infants are diagnosed with permanent hearing loss in Canada. Hearing loss has detrimental impacts on language development, a vital health determinant for communication, academic performance and employability. Additionally, it also impacts family life, including stressful treatment decision-making, expensive treatment costs, and family-child communication struggles. International consensus therefore emphasizes the importance of early intervention to diminish these negative impacts. However, with the latest Census revealing that 20% of Canadians identify themselves as a minority or foreign born, there is an important need to explore whether Western-influenced interventions are appropriate and effective for minority culture populations. This investigation is of particular importance as the core focus of early intervention is language development and inclusion into mainstream society and cultural competence may help facilitate optimal language outcomes. In order to facilitate change in these early interventions, knowledge on how cultural differences may affect health care services is required. However, research in this field is limited and often dated, anecdotal, and reflects stereotypical views. This highlights the need for empirical research to inform strategies for increasing culturally competent interventions. The purpose of this research project was therefore to gain a deeper understanding of the impact of cultural diversity in a setting that is typically tailored to meet the needs of the majority culture.

OBJECTIVES: 1) to review and assess the state of knowledge with respect to barriers and facilitators of cultural competence in rehabilitation services; 2) to explore practitioners' experiences with providing services to minority culture families who have children with hearing loss; and 3) to explore the experiences of minority culture families receiving services for their child's hearing loss.

METHODOLOGY: This study employed a mixed methodology. In order to address the first objective, a scoping review was performed in the rehabilitation services literature as the number of studies solely in childhood hearing loss was limited. The second objective was addressed in two stages: Stage 1 involved individual semi-structured interviews with 19 practitioners working in hearing loss and 10 caregivers of minority culture backgrounds whose children were receiving services for hearing loss. Recruitment occurred at the Children's Hospital of Eastern Ontario in Ottawa, which services a diverse population. In Stage 2, results from the interviews were used to inform the development of a survey tailored to practitioners working in hearing loss. A total of 109 practitioners' responded from across Canada.

RESULTS: Cultural barriers occurred at each stage of service delivery, from diagnostic testing to the provision of interventions. Language barriers, stigma, and the lack of culturally appropriate materials (e.g., assessments, therapy materials) were consistently shown to be key challenges experienced both by practitioners and families. A wide range of facilitators were also reported. The promotion of the preservation of home languages,

the provision of culturally appropriate materials (e.g., translated documents, tailored assessments and intervention sessions), the use of communication strategies (e.g., simple language, pictures or videos), explanations of how disability is perceived in Canada, and explanations of the health care system were all viewed as key to providing culturally competent care.

CONCLUSION: The findings from this dissertation are the first to capture barriers and facilitators experienced by families of minority culture backgrounds receiving early hearing loss services and by practitioners who provided those services. The results of this program of research can be used to inform practitioners seeking to provide culturally competent care. In addition, this dissertation provides empirical research needed to help initialize a knowledge-to-action intervention seeking to capture and improve cultural competence in hearing loss services in Canada.

Acknowledgements

This dissertation could not have been completed without my incredible thesis supervisors (Elizabeth Fitzpatrick & Roanne Thomas) and committee members (Beth Potter & Lindsey Sikora). I cannot thank you enough for your unending support and feedback. I would also like to acknowledge the team from Child Hearing Lab (CHEO RI) for their helpful support, especially JoAnne Whittingham. I'd also like to thank the wonderful women in my cohort for your support and solitude in this very long journey. Finally, a big thank you to the participants in my studies for sharing your time and giving insight into a topic that is so dear to my heart.

Chapter 1: Introduction

Cultural competence in pediatric hearing loss services is required to support language development amongst Canada's diverse population. Approximately 2-4 in 1000 infants in Canada are born with some degree of hearing loss or will develop childhood hearing loss (Prieve & Stevens, 2000; Watkin & Baldwin, 2010; Wood, Sutton, & Davis, 2015). Hearing loss can impact language development, a vital health determinant for communication, academic performance, and employability (Duncan, Rhoades, & Fitzpatrick, 2014; Fischer & Lieu, 2014; Lederberg, Schick, & Spencer, 2013). It might also have detrimental impacts on family life, including stressful treatment decision-making and family-child communication struggles (Duncan, Rhoades, & Fitzpatrick, 2014; Quittner et al., 2010; Sarant & Garrard, 2014; Wake, Hughes, Poulakis, Collins, & Rickards, 2004; Wheeler, Archbold, Gregory, & Skipp, 2007).

As roughly 96% of American parents of children with hearing loss have no family history of hearing impairment (Mitchell & Karchmer, 2004), learning about and managing hearing loss in day-to-day life requires extensive and ongoing support (Bernstein & Eriks-Brophy, 2010). International consensus therefore emphasizes the importance of early intervention to diminish these negative impacts (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Early hearing loss services involve amplification decisions, assistive technology (e.g., hearing aids), and language therapy. Experts have stated these services are tailored to the cultural values of the majority population, and, as a result, do not equally serve all cultural groups (Phillips, Worley, & Rhoades, 2010; Rhoades, 2008; Rhoades, Price, & Perigoe, 2004). This is problematic as the latest census indicates that, by 2036, almost half of the Canadian population will be immigrants (Statistics Canada, 2017).

Statistics Canada (2016a) defines visible minorities as "persons, other than Indigenous peoples, who are non-Caucasian in race or non-white in colour. Categories in the Visible minority variable include South Asian, Chinese, Black, Filipino, Latin American, Arab, Southeast Asian, West Asian, Korean, Japanese, Visible minority, n.i.e. ('n.i.e.' means 'not included elsewhere'), and Multiple visible minorities". The Canadian Indigenous population, comprised of First Nations, Métis, and Inuit people, represents 4.9% of the country's population (Statistics Canada, 2016b). For the purposes of this research the term 'minority cultures' was used to describe any cultural group that is not representative of the majority culture in Canada, including Indigenous peoples.

Increasing diversity in Canada highlights the need for culturally competent early hearing loss services. Betancourt, Green, Carrillo, and Ananeh-Firempong's (2003) literature review defines cultural competence from a healthcare context as:

... 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.
(p.293)

When considering the high prevalence rates of hearing disorders such as otitis media and conductive hearing loss amongst Canadian Indigenous children (Bowd, 2005; SAC, 2010), the need for culturally competent services is

reinforced. To improve cultural competence in services for children with hearing loss, an understanding of how cultural differences can affect services is required. However, research with respect to cultural competence in the fields of pediatric speech-language and hearing services is often dated, anecdotal, and might reflect stereotypical views (Ball & Lewis, 2014; Eriks-Brophy, 2014).

The aim of this dissertation was therefore to gain a deeper understanding of how culture can affect early hearing loss services, as documented in existing literature and from the perspectives of both practitioners and families. The objectives were to: 1) review and assess the state of knowledge with respect to barriers and facilitators of cultural competence in rehabilitation services; 2) explore practitioners' experiences with providing services to minority culture families of children with hearing loss; and 3) explore the experiences of families of minority culture backgrounds receiving services for their child's hearing loss.

To address the first objective, a scoping review was performed (Chapter 2) in rehabilitation services, as literature solely on childhood hearing loss yielded minimal results. The second and third objectives were addressed in two qualitative studies as well as a quantitative study. The qualitative studies involved interviews with practitioners (Chapter 3) and minority culture families (Chapter 4). The quantitative study involved a survey with practitioners (Chapter 5). Each study helped develop the next in an iterative process. For example, the results of the scoping review were used to inform the interview protocol for practitioners and minority culture families. Findings stemming from both interview studies informed the development of the quantitative survey for practitioners, which addressed the second objective from a broader context.

The following section provides key features of childhood hearing loss (e.g. characteristics, impacts, outcomes), intervention services, information about cultural competence with an overview of known barriers and facilitators in a healthcare context, and, finally, a description of the framework used to guide this dissertation.

Childhood hearing loss

Permanent hearing loss affects approximately 2-4 per 1000 screened infants (Prieve & Stevens, 2000; Watkin & Baldwin, 2010; Wood, Sutton, & Davis, 2015). It is typically categorized by degree (e.g., mild, moderate, moderate-severe, severe, and profound) and by type (e.g., conductive, progressive, sensorineural, mixed, auditory neuropathy). Hearing loss can be stable or progressive as well as unilateral or bilateral. Depending on the onset, childhood hearing loss is classified as either congenital or acquired.

Impacts and outcomes

In comparison to typically developing individuals, children with permanent hearing loss have an increased risk of speech and language delays (Vohr et al., 2012) and can experience difficulties with speech and language development. Childhood hearing loss can also increase parental stress and affect family life, interpersonal relationships, and

academic performance (Bess, Dodd-Murphy, & Parker, 1998; Duncan, Rhoades, & Fitzpatrick, 2014; Fischer & Lieu, 2014; Fitzpatrick, Crawford, Ni, & Durieux-Smith, 2011; Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Quittner et al., 2010; Sarant & Garrard, 2014; Wake, Hughes, Poulakis, Collins, & Rickards, 2004).

Hearing loss identification and management

Screening

The implementation of newborn hearing screening programs has led to a reduction in the age of identification and in the length of time to initiating interventions (Durieux-Smith, Fitzpatrick, & Whittingham, 2008; Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Watkin & Baldwin, 2010). Screening programs have become a standard of care in Ontario, Canada, and most developed countries have well-established protocols in place (Wood, Sutton, & Davis, 2015). Prior to the availability of screening, hearing loss confirmation occurred through parental concern and referrals. During this time, hearing loss was typically identified after 2 years of age (Cone-Wesson et al., 2000; Patel & Feldman, 2014; Russ et al., 2003), with mild bilateral and unilateral hearing loss being identified at 4 to 5 years of age (Fitzpatrick, Durieux-Smith, & Whittingham, 2010).

In most developed countries, the process from hearing loss identification to management first involves babies being screened at birth for hearing loss. During the screening stage, if a child does not pass, he/she will then be referred for audiological assessment. The goal of newborn hearing screening programs is to identify hearing loss early and therefore to help children achieve age-equivalent language milestones. However, early identification is not sufficient to support typical language development; additional supports such as auditory rehabilitation services are required. These services include counselling regarding amplification, fitting of hearing technology (e.g., hearing aids, remote microphone systems), and language therapy. Figure 1 provides a visual representation of this process.

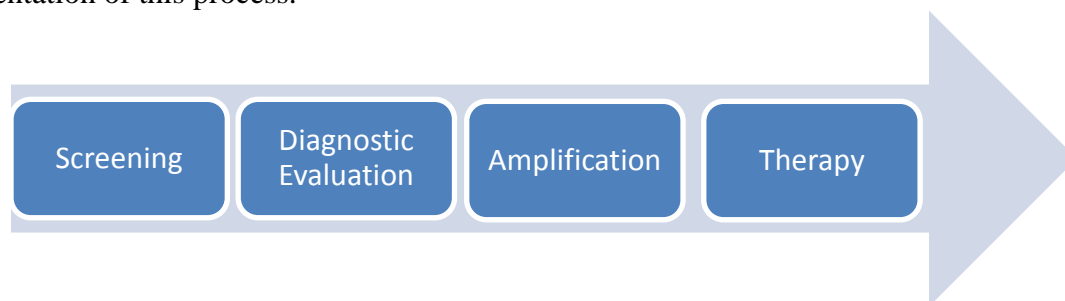


Figure 1. Route to early hearing loss intervention

Culture can influence the reactions of families during any of these stages. For example, caregivers might conceal their child's hearing loss if their culture considers disabilities to be a source of shame (Zhang & Bennett, 2003). As result, parents of such cultural backgrounds might oppose amplification or only use it at home. For these reasons, it is important for practitioners to be aware of the influential nature of culture in order to ensure optimum language outcomes.

Diagnosis

The discovery of permanent hearing loss in a child can lead caregivers to experience an array of emotions such as shock, grief, denial, fear, and uncertainty (Burger et al., 2005; Neuss, 2006). Reactions can be influenced by individual differences, family structures, ideologies, and culture (Li, Bain, & Steinberg, 2004; Rhoades & Duncan, 2010). Families in this situation undoubtedly experience numerous sources of stress; however, families of minority culture backgrounds might encounter additional challenges.

Perception of disability varies across the world. Hearing loss is met with social stigma in some cultures (Bernstein & Eriks-Brophy, 2010). In other cultures, parents might react negatively to the diagnosis, believing the disability to be a punishment from a higher being. Such families might attempt to conceal the disability (Zhang & Bennett, 2003). In one study, a mother of Egyptian descent explained that her culture views hearing loss as shameful. Because of her child's hearing loss, some family members severed their relationships with her (Jackson, Traub, & Turnbull, 2008). Other cultures might see the disability as a gift from God and refuse interventions (Zhang & Bennett, 2003).

Amplification

Conveying the diagnosis and discussing amplification should be done in a sensitive manner (Fitzpatrick, Angus, Durieux-Smith, Graham & Coyle, 2008). Amplification fitting is often a critical moment for families where the reality of their child's hearing loss becomes actualized (Phillips et al., 2010; Spahn, Richter, Burger, Löhle & Wirsching, 2003). Families of minority culture background might experience additional hardship if their culture stigmatizes children with hearing loss. As result, it is important that practitioners have some knowledge of their patient's cultural background prior to discussing amplification in order to be sensitive to their needs.

Therapy

Language therapy involves three general communication approaches: visual approaches, which involve teaching signed languages; spoken language approaches, which emphasize oral language; and total communication approaches, which combine both oral and signed speech. Although visual interventions are a respected approach and foster communication development, this dissertation focused exclusively on spoken language interventions. The reason for this focused is that visual approaches are often rooted in Deaf culture, which introduces another dimension. In addition, the majority of families in Ontario choose spoken language approaches.

Spoken language interventions have been successful in achieving optimal language outcomes (Duncan et al., 2014; Fairgray, Purdy, & Smart, 2010; Yanbay, Hickson, Scarinci, Constantinescu, & Dettman, 2014). Auditory-Verbal Therapy (AVT) is one type of spoken language intervention that promotes early diagnosis of hearing loss, immediate and ongoing speech and language assessments, and family-centered education that emphasizes listening skills to facilitate optimal spoken language development. Although spoken language therapy has many benefits, limitations must be considered. For instance, intervention content might not be appropriate for minority cultures (Rhoades, 2008; Rhoades et al., 2004). This can become an added source of stress for minority culture families and, as a result, can negatively impact their perceptions of this

approach (Phillips et al., 2010). Other limitations experienced by minority culture families relate to language and cultural barriers; these topics are discussed in more detail in later sections.

Barriers to cultural competence in early hearing loss services

Language barriers: decisions about home language

After receiving a hearing loss diagnosis, minority culture families might encounter decision-making challenges regarding at-home language use (e.g., decisions to use one or more languages) (Crowe, McLeod, & Ching, 2012). Historically, multilingualism was generally discouraged by practitioners. Reasoning for this stance was that children with hearing loss already receive degraded auditory stimulation, and having incomplete input from two or more language systems can further interfere with language acquisition (McConkey Robbins, Green, & Waltzman, 2004).

In addition, recent immigrant families can experience pressure to learn the dominant language, which can result in loss of the home language (Wu, 2005). However, with recent technological advances (e.g., amplification) and evidence of children successfully acquiring a second language without compromising the development of their first (Bunta & Douglas, 2013; Guiberson, 2014), raising a multilingual child with hearing loss is increasingly possible (Crowe et al., 2012; McConkey Robbins, Green, & Waltzman, 2004). Multilingualism in children with hearing loss should therefore continue to be promoted by practitioners as their support can help establish trust and culturally sensitive practices.

Language and cultural barriers in health care services

Minority culture families with limited proficiency in the dominant language might encounter challenges navigating health care systems. For example, families unable to adequately communicate with practitioners might not be able to understand the benefits of consistent amplification use. In addition, they might not be aware of available supports (e.g. social, financial, etc.).

Minority culture families can also experience cultural barriers when receiving health care services. For example, First Nations children may avoid eye contact while conversing as a strategy to ensure maximum comprehension; a behavior which can be interpreted as distracting by non-Indigenous health care practitioners (Ball & Lewis, 2014). In return, such misinterpretations might lead to caregivers' mistrusting practitioners' competencies. In addition, some Indigenous cultures prefer collaborative learning activities as opposed to independent competitive tasks typically used in mainstream schools (Eriks-Brophy & Crago, 1994, 2004). Essentially, lack of knowledge regarding cultural variation in learning styles can result in the misunderstanding of competencies (Crago, Eriks-Brophy, Pesco, & McAlpine, 1997; SAC 2010).

Cultural barriers in patient-practitioner partnership

Partnership between caregivers and practitioners is crucial for interventions to be successful. Partnership involves honouring cultural diversity and providing flexible services to minority culture clients (Rhoades, 2010), and is advocated for in family-centered care, a practice generally endorsed by hearing loss practitioners in North America. According to an international consensus position paper, family-centered care is

the recommended approach to improving health-related outcomes for children with hearing loss and their families (Moeller et al., 2013).

Although the consensus among practitioners and policy-makers is a need for cultural competence in family-centered practices (American Academy of Pediatrics, 2007; Bernstein & Eriks-Brophy, 2010; Brown & Bortoli, 2010; Moeller et al., 2013; Rhoades, 2010), barriers to developing patient-practitioner partnerships remain. For example, cultural and linguistic mismatches between practitioners and patients can lead to misinterpretations of assessments and performance in interventions (D'Souza, Kay-Raining Bird, & Deacon, 2012; Eriks-Brophy, Quittenbaum, Anderson, & Nelson, 2008; Fitzpatrick & Doucet, 2013; Phillips, Worley, & Rhoades, 2010; Rhoades, 2008). To provide effective services to minority culture families, practitioners must understand the influence culture can have on the values, beliefs, behaviour, and health-related practices of their patients.

Cultural barriers in assessments

Literature indicates concerns regarding the effectiveness of services for minority culture populations (Duncan et al., 2014; Rhoades et al., 2004; Rhoades, 2008; Phillips et al., 2010). For example, speech and language assessments (receptive and/or expressive) are one of the most common approaches to determining progress, delays, or disorders. However, the accuracy of these assessments can be limited when applied to minority culture patients. Existing assessments are generally developed according to the majority's cultural environment (Baydala et al., 2009; Choi & Pak, 2005) and can be insensitive to cultural variations. As such, culturally appropriate assessments are required amongst these populations to facilitate cultural competence in pediatric hearing loss services (Eriks-Brophy, 2014).

Lack of culturally appropriate assessments can lead to assessment bias or interpretation of a patient's linguistic competence that might not reflect their actual capabilities (Peltier, 2014; Sterzuk, 2008). Forms of assessment bias include examiner bias, linguistic bias, and value bias (Eriks-Brophy, 2014).

Examiner bias occurs when the practitioner administering the assessment projects his or her own beliefs, values, and cultural norms onto the patient receiving the assessment. Linguistic bias occurs when practitioners are not aware of speech and language differences that occur in different dialects. For instance, a variety of Indigenous English dialects are distinctly different from Standard English used to develop the assessments; this might put Indigenous children at a disadvantage during speech and language evaluations (Ball & Bernhardt, 2008; Peltier, 2014). Value bias is encountered when tests include information unfamiliar to the child. Eriks-Brophy et al. (2008) noted the occurrence of value bias in several items in the Preschool Language Scale (PLS-4), a standardized assessment examining receptive and expressive vocabulary and language. Practitioners might misinterpret language capabilities if they do not possess the cultural knowledge necessary to recognize the presence of bias (Eriks-Brophy et al., 2008).

Overall, assessment bias can result in misdiagnosis (Ball, 2009; Eriks-Brophy, 2014; SAC, 2010). For example, discerning language disorders or delays in multicultural and linguistically diverse patients can be difficult (Crago, 1990; Prelock, 2008). This concern remains due to the lack of available tools to support distinguishing whether a

child's language performance reflects impairments or simply cultural and/or linguistic differences (Ball & Bernhardt, 2008).

Facilitators of cultural competence in early hearing loss services

Improving cultural competence

There are many recommendations for developing or improving cultural competence in health care services. For example, practitioners can acknowledge their own discomforts or lack of cultural knowledge (Moeller et al., 2013). Additionally, honesty and awareness of cultural differences can foster patient-practitioner partnerships. Education in these areas may help facilitate improved patient outcomes (Moeller et al., 2013). In recommendations for developing cultural competence, Bernstein and Eriks-Brophy (2010) suggest practitioners use jargon free language, provide interpreters where available, connect patients of the same cultural/linguistic background undergoing similar experiences, and establish a library containing information about cultures and cultural competence in their work environment.

Knowledge of cultural differences can be further improved with the use of genograms, talking maps, and/or mimicry. *Genograms* involve practitioners taking notes about their patients' family history, including culture (McGoldrick, Gerson, & Shellenberger, 1999). Brown and Bortoli (2010) recommend using *talking maps* (Brown & Nott, 2006) to capture family structures and experiences. Talking maps involve asking about routines, activities, and caregiver roles, and thus provide insight into a given family's cultural background. *Mimicry* is also viewed as an effective strategy for developing cultural competence and partnership (Rhoades, 2008). This strategy requires practitioners to adapt to families' cultural or linguistic backgrounds by observing and using their mannerisms and colloquialisms. Practitioners using such strategies provide culturally competent services by understanding and respecting cultural differences and adapting care to be inclusive of the needs of minority families.

A variety of approaches have been recommended to improve cultural competence in early hearing loss interventions. In a position paper on multiculturalism, Crago and Westernoff (1997) recommend that audiologists be critically reflective when providing services to minority culture patients to avoid assessment bias. One such approach is for practitioners to become familiar with the language-learning environments of their patients. For example, participation in community activities is an approach practitioners can use to familiarize themselves with community norms (Kay-Raining Bird, 2014). Such methods can be useful for determining true instances of language disorders (Eriks-Brophy, 2014). Other approaches involve changes to assessments and the administration thereof. Some hearing loss practitioners modify assessments for minority culture patients by changing the scoring system (Eriks-Brophy, 2014). Other approaches involve administering subtests as opposed to a complete battery of assessments. These approaches might reduce assessment bias but can also invalidate the results (Eriks-Brophy, 2014).

Another strategy is to translate and adapt the content of assessments to reflect the target population's culture, thereby allowing for a more accurate representation of the assessed competencies. However, assessment translations have the potential for bias. Direct translations often do not take cultural context into consideration, thus highlighting the importance of using standard translation practices. Current standard translation

practices involve translating the assessment into the foreign language by a native speaker and then having another individual translate the assessment back into its original language. These translations are then compared for inconsistencies (Aschengrau & Seage, 2013). However, a limitation to this approach is the cost and time involved.

The need for empirical evidence

Although this literature review provides an overview of what is known about cultural competence in early hearing loss services, it is not a complete picture. The majority of the information used in this literature review is not empirically based. Increasing diversity is creating an urgent need for the provision of culturally appropriate services. This need is particularly salient in early hearing loss services as cultural competence might help to facilitate optimal language outcomes. Empirical research can contribute to a better understanding of barriers and facilitators to cultural competence, thereby providing opportunities for improvements to service delivery amongst minority culture populations.

Theoretical framework

This program of research utilized Bronfenbrenner's bioecological systems theory (1977) as a framework to guide the studies. This theory conceptualizes multiple environmental contexts surrounding a developing individual and sufficiently guided this research as it captures the influence of a patient's cultural background. Bronfenbrenner posits individuals and their surrounding environments are interconnected. Environments surrounding the developing person are represented by a layered system starting from the microsystem, and moving outwards to the mesosystem, exosystem, macrosystem, and chronosystem.

Figure 2 provides a visual representation of Duncan's (2010) and Neuss's (2006) interpretation of Bronfenbrenner's theory. The microsystem (layer 1) represents the immediate environment. This includes the home environment (e.g., family), the school environment (e.g., peers, classmates, teachers), and the work environment (e.g., coworkers, management). The mesosystem (layer 2) represents interrelations between microsystems encompassing the individual. This involves interrelations between work and home environments that can impact development. The exosystem (layer 3) contains extensions of mesosystems. These extensions do not directly affect the individual, but have the potential to influence other mesosystems or microsystems. Examples of exosystems include neighborhoods, mass media, societal institutions, and government. The macrosystem (layer 4) consists of cultural and societal influences. This can include ethnicity, language, education, and political systems, all of which directly and indirectly impact the other systems. The chronosystem considers the dimension of time. It represents events and transitions in each system that influences development over time (Bronfenbrenner & Morris, 2006). Though some argue this theory positions culture too far from the individual (Weisner, 2008), Bronfenbrenner emphasizes that each system should not be viewed as a separate entity but instead as integrated with other systems.

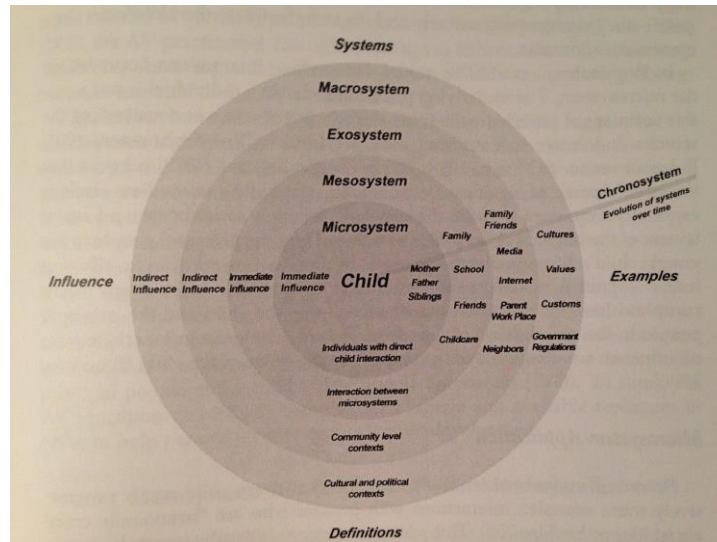


Figure 2. Circles of influence (Duncan, 2010)

In a healthcare context, Bronfenbrenner's theory advocates for practitioners to consider environments influencing development, while also paying attention to how these environments change over time. These considerations are particularly important when practitioners are working with minority culture families who might experience limitations related to the Western-influenced care being provided (Rhoades, 2008).

Objectives

The aim of this dissertation was to gain a deeper understanding of how culture can affect early hearing loss services. The objectives were: 1) to review and assess the state of knowledge with respect to barriers and facilitators of cultural competence in rehabilitation services; 2) to explore practitioners' experiences with providing services to minority culture families; and 3) to explore the experiences of minority culture families receiving services for their child's hearing loss.

Methodology

To address the first objective, a scoping review was performed (Chapter 2) in rehabilitation services, as literature solely in childhood hearing loss is limited. The second and third objectives were addressed in two stages: interviews with practitioners and minority culture families, as well as a survey for practitioners. The results of the scoping review were used to develop the interview protocol for practitioners (Chapter 3) and minority culture families (Chapter 4). Findings stemming from both interview studies informed the development of the survey for practitioners (Chapter 5) which addressed the second objective from a broader context. Table 1 provides an overview of each study's methods and objectives.

Table 1
Study methodologies and objectives

Study	Methodology	Objectives
Scoping Review, Chapter 2	Qualitative	To explore barriers and facilitators to cultural competence in: <ul style="list-style-type: none"> • Rehabilitation services in general • Early hearing loss interventions more specifically
Practitioner Interviews, Chapter 3	Qualitative	To gain insight into practitioners' experience with offering hearing loss services to minority culture families
Caregiver Interviews, Chapter 4	Qualitative	To gain insight into the experiences of minority culture caregivers of children receiving services for hearing loss
Practitioner Survey, Chapter 5	Quantitative	To gain insight into practitioners' experiences with offering early hearing loss services to minority culture families from a broader context across Canada

Scoping review (Chapter 2)

A scoping review in the field of rehabilitation was performed. This review addressed the following questions:

What are the barriers and facilitators to cultural competence in:

- a. Rehabilitation services in general?
- b. Early hearing loss interventions more specifically?

Scoping reviews involve a broad examination of literature in a specific area of research. Despite no consensus on a formal definition, key features of this method include a rigorous procedure, exploration of grey literature, often no quality appraisals, and an (optional) consultation session (Arksey & O'Malley, 2005; O'Brien et al., 2016; Pham et al., 2014). Scoping reviews are typically used for the following reasons: 1) to uncover what is known about the research topic; 2) to evaluate the need for a systematic review; 3) to capture and disseminate information on a research topic; or 4) to identify a gap in the literature (Arksey & O'Malley, 2005). The objectives of this research required the exploration of a topic that has garnered little attention and as result, supported the selection of a scoping review methodology.

Interviews (Chapter 3, 4)

The aim of this qualitative inquiry was to uncover possible barriers and facilitators to cultural competence in early hearing loss interventions. Specifically, the objectives were:

1. to gain insight into practitioners' experience with offering hearing loss services to minority culture families, and
2. to gain insight into the experiences of minority culture caregivers of children receiving services for hearing loss.

Qualitative interviews were conducted with practitioners (Chapter 3) and caregivers (Chapter 4) to address these objectives. Results from the scoping review informed the content of the interview protocols for practitioners (Appendix D) and caregivers (Appendix E).

Surveys (Chapter 5)

A questionnaire for practitioners was developed in both English and French (Appendices M & N) to explore possible barriers and facilitators to improving cultural competence in early hearing loss interventions. Specifically, the objective was to gain insight into practitioners' experiences with offering early hearing loss services to minority culture families. Questionnaire development was informed by results obtained from the scoping review and the interviews.

References

- American Academy of Pediatrics. (2007). Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 120(4), 898–921.
- Arksey, H., & O'Malley, L. (2005) Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32.
- Aschengrau, A., & Seage, G. (2013). *Essentials of epidemiology in public health*, (3rd ed.). Burlington, MA: Jones & Bartlett Learning.
- Ball, J. (2009). Supporting young Indigenous children's language development in Canada: A review of the research on needs and promising practices. *Canadian Modern Language Review*, 66(1), 19–47.
- Ball, J., & Bernhardt, B. M. (2008). First Nations English dialects in Canada: Implications for speech-language pathology. *Clinical Linguistics and Phonetics*, 22(8), 570–588.
- Ball, J. & Lewis, M. (2005). Talking points: What can speech-language partners contribute to Aboriginal early childhood development? *Research Connections Canada: Supporting Children and Families*, 12, 21–40.
- Ball, J., & Lewis, M. (2014). First Nations elders' and parents' views on supporting their children's language development. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 224–237.
- Baydala, L., Rasmussen, C., Birch, J., Sherman, J., Wikman, E., Charchun, J., . . . Bisanz, J. (2009). Self-beliefs and behavioral development as related to academic achievement in Canadian Aboriginal children. *Canadian Journal of School Psychology*, 24(1), 19–33.
- Bernstein, A., & Eriks-Brophy, A. (2010). Supporting families. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.225–257). Springfield, IL: Charles C Thomas Publisher.
- Bess, F. H., Dodd-Murphy, J., & Parker, R. A. (1998). Children with minimal sensorineural hearing loss: prevalence, educational performance, and functional status. *Ear and Hearing*, 19(5), 339-354.
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong 2nd, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118(4), 293-302.
- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity*, 36(4), 391-409.
- Bowd, A. D. (2005). Otitis media: health and social consequences for aboriginal youth in Canada's North. *International Journal of Circumpolar Health*, 64(1), 5-15.

- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513–531.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Daman, and R. M. Lerner (Eds.), *Handbook of child psychology, Vol. 1: Theoretical models of human development* (pp. 793-898). New York: Wiley.
- Brown, P. & Bortoli, A. (2010). Family-centered assessment. In, E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.259–280). Springfield, IL: Charles C Thomas Publisher.
- Brown, P., & Nott, P. (2006). Family-Centered practice in early intervention for oral language development: Philosophy, methods and results. In, P. Spencer, & M. Marschark (Eds.), *Advances in the spoken language development of deaf and hard-of-hearing children* (pp. 136–165). New York: Oxford University Press.
- Bunta, F., & Douglas, M. (2013). The effects of dual language support on the English language skills of bilingual children with cochlear implants and hearing aids as compared to monolingual peers. *Language, Speech and Hearing Services in Schools*, 44, 281-290.
- Burger, T., Spahn, C., Richter, B., Eissele, S., Löhle, E., & Bengel, J. (2005). Parental distress: The initial phase of hearing aid and cochlear implant fitting. *American Annals of the Deaf*, 150(1), 5–10.
- Choi, B., & Pak, A. (2005). A catalog of biases in questionnaires. *Prevention of Chronic Diseases*, 2(1), 1–13.
- Cone-Wesson, B., Vohr, B. R., Sininger, Y. S., Widen, J. E., Folsom, R. C., Gorga, M. P., & Norton, S. J. (2000). Identification of neonatal hearing impairment: infants with hearing loss. *Ear and Hearing*, 21(5), 488-507.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage publications.
- Crago, M. (1990). Development of communicative competence in Inuit children: Implications for speech-language pathology. *Journal of Childhood Communication Disorders*, 13(1), 75–83.
- Crago, M. B., Eriks-Brophy, A., Pesco, D., & McAlpine, L. (1997). Culturally based miscommunication in classroom interaction. *Language, Speech, and Hearing Services in Schools*, 28(3), 245–254.
- Crago M., & Westernoff, F. (1997). SAC position paper on speech-language pathology and audiology in the multicultural, multilingual context. *Canadian Journal of Speech-Language Pathology and Audiology*, 21, 223–224.
- Creswell, J. W. (2014). *Research Design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Crowe, K., McLeod, S., & Ching, T. Y. (2012). The cultural and linguistic diversity of 3-year-old children with hearing loss. *Journal of Deaf Studies and Deaf Education*, 17(4), 421-438.
- de Nobrega, M., Weckx, L. L. M., & Juliano, Y. (2005). Study of the hearing loss in children and adolescents, comparing the periods of 1990–1994 and 1994–2000. *International Journal of Pediatric Otorhinolaryngology*, 69(6), 829-838.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview.

- Medical Education*, 40(4), 314-321.
- Dillman, D., Smyth, J., & Christian, L. (2009). *Internet, mail and mixed-mode surveys: The tailored design method* (3rd ed.). Hoboken, NJ: John Wiley & Sons, Inc.
- D'Souza, C., Kay-Raining Bird, E., & Deacon, H. (2012). Survey of Canadian speech-language pathology service delivery to linguistically diverse clients. *Canadian Journal of Speech-Language Pathology & Audiology*, 36(1), 18–39.
- Duncan, J. (2010). Circles of Influence. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp. 97-111). Springfield, IL: Charles C Thomas Publisher.
- Duncan, J., Rhoades, E. A., & Fitzpatrick, E. M. (2014). *Auditory (Re) Habilitation for Adolescents with Hearing Loss: Theory and Practice*. Oxford University Press.
- Durieux-Smith, A., Fitzpatrick, E., & Whittingham, J. (2008). Universal newborn hearing screening: A question of evidence. *International Journal of Audiology*, 47(1), 1-10.
- Eriks-Brophy, A. (2014). Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 152–173.
- Eriks-Brophy, A., & Crago, M. (1994). Transforming classroom discourse: An Inuit example. *Language and Education*, 8(3), 105–122.
- Eriks-Brophy, A., & Crago, M. (2004). Variation in instructional discourse features: Cultural or linguistic? Evidence from Inuit and non-Inuit teachers of Nunavik. *Anthropology & Education Quarterly*, 34(4), 396–419.
- Eriks-Brophy, A., Quittenbaum, J., Anderson, D., & Nelson, T. (2008). Part of the problem or part of the solution? Communication assessments of Aboriginal children residing in remote communities using videoconferencing. *Clinical Linguistics & Phonetics*, 22(8), 589–609.
- Fairgray, E., Purdy, S. C., & Smart, J. L. (2010). Effects of auditory-verbal therapy for school-aged children with hearing loss: an exploratory study. *Volta Review*, 110(3), 407-433.
- First Years. (2011). Speech Banana. Retrieved from <http://www.firstyears.org/lib/banana.htm>.
- Fischer, C., & Lieu, J. (2014). Unilateral hearing loss is associated with a negative effect on language scores in adolescents. *International Journal of Pediatric Otorhinolaryngology*, 78(10), 1611-1617.
- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, 17(1), 38-49.
- Fitzpatrick, E. M., Crawford, L., Ni, A., & Durieux-Smith, A. (2011). A descriptive analysis of language and speech skills in 4-to 5-yr-old children with hearing loss. *Ear and Hearing*, 32(5), 605-616.
- Fitzpatrick, E.M. & Doucet, S. (2013). Creating optimal listening and learning environments in the first years. In *Pediatric audiologic rehabilitation* (pp. 68–89). New York, NY: Thieme Medical Publishers, Inc.
- Fitzpatrick, E. M., Durieux-Smith, A., & Whittingham, J. (2010). Clinical practice for

- children with mild bilateral and unilateral hearing loss. *Ear and Hearing*, 31(3), 392-400.
- Fitzpatrick, E. M., Whittingham, J., & Durieux-Smith, A. (2014). Mild bilateral and unilateral hearing loss in childhood: a 20-year view of hearing characteristics, and audiologic practices before and after newborn hearing screening. *Ear and Hearing*, 35(1), 10-18.
- Guiberson, M. (2014). Bilingual skills of deaf/hard of hearing children from Spain. *Cochlear Implants International*, 15(2), 87-92.
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82-98.
- Kay-Raining Bird, E. (2014). A resource kit to assist speech-language pathologists and audiologists in providing informed services to first nations, Inuit, and Métis people. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 238-250.
- Kelly, S. (2012) Qualitative interviewing techniques and styles. In J. F. Gubrium (Eds.), *The Sage handbook of interview research: The complexity of the craft* (pp. 243-254). Thousand Oaks, CA: Sage.
- Khangura, S., Konnyu, K., Cushman, R., Grimshaw, J., & Moher, D. (2012). Evidence summaries: the evolution of a rapid review approach. *Systematic Reviews*, 1(1), 1-9.
- Lederberg, A. R., Schick, B., & Spencer, P. E. (2013). Language and literacy development of deaf and hard-of-hearing children: successes and challenges. *Developmental Psychology*, 49(1), 15-30.
- Li, Y., Bain, L., & Steinberg, A. G. (2004). Parental decision-making in considering cochlear implant technology for a deaf child. *International Journal of Pediatric Otorhinolaryngology*, 68(8), 1027-1038.
- McConkey Robbins, A., Green, J. E., & Waltzman, S. B. (2004). Bilingual oral language proficiency in children with cochlear implants. *Archives of Otolaryngology-Head & Neck Surgery*, 130(5), 644-647.
- McGoldrick, M., Gerson, R., & Shellenberger, S. (1999). *Genograms assessment and intervention* (2nd ed.). New York: W. W. Norton.
- Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4(2), 138-163.
- Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18(4), 429-445.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine*, 151(4), 264-269.
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... & Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1), 1.
- Neuss, D. (2006). The ecological transition to auditory-verbal therapy: Experiences of

- parents whose children use cochlear implants. *Volta Review*, 106(2), 195–222.
- O'Brien, K. K., Colquhoun, H., Levac, D., Baxter, L., Tricco, A. C., Straus, S., ... & O'Malley, L. (2016). Advancing scoping study methodology: a web-based survey and consultation of perceptions on terminology, definition and methodological steps. *BMC Health Services Research*, 16(1), 305.
- Ontario Ministry of Children and Youth Services. (2007). *Ontario's early childhood development and early learning and child care: Investments and outcomes. 2006/2007 annual report* [Data file]. Retrieved from: http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/OECDELCCIO_2006-2007.aspx.
- Patel, H., & Feldman, M. (2014). Universal newborn hearing screening. *Paediatrics & Child Health*, 16(5), 301-305.
- Peltier, S. (2014). Assessing Anishinaabe children's narratives: An ethnographic exploration of elders' perspectives. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 174–193.
- Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research synthesis methods*, 5(4), 371-385.
- Phillips, R., Worley, L., & Rhoades, E. (2010). Socioemotional considerations. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.187–223). Springfield, IL: Charles C Thomas Publisher.
- Pit, S. W., Vo, T., & Pyakurel, S. (2014). The effectiveness of recruitment strategies on general practitioner's survey response rates-a systematic review. *BMC Medical Research Methodology*, 14(1), 76.
- Prieve, B. A., & Stevens, F. (2000). The New York State universal newborn hearing screening demonstration project: Introduction and overview. *Ear and Hearing*, 21(2), 85-91.
- Prelock, P. A., Hutchins, T., & Glascoe, F. P. (2008). Speech-language impairment: how to identify the most common and least diagnosed disability of childhood. *The Medscape Journal of Medicine*, 10(6), 136.
- Quittner, A. L., Barker, D. H., Cruz, I., Snell, C., Grimley, M. E., Botteri, M.; & The CDaCI Investigative Team. (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. *Parenting: Science and Practice*, 10, 136–155.
- Rhoades, E. A. (2008). Working with multicultural and multilingual families of young children. In J. Madell & C. Flexer (Eds.), *Pediatric audiology: Diagnosis, technology, and management* (pp. 262-268). New York, NY: Thieme Medical Publishers.
- Rhoades, E. (2010). Toward family-centered practice. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp. 167–186). Springfield, IL: Charles C Thomas Publisher.
- Rhoades, E. A., & Duncan, J. (Eds.). (2010). *Auditory-verbal practice: Toward a family-centered approach*. Springfield, IL: Charles C Thomas Publisher.
- Rhoades, E. A., Price, F., & Perigoe, C. B. (2004). The changing American family & ethnically diverse children with hearing loss and multiple needs. *Volta Review*, 104(4), 285–305.

- Russ, S. A., Poulakis, Z., Barker, M., Wake, M., Rickards, F., . . . Oberklaid, F. (2003). Epidemiology of congenital hearing loss in Victoria, Australia: Epidemiología de la hipoacusia congénita en Victoria, Australia. *International Journal of Audiology*, 42(7), 385-390.
- SAC. (2010). *Speech, language and hearing services to First Nations, Inuit, and Metis children in Canada, with a focus on children 0 to 6 years of age*. Retrieved from <http://sac-oac.ca/sites/default/files/resources/Complete%20report%20-%20English.pdf>.
- SAC. (2014). *Early hearing detection and intervention: Info sheet*. Retrieved from <http://sac-oac.ca/sites/default/files/resources/Early%20Hearing%20Detection%20and%20Intervention.pdf>.
- Sarant, J., & Garrard, P. (2014). Parenting stress in parents of children with cochlear implants: Relationships among parent stress, child language, and unilateral versus bilateral implants. *Journal of Deaf Studies and Deaf Education*, 19(1), 85-106.
- Spahn, C., Richter, B., Burger, T., Löhle, E., & Wirsching, M. (2003). A comparison between parents of children with cochlear implants and parents of children with hearing aids regarding parental distress and treatment expectations. *International Journal of Pediatric Otorhinolaryngology*, 67(9), 947-955.
- Statistics Canada. (2016a). *Dictionary, Census of population, visible minority*. Retrieved from: <http://www12.statcan.gc.ca/census-recensement/2016/ref/dict/pop127-eng.cfm>.
- Statistics Canada. (2016b). *Aboriginal peoples in Canada: Key results from the 2016 Census*. Retrieved from: <http://www.statcan.gc.ca/daily-quotidien/171025/dq171025a-eng.htm>
- Statistics Canada. (2017). *Study: A look at immigration, ethnocultural diversity and languages in Canada up to 2036, 2011 to 2036*. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/170125/dq170125b-eng.htm>.
- Sterzuk, A. (2008). Whose English counts? Indigenous English in Saskatchewan schools. *McGill Journal of Education*, 43(1), 9–19.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Thompson, D. C., McPhillips, H., Davis, R. L., Lieu, T. A., Homer, C. J., & Helfand, M. (2001). Universal newborn hearing screening: summary of evidence. *Jama*, 286(16), 2000-2010.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169-177.
- Thorne, S., Kirkham, S. R., & O’Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-11.
- Vohr, B., Topol, D., Girard, N., Pierre, L. S., Watson, V., & Tucker, R. (2012). Language outcomes and service provision of preschool children with congenital hearing loss. *Early Human Development*, 88(7), 493-498.
- Wake, M., Hughes, E. K., Poulakis, Z., Collins, C., & Rickards, F. W. (2004). Outcomes of children with mild-profound congenital hearing loss at 7 to 8 years: A population study. *Ear and Hearing*, 25(1), 1-8.

- Watkin, P. M., & Baldwin, M. (2010). Identifying deafness in early childhood: Requirements after the newborn hearing screen. *Archives of Disease in Childhood*, 96(1), 62-66.
- Weisner, T. (2008). The Urie Bronfenbrenner top 19: Looking back at his bioecological perspective. *Mind, Culture, and Activity*, 15, 258–262.
- Wheeler, A., Archbold, S., Gregory, S., & Skipp, A. (2007). Cochlear implants: The young people's perspective. *Journal of Deaf Studies and Deaf Education*.
- Wood, S. A., Sutton, G. J., & Davis, A. C. (2015). Performance and characteristics of the Newborn Hearing Screening Programme in England: The first seven years. *International Journal of Audiology*, 54(6), 353-358.
- Wu, C.H. (2005). *Attitude and behavior towards bilingualism for Chinese parents and children*. Paper presented at the Attitude and Behavior toward Bilingualism for Chinese Parents and Children, Somerville, MA.
- Yanbay, E., Hickson, L., Scarinci, N., Constantinescu, G., & Dettman, S. J. (2014). Language outcomes for children with cochlear implants enrolled in different communication programs. *Cochlear Implants International*, 15(3), 121-135.
- Zhang, C., & Bennett, T. (2003). Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other Developmental Disabilities*, 18(1), 51–59.

Barriers and facilitators to cultural competence in rehabilitation services:

A scoping review

Viviane Grandpierre, Victoria Milloy, Lindsey Sikora, Elizabeth Fitzpatrick, Roanne Thomas, Beth Potter

Published in BMC Health Services Research, 2018, 18:23

Chapter 2: Scoping review

Background

According to the latest Census, 20% of Canadians identify themselves as a minority or foreign born (1). By 2044, the US population is expected to be composed mainly of minority groups (2). Given North America's increasingly diverse population, cultural competence in rehabilitation services is a major concern (3-5). While requiring rehabilitation services are significant for most individuals and families, cultural minorities experience additional compounding issues. They encounter language barriers, limited social support systems, and cultural barriers, all while undergoing acculturation (6-8). Such challenges can affect access to care, leading to issues with treatment compliance and outcome success (6, 9). Immigrants and refugees face the additional challenge of navigating unfamiliar health care systems (10-12). Such challenges are critical as communication serves as a pillar for optimal outcomes in successful interventions.

Betancourt, Green, Carrillo, and Ananeh-Firempong's literature review (13) defines cultural competence from a healthcare context as:

... 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 (p.293).

Despite the increasing attention paid to cultural competence, providing culturally competent services can often be challenging for several reasons. First, culture may influence patients' values, beliefs, and health-related practices (13, 14). Second, rehabilitation interventions are typically tailored to meet the needs of the majority populations' cultural values, which as result do not serve all cultural groups (15-17). A third challenge is related to assessment bias where incorrect interpretations of patients' competence occur, may arise (18) and can lead to misdiagnosis amongst minority culture populations (19-21). Other challenges stem from the influence of culture on patients responses from diagnosis to treatment. For example, parents may seek to conceal their child's disability if their culture dictates that disabilities are a source of shame (6, 22). As a result, parents from some cultural backgrounds may decline an intervention or keep disabilities hidden when in public.

To improve cultural competence in rehabilitation services, an evaluation of whether services effectively address the needs of minority culture populations is required. Before such an evaluation can take place however, there needs to be an understanding of how culture can affect services (23). Yet, experts have stated that research in cultural competence in the rehabilitation fields is often dated, anecdotal, and may reflect stereotypical views (20, 24). Additionally, there appears to be a need for evidence-informed culturally competent services. For example, Aboriginal Early Childhood Development practitioners and parents have expressed frustration about the lack of culturally appropriate assessment tools (19, 21, 25).

This review was therefore undertaken to review and assess the state of knowledge with respect to barriers and facilitators of cultural competence in rehabilitation services. In order to address this objective, this review considered literature from several fields

within the broad area of rehabilitation services. This included services for adults in addition to pediatric care. The research question addressed in this review was: What are the barriers and facilitators to cultural competence in rehabilitation services?

Methods

A scoping review methodology was employed. Scoping reviews involve a thorough examination of literature on a specific area of research. As the goal is to provide an overview of evidence as opposed to assessing the evidence, quality appraisals are often omitted (26, 27). This research was informed by Arksey & O'Malley's (26) methodological framework for scoping reviews. This methodological framework consists of 5 stages: 1) formulating a research question; 2) identifying appropriate studies with a search strategy by examining electronic databases, and reference lists; 3) selecting eligible studies by creating inclusion and exclusion criteria which can then be applied at the article screening level to determine relevance; 4) recording and categorizing key results (e.g. location of study, intervention, comparator, study populations, study objectives, outcome measures, results, etc.); 5) summarizing and disseminating the results through tables and charts.

In addition, our review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (28), a checklist that is intended as a guideline for the reporting of systematic reviews but has broader applicability across other types of knowledge synthesis studies.

Definitions

The conceptualization of cultural competence, sociocultural barriers, and rehabilitation services will be used to guide the study selection criteria. The conceptualization of *cultural competence* varies widely in different fields. For the purposes of this research, it will be defined in a healthcare context according to Betancourt et al.'s (13) definition previously provided. As cultural competence is a goal in healthcare services, it is important to understand factors that hinder or facilitate its development, maintenance, and improvement. Betancourt et al. (13) state that a critical component of cultural competence is understanding that social factors (e.g. socioeconomic status and environmental factors such as supports, stressors, and hazards) are intricately woven into cultural factors and thus cannot be separated. *Sociocultural barriers* describe this impermeable link. As a result, it is important to understand the social context when describing cultural competence.

In consultation with a librarian (LS) within the medical field, the rehabilitation services chosen for this review are from the following fields: audiology, speech-language pathology, physio/physical therapy, occupational therapy, and nursing articles related to any of these four fields.

Selection criteria

Eligible articles were considered if they: 1) discussed health care practitioners in rehabilitation and/or recipients of rehabilitation health care services and where appropriate, their caregivers; and 2) reported on perceived barriers and facilitators to cultural competence in the context of practitioner-patient interactions.

There were no age restrictions for participants, however to prevent response bias, articles were excluded if the study population reported external factors that risked influencing their responses (e.g. war victims, refugees, substance abuse, victims of spousal violence, etc.). Individuals with such sensitive external factors may be influenced by socially desirable responses when providing self-reports (29).

Finally, non-scientific articles (e.g. magazine articles) were excluded at the screening level. Due to time limitations and feasibility, all eligible articles were then rescreened to exclude literature reviews, case studies (n=5 or <), commentaries, editorials, conference papers, and posters.

Search strategy

A search strategy (Appendix A) was developed in consultation with a librarian (LS) within the health sciences field to identify relevant articles published from the inception of databases until April 2015. This strategy was applied to the following databases: the Medical Literature Analysis and Retrieval System Online (Medline) database, the Excerpta Medica Database (Embase), the Psychological Information Database (PsycINFO), the Cumulative Index to Nursing & Allied Health Literature (CINAHL) database, the Linguistics and Language Behavior Abstracts (LLBA) database, the Communication, Sciences, and Disorders Dome (ComDisDome) database, the Allied and Complementary Medicine Database (AMED), Occupational Therapy Systematic Evaluation of Evidence (OT Seeker) database, and the Physiotherapy Evidence Database (Pedro).

Major concepts in the search strategy were cultural competence, rehabilitation services, and sociocultural barriers and facilitators. A sample of subject headings and key words used in the search strategy include: cultural competence, cultural sensitivity, minority health, physiotherapy, occupational therapy, audiology, nursing, sociocultural barriers, healthcare disparities, and culturally responsive care. Relevant articles found in the field of nursing were screened to ensure that the fields included rehabilitation.

Two independent reviewers (VG and VM) underwent piloting with 10% of the retrieved articles. The reviewers performed abstract screening independently, after which the reviewers met to assess whether calibration was achieved. Disagreements were discussed with a third party (LS) until consensus was reached. After this training was completed, the reviewers applied the eligibility criteria to retrieved titles and abstracts by using a liberal-accelerated approach (30). This approach consists of two levels of screening. In level one, the first reviewer screening all citations, and a second reviewer screening all excluded citations. In level two, for those titles and abstracts not excluded by both reviewers, full text articles were then screened against the inclusion criteria by both reviewers independently to determine eligibility. Reviewing literature beyond the search strategy involved screening the bibliographies of eligible articles against the inclusion criteria.

A data abstraction form (Appendix B) was piloted amongst a random sample of 10% of included articles to see whether the content was sufficient to answer the research questions. Abstracted items included: study characteristics and outcomes related to the barriers and facilitators of cultural competence in rehabilitation health care services. This pilot was performed by the same independent reviewers (VG and VM). All remaining

articles were abstracted using the improved form by the first reviewer. Completed forms were then verified by the second reviewer.

Analysis

In order to assist with collating, summarizing, and reporting the results as per Arksey & O'Malley's framework (26), data abstraction files were analyzed in NVivo (version 10.1.2), a qualitative software program. A constant comparative coding method was then used to help present an overview of the results. This process was based on Corbin & Strauss's (31) open, axial, and selective coding methods. One researcher (VG) performed open coding, which typically consists of studying and assigning labels to each passage. Comparisons of these labels were then made to further refine and conceptualize codes. Selective coding was then performed in order to examine similar concepts and collapse similar codes into major themes.

Results

The flow chart (Appendix C) provides a visual representation of the literature review and search process. After all duplicates were removed, a total of 4303 records were retrieved from the databases as well as additional sources (e.g. recommendations by coauthors, reference lists) were screened at level 1. After excluding 3572 records that did not meet the inclusion criteria, 731 proceeded to a level 2 analysis of the full text. At this level, 700 articles did not meet the criteria for reasons listed in *Figure 1*. Of these articles, 8 full text articles could not be retrieved. After all the screenings, only 31 articles were retained. Table 1 describes the eligible articles in detail.

Study Characteristics

Of the 31 eligible articles, 17 were in occupational therapy (OT), 11 in speech-language pathology (SLP), six in physiotherapy (PT), and one in audiology (Aud). Four of these articles reported on multiple rehabilitation fields (note: Although this adds up to a total of 35, it should be noted that 3 studies reported on multiple rehabilitation service providers). Table 2 displays the number of participants within each field. Fifteen articles discussed experiences within a pediatric-context: one in audiology, one in physiotherapy, six in occupational therapy, and eight in speech-language pathology (note: one article had OT and SLP participants). Seventeen articles used qualitative methods, 12 used quantitative, and two used mixed methods. The majority of these studies took place in Canada and the USA, with other study locations in Malaysia, Austria, Germany, Australia, England, Netherlands, Scotland, Bangladesh, Oman, Singapore, and the United Kingdom (Table 1).

Table 1
Study Characteristics

Study	Rehabilitation field	Location	Design	No. Of Participants	Study goals
Al Busaidy & Borthwick, 2012 (48)	OT	Oman	Interviews	11 Practitioners	Inquired about service provision experiences
Centeno, 2009 (33)	SLP	USA	Surveys	33 Practitioners	Inquired about service provision experiences
Dogan et al, 2009 (34)*	PT	Turkey	Surveys	50 Practitioners	Inquired about service provision and reception experiences
Dressler & Pils, 2009 (35)	PT, SLP, OT	Austria	Interviews	28 Practitioners: 1 SLP, 2 OTs, 1 PT; 24 others	Examines practitioners perception of cross-cultural communication experiences
Drolet et al., 2014 (32)	OT, SLP	Canada	Focus groups	43 Practitioners: 21 in health**, 22 in social services	Inquired about service provision experiences
Guiberson & Atkins, 2012 (36)	SLP	USA	Survey	154 Practitioners	Inquired about practitioners backgrounds, training, and experiences with service delivery
Jaggi & Bithell, 1995 (44)	PT	Bangladesh	Survey	68 Practitioners	Inquired about practitioners experiences, knowledge, and attitudes regarding service delivery
Khamisha, 1997 Part 1 & 2 (37, 53)	OT	Glasgow	Survey	94 Practitioners	Inquired about practitioners perceptions, experiences, knowledge, and attitudes regarding service delivery
Kinebanian & Stomph 1992 (46)	OT	Netherlands	Interview	25 Practitioners	Inquired about service provision experiences
Kirkham et al., 2009 (57)	Aud	USA	Survey	103 Practitioners	Inquired about perceptions of speech and language outcome disparities and recommendations to reduce disparities
Kirsh, Trentham & Cole, 2006 (61)	OT	Canada	Interviews	14 Consumers	Inquired about minorities' experiences with receiving services
Kohnert et al., 2003 (38)	SLP	USA	Survey	104 Practitioners	Inquired about service provision experiences
Kramer-Roy, 2012 (62)	OT	United Kingdom	Interviews	6 caregivers	Inquired about the service needs of Pakistani families with disabled children
Kummerer & Lopez-Reyna, 2006 (60)	SLP	USA	Interviews	14 caregivers	Explored the views and beliefs of language development, disabilities, therapy experiences of Mexican immigrant mothers
Lee, Sullivan & Lansbury,	PT	Australia	Interviews & Observations	6 Practitioners	Explored practitioners strategies with service delivery

2006 (58)					
Lindsay et al., 2012 (12)	OT, PT	Canada	Interviews & Focus Groups	13 Practitioners & coordinators: 2 PTs, 2 OTs, 9 others	Inquired about service provision experiences
Lindsay et al., 2014 (39)	OT	Canada	Interviews	17 Practitioners	Explored practitioners strategies with service delivery
Maul, 2010 (54)	SLP	USA	Interviews	9 Practitioners	Explored cultural competency skills in practitioners
Munoz, 2007 (55)	OT	USA	Interviews	12 Practitioners	Explored practitioners' perceptions of culturally competent service delivery
Nelson & Allison, 2007 (43)	OT	Australia	Part 1: Interviews & focus groups Part 2: Surveys	Part 1: 25 Stakeholders including 8 caregivers Part 2: 50 Practitioners	Explored practitioners' perceptions of culturally competent service delivery
Nelson, Allison, & Copley, 2007 (49)	OT	Australia	Part 1: Survey Part 2: Focus groups & Interviews	Part 1: 50 Practitioners Part 2: 25 Stakeholders including 8 caregivers	Inquired about service provision and reception experiences
Nelson et al., 2011 (56)	OT	Australia	Survey & Workshop discussion	41 Practitioners	Inquired about service provision experiences
Phipps, 1995 (40)	OT	Australia	Survey	65 Practitioners	Inquired about service provision experiences
Phoon & Maclagan, 2009 (50)	SLP	Malaysia	Survey	38 Practitioners	Explored practitioners experiences with using assessments
Roseberry - McKibbin & Eicholtz, 1994 (41)	SLP	USA	Survey	1145 Practitioners	Inquired about service provision experiences
Roseberry - Mckibbin, Brice & O'Hanlon, 2005 (42)	SLP	USA	Survey	1736 Practitioners	Inquired about service provision experiences
Stedman & Thomas, 2011 (51)	OT	Australia	Interviews	7 Practitioners	Inquired about service provision experiences
Watts & Carlson, 2002 (52)	OT	Australia	Interviews	8 Practitioners	Inquired about practitioners' experiences, perspectives and recommendations regarding service provision
Williams &	SLP	Australia	Survey	128 Practitioners	Inquired about practitioners' experiences and perspectives

McLeod, 2012 (45)					regarding service provision
Yang et al., 2006 (47)	OT	Singapore	Interviews	9 Practitioners	Explored the applicability of OT frameworks in Oman context
Yeowell, 2010 (59)	PT	England	Interviews	6 Patients	Inquired about the service needs of Pakistani women

OT= Occupational Therapy, PT = Physiotherapy, SLP = Speech-language pathology, Aud = Audiology

* This study did not have/require ethical clearance

** This study does not specify the number of practitioners per rehabilitation field

Table 2

Number of participants per rehabilitation field

Field	# of health care practitioners	# of patients/caregivers
Occupational therapy	343*	28
Audiology	103	N/A
Speech language pathology	3348*	14
Physiotherapy	127	6

* Drolet 2014 (32) was excluded from the count as it did not specify the number of practitioners in each field; N/A = not applicable due to no study availability on patient/caregiver perspectives.

Practitioner perspectives

We identified a multitude of barriers and facilitators to service delivery and reception, which will be reported below from the perspectives of practitioners and patients/caregivers. Table 3 displays and compares various common themes reported by the practitioners and patients/caregivers of the reviewed articles. Though overlap occurs between categories, the results provide an overview in understanding how service delivery and reception can be impacted by diversity.

Table 3

A comparison of barriers and facilitators between patients/caregivers' and practitioners perspectives in rehabilitation services

BARRIERS	OT HCP	OT PTs	PT HCP	PT PTs	SLP HCP	SLP PTs	Aud HCP	AUD PTs
Language barriers	✓	✓	✓	✓	✓			N/A
Limited resources	✓		✓	✓	✓			N/A
Influence of cultural differences	✓		✓		✓			N/A
FACILITATORS								
Cultural awareness amongst practitioners	✓	✓		✓	✓	✓		N/A
Cultural awareness in services	✓	✓	✓	✓	✓		✓	N/A
Explanations of health care systems	✓	✓	✓	✓		✓		N/A

OT= Occupational Therapy, PT = Physiotherapy, SLP = Speech-language pathology, Aud = Audiology, HCP = Health care practitioners, PTs = Patients/caregivers, N/A = not applicable due to no study availability on patient/caregiver perspectives

Barriers reported by practitioners

Practitioners described many barriers in providing rehabilitation services to minority culture service patients. Three major categories emerged from the data: The effect of language barriers, the influence of cultural differences on service delivery, and limited resources to facilitate culturally competent care. Table 4 provides an overview of the

primary barriers experienced by both practitioners and patients/caregivers and how they influenced various aspects of healthcare delivery.

The effect of language barriers

Language barriers were reported by speech language pathologists, physical therapists, and occupational therapists. Practitioners who were unable to speak the language of their patients felt that language barriers limited their abilities to provide information and instructions (12, 32-42). Not being able to communicate effectively with service recipients was also said to impact the development of effective relationships (43) and as a result, it took longer to establish rapport (39). Difficulties in service delivery were reported to also arise when the child’s primary caregiver (typically who is most knowledgeable of the child’s behaviors) was unable to speak the language, leaving the other parent to act as the family spokesperson (12). Finally, language barriers were also said to hinder and sometimes impede therapy delivery(35) and potentially affect treatment compliance (44).

Table 4

Overview of the primary barriers and how they influenced various aspects of healthcare delivery/reception.

Primary barriers to culturally competent care	Areas of health care service delivery/reception affected
Language barrier	<ul style="list-style-type: none"> • Practitioner-patient/caregiver communication • Establishing rapport • Information provision and instruction • Establish rapport • Engagement in intervention/therapy
Cultural barriers	<ul style="list-style-type: none"> • Practitioner-patient/caregiver communication • Establishing rapport • Diagnosis (e.g. belief of diagnosis) • Decision-making on treatment • Engagement in intervention/therapy
Limited resources	<ul style="list-style-type: none"> • Practitioner-patient/caregiver communication • Establishing rapport • Diagnosis • Assessments • Engagement in intervention/therapy

The influence of cultural differences on service delivery

Speech language pathologists, physical therapists, and occupational therapists reported cultural differences affecting service delivery. In a pediatric context, cultural differences were seen in child-rearing strategies. Interacting with fathers was reported to be challenging due to gender attitudes varying cross-culturally (45). Occupational therapists also identified cultural differences in play. Therapists spoke of cultures where parents do not play with their children. This was seen to complicate service delivery as therapists felt conflicted about encouraging parents to use play in therapy (39).

Cultural differences were also said to occur in the caregiver’s views of disability, independence, decision-making, and gender roles. Differing views of disability

sometimes affected treatment compliance. For example, an occupational therapist participating in a focus group had stated:

“Some recommendations you’ll give a child for safety concerns or you provide a child with equipment so they’re better supported so feeding could be more successful and more in a safe way and yet they still have a lot of [difficulty] culturally [with] their food, they want to be feeding that even though a different food is suggested”. Lindsay et al., 2012 (12), pp. 2011.

Views of independence were also said to vary across cultures (12, 39, 40, 46, 47).

Western-based practices value the promotion of independence however the assumption that this is a universal value has limited the provision of culturally competent care. Yang (47) described challenges experienced by occupational therapists where patients did not believe achieving independence was important as it was the responsibility of their families or maids to care for their children. Additionally, activities of daily life used in occupational therapy were not seen as meaningful by some cultures (40, 47).

Differences in decision-making were documented in several studies (12, 39, 45, 47). In particular, patients were seen to be reluctant in making decisions, as they believed such decisions should be left to experts.

Finally, cultural differences in gender roles were seen to impact service delivery (12, 35, 39, 48). In some cases, male service recipients requested male practitioners (35, 48). In a pediatric case, therapists experienced challenges in requesting information regarding the needs and abilities of children, as mothers (typically the primary caregiver) stayed silent during assessments since fathers were the family spokesperson.

Limited resources to facilitate culturally competent care

Speech language pathologists, physical therapists, and occupational therapists cited limited resources in providing culturally competent care. This included Western-based practices, linguistically-relative materials, lack of bilingual practitioners, lack of interpreters, and a lack of sufficient training and/or education.

Several studies described how Western-based notions of rehabilitation complicated service delivery (39, 46, 48, 49). For example, service models adhering to Western values typically promote independence, which as previously shown, was not always considered to be important by some cultural groups. Barriers also included culturally and/or linguistically-relative materials, assessments, and treatments. The lack of these resources was frequently cited as a barrier to culturally competent service delivery (12, 33, 35, 36, 38-42, 46, 47, 49-52).

In terms of linguistically-relative materials, offering information and recommendations to service recipients in English created challenges in providing therapy (35). These limitations affected relationship-building opportunities (12). Regarding service materials, several studies discussed challenges with providing appropriate assessment materials, treatment planning, treatment materials, and treatment goals (33, 36, 38-40, 42, 45-47, 49, 50, 52). In particular, studies cited a lack of appropriate assessment/screening instruments creating barriers to culturally competent service delivery (33, 36, 38, 40-42, 49, 50, 52). Such limitations become increasingly worrisome when there are already difficulties in differentiating a language difference from a language disorder (41, 42).

Difficulties in the provision of culturally competent services were also attributed to a lack of bilingual practitioners or practitioners who speak their clients' language (33, 36, 38, 41, 42), lack of available interpreters (41), and practitioners receiving minimal or no training and/or education on servicing minorities (12, 33, 38-41, 45, 53).

Facilitators reported by practitioners

Practitioners described a variety of facilitators in providing rehabilitation services to minority culture patients. Three major categories emerged from the data: Increasing cultural awareness, fostering a culturally competent work environment, and explaining healthcare to minority culture patients. Table 5 provides an overview of the primary facilitators experienced by both practitioners and patients/caregivers and how they influenced various aspects of healthcare delivery.

Table 5

Overview of the primary facilitators and how they influenced various aspects of healthcare delivery/reception.

Primary facilitators to culturally competent care	Impact on health care service delivery/reception
Cultural awareness amongst practitioners	<ul style="list-style-type: none"> • Helped establish rapport • Helped with provision of appropriate care, therapy • Helped to tailor care, therapy when needed • Helped with understanding patient/caregiver health-related goals
Cultural awareness in services	<ul style="list-style-type: none"> • Improved practitioner-patient/caregiver communication • Helped establish rapport • Increased attendance and compliance • Helped to learn about patients/caregivers values and needs • Helped diminish negative experiences • Created a comfortable atmosphere • Helped support patients/caregivers with long-term treatment management
Explanations of health care systems	<ul style="list-style-type: none"> • Increased patient/caregiver understanding of available services and resources • Increased patient/caregiver understanding of available funding • Increased patient/caregiver understanding of available support networks • Increased patient/caregiver understanding of benefits of treatment compliance

Increasing cultural awareness

This category emerged from data discussing methods that enabled culturally competent care. Asking questions was one method that helped determine cultural differences which might require tailoring care. Inquiring about patients' day-to-day practices was seen as a helpful strategy to learning about cultural differences and providing appropriate therapy

(39, 46, 51, 54). Asking about family roles may help with service provision. For example, according to Nelson's (49) study, therapists experienced difficulties in communicating with the same caregiver as Indigenous patients often have multiple caregivers or extended families. This led to uncertainty about compliance as it was difficult to know if the information was being understood and transferred at home.

Understanding patients' cultural backgrounds was viewed as important in many studies (39, 49, 51, 54). Such knowledge helped practitioners better understand patient goals and offer more appropriate recommendations (39). Learning about the histories of cultural groups was also seen as a facilitator to providing culturally competent care. For example, discrimination and marginalization experienced by Indigenous Australians may lead to patients feeling disempowered and wary of government services and may effect attendance (49, 52). Strategies used by practitioners to address the impact of such histories include environmental considerations, such as conducting therapy sessions outdoors or in areas where patients are more comfortable (52).

Learning about the role of religion and traditional healing methods was also seen as an important facilitator. Unlike Western medicine, where illness and religion are separate entities, cultures exist where religious and traditional healing roles govern perceptions of illness as well as every day practices (46, 48). Having an awareness of the ties between religion and health may allow practitioners to better tailor care to meet the needs of their minority patients. Practitioners seeking to gain knowledge about cultural differences, cultural histories, and/or the roles of religion and traditional healing methods can educate themselves with the use of books and media (33, 37, 40).

Establishing meaningful relationships, engaging in cross-cultural encounters, having respect for cultures, and being reflective were also identified as approaches to developing cultural awareness. Establishing a meaningful relationship was seen as an essential factor for ensuring the provision of appropriate and successful interventions (43, 51). Such relationships can result in patients providing relevant information needed to develop appropriate treatment plans. This involves knowing how to formulate questions, although this was seen as challenging as patients sometimes limit their responses to 'yes' or 'no' (51). Approaches to establishing and maintaining relationships include inquiring about patients' cultural backgrounds, learning certain key words and phrases in the patients' primary language, understanding the patient's values, and being mindful of verbal and non-verbal communication (39, 40, 43, 52, 54, 55). Having respect for cultures can also facilitate beneficial exchanges with patients (43).

Engaging in cross-cultural encounters was also viewed as a useful strategy to developing cultural awareness. This can involve creating links with cultural agencies, attending cultural events, interacting with communities, or simply engaging in day-to-day interactions with culturally diverse individuals (49, 54-56).

Finally, being reflective was noted by numerous studies as an important requirement for developing cultural awareness. This involved practitioners examining their own cultural identity, values, prejudices, biases, and/or assumptions and the influence it can have on service delivery (39, 49, 51, 55, 56).

Fostering a culturally competent work environment

Numerous studies called for a need to foster culturally competent work environments. One approach for achieving this goal was to have a more diverse workforce (57).

Flexibility was also seen as an important trait in providing services to minority culture patients (12, 39, 43, 49). Flexibility helped create a better understanding of patients' day-to-day activities (39) and build relationships (12). One strategy to becoming flexible can involve increasing appointment time when working with minority culture patients (12).

Another approach to foster a culturally competent work environment was training and/or education on providing services to minorities (33, 34, 42, 44, 52, 57). Such training/ education was often cited as a need (49, 53, 56).

Having registration forms that collect linguistic and cultural background was seen as a helpful method to providing appropriate care (12). Using the services of other professionals, such as colleagues with experience in working with cultural minorities, interpreters, and cultural liaisons was sometimes seen as helpful (12, 33, 38, 40, 41, 43-45, 49, 52, 56, 57). Working with interpreters however was also reported as challenging in terms of cost, increased time and effort with interactions, trust issues, minimal knowledge of professional jargon, and creating barriers with building rapport (12, 54, 55). Using colleagues as interpreters was also flagged as inadvisable due to the lack of training, which certified interpreters are required to undergo (58).

Rehabilitation services that incorporate family members into practice was seen as a useful strategy to help build culturally competent services as there are cultures where immediate and extended family members can have a significant role in a patient's life (40, 52). Another strategy that recognizes the importance of relationships was using small group sessions in therapy. For example, Australian Indigenous children may experience a sense of shame for having to see a therapist and having small group sessions can help diminish such negative experiences (43). Services that network with cultural agencies and/or organizations was reported as another useful strategy that helped with initial patient encounters, developing relationships, and attaining consistent follow-up (40, 43, 51).

Specific strategies to facilitating culturally-competent work environments were also reported. Matching practitioners with patients of similar cultural background was one recommendation (12, 40). Another approach involved the use of culturally sensitive materials (32, 52, 56). For example, use of pictorial images to help improve communication was reported to help patients who do not speak the service language (56).

Specific strategies for assessments and treatments were also reported. Tailoring assessments and treatments can first involve gathering cultural data through interviews and observations (48, 54, 55). Gathering such information can be challenging, however there were a variety of solutions identified for overcoming this barrier: using pauses (e.g. giving time for patients to respond), soft voices, informal language, and/or non-verbal media such as pictorial brochures to support communication (52, 56). Next, modifications to care can occur with the use of: interpreters, tests developed for multicultural populations, informal assessments (e.g. language samples, checklists), translated materials, toys familiar to children, communication equipment (e.g. video conferencing materials) for rural and remote patients, and selecting culturally-meaningful treatments (40, 45, 46, 50-52, 54, 55, 58, 59).

Finally, practitioners called for more research on cultural differences. Such information would help inform culturally competent practices (52, 56).

Explaining healthcare to minority culture patients

Supporting minority culture patients navigating the health care system was identified as an important feature for providing culturally competent care, as many may not know about the resources available to them. Helping patients understand the health care system can include providing home visits, connecting them to resources, explaining how equipment is funded, and/or offering personalized support networks (12, 39). Explaining perceptions of disability in the country where the service is being provided was also highlighted as important to helping patients understand the health system as there are cultures where disability is stigmatized and hidden (39).

Finally, explaining what is involved in assessments and treatments was also felt to be important by practitioners. This can be achieved by using appropriate terminology, written material with simple language, cultural liaisons, and/or information sessions (39, 49, 60).

Patient/Caregiver perspectives

Although results regarding patient/caregiver perspectives on culturally competent care were limited as only five studies enrolled patient/caregiver participants, a variety of barriers and facilitators were nonetheless found.

Barriers reported by patients/caregivers

Patients/caregivers described a variety of barriers to receiving high quality rehabilitation services. Two major categories emerged from the data: The effects of language and cultural barriers and the effects of limited resources in services.

The effects of language and cultural barriers

Patients described instances of being unable to communicate thoughts and feelings (59). There were also descriptions of service recipients experiencing attitudinal issues whereby practitioners used unfamiliar language. This resulted in service recipients questioning whether they were experiencing discrimination due to their minority status (61). Language barriers also affected caregivers understanding of meaningful treatment goals that would help improve development outcomes (60).

The effects of limited resources in services

Services that do not provide interpreters and assume that the patient will bring someone who can translate for them were seen as a barrier. For example, not having an interpreter was noted to have affected attendance in one study (59).

Another barrier cited was the use of written information during service provision. Even if materials were translated, some service recipients noted that they could not read in their native language (59).

Facilitators reported by patients/caregivers

Patients/caregivers described a variety of facilitators in receiving culturally competent rehabilitation services. Three major categories emerged from the data: cultural awareness amongst practitioners, cultural awareness in services, and explanations of health care systems.

Cultural awareness amongst practitioners

According to patients/caregivers, a key facilitator to receiving culturally competent services was having practitioners who demonstrated cultural awareness. This involved practitioners developing an understanding of culture, including cultural history, how it affects patients/caregivers' everyday practices (e.g. ritual occupations and traditions) and making an effort to be non-judgemental (43, 49, 61, 62). Suggestions for gaining such knowledge were to spend time with different cultural groups and have conversations with professionals with cultural experience or cultural liaisons (49).

Cultural awareness also involves recognizing that there are cultural differences in the perceptions of disability, such as etiology of the disability (61, 62). Differences also occur in activities such as play. Discussing service recipients' views of play may help improve the success of interventions as therapy can be better tailored to reflect the caregivers' everyday environment (62).

Patients/caregivers also spoke of the importance of relationships with practitioners and the need to work in partnership within that relationship (43). They reported how important it was to have practitioners share information about their lives (e.g. social, cultural, historical aspects) (61). Patients/caregivers also described the need to have the same therapist in order to facilitate long-term relationships (43). Having a practitioner with the same cultural background and/or sex can help establish a relationship as the practitioner may be seen as someone who would be familiar with taboos. However it should be noted that some patients also expressed concerns regarding this facilitator in terms of maintaining confidentiality within the community (61).

Exploring caregivers' expectations of development was also valuable as knowledge of such interpretations can help facilitate effective therapy strategies. Without such information, compliance may be affected as service recipients may not understand the value of treatment plans (62). Eliciting information on expectations of language milestones can include encouraging story-sharing with the use of videotapes and/or journal entries (60). Although the strategies mentioned in this section can help develop relationships, caregivers reported that the personal qualities of practitioners were also essential to developing cultural awareness (49).

Cultural awareness in services

Patients/caregivers expressed an appreciation for services that incorporated cultural awareness into practice protocols. This involved services using culturally appropriate materials and tailoring care to meet the needs of minority patients/caregivers.

Culturally appropriate assessment and intervention materials were valued by service recipients because otherwise such resources were typically developed for North Americans (49, 61). To overcome this limitation, one suggestion was to use observations to complement assessments. Another suggestion was the use of photographic or visual home programmes for those who do not have strong literacy skills (49). An alternative is the provision of written instructions with pictures (59).

Tailoring care involved understanding patient needs. Patients indicated a preference for having practitioners of the same gender and for single-sex group sessions. Tailoring care in this manner may have a positive effect of compliance and attendance (59). Having longer appointment times for patients who do not speak the service

language was also recommended to facilitate culturally competent service provision (59). One patient discussed how speaking English as a second language takes time and that it would be helpful for practitioners to be aware of this. To ensure comprehension, this patient recommended practitioners to go slowly:

“If I’m talking English and you’re speaking English, I’ve got to take it in as English, but if I don’t speak good English, when you’re speaking in English I’ve got to take it in and translate it in my head and translate it into your language and then back into English to speak it. Yes. So I think you need to give them space and check they’ve understood before they go on to the next sentence. That would help.” Yeowell, 2010 (59), pp. 261

Caregivers may also benefit from services such as support groups that include participants’ cultural/religious backgrounds. This strategy can help support caregivers with long-term treatment management (62).

Explanations of health care systems

Patients/caregivers expressed the need for understanding rehabilitation services. Specifically, the purpose of therapy, how long it will take, the roles of family members in supporting it, and the benefits of compliance, particularly if aspects of treatment (e.g. exercise) are not a part of their culture (49, 59, 60). Practitioners who possess cultural awareness and are able to offer such explanations are therefore in a better position to provide culturally competent care.

Discussion

Summary

Increasing diversity has called attention to the need for culturally competent health care services. This scoping review sought to identify practitioner and patient/caregivers’ perspectives on barriers and facilitators to cultural competence in rehabilitation services. Three major barriers emerged from the data reporting on practitioner perspectives: The effect of language barriers, the influence of cultural differences on service delivery, and limited resources to facilitate culturally competent care. Major facilitators identified were: increasing cultural awareness, fostering a culturally competent work environment, and explaining healthcare to minority culture patients. Two major barriers emerged from data on patient/caregiver perspectives: the effects of language and cultural barriers and the effects of limited resources in services. Major facilitators were: cultural awareness amongst practitioners, cultural awareness in services, and explanations of health care systems.

Comparing barriers and facilitators in pediatric services with adult services

There was much overlap in the barriers and facilitators reported by both adult and pediatric services, however, there were a few notable differences. Barriers listed in articles discussing pediatric care were reportedly due to the influence of cultural differences. Specifically, cultural differences in child rearing (45) and play (39) presented challenges to intervention practices. Differences in the understanding of disability were also seen to impact service delivery. Practitioners reported how perceptions of disabilities were difficult to manage as these views sometimes extended to expectations of how it can be fixed as opposed to managed (12, 45).

Differences in facilitators for pediatric services included cultural awareness in services. Specifically, the call for hospitals to collect information on cultural backgrounds upon registration (12) was unique to a pediatric study and was not seen in adult services. In addition, explanations of health care systems were identified as a facilitator unique to pediatric services (12, 39, 49). Knowledge of these barriers and facilitators may help rehabilitation practitioners better tailor care when working with multicultural families of children with disabilities.

Comparing patient/caregiver perspectives with practitioner perspectives

Five studies investigated patient/caregivers perspectives regarding service needs and experiences (note: the Nelson articles (43, 49) stemmed from one study and were therefore counted once here). Sample sizes in these studies were smaller in comparison to practitioner participants. This highlights a need for more research on minority patient/caregiver perspectives. Indeed, research exploring dual perspectives of both practitioners and patients/caregivers could be compared, thereby providing a rich source of information which could be used to inform practice guidelines.

The majority of studies on practitioners investigated their perspectives and experiences with service delivery to multicultural populations. Two studies focused specifically on therapy outcome disparities and applicability of a Western therapy framework in a foreign country (47, 57). Interestingly, there were more remarks about barriers than facilitators in patient/caregiver perspectives compared to practitioner perspectives. This finding suggests a need to investigate feasible solutions to known barriers when working with a diverse population.

A comparison of barriers and facilitators revealed similarities between patients/caregivers' and practitioners perspectives. Both practitioners and patients/caregivers experienced service limitations stemming from language barriers and a lack of resources. Facilitators suggested by both practitioners and patients/caregivers included having practitioners who possess cultural awareness and offer explanations of health care systems, as well as having services that incorporate cultural awareness into practice protocols.

Comparing results across disciplines

In examining results across disciplines, there appeared to be strong consensus regarding barriers as reported by practitioners. All rehabilitation fields with the exception of audiology described barriers according to the three themes presented here. The study in audiology, however, mainly investigated disparities in speech and language therapy outcomes and as such, it is difficult to know what the state of barriers are in this field.

Differences across disciplines were more noticeable in facilitators as reported by practitioners. The theme of increasing cultural awareness was discussed extensively in occupational therapy studies. It also emerged in one speech language pathology study, although it did not appear in the remaining rehabilitation disciplines with the exception of one physiotherapy study that reported on patient/caregiver perspectives. Only studies in occupational and physiotherapy described a need for explanations of healthcare systems. This theme was however discussed in a speech-language pathology study on patient/caregiver perspectives. The need for cultural awareness was discussed in every discipline with the exception of patient/caregiver perspectives in audiology.

Limitations

Our review was not without limitations. First, the lack of research in audiology resulted in exploring disciplines beyond the original focus of this paper. Second, the search strategy was restricted to English articles. As such, perspectives are not globally representative. Third, screening articles beyond the search strategy was limited to scanning bibliographies of eligible studies due to time constraints. As a result, there is a possibility that articles were missed. Nonetheless, considerations for how to engage in culturally competent rehabilitation services were provided, along with suggestions for how to overcome common barriers when interacting with multicultural populations.

Conclusion

This scoping review summarized barriers and facilitators to cultural competence in rehabilitation services. Insufficient studies were found to draw any conclusions with regards to audiological services. Minimal perspectives based on patient/caregiver experiences in this field underscore a research gap. Future studies should aim to explore both patient/caregiver and practitioner perspectives on service provision and reception as such data can help inform evidence-based practices when providing services to minorities.

Abbreviations

Aud = Audiology,

HCP = Health care practitioners,

PT = Physiotherapy,

PTs = Patients,

PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses,

OT= Occupational Therapy,

SLP = Speech-language pathology

Declarations

Ethics approval and consent to participate: N/A

Consent for publication: N/A

Availability of data and material: The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests

Funding: N/A

Authors' contributions: All authors have participated in the concept and design; analysis and interpretation of data; drafting or revising of the manuscript. They have approved the manuscript as submitted and are responsible for reported research

Acknowledgements: We would like to thank everyone at the Child Hearing Lab at the Children's Hospital of Eastern Ontario Research Institute for their resources and assistance with this research project.

References

1. Canada S. Ethnic diversity and immigration 2016 [May 9, 2017]. Available from: <http://www.statcan.gc.ca/pub/11-402-x/2011000/chap/imm/imm-eng.htm>.
2. Bureau UC. New Census Bureau report analyzes U.S. population projections 2015 [May 9, 2017]. Available from: <https://www.census.gov/newsroom/press-releases/2015/cb15-tps16.html>.
3. Balcazar FE, Suarez-Balcazar Y, Taylor-Ritzler T. Cultural competence: Development of a conceptual framework. *Disability and Rehabilitation*. 2009;31(14):1153-60.
4. Hasnain R, Kondratowicz DM, Borokhovski E, Nye C, Balcazar F, Portillo N, et al. Do cultural competency interventions work: A systematic review on improving rehabilitation outcomes for ethnically and linguistically diverse individuals with disabilities. *FOCUS Technical Brief*. 2011;31:1-12.
5. Rhoades E. Working with multicultural and multilingual families of young children with hearing loss. In: Madell J FC, editor. *Pediatric audiology: Diagnosis, technology, and management*. New York: Thieme Medical Publishers; 2013. p. 262-8.
6. Brassart E, Prévost C, Bétrisey C, Lemieux M, Desmarais C. Strategies developed by service providers to enhance treatment engagement by immigrant parents raising a child with a disability. *Journal of Child and Family Studies*. 2017;26:1230-44.
7. Badu E, Agyei-Baffour P, Opoku MP. Access barriers to health care among people with disabilities in the Kumasi Metropolis of Ghana. *Canadian Journal of Disability Studies*. 2016;5(2):131-51.
8. Clough J, Lee S, Chae DH. Barriers to health care among Asian immigrants in the United States: A traditional review. *Journal of Health Care for the Poor and Underserved*. 2013;24(1):384-403.
9. Jolly K, Greenfield SM, Hare R. Attendance of ethnic minority patients in cardiac rehabilitation. *Journal of Cardiopulmonary Rehabilitation and Prevention*. 2004;24(5):308-12.
10. Baker DL, Miller E, Dang MT, Yaangh C-S, Hansen RL. Developing culturally responsive approaches with Southeast Asian American families experiencing developmental disabilities. *Pediatrics*. 2010;126(Supplement 3):S146-S50.
11. Khanlou N, Haque N, Sheehan S, Jones G. “It is an issue of not knowing where to go”: Service providers’ perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*. 2015;17(6):1840-7.
12. Lindsay S, King G, Klassen AF, Esses V, Stachel M. Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*. 2012;34(23):2007-17.
13. Betancourt JR, Green AR, Carrillo JE, Owusu Ananeh-Firempong I. Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*. 2003;118:293-302.
14. King G, Lindsay S, Klassen A, Esses V, Mesterman R. Barriers to health service utilization by immigrant families raising a disabled child: Unmet needs and the role of discrimination. *Citizenship and Immigration Canada*, 2011.

15. Phillips R, Worley, L., & Rhoades, E. . Socioemotional considerations. In: Rhoades E DJ, editor. *Auditory-verbal practice: Toward a family-centered approach*. Springfield: Charles C Thomas Publisher; 2010. p. 187–223.
16. Rhoades E. Working with multicultural and multilingual families of young children. In: Madell J FC, editor. *Pediatric audiology: Diagnosis, technology, and management*. New York: Thieme Medical Publishers; 2008. p. 262-8.
17. Rhoades EA, Price F, Perigoe CB. The changing American family & ethnically diverse children with hearing loss and multiple needs. *The Volta Review*. 2004;104(4):285-305.
18. Sterzuk A. Whose English counts? Indigenous English in Saskatchewan schools. *McGill Journal of Education/Revue des sciences de l'éducation de McGill*. 2008;43(1):9-19.
19. Ball J. Supporting young indigenous children's language development in Canada: A review of research on needs and promising practices. *Canadian Modern Language Review*. 2009;66(1):19-47.
20. Eriks-Brophy A. Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language Pathology & Audiology*. 2014;38(2):152–73.
21. O'Hara M, Rowlandson, J, Canadian Association of Speech-Language Pathologists and Audiologists. *Speech, language and hearing services to First Nations, Inuit, and Metis children in Canada, with a focus on children 0 to 6 years of age 2010* [May 9, 2017]. Available from: <http://sac-oac.ca/sites/default/files/resources/Complete%20report%20-%20English.pdf>.
22. Zhang C, Bennett T. Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other Developmental Disabilities*. 2003;18(1):51-9.
23. CASLPO. *Guide for service delivery across diverse cultures 2016* [May 9, 2017]. Available from: http://www.caslpo.com/sites/default/uploads/files/GU_EN_%20Service_Delivery_Across_Diverse_Cultures.pdf.
24. Ball J, Lewis M. First Nations elders' and parents' views on supporting their children's language development. *Canadian Journal of Speech-Language Pathology and Audiology* 2014;38(2):224–37.
25. Ball J, Lewis M. Talking points: What can speech-language partners contribute to Aboriginal early childhood development. *Research Connections Canada: Supporting Children and Families*. 2005;12:21-40.
26. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*. 2005;8(1):19-32.
27. Pham MT, Rajić A, Greig JD, Sargeant JM, Papadopoulos A, McEwen SA. A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. *Research Synthesis Methods*. 2014;5(4):371-85.
28. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*. 2009;6(7):264-9.
29. Van de Mortel TF. Faking it: Social desirability response bias in self-report research. *Australian Journal of Advanced Nursing*. 2008;25(4):40-8.

30. Khangura S, Konnyu K, Cushman R, Grimshaw J, Moher D. Evidence summaries: The evolution of a rapid review approach. *Systematic Reviews*. 2012;1(1):1-9.
31. Corbin J, Strauss A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks: Sage Publications, Inc.; 2008.
32. Drolet M, Savard J, Benoît J, Arcand I, Savard S, Lagacé J, et al. Health services for linguistic minorities in a bilingual setting: Challenges for bilingual professionals. *Qualitative Health Research*. 2014;24(3):295-305.
33. Centeno JG. Issues and principles in service delivery to communicatively impaired minority bilingual adults in neurorehabilitation. *Seminars in Speech and Language*. 2009;30:139-52.
34. Dogan H, Tschudin V, Hot İ, Özkan İ. Patients' transcultural needs and carers' ethical responses. *Nursing Ethics*. 2009;16(6):683-96.
35. Dressler D, Pils P. A qualitative study on cross-cultural communication in post-accident in-patient rehabilitation of migrant and ethnic minority patients in Austria. *Disability and Rehabilitation*. 2009;31(14):1181-90.
36. Guiberson M, Atkins J. Speech-language pathologists' preparation, practices, and perspectives on serving culturally and linguistically diverse children. *Communication Disorders Quarterly*. 2012;33(3):169-80.
37. Khamisha C. Cultural diversity in Glasgow, part 1: Are we meeting the challenge? *British Journal of Occupational Therapy*. 1997;60(1):17-22.
38. Kohnert K, Kennedy MR, Glaze L, Kan PF, Carney E. Breadth and depth of diversity in Minnesota challenges to clinical competency. *American Journal of Speech-Language Pathology*. 2003;12(3):259-72.
39. Lindsay S, Tétrault S, Desmaris C, King GA, Piérart G. The cultural brokerage work of occupational therapists in providing culturally sensitive care. *Canadian Journal of Occupational Therapy*. 2014;81(2):114-23.
40. Phipps DJ. Occupational therapy practice with clients from non-English speaking backgrounds: A survey of clinicians in south-west Sydney. *Australian Occupational Therapy Journal*. 1995;42(4):151-60.
41. Roseberry-McKibbin CA, Eicholtz GE. Serving children with limited English proficiency in the schools: A national survey. *Language, Speech, and Hearing Services in Schools*. 1994;25(3):156-64.
42. Roseberry-McKibbin C, Brice A, O'Hanlon L. Serving English language learners in public school settings: A national survey. *Language, Speech, and Hearing Services in Schools*. 2005;36(1):48-61.
43. Nelson A, Allison H. Relationships: The key to effective occupational therapy practice with urban Australian Indigenous children. *Occupational Therapy International*. 2007;14(1):57-70.
44. Jaggi A, Bithell C. Relationships between physiotherapists' level of contact, cultural awareness and communication with Bangladeshi patients in two health authorities. *Physiotherapy*. 1995;81(6):330-7.
45. Williams CJ, McLeod S. Speech-language pathologists' assessment and intervention practices with multilingual children. *International Journal of Speech-Language Pathology*. 2012;14(3):292-305.

46. Kinébanian A, Stomph M. Cross-cultural occupational therapy: A critical reflection. *American Journal of Occupational Therapy*. 1992;46(8):751-7.
47. Yang S, Shek MP, Tsunaka M, Lim HB. Cultural influences on occupational therapy practice in Singapore: A pilot study. *Occupational Therapy International*. 2006;13(3):176-92.
48. Al Busaidy NSM, Borthwick A. Occupational therapy in Oman: The impact of cultural dissonance. *Occupational Therapy International*. 2012;19(3):154-64.
49. Nelson A, Allison H, Copley J. Understanding where we come from: Occupational therapy with urban Indigenous Australians. *Australian Occupational Therapy Journal*. 2007;54(3):203-14.
50. Phoon HS, Maclagan MA. A survey of Malaysian speech-language pathologists' perception of articulation and phonological assessments. *Asia Pacific Journal of Speech, Language and Hearing*. 2009;12(4):315-32.
51. Stedman A, Thomas Y. Reflecting on our effectiveness: Occupational therapy interventions with Indigenous clients. *Australian Occupational Therapy Journal*. 2011;58(1):43-9.
52. Watts E, Carlson G. Practical strategies for working with Indigenous people living in Queensland, Australia. *Occupational Therapy International*. 2002;9(4):277-93.
53. Khamisha C. Cultural diversity in Glasgow, part 2: How do we meet the challenge? *The British Journal of Occupational Therapy*. 1997;60(2):73-6.
54. Maul C. Identifying culturally competent clinical skills in speech-language pathologists in the central valley of California: University of California; 2010.
55. Munoz JP. Culturally responsive caring in occupational therapy: A grounded theory: University of Pittsburgh; 2002.
56. Nelson A, Gray M, Jensen H, Thomas Y, McIntosh K, Oke L, et al. Closing the gap: Supporting occupational therapists to partner effectively with First Australians. *Australian Occupational Therapy Journal*. 2011;58(1):17-24.
57. Kirkham E, Sacks C, Barody F, Siddique J, Nevins ME, Woolley A, et al. Health disparities in pediatric cochlear implantation: An audiology perspective. *Ear and Hearing*. 2009;30(5):515-25.
58. Lee T, Sullivan G, Lansbury G. Physiotherapists' communication strategies with clients from cultural diverse backgrounds. *Advances in Physiotherapy*. 2006;8(4):168-74.
59. Yeowell G. What are the perceived needs of Pakistani women in the North west of England in relation to physiotherapy, and to what extent do they feel their needs are being met? *Physiotherapy*. 2010;96(3):257-63.
60. Kummerer SE, Lopez-Reyna NA. The role of Mexican immigrant mothers' beliefs on parental involvement in speech-language therapy. *Communication Disorders Quarterly*. 2006;27(2):83-94.
61. Kirsh B, Trentham B, Cole S. Diversity in occupational therapy: Experiences of consumers who identify themselves as minority group members. *Australian Occupational Therapy Journal*. 2006;53(4):302-13.
62. Kramer-Roy D. Supporting ethnic minority families with disabled children: Learning from Pakistani families. *British Journal of Occupational Therapy*. 2012;75(10):442-8.

**Barriers and facilitators to cultural competence in early hearing loss services:
A qualitative analysis**

Viviane Grandpierre, Elizabeth Fitzpatrick, Roanne Thomas, Oreen Mendonca, Lindsey Sikora, Beth Potter

Submitted to Canadian Journal of Speech Language Pathology and Audiology;
Accepted with minor revisions, 2018

Chapter 3: Practitioner interviews

Background

Increasing diversity in Canada has direct implications for pediatric hearing loss services. The latest census projects that, by 2036, almost half of the population of Canada will be immigrants or children of immigrants (Statistics Canada, 2017). In such a multicultural population, cultural differences can create challenges for health care systems, which are typically tailored to meet the needs of the majority population. Culture can influence values, beliefs, and health-related practices, and can impact all aspects of health care service delivery (Betancourt, Green, Carrillo, Owusu, & Ananeh-Firempong, 2003).

Consideration of culture is of particular importance in pediatric hearing loss services as culture can influence how families respond to services at various stages in the process, from identification to intervention. For example, hearing loss is stigmatized in some cultures and can be seen as the fault of the parents and a source of shame (Jackson, Traub, & Turnbull, 2008). Having a child with permanent hearing loss can even result in family relationships being severed (Jackson et al., 2008; Yucel, Derim, & Celik, 2008). In some situations, parents may refuse interventions in an attempt to conceal their child's hearing loss. In addition, concerns have been raised regarding the additional stress multicultural families may experience when their cultural norms differ from those of practitioners and the interventions they use (Phillips, Worley, & Rhoades, 2010). Thus, practitioners who provide early hearing detection and intervention (EHDI) services should be aware of cultural differences and practice culturally competent care.

In their literature review, Betancourt et al. (2003) define cultural competence in health care as:

... 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. (p. 293)

Efforts to improve cultural competence in EHDI should be informed by evidence on how cultural differences can impact services; however, our scoping review identified limited empirical research in this area (Grandpierre et al., 2018). In addition, available literature is dated, anecdotal, and possibly reflects stereotypes (Ball & Lewis, 2014; Eriks-Brophy, 2014). Although there is extensive research on cultural competence in other rehabilitation fields which detail the perspectives of practitioners and patients of minority culture backgrounds (see Al Busaidy & Borthwick, 2012; Centeno, 2009; Dogan, Hot, & Özkan, 2009; Dressler & Pils, 2009; Drolet et al., 2014; King, Desmarais, Lindsay, Piérart, & Tétreault, 2015; Lindsay, King, Klassen, Esses, & Stachel, 2012; Yang, Shek, Tsunaka, & Lim, 2006), one source of untapped information is the viewpoint of practitioners in pediatric hearing loss with respect to their experiences providing services to cultural minorities. Therefore, the goal of this study is to contribute empirical data to address this research gap.

Context

Most provinces in Canada have implemented Newborn Hearing Screening services. In Ontario, the main context of the study, each infant is screened at birth for hearing loss. If a referral is required, infants will then receive diagnostic assessments. The confirmation of a hearing loss diagnosis will lead to intervention discussions with audiologists regarding technological options as well as language therapy options. Language therapy options typically include spoken language approaches (oral), visual approaches (sign), and total communication approaches (oral + sign). In the context of this study, auditory verbal therapists who participated reported to prescribe to spoken language approaches. All services are publicly funded, excluding the purchase of hearing technology.

Objectives

As part of a larger program of work that investigates cultural influences on EHDI from the perspectives of both practitioners and families of minority culture backgrounds, the objective of this study was to explore the experiences of practitioners in the provision of services to families of minority culture backgrounds.

Methods

Participants

Practitioners in the field of childhood hearing loss (e.g., audiologists, listening and spoken language therapists, itinerant teachers of the deaf and hard of hearing, speech-language pathologists, etc.) were eligible to participate if they provided: 1) early hearing detection and intervention services to children with permanent hearing loss; and 2) services to families of minority culture backgrounds (e.g., not the dominant culture in Canada: English and/or French Canadian).

Health care practitioners offering services to children with permanent hearing loss were recruited from the Children's Hospital of Eastern Ontario (CHEO), a tertiary care hospital located in Ottawa. The Professional Practice Leader of the Audiology in CHEO Clinic was approached regarding recruiting her team for the study. Upon approval, all team members were approached for recruitment. Recruitment also occurred at a local conference in Ottawa (Dual-Language Learning conference, 2017) which was open to practitioners in the fields of audiology and speech language pathology. During scheduled breaks, practitioners were approached regarding interest in participation.

Recruitment and data collection was informed by Thorne, Kirkham, & MacDonald-Emes's (1997) Interpretive Description (ID) method. ID draws strongly on features of grounded theory, ethnography, and naturalistic inquiry and attempts to gather a meaningful account of a clinical phenomenon of interest and make it accessible to clinical understanding. This can be achieved by drawing on data collected from small samples through methods such as interviews. A convenience sample of 12-20 participants was therefore anticipated to be a suitable number for obtaining relevant information. However, when 26 practitioners responded to the invitation to participate, the study protocol was reviewed for feasibility. As this topic is underexplored, all 26 respondents were elected to interview be interviewed, however only 19 participated. Of those, 14 practitioners were recruited at CHEO and five from a local conference; the latter group practiced at centers (e.g. public and private health care facilities) in various cities in two

Canadian provinces (Ontario and Nova Scotia). One participant provided written feedback to the interview questions but did not participate in an oral interview. Table 1 provides a description of participant characteristics.

Table 1
Participant Characteristics

	All Practitioners
Number (%)	19 (100)
Sex, n (%)	
Male	1 (5.2)
Female	18 (94.7)
Languages*, n (%)	
English	19 (100)
French	16 (84.2)
American Sign Language	2 (10.5)
Arabic	1 (5.2)
Spanish	1 (5.2)
Cultural backgrounds*, n (%)	
Francophone (Canada, France)	7 (36.8)
Canadian	7 (36.8)
British	3 (15.7)
Italian	2 (10.5)
Scottish	1 (5.2)
Australian	1 (5.2)
Welsh	1 (5.2)
German	1 (5.2)
Irish	1 (5.2)
Arab	1 (5.2)
Spain	1 (5.2)
Position, n (%)	
Audiologist	7 (36.8)
Speech language pathologist	3 (15.7)
Auditory verbal therapist	4 (21.1)
Auditory verbal therapist and DHH**	1 (5.2)
Auditory verbal educator and DHH**	1 (5.2)
Itinerant teacher of the deaf	1 (5.2)
Case assistant worker	1 (5.2)
Hearing resource teacher	1 (5.2)
Years of experience, median, (range)	17 (3-40)
Received cultural sensitivity education, n(%)	12 (63.1)

*Many practitioners were multilingual and multicultural

**DHH = itinerant teacher of the deaf

To gain multiple perspectives from practitioners in different roles within pediatric audiology, a diverse sample of various professions was selected. Practitioners were audiologists, auditory-verbal therapists, an auditory-verbal educator, itinerant teachers of

the deaf and hard of hearing, a hearing resource teacher, a case assistant worker in audiology, and speech language pathologists who work in audiology clinics. Experience in these fields ranged from 3 to 40 years.

The majority of the practitioners had reported receiving prior education on cultural sensitivity in the form of training and/or lectures, varying from one-hour lectures to a series of workshops. The majority were French and/or English speakers with Canadian and/or Francophone (Canada, France) cultural backgrounds. Practitioners serviced a large variety of cultures, mainly consisting of Canadian Aboriginal, Chinese, Arabic, Somalian, Persian, and North African.

The purpose of the interviews was to explore practitioners' experiences providing services to families of minority culture backgrounds. Three themes emerged from the interview data: barriers to service provision, facilitators to service provision characteristics of a culturally competent practitioner, and characteristics of a culturally competent practitioner. A note to readers: the majority of practitioners (74%) commented on the difficulty of attributing their patients' families' responses to cultural differences as opposed to typical stress responses. The results therefore represent when practitioners felt confident that their experiences with families reflected cultural differences. This study received ethical clearance from the research ethics boards of Children's Hospital of Eastern Ontario Research Institute and the University of Ottawa.

Procedure

Data were collected through individual interviews, conducted in English. Prior to the interviews, participants were asked to complete a brief form to record demographics and job-related information. This included data such as profession title, practice setting, years of experience, and percentage of time working with patients of minority culture backgrounds. A semi-structured format was used to guide the interview from a pre-determined list of questions developed by the lead researcher (see appendix). The interview protocol was informed by findings in our scoping review (Grandpierre et al., 2018). The interview consisted of open-ended questions on experiences with service provision to families of minority culture backgrounds. Prompts to seek new leads or request clarifications were incorporated into the interview protocol. Seven interviews were conducted over the phone due to distance (e.g. five were located outside Ottawa; two were not available to be in Ottawa at the time of the interview). Live interviews took place at practitioners' offices in CHEO. Field notes were taken by the researcher (VG) during interviews. All interviews were conducted by the researcher (VG).

Analysis

Interviews were audio recorded and transcribed verbatim. In addition, field notes were recorded and consulted during analysis. All data were entered into NVivo (version 10.1.2), a qualitative software program used for coding and qualitative research analysis. Demographic information was entered into Excel.

Analysis of transcripts occurred concurrently with data collection (DiCicco-Bloom & Crabtree 2006). In the ID method, inductive data analysis techniques are often used to highlight thematic patterns and commonalities to help characterize the topic of interest (Thorne et al., 2004). Transcripts were analyzed using a coding process known as the constant comparative method based on Strauss and Corbin's (1990) open, axial, and

selective coding methods, an approach that fits well within the ID methodology (Thorne et al., 2004). Open coding involves reviewing and assigning labels to each passage. Axial coding involves a comparison of characteristics for each label between interviews. In selective coding, concepts become further refined by examining similarities of labels and collapsing these categories into major themes.

Abiding by qualitative research practices, the concept of trustworthiness (Krefting, 1991) was used to ensure quality and transparency in this study. Components of trustworthiness are credibility, transferability, dependability, and confirmability. Credibility is evidenced by data collected from various participants in different fields within audiology. Transferability was demonstrated by the collection of in-depth data with detailed descriptions of the setting and the participants. Dependability was achieved with a clear description of the research process. In addition, peer debriefing with the coauthors occurred throughout each stage of the study. Finally, confirmability was evidenced by the use of detailed field notes to help ensure neutrality of the data. Consulting coauthors with expertise in qualitative research, health sciences, and medical research regarding the decision-making on the research process also contributed to achieving confirmability.

Results

Barriers to service provision

Practitioners described various barriers to care. Barriers were encountered throughout the care process, such as during audiological testing, diagnosis, amplification, language assessments, and interventions.

Language barriers

Language barriers affected every stage of treatment and were noted to be problematic even when professional interpreters or someone who could translate (e.g., colleagues or extended family members) were available.

Language barriers can be the biggest impediment for the family I think. In terms of making sure ...let's say, often... we have one parent who speaks English and... they are acting as the interpreter for their husband which really is not ideal.
(Participant 22)

I think the hardest thing when working with families is when French or English is not their first language and they are working with an interpreter. What happens is that when an interpreter is working with you, you don't know how much filtering is going on because you don't know that other language, so when you are working with a family to get informed consent for something like a CI [cochlear implant] surgery you really want to make sure that parent really understands and certainly we've had families with English as a second language where you're hoping that the parent is saying that this is what they want and you are trying to make sure they have all the tools needed to make the right choice, with that interpreter.
(Participant 7)

Language barriers also occurred in service provision when parents' interaction with their children at home was minimal. The level of parent-child interaction varies with culture and can affect services (e.g., spoken language development) that depend on family engagement for optimal outcomes. For example, auditory verbal therapists typically promote ongoing verbal communication in families to support language development, however, if cultures dictate minimal parent-child interaction, this can

So how do the parents interact with the kids because...they may not talk to their child as much or interact in the same ways we might expect so I think there has to be some sensitivity around what our expectations are for interacting with their kids...there's not only the nonverbal but the verbal... In terms of nonverbal, I've worked with – it was actually the First Nations population in Canada where eye contact was very different. So they don't give direct eye contact when they communicate. So being aware of that was really important as a clinician.
(Participant 10)

Cultural challenges during audiological testing

In addition to language barriers, challenges to audiological testing were noted when caregivers were not comfortable receiving services from a practitioner due to gender. Practitioners described instances where families were not receptive to the information provided. Sometimes male practitioners were requested to relay the information. Other situations were more delicate, such as requesting the removal of children's religious attire during audiological testing.

When a child is coming in for a hearing assessment and we have a 30 minute time and from a clinical perspective it would be very lightly touched on if a child came in and for example, they wear a hijab and you had to ask them to remove it and there was a male audiologist at the time, he would be asked to change [to leave] at that time because that would be appropriate. (Participant 7)

Cultural challenges during discussions of hearing loss diagnosis

Almost all practitioners commented on surprising reactions when diagnoses were communicated, which were attributed to cultural differences. They discussed how, in some cultures, disability is stigmatized and seen as something shameful. This perception sometimes led to caregivers denying the hearing loss or refusing amplification for their children.

...when I worked in Vancouver, I worked with many Asian families, specifically, Chinese families. And it was seen within ...at least the family group of one of the patients that I worked with...the family was embarrassed about the diagnosis and so it was very challenging to get them to accept that the hearing loss was in fact a permanent thing and to get them to accept that if they wanted a listening and spoken language mainstream-schooling outcome, the way to achieve that was through regular hearing aid use and therapy. One family in particular, they actually sought out alternative Chinese medicine to try and cure the hearing loss.
(Participant 10)

I have experienced two Lebanese families where the parent made it very clear, that when they went back to Lebanon to visit, that they took the hearing aids off. And the mother said ‘I don’t even wear my glasses when I go back to Lebanon. I wear glasses now because I need them - but if I wear glasses as a young woman, I never would have found a husband’. (Participant 12)

Cultural challenges during administration of standardized language assessments

Standardized language assessments also presented challenges for practitioners. Specifically, the assessment content was not always reflective of everyday environments. Most of the practitioners commented on how these assessments were normed on majority populations and that culturally inappropriate items affected scoring.

...kids from Nunavut who don’t know [farm] animals. They don’t know about vehicles, trains and stuff like that. We use an Inuktitut screening tool with them because they don’t have knowledge of toys, a lot of the pictures are just absolutely meaningless to them. (Participant 11)

...having the proper assessment tools, [it is] very important. For example, you cannot use – immigrant families coming to Canada, [they have never seen] the Christmas tree and they never see snow, and they don’t have any [idea of] what the snow looks like, they [have] never seen it in their country, so it would be like ‘what’...It’s not appropriate to talk about snow without them experiencing it... I cannot assess them with snow. Like I’m talking to a Canadian child about the desert and camel, they [have] never seen a camel and I cannot mention a camel in my first assessment because they don’t have any experience with the camel, what it looks like, what sounds it makes, you know? So this knowledge is very important. (Participant 15)

Cultural challenges during language interventions

Many practitioners commented on barriers encountered when providing interventions to families of minority culture backgrounds. A variety of reasons were indicated, such as language barriers, limited culturally sensitive materials, differences in expectations between practitioner and parents regarding who will do the therapy, and differences in language output expectations between practitioner and parents.

I have to say, some of our books are white-centric, but I have newer books that I’ve bought for the little ones that have more different racial groups represented. (Participant 13)

In some families...a few Somali families – no toys at home. And so we had to either provide some toys to show the mom what we wanted to do with them and modify our expectations in terms of sort of seeing what the mom did do with the kids and maybe building routines around or building language into daily routines and you know, dressing, and having the child help you know with food, meal time and that kind of thing. Um so ...I guess the cultural expectation of what a parent

does in terms of how much do they actually play with their child or talk to their child – that would come into play. (Participant 12)

Barriers also occurred in service provision when parents' interaction with their children at home was minimal. The level of parent-child interaction varies with culture and can affect services (e.g., spoken language development) that depend on family engagement for optimal outcomes.

So how do the parents interact with the kids because...they may not talk to their child as much or interact in the same ways we might expect so I think there has to be some sensitivity around what our expectations are for interacting with their kids...there's not only the nonverbal but the verbal... In terms of nonverbal, I've worked with – it was actually the First Nations population in Canada where eye contact was very different. So they don't give direct eye contact when they communicate. So being aware of that was really important as a clinician. (Participant 10)

Facilitators to service provision

Although many challenges were noted, practitioners proposed a number of strategies to overcome barriers. Facilitators included communication strategies, learning about cultural differences, and strategies throughout the process of intervention.

Communication strategies

Communication strategies included ensuring comprehension by asking caregivers to repeat what was said. Using simple language, learning key phrases in the caregivers' language, speaking slowly, and using visual aids (e.g., writing key words or showing pictures or videos) were also seen as useful.

When we ask people if they understand what we are saying, and we know they have a different first language, initially when people nodded I assumed they were getting along ok. I learned over time that this is good in counselling but this is particularly important when there is a language barrier is that you need to get them to repeat back to you what they think you've said. Sometimes you see that there are huge gaps. (Participant 5)

I find written communication as a backup, even if I'm there in person, so I always have 'what we do', 'what we did' in writing so that they can go [to] somebody and say what exactly does this mean or, those kinds of things. So I would certainly use simpler speech, vocabulary, or I would show them what I'm talking about through either a picture or I would Google it or I would show them physically something in their home. I would say in English, you know, what do you refer this for example a sofa or couch, what would you call that? (Participant 19)

Strategies to learn about cultures

Many practitioners stated that learning about cultural practices was an important facilitator to culturally competent service provision. Strategies to learn about cultural differences included attending lectures, workshops, or training and asking families questions about their daily routine, religious holidays, cultural traditions, and practices. Some stated that asking families about how disability was perceived provided helpful feedback on how to approach interventions. In addition, home visits were considered invaluable for learning about differences to better tailor care to meet the needs of the family.

If they've come from a country where this is viewed as a stigma then the first question to ask is how is hearing loss viewed in your culture... I try to get the info from the family, how do you feel about this. Then I can address their concerns, will he struggle wearing the hearing aids, do they show?... If they are obviously immigrants or refugees then I will ask them about their country. (Participant 5)

I think doing a home visit is a really good way of [taking] a peek into the culture. I think home visits are generally a good idea, when you are first meeting a family. But I think particularly when you have a family from a different culture, you can learn a lot when you go to their home. So being respectful of their traditions, doing a home visit to find out more about their traditions. And also, I think home visit puts them at ease so they can talk a little bit more about themselves. (Participant 9)

Strategies during intervention

Strategies for different stages of the intervention process were proposed. These included explaining the health care system and modifying standardized language assessments and interventions. Describing the health care system involved not only explaining the services the practitioner provides, but also what is generally available to families from the health care system (e.g., coverage funding for hearing aids). Health care models vary across cultures, and immigrants may not be aware of what they can access.

It's really a learning experience to go and understand that here [in Canada] you can actually push and that you have rights to ask for more different things. So when the medical team is in front of you, they have no idea that you would not go and look for other options... So knowing that some people may not go look, it's important that they will be informed of every kind of choice they would have. And I think this is part of what is lacking in terms of being sensitive to the culture. Because here [in Canada], [if] they have little information, they [can] go look and they connect with other people. This is definitely not what would be done in some other cultures. If I look at an African family I have on my caseload - the kid is falling through the crack. The parents didn't ask [about what they have access to] 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 [an] immigrant, they come and trust what is happening and then if the kid falls through the crack, they won't see it. (Participant 18)

When practitioners encounter challenges with standardized assessments, they use various strategies to overcome these challenges. This includes adapting standardized assessments by administering a subset from a battery of tests, informing caregivers and recording that the score does not present an accurate assessment of competencies, or using non-standardized checklists or vocabulary lists to gain insight into language abilities.

I will have them fill out like a 50-word beginning words that we have. And I'll have them fill out their understanding in their own language as well as English so that I have an idea of how the child is doing overall, you know, is the child learning a language – period? And then, you know kind of combining the two to gives me an idea of how well the child is doing. (Participant 9)

Challenges in interventions were overcome by making an effort to use culturally sensitive materials and by tailoring the content to reflect family home environments. This included making decisions on the content of the therapy and even on the décor of the office.

You know I do a little garden with pudding and cookie crumbs and then those gummy worms when we're talking about gardens...this is a fun kind of activity of mine and again I would check with the families, tell them what I'd like to do, this has gelatine in it, are you okay with that, if they aren't, I'll find something else to do. (Participant 19)

I'm sensitive to using themes that are appropriate to the family. When I decorate the room I try to make sure that I...you know, I want to observe North American cultural preferences but I don't want to make them such that they are uncomfortable for something else... Even asking parents, oh you know I understand Eid is coming, could you bring in some stuff and we can share it together. (Participant 13)

Characteristics of a culturally competent practitioner

Practitioners described various characteristics of a culturally competent practitioner, with Table 2 listing those described by all practitioners. The most common characteristics included being respectful of culture and language, having knowledge of cultural practices, and self-reflection.

Table 2

Characteristics of a culturally sensitive practitioner

- | |
|--|
| <ul style="list-style-type: none">• Respects culture, languages• Knowledgeable of cultural practices• Reflects on own cultural identity, values, prejudices, biases, and assumptions• Are open-minded• Modifies sessions (e.g. appointment times, content) when needed• Explains sessions to families in advance to determine if content is culturally appropriate• Engages in cross-cultural encounters (e.g. multicultural events) |
|--|

Many practitioners commented on the importance of being respectful of cultural practices. Respect involves acknowledging and accepting different cultural practices, thereby creating a safe space for families to receive services.

I think being respectful of cultural differences and value differences. I have a couple of adolescent Muslim girls who wear a hijab, respectful of practices, closing the door to the room when asking them to remove their hijab to work with the device. And I also realised that because that is their dress, garb, when I'm doing assessments in terms of hearing, I always do my assessments with them wearing their hijab because that's their typical wearing option. (Participant 7)

Well I think respect for the other cultures you're dealing with, as with any family, respect and trust have to be the basis of the relationship because we are asking them to buy in to the fact that their child with hearing aids or cochlear implants is going to learn to speak, and that is a leap of faith for most people, and if you've come from a culture or country where people who have hearing loss don't learn to speak, then it's even more of a leap. And so for them to believe you and to do what you are asking them to do at home, there has to be a foundation of trust in the therapist and so I try as hard as I can to create that trust and I think that begins with respecting their traditions and being open to whatever they want to tell me. (Participant 9)

Being respectful of the home language was also considered vital to culturally sensitive care. Practitioners noted on several occasions that they should be aware of a family's preferences to preserve their home language. Advocating for this approach was seen to help establish trust.

Also, respecting their language in terms of teaching it to the child. So most times, parents want their children to learn their own language. Because there's grandparents involved – because the parents themselves are very attached to their language. So they go ahead and do that and we do the therapy in English and they will translate to the child's language. I think it works well when there can be someone who speaks English and then another speaks the native home language so that the child really has a bilingual kind of setting. So to be respectful of their language. I mean, in our situation, because it's a language-based program – that's HUGE! (Participant 9)

So just to respect their culture and their language, because I don't want them to lose that as well, right? Cus I know that when I speak to parents they'll be like, oh we want them to...even if they don't understand fully the language they speak at home even if they are somewhat exposed to it. (Participant 17)

Many practitioners also noted the importance of having some knowledge of their patient's cultural background prior to proceeding with service delivery in order to be sensitive to their needs. Strategies for learning about cultural practices include asking

families about their day-to-day routines or describing the content of the therapy session in advance to see if everything is appropriate.

Culturally sensitive [care] would mean that you would want to have some knowledge of what the cultural practices are for that particular family. You would want to know their religious observances... It would be being able to incorporate those things into the therapy, asking families you know 'I'm doing it this way, how would you do that at home, what would be more appropriate as something I could help you with at home'. (Participant 13)

I might also discuss with the families – well we do this anyways but – what are their routines at home, what types of toys they have and that's a big one because depending on the culture, they may or may not have the toys you expect them to have, so that the variety or the group of toys they may have could look very different ...the types of songs they might sing or the types of play and routines they have could look very different too...so just not making assumptions around the fact that they are playing at home with the games and songs that I would expect to have in my house. (Participant 10)

Nearly half of the practitioners commented on the importance of reflecting on personal cultural identity, values, prejudices, biases, and assumptions. Performing self-reflection was believed to help increase relationship-building opportunities and also establish trust.

If you're entering into the relationship without your own cultural biases... you're working with a family and you're accepting them...you're willing to listen to what their expectations are, what their needs are what they want to get out of the services that you're providing. What they see as their priorities. Not your priorities. It's really very key to that work. (Participant 16)

I always have to be mindful that my own culture ...that's a bit different from the culture here...I have to be mindful that what I think could be pretty normal for me [but] may not be for everybody because we don't have exactly the same background.... (Participant 18)

Descriptions of other characteristics of culturally competent practitioners included being open-minded, flexible with appointment scheduling, modifying sessions when needed (e.g., appointment times, content), explaining sessions to families in advance to determine if content is culturally appropriate, and engaging in multicultural events (e.g. cultural festivities) to increase experiences with cross-cultural encounters.

Discussion

The aim of this study was to explore the experiences of practitioners with providing services to families of minority culture backgrounds. Practitioners encountered barriers throughout the process of service delivery with language barriers affecting every stage. Gender issues, lack of culturally sensitive materials, and Westernized language therapy

programs occasionally presented challenges in service provision to families of minority culture backgrounds. Disabilities are also stigmatized in some cultures, which can present additional challenges to care provision. Differences in child-rearing practices can also present challenges for family-centered services.

Research in the field of rehabilitation services has described barriers to providing care to families of minority culture backgrounds similar to what we found in the field of pediatric hearing loss. For example, language barriers have been noted to impact rehabilitation service delivery (Centeno, 2009; Dogan et al., 2009; Drolet et al., 2014; King et al., 2015) and male patients from some cultures sometimes explicitly request male practitioners (Al Busaidy & Borthwick, 2012; Dressler & Pils, 2009). Finally, cultural differences in language (verbal and nonverbal), play, independence, family structure, and perception of disability can also affect service provision (Al Busaidy & Borthwick, 2012; Cochrane, Brown, Siyambalapitiya, & Plant, 2016; Dressler & Pils, 2009; Phipps, 1995; Pidgeon, 2015; Lindsay et al., 2012; Yang et al., 2006). Practitioners were able to mitigate these barriers with communication strategies, learning about cultural differences, explaining the health care system, and tailoring standardized assessments and therapy-based interventions when required.

Facilitators and strategies described by the participants in this study align with an international consensus paper on best practices in EHDI (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). This document states practitioners should be supportive of differing cultural beliefs and practices. Additionally, the document recommends practitioners to be reflective of personal discomforts and cultural biases as well as knowledgeable regarding how differing cultural practices can impact care.

Similarly, studies in rehabilitation have identified facilitators to culturally competent care that are consistent with our study. Practitioners seeking to learn about different cultural practices felt that asking patients about their values, beliefs, and daily routines helped to appropriately tailor care (Kinébanian & Stomph, 1992; Lindsay et al., 2012; Maul, 2010; Pidgeon, 2015; Stedman & Thomas, 2011). In addition, the literature supports modifying care to ensure cultural competence practices such as informal assessments, translated materials, and considerations for material selection and culturally meaningful treatments (Cochrane et al., 2016; Pidgeon, 2015; Rhoades & Duncan, 2013; Williams & McLeod, 2012).

This study also uncovered key characteristics of a culturally competent practitioner. Key characteristics include practitioners being respectful, knowledgeable of cultures, reflective, open-minded, and tailoring care when needed. These characteristics align with the values of family-centered care, which advocates for partnerships between practitioners and diverse families (Rhoades, 2016).

Although culturally competent practices can help to improve patient experiences and outcomes, little information has been available about the barriers and facilitators that practitioners working in pediatric hearing loss have encountered in providing services to families of minority culture backgrounds. To the best of our knowledge, this is the first study to contribute to research on culturally competent care in EHDI services. Our study is not without limitations. It is possible that some examples described in this article may not accurately portray the values, intents, and practices of an entire culture. However, the goal of the paper was not to describe the culture but instead to portray how cultural differences can affect treatment. Other limitations include the study location; Canadian

health care is publicly funded and therefore cannot represent global views. In addition, the setting of this study uses one particular service model, whereas other locations use different models. These limitations provide directions for future studies investigating cultural competence from the perspective of practitioners in pediatric hearing loss.

Increasing diversity can create challenges for EHDI services which are typically tailored to meet the needs of the majority population. Our study provides insight into barriers practitioners may encounter when providing services to families of minority culture backgrounds. Additionally, the findings in this study also offer strategies that can be used to help overcome cultural challenges experienced by practitioners in hearing loss services. Future research in different provinces utilizing various service models across Canada may also help provide sufficient data to inform a knowledge-to-action intervention seeking to improve and maintain culturally competent practices in EHDI services.

Abbreviations

EHDI: Early Hearing Detection and Intervention

References

- Al Busaidy, N. S. M., Borthwick, A. (2012). Occupational therapy in Oman: The impact of cultural dissonance. *Occupational Therapy International*, 19(3), 154-164.
- Ball, J., Lewis, M. (2014). First Nations elders' and parents' views on supporting their children's language development. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 224-237.
- Betancourt, J. R., Green, A.R., Carrillo, J.E., Owusu Ananeh-Firempong, I. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118, 292-303.
- Cochrane, F. C., Brown, L., Siyambalapitiya, S., & Plant, C. (2016). "... Trial and error...": Speech-language pathologists' perspectives of working with Indigenous Australian adults with acquired communication disorders. *International Journal of Speech-Language Pathology*, 18(5), 420-431.
doi:10.3109/17549507.2015.1101157
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321. doi: 10.1111/j.1365-2929.2006.02418.x
- Dogan H, T. V., Hot I, Özkan I. (2009). Patients' transcultural needs and carers' ethical responses. *Nursing Ethics*, 16, 683-696. doi:10.1177/0969733009341396
- Dressler, D., & Pils, P. (2009). A qualitative study on cross-cultural communication in post-accident in-patient rehabilitation of migrant and ethnic minority patients in Austria. *Disability and Rehabilitation*, 31(14), 1181-1190.
doi:10.1080/09638280902773786
- Drolet, M., Savard, J., Benoît, J., Arcand, I., Savard, S., Lagacé, J., Lauzon, S., Dubouloz, C.J. (2014). Health services for linguistic minorities in a bilingual setting challenges for bilingual professionals. *Qualitative Health Research*, 24, 295-305. doi:10.1177/1049732314523503
- Eriks-Brophy, A. (2014). Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language Pathology & Audiology*, 38(2), 152-173.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*, 18(1), 23. doi: 10.1186/s12913-017-2811-1
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82-98. doi: 10.1177/1525740108314865
- Kinébanian, A., & Stomph, M. (1992). Cross-cultural occupational therapy: A critical reflection. *American Journal of Occupational Therapy*, 46(8), 751-757.
doi:10.5014/ajot.46.8.751
- King, G., Desmarais, C., Lindsay, S., Piérart, G., & Tétréault, S. (2015). The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. *Disability and Rehabilitation*, 37(15), 1372-1381. doi: 10.3109/09638288.2014.972580
- Krefting, L. (1991). Rigour in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45, 214-222. doi: 10.5014/ajot.45.3.214

- Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation, 34*(23), 2007-2017. doi:10.3109/09638288.2012.667192
- Maul, C. (2010). *Identifying culturally competent clinical skills in speech-language pathologists in the central valley of California*. University of California.
- Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education, 18*(4), 429-445. doi: 10.1093/deafed/ent034.
- Phillips, R., Worley, L., & Rhoades, E. (2010). Socioemotional considerations. In E. Rhoades, Duncan, J. (Ed.), *Auditory-verbal practice: Toward a family-centered approach* (pp. 187–223). Springfield: Charles C Thomas Publisher.
- Pidgeon, F. (2015). Occupational therapy: what does this look like practised in very remote Indigenous areas. *Rural and Remote Health, 15*(3002).
- Rhoades, E., Duncan, J. (2013). Working with multicultural and multilingual families of young children with hearing loss. In J. F. C. Madell (Ed.), *Pediatric audiology: Diagnosis, technology, and management*. (pp. 262-268). New York: Thieme Medical Publishers.
- Rhoades, E. (201). Toward Family-Centered Practice. In E. Rhoades, Duncan, J. (Ed.), *Auditory-verbal practice: Family-Centered Early Intervention*. (pp. 250-285). Springfield: Charles C Thomas Publisher.
- Statistics Canada. (2017). Study: A look at immigration, ethnocultural diversity and languages in Canada up to 2036, 2011 to 2036. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/170125/dq170125b-eng.htm>.
- Stedman, A., & Thomas, Y. (2011). Reflecting on our effectiveness: Occupational therapy interventions with Indigenous clients. *Australian Occupational Therapy Journal, 58*(1), 43-49. doi:10.1111/j.1440-1630.2010.00916.x
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*(2), 169-177.
- Williams, C. J., & McLeod, S. (2012). Speech-language pathologists' assessment and intervention practices with multilingual children. *International Journal of Speech-Language Pathology, 14*(3), 292-305. doi:10.3109/17549507.2011.636071
- Yang, S., Shek, M. P., Tsunaka, M., & Lim, H. B. (2006). Cultural influences on occupational therapy practice in Singapore: A pilot study. *Occupational Therapy International, 13*(3), 176-192. doi:10.1002/oti.217
- Yucel, E., Derim, D., & Celik, D. (2008). The needs of hearing impaired children's parents who attend to auditory verbal therapy-counseling program. *International Journal of Pediatric Otorhinolaryngology, 72*(7), 1097-1111. doi:10.1016/j.ijporl.2008.03.020

Chapter 4: Caregiver Interviews

Background

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, 2017a). 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, 2011; Grandpierre et al., 2018; Grandpierre et al., submitted). 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 et al., 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, behaviors, 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 caregivers' experiences with receiving early hearing loss (EHL) services for their children. This study is part of a larger program of research seeking to gain insight into barriers and facilitators to culturally competent EHL services.

Methods

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: 1) a child/ children with permanent hearing loss who received early intervention services within the past 5 years; and 2) 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, 2012), a total of 6-10 participants was considered sufficient for gaining relevant insights into a subject that has received minimal attention. The Children's Hospital of Eastern Ontario and the University of Ottawa Research Ethics Boards approved this study.

Procedure

Interpretive Description (ID) method informed the data collection in this study (Thorne, 2016). Drawing on elements of grounded theory, naturalistic inquiry, and ethnography, ID attempts to capture an account of a clinical phenomenon and make it accessible. Its foundation of qualitative inquiry is on a smaller scale in that it does not attempt to generate new theories, but instead produce a 'tentative truth claim' (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 6). 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. 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 socio-demographic questions (e.g., cultural and linguistic background, education, income, child's audiological information) as well as open-ended questions to help explore participant experiences (see Appendix E for Interview Protocol). Medical records (see Appendix K) 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 also taken during as well as immediately after the 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 transcriptions. 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. 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 ensure 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 range from several days a week, to once a week, to monthly.

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 (IQR: 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 (SD: 2.6) at the time of the interviews, and, as such, parents had over three years of experience with hearing loss.

Table 1
Child characteristics

Characteristics:	Children (<i>n</i> = 9)
Sex, <i>n</i> (%)	
Female	3 (33.3%)
Route to confirmation of hearing loss, <i>n</i> (%)	
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, <i>n</i> (%)	
Congenital	3 (33.3%)
Early onset	2 (22.2%)
Late onset	1 (11.1%)
Unknown	3 (33.3%)
Hearing loss description, <i>n</i> (%)	
Bilateral	9 (100%)
Degree of hearing loss, <i>n</i> (%)	
Moderate	3 (33.3%)
Mod-severe	2 (22.2%)
Severe	1 (11.1%)
Profound	3 (33.3%)
Amplification, <i>n</i> (%)	
Hearing aids	3 (33.3%)
Cochlear Implants	6 (66.6%)
Etiology, <i>n</i> (%)	
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: Abbreviations: IQR, interquartile range; NICU, Neonatal Intensive Care Unit; ENT, Ear, nose, and throat.

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

Table 2 provides characteristics of the caregiver participants. Three families had immigrated to Canada within the past three years; two had lived in Canada between 10-17 years, and the remaining, over 20 years. The majority 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 \$80,000 (Statistics Canada, 2017b). One family chose not disclose their income.

Table 2
Parent Characteristics

Characteristics:	Participants (<i>n</i> = 10)
Interviewee	
Mother only	8 (80%)
Father only	1 (10%)
Both parents	1 (10%)
Languages spoken at home, <i>n</i> (%)	
English	9 (90%)
French	3 (30%)
Chinese	1 (10%)
Arabic	4 (40%)
Somali	1 (10%)
Russian	2 (20%)
Creole	1 (10%)
Countries of origin	
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, <i>n</i> (%)	
None, <i>n</i> (%)	1 (10%)
College/university, <i>n</i> (%)	9 (90%)
Family income, <i>n</i> (%)	
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%)

Thematic results

The goal of the interview was to gain 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.

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 Kelly, 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).

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 make a decision 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 cliental and different cultures, then they are more open to other peoples' ideas. For others who generally dealt with certain cliental - 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)

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, Allison, & Copley, 2007; Yeowell, 2010).

Practitioners experienced in delivering services to multicultural patients were also viewed as a valuable asset 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,

Tétrault, Desmaris, King, & Piérart, 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. However, the limitations in this study provide direction for future researchers 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.

References

- Al Busaidy, N. S. M., & Borthwick, A. (2012). Occupational therapy in Oman: the impact of cultural dissonance. *Occupational Therapy International*, 19(3), 154-164.
- Ball, J. (2008). Promoting equity and dignity for aboriginal children in Canada. *Institute for Research on Public Policy Choices*, 14(7), 1-30.
- Bernstein, A., & Eriks-Brophy, A. (2010). Supporting families. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.225–257). Springfield, IL: Charles C Thomas Publisher.
- Bonilla, Z. E. (2011). Difficulties encountered by health care providers serving Latino families and their children with craniofacial conditions. *Hispanic Health Care International*, 9(2), 61-72.
- Creswell, J. W. (2014). *Research Design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Eriks-Brophy, A. (2014). Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language Pathology & Audiology*, 38(2), 152–173.
- Findlay, I., & Janz, t. (2012a). Health of First Nations children living off reserve and Métis children younger than 6. Statistics Canada, Catalogue no. 82-003-XPE. *Health Reports*, 23(1), 1-9.
- Findlay, I., & Janz, t. (2012b). The health of Inuit children under age 6 in Canada. *International Journal of Circumpolar Health*, 71, 18580.
- Fischer, C., & Lieu, J. (2014). Unilateral hearing loss is associated with a negative effect on language scores in adolescents. *International Journal of Pediatric Otorhinolaryngology*, 78(10), 1611-1617.
- Grandpierre, V., Mendonca, O., Fitzpatrick, E., Thomas, R., Potter, B., & Sikora, L. (Submitted). Barriers and facilitators to cultural competence in early hearing loss services: A qualitative analysis. CJSLPA.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*.
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82–98.
- Jaggi, A., & Bithell, C. (1995). Relationships between physiotherapists' level of contact, cultural awareness and communication with Bangladeshi patients in two health authorities. *Physiotherapy*, 81(6), 330-337.
- Kelly, S. (2012) Qualitative interviewing techniques and styles. In J. F. Gubrium (Eds.), *The Sage handbook of interview research: The complexity of the craft* (pp. 243-254). Thousand Oaks, CA: Sage.
- Kummerer, S. E., & Lopez-Reyna, N. A. (2006). The Role of Mexican Immigrant Mothers' Beliefs on Parental Involvement in Speech-Language Therapy. *Communication Disorders Quarterly*, 27(2), 83-94.
- Lederberg, A. R., Schick, B., & Spencer, P. E. (2013). Language and literacy

- development of deaf and hard-of-hearing children: successes and challenges. *Developmental Psychology*, 49(1), 15-30.
- Lee, T., Sullivan, G., & Lansbury, G. (2006). Physiotherapists' communication strategies with clients from cultural diverse backgrounds. *Advances in Physiotherapy*, 8(4), 168-174.
- Lindsay, S., Tétrault, S., Desmaris, C., King, G. A., & Piérart, G. (2014). The cultural brokerage work of occupational therapists in providing culturally sensitive care. *Canadian Journal of Occupational Therapy*, 81(2), 114-123.
- Nelson, A., Allison, H., & Copley, J. (2007). Understanding where we come from: Occupational therapy with urban Indigenous Australians. *Australian Occupational Therapy Journal*, 54(3), 203-214.
- Statistics Canada (2008). *Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations, 2006 census*. Retrieved from <http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/pdf/97-558-XIe2006001.pdf>.
- Statistics Canada. (2017a). Study: A look at immigration, ethnocultural diversity and languages in Canada up to 2036, 2011 to 2036. Retrieved from: <http://www.statcan.gc.ca/daily-quotidien/170125/dq170125b-eng.htm>.
- Statistics Canada. (2017b). Median total income, by family type, by province and territory (All census families). Retrieved from <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/famil108a-eng.htm>.
- Stedman, A., & Thomas, Y. (2011). Reflecting on our effectiveness: Occupational therapy interventions with Indigenous clients. *Australian Occupational Therapy Journal*, 58(1), 43-49.
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-11.
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice*. Walnut Creek, US: Left Coast Press Inc.
- United States Census Bureau. (March 3, 2015). New Census Bureau report analyzes U.S. population projections 2015. Retrieved from: <https://www.census.gov/newsroom/press-releases/2015/cb15-tps16.html>.
- Williams, C. J., & McLeod, S. (2012). Speech-language pathologists' assessment and intervention practices with multilingual children. *International Journal of Speech-Language Pathology*, 14(3), 292-305.
- Yeowell, G. (2010). What are the perceived needs of Pakistani women in the North west of England in relation to physiotherapy, and to what extent do they feel their needs are being met?. *Physiotherapy*, 96(3), 257-263.
- Zhang, C., & Bennett, T. (2003). Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other Developmental Disabilities*, 18(1), 51-59.

Chapter 5: Practitioner surveys

Introduction

Increasing diversity in North America can create challenges for practitioners providing pediatric hearing loss services to minority culture families. The latest Canadian census projects that close to 50% of the population will be immigrants by 2036. The census from the United States closely mirrors this finding, reporting that, by 2044, over half the population will be made up of minority groups (United States Census Bureau, 2015). Pediatric hearing loss services are informed by the needs of majority populations, which may hinder the provision of culturally competent care. 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 et al., 2003, p. 293).

Efforts to improve cultural competence should be informed by evidence of how culture can affect services. Yet, our previous research indicates a scarcity of evidence on barriers and facilitators to cultural competence in hearing loss services (Grandpierre et al., 2018). This finding is critical, as intervention practices need to be appropriate for patients of all cultural backgrounds for practitioners to provide effective services.

Diagnosis and Amplification

Diagnosis of hearing loss in a child can be understandably traumatic for families. However, minority culture families might have additional reasons for experiencing hardship when learning of the loss. Hearing loss is severely stigmatized in some cultures and can be seen as a source of shame and/or punishment (Bernstein & Eriks-Brophy, 2010; Grandpierre et al., 2018). Family members may sever ties to relatives with hearing loss (Jackson, Traub, & Turnbull, 2008) and, as a result, the disability is sometimes hidden from the public and even family members (Grandpierre et al., 2018). Practitioners without knowledge of their patient's cultural background might not understand reactions to the diagnosis or be adequately equipped to provide such patients with the best care.

Communicating the diagnosis and discussing amplification should be done in a sensitive manner (Fitzpatrick, Angus, Durieux-Smith, Graham & Coyle, 2008; Young & Tattersall, 2007). Amplification fitting is often a critical moment for families where suddenly the disability becomes visible (Phillips et al., 2010; Spahn, Richter, Burger, Löhle & Wirsching, 2003; Sjoblad, Harrison, Roush, & McWilliam, 2001). Because of the challenges some minority culture families may experience, it is important for practitioners to have some knowledge of their patient's cultural background prior to discussing amplification to be sensitive to their needs. However, the paucity of research on cultural competence in the field of hearing loss presents an important limitation to practitioners seeking to provide appropriate care (Grandpierre et al., 2018). Indeed, experts in this field and closely related fields (e.g., speech language pathology) report that research on this topic is anecdotal, stereotypical, and dated (Ball & Lewis, 2014; Eriks-Brophy, 2014).

Language interventions

International consensus emphasizes the importance of early intervention to achieve optimal language outcomes (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Spoken language interventions have demonstrated positive language outcomes for children with hearing loss (Fairgray, Purdy, & Smart, 2010; Kaipa & Danser, 2016; Yanbay, Hickson, Scarinci, Constantinescu, & Dettman, 2014), yet important limitations must be considered when working with diverse populations. For instance, practitioners have suggested that auditory-based practices might not be reflective of minority cultures (Rhoades, 2008; Rhoades, 2013; Rhoades et al., 2004). This can become an added source of stress for minority culture families and also negatively impact the way therapy is perceived (Phillips et al., 2010). Other limitations experienced by minority culture families relate to cultural and language barriers.

Culture is embedded into individuals' environments and can influence values, beliefs, and health-related practices. In health care, culture can impact service delivery from the practitioner-patient communication level to the intervention delivery level (Betancourt et al., 2003). Cultural differences can create challenges for health care systems, which are typically tailored to meet the needs of the majority population. For example, assessments are generally developed to be representative of the majority cultural population (Baydala et al., 2009; Choi & Pak, 2005). Lack of culturally appropriate assessments may lead to assessment bias, that is, incorrect interpretations of patients' linguistic competence that may not be reflective of their actual capabilities (Peltier, 2014; Sterzuk, 2008). It is therefore crucial for practitioners to understand the influence culture can have on values, beliefs, behaviour, and health-related practices in order to provide effective services to minority culture families.

Service delivery challenges can also occur due to the presence of language barriers. In Canada, almost 20% of the population do not speak French or English as their first language (Statistics Canada, 2011). Access to translators/interpreters is one method to overcome this barrier, yet their lack of knowledge of medical jargon can limit communication (Grandpierre et al., under review). When families cannot understand the languages commonly used in health care services, they may not be able to fully comprehend the situation or make informed decisions (Rhoades, 2010).

Limited knowledge of the official language(s) can lead to misinterpretation, which becomes particularly salient when health care practitioners are discussing sensitive information with their patients' family members. Reasons for misinterpretations include limited understanding of syntactic, phonological, and semantic structures. More complex reasons can include differences in nonverbal behaviour, such as differences in eye contact or body language (Santilli & Miller, 2011).

Our qualitative research suggests culturally competent health care services may help overcome these challenges by providing care that embraces different cultural beliefs, behaviors, and practices (Grandpierre et al., 2018a, 2018b; Grandpierre et al., under review). In other words, services that are inclusive of cultural differences have the potential to reduce the limitations experienced by minority culture families and their practitioners. However, empirical evidence from the various regions of Canada is needed to inform services. Therefore, the aim of this study was to gain insight into practitioners' experiences with offering early hearing loss services to minority culture families. Specifically, the objective was to examine possible barriers and facilitators to improving

cultural competence in early hearing loss services by exploring the perspectives of the providers of care from across the country.

Methods

Participants

Canadian practitioners with the following characteristics were considered eligible to participate in this survey study:

1) have provided early hearing loss services (e.g., diagnostic and therapy-related services) to children with permanent hearing loss, and 2) have provided services to minority culture children (e.g., not the majority culture in Canada: English and/or French Canadian). The Children's Hospital of Eastern Ontario and the University of Ottawa Research Ethics Boards approved the study protocol.

No existing list of providers of pediatric hearing loss services in Canada was available. Thus, practitioners were recruited from workplace lists accessed through relevant provincial/ territorial regulatory bodies (e.g., College of Audiologists and Speech-Language Pathologists of Ontario). Public (e.g., hospitals) and private practices were also contacted via email, phone, and paper mail. Appendix Q contains a list of contacts and organizations that were mailed paper copies of the questionnaires. Questionnaires were mailed to practitioners' workplaces. In addition, an online version was created using Research Electronic Data Capture (REDCap) electronic data capture tools hosted and supported by the CHEO Research Institute. REDCap is a secure web application designed to develop and maintain online databases and surveys. The electronic version was emailed to professional associations and to public and private practices that offered pediatric services. Both modes of distribution were available in French and English.

Online postings of the survey were also made available on several professional association websites and social media accounts (e.g., Twitter, Facebook), as well as via monthly e-newsletter distribution. Speech-Language Pathology and Audiology Canada, Association Québécoise des Orthophonistes et des Audiologistes, Académie Canadienne D'Audiologie, the Ontario Association of Speech-Language Pathologists and Audiologists, and the Canadian Academy of Audiology were all contacted by these methods. As a result of our broad strategy for reaching the target population, the total number of practitioners who were invited to participate in the survey could not be counted. However, over 200 surveys were sent directly to individuals by mail or email. Professional associations listed above made online postings available for up to three months. Their e-newsletters which contained links to the survey were also sent to members up to three times.

Questionnaire

The questionnaire content was informed by results of our previous studies (Grandpierre et al., 2018a, 2018b; Grandpierre et al., under review). The 21-question survey contained mostly closed-ended questions, with options to elaborate on responses to questions in open text boxes, as well as three open-ended questions (Appendix M & N). The survey included questions on demographics (e.g., education, profession, cultural background), experiences in delivering services to cultural minority families, as well as perceived barriers and facilitators to delivering culturally competent care.

Pilot

A draft of the questionnaire was piloted amongst 15 audiologists, therapists, and PhD candidates in the field of audiology to determine ease of completion, relevancy, clarity, respondent fatigue, and length of time for completion. Feedback was then incorporated into the final version of the questionnaire for distribution.

Analysis

A coding dictionary of variables was developed in consultation with a statistician (JW). Data were entered in the Statistical Package for the Social Sciences (SPSS) by a research assistant (JT). An independent reviewer, the lead researcher, verified 12% of the data in hard copies and found less than 1% errors.

Since this survey addressed a relatively unexplored topic, responses to all survey questions were analyzed descriptively using proportions to summarize the characteristics of the study population and to identify the most common barriers and facilitators to providing culturally competent care across different aspects of practice. We were also interested, *a priori*, in whether participants' perceptions about barriers, strategies, and characteristics of culturally sensitive practice were associated with their professional titles/roles (e.g., audiologist, speech-language pathologist) and/or their recollections of specific training they received. To evaluate these associations, we reported proportions separately by professional title and training status, formally testing statistical significance with chi-square tests of association (p-values of <0.05 were considered statistically significant).

Open-ended questions were analyzed by simple content analysis with the use of open coding. Open coding consists of studying individual responses and assigning labels to each response (Corbin & Strauss, 2008). These labels were then refined and conceptualized into themes.

Results

Participant characteristics

A total of 130 surveys were received. Of those, 111 were eligible according to the inclusion criteria; the remainder indicated they had not provided pediatric hearing loss services. Forty-seven surveys were completed in electronic format and the remainder were returned by mail. A summary of participant characteristics is shown in Table 1. Less than 5% of responses were missing for any single variable analyzed. One mailed survey was returned with the demographics page missing. Data were analyzed using the total number of respondents who answered each question.

The majority of participants were audiologists (75.2%). Other respondents included auditory-verbal therapists (AVTs) and speech-language pathologists (SLPs) and one itinerant teacher of the deaf and hard of hearing. As recruitment occurred during the summer months, itinerant teachers of the deaf and hard of hearing were likely to have been unavailable to participate, although one did respond. The majority of participants were female (88.3%). Participant experience in their respective fields ranged from less than one to 42 years (mean: 16.1 years). A total of 14.8% of practitioners reported having 60% or more minority culture families on their current caseload.

Table 1
Participant Characteristics

Characteristics:	Participants n (%) n = 111
Sex	
Female	98 (88.3)
Profession, n=109	
Audiologists	82 (75.2%)
Auditory Verbal Therapists	12 (11%)
Speech language pathologists	18 (16.5%)
Itinerant teacher of the deaf and hard of hearing	1 (0.91%)
Years of experience providing early hearing loss services (mean)	42 (16.1)
Percentage of patients of cultural minority background on current caseload, n=108	
<10%	18 (16.6%)
10-19%	27 (25%)
20-39%	20 (18.5%)
40-59%	27 (25%)
60-79%	8 (7.4%)
>80%	8 (7.4%)
Cultural competence training received, n=51	
Training received from university/college	10 (19.6%)
Training received from place of employment	29 (56.8%)
Training received from courses, training, webinars	20 (39.2%)
Training received from other locations (e.g., culture-specific workshops)	4 (7.8%)
Languages, n=110	
English	108 (98.1%)
French	66 (60%)
Signed Languages**	11 (10%)
Other***	13 (11.8%)
Culture, n=110	
Canadian (English, French)	98 (89.1%)
British	8 (7.27%)
Scottish	7 (6.36%)
Irish	6 (5.45%)
Chinese	5 (4.54%)
Dutch (Netherlands)	5 (4.54%)
Other****	20 (18.1%)
Education, n=110	
Bachelor's	4 (3.63%)
Master's	97 (88.1%)
PhD	9 (8.18%)

*Several practitioners reported to work in different professions

**Signed languages = American Sign Language, Québec Sign Language or Langue des signes du Québec, Signed English

****Other* represents languages grouped together where <5 spoke the language and included Chinese, Spanish, Vietnamese, Italian, Arabic, Punjabi, Hebrew, Dutch, Bengali, and Urdu

*****Other* represents cultures grouped together where <5 were of cultural backgrounds that included South Asian (East Indian, Pakistani, Punjabi, Sri Lankan), French (France), Arab/West Asian (Armenian, Egyptian, Iranian, Lebanese), German, Italian, Korean, Welsh, Israeli, and Spanish

Note: Questions regarding languages and cultures were 'select all that apply'

Nearly half of participating practitioners (n=51) reported receiving training in cultural competency. These participants were asked where they received training; settings where training was reported to have taken place included (19.6%), work (56.8%), additional courses (39.2%), and/or other locations (7.8%). There were 78 respondents who were multilingual (70.9%), speaking/and or signing a variety of languages, including Chinese, Spanish, Quebec French Sign Language, American Sign Language, etc.

Returned mailed surveys came from a range of provinces (i.e., Alberta, Ontario, Quebec, Nova Scotia, British Columbia, Newfoundland, and New Brunswick). Locations for those who completed electronic surveys were not known. Results are organized according to perceived barriers, facilitators, and essential characteristics of a culturally competent practitioner.

Barriers to the provision of culturally competent hearing loss services

Practitioners reported barriers at each stage of service delivery: during diagnoses, amplification discussions, language assessments, and interventions. Barriers varied according to profession. Table 2 summarizes the proportions of practitioners who experienced challenges related to the provision of culturally competent care, stratified by profession. As only one itinerant teacher participated in this study, the data for this profession was excluded.

Cultural challenges during audiological testing

Diagnostic testing is performed by audiologists, while auditory-verbal therapists and speech language pathologists typically provide language-based therapy. Over 70% of audiologists reported experiencing cultural challenges when providing audiological testing (Table 2). Reasons for challenges were the child/parent did not understand the instructions (53.1%), testing was difficult due to religious attire (e.g., the sensitive nature of requesting hijabs be removed) (11.1%), and caregivers preferred a practitioner of a different gender (9.9%). A total of 27.2% also selected other reasons for challenges, with the most common themes among open-ended responses being language barriers and denial of diagnosis due to cultural stigma of disabilities.

Cultural challenges during discussions of hearing loss diagnosis

The majority of audiologists (71.2%), auditory-verbal therapists (88.9%), and speech language pathologists (90%) reported encountering unexpected reactions when discussing the diagnosis with families due to cultural reasons (Table 2). There was no statistically significant association found between professional group and reporting unexpected reactions when communicating the diagnosis ($p=0.341$).

Table 2
Cultural challenges experienced by practitioners

Cultural challenge	Audiologists n (%)	Auditory- verbal therapists n (%)	Speech- language pathologists n (%)	Association with professional group X ² (p value)*
Cultural challenges when conducting audiologic testing	57/81 (71.3)	--	--	--
Reasons for testing challenges:				
Instructions not understood	43/81 (53.1)	--	--	--
Religious attire	9/81 (11.1)	--	--	--
Different practitioner gender preferred	8/81 (9.9)	--	--	--
Other	22/81 (27.2)	--	--	--
Unexpected reactions related to culture when communicating the diagnosis	52/73 (71.2)	8/9 (88.9)	9/10 (90.0)	2.124 (0.341)
Reactions due to cultural stigma	49/73 (67.1)	7/9 (77.7)	7/10 (70.0)	--
Hearing loss seen as divine gift	10/73 (13.7)	3/9 (33.3)	0	--
Hearing loss seen as a consequence	17/73 (23.3)	4/9 (44.4)	5/10 (50.0)	--
Other	16/73 (21.9)	1/9 (11.1)	1/10 (10.0)	--
Cultural challenges when discussing amplification	63/75 (84.0)	8/9 (88.9)	8/9 (88.9)	0.153 (~1.0)
Dismissive or denial of hearing loss	50/75 (66.7)	7/9 (77.8)	7/9 (77.8)	--
Caregivers keep hearing loss hidden	46/75 (61.3)	7/9 (77.8)	6/9 (66.7)	--
Concerns for marriageability	17/75 (22.7)	1/9 (11.1)	2/9 (22.2)	--
Belief hearing loss can be cured	31/75 (41.3)	5/9 (55.6)	6/9 (66.7)	--
Other	11/75 (14.7)	1/9 (11.1)	0	--
Cultural challenges when conducting language assessments	46/67 (68.7)	9/11 (81.8)	13/14 (92.9)	3.683 (0.154)
Lack of culturally appropriate assessments	15/67 (22.4)	8/11 (73.0)	13/14 (92.9)	--
Lack of assessments available in the caregivers' language(s)	38/67 (56.7)	8/11 (73.0)	13/14 (92.9)	--
Other	9/67 (13.4)	1/11 (9.1)	2/14 (14.3)	--
Cultural challenges when providing interventions	26/42 (61.9)	10/12 (83.3)	13/14 (92.9)	5.65 (0.058)
Level on family verbal interaction varies according to culture	16/42 (38.1)	9/12 (75)	11/14 (78.6)	--
Lack of culturally appropriate assessments	12/42 (28.6)	7/12 (58.3)	7/14 (50.0)	--
Different expectations regarding who conducts therapy	13/42 (31.0)	7/12 (58.3)	9/14 (64.3)	--
Different listening and language expectations	12/42 (28.6)	8/12 (66.7)	7/14 (50.0)	--
Primary caregiver(s) do not attend appointments	9/42 (21.4)	5/12 (41.7)	5/14 (35.7)	--
Other	5/42 (12.0)	1/12 (8.3)	1/14 (5.9)	--

* Based on Fisher's Exact test.

Among all three professional groups, the most common reason reported for unexpected reactions during communication of the diagnosis due to cultural reasons was that hearing loss is stigmatized in the caregiver's culture (reported by 67.1% of audiologists, 77.7% of AVTs, and 70% of SLPs; Table 2). This was followed by hearing loss is seen as a consequence of the caregiver's actions or lack thereof (23.3% of audiologists, 44.4% of AVTs, and 50% of SLPs) and hearing loss is perceived as a divine intervention or a gift (13.7% of audiologists, 33.3% of AVTs, and 0% of SLPs). An additional reason for challenges reported by audiologists was parental concerns with respect to their child's marriageability, regardless of gender.

Cultural challenges during discussions of amplification

The majority of practitioners in each profession also reported experiencing cultural challenges when discussing amplification, with similar proportions of auditory-verbal therapists (88.9%), audiologists (84%), and speech language pathologists (88.9%) reporting such challenges (Table 2). The association between professional group and reporting cultural challenges during amplification discussions was not statistically significant ($p \approx 1.0$, Table 2).

Among each profession, caregivers having a dismissive attitude or denial of hearing loss (e.g., disability is stigmatized and/or seen as shameful) was the most commonly reported reason for challenges (reported by 66.7% of audiologists and 77.8% of both AVTs and SLPs), although an equivalent proportion of AVTs reported as a reason that caregivers preferred to keep hearing loss hidden from family and/or public. The belief that hearing loss could be cured through prayer, traditional medicines, and/or complementary and alternative medicines was also cited as another common reason for experiencing challenges when discussing amplification (reported by 41.3% of audiologists, 55.6% of AVTs, and 66.7% of SLPs). Parental concerns for marriageability following amplification were more rarely reported as a barrier in each profession (22.7% of audiologists, 11.1% of AVTs, and 22.2% of SLPs).

Audiologists reported several other barriers to discussing amplification, such as rejecting intervention because hearing loss was believed to be a divine gift or because of a belief that amplification (e.g., hearing aids, cochlear implants, etc.) should be the choice of the child.

Cultural challenges when conducting language assessments

The majority of practitioners in each profession (68.7% of audiologists, 81.8% of AVTs, and 92.9% of SLPs) reported experiencing cultural challenges when conducting parent questionnaires and/or standardized assessments with minority culture families. No statistically significant association was found between professional group and the presence of barriers to conducting assessments ($p=0.154$, Table 2).

The most common barriers reported by AVTs and SLPs were the lack of culturally appropriate assessment materials (e.g., 73% and 92.9%, respectively) and the lack of assessments available in the language of the family (73% and 92.9% respectively). Audiologists reported the lack of assessments available in the language of the family as the most common barrier they encountered (56.7%), followed by the lack of

culturally appropriate assessments (22.4%). Other barriers reported by practitioners were the potential for misunderstanding due to language barriers and difficulties working with translators or interpreters.

Cultural challenges when providing interventions

The majority of audiologists, auditory-verbal therapists, and speech language pathologists reported experiencing challenges when providing interventions (e.g., language therapy) due to cultural reasons (61.9%, 83.3%, & 92.9% respectively, (Table 2). Despite this variation across professional groups, the association between profession and the presence of barriers to conducting assessments was not statistically significant ($p=0.058$).

The most common barrier across professions was variance in the amount of interaction between caregivers and children across cultures (e.g., in some cultures, there is minimal interaction between parents and children) (reported by 38.1% of audiologists, 75% of AVTs, and 78.6% of SLTs), followed by a lack of culturally appropriate assessments (28.6% of audiologists, 58.3% of AVTs, and 50% of SLPs). Other barriers such as caregivers having different expectations regarding who should conduct the therapy, caregivers having different listening and language expectations than what practitioners expect to successfully conduct therapy, and challenges from not having the primary caregiver attend therapy sessions were experienced to varying degrees by each profession (Table 2). Other reasons described by practitioners from each profession include possible misunderstandings regarding the importance of intervention due to language barriers and having a clinic policy that only one caregiver is allowed to attend the sessions.

Facilitators of the provision of culturally competent hearing loss services

Practitioners were asked to report the frequency with which they used various strategies to ensure cultural competence in hearing loss services at each stage of service delivery (all of the time, most of the time, some of the time, or never): during diagnosis, amplification discussions, language assessments, and interventions. These strategies varied according to profession. Table 3 summarizes the proportions of practitioners who reported that they used each strategy either 'all of the time' or 'most of the time'.

Strategies for facilitating communication

Practitioners from all professions reported using a variety of strategies to facilitate communication with families with limited proficiency in English and/or French. These included using simple language, using an interpreter or someone proficient in the language of the caregivers, writing out key words, using visual aids (e.g., pictures, diagrams, videos, or the internet), and learning a few words or key phrases in the language of the caregivers. The most used strategy for audiologists (91%), auditory-verbal therapists (83.3%), speech language pathologists (86.7%) was using simple language.

Table 3
Proportion of practitioners who used strategies

Facilitators: proportion of practitioners who reported that they used strategies “all” or “most” of the time	Audiologists n (%)	Auditory-verbal therapists n (%)	Speech-language pathologists n (%)
Strategies for facilitating communication			
Use simple language	71/78 (91.0)	10/12 (83.3)	13/15 (86.7)
Use interpreters	53/78 (68.0)	4/12 (33.3)	8/15 (53.3)
Write key words	12/77 (15.6)	3/12 (25)	2/15 (13.3)
Use visual aids	34/77 (44.2)	2/12 (16.7)	6/15 (40.0)
Learn key phrases in patient’s language	6/79 (7.6)	4/12 (33.3)	6/15 (40.0)
Strategies for ensuring culturally competent care			
Select culturally relevant materials	44/72 (61.1)	8/11 (72.7)	12/15 (80.0)
Encourage all family members to attend	45/69 (65.2)	9/12 (75.0)	11/15 (73.3)
Use some of family’s home language	17/70 (24.3)	8/12 (66.7)	8/15 (53.3)
Use interpreters	68/75 (90.7)	6/12 (50.0)	11/15 (73.3)
Modify assessments	44/65 (67.7)	8/12 (66.7)	11/14 (78.6)
Modify interventions	14/68 (20.6)	1/12 (8.3)	9/15 (60.0)

Strategies for ensuring the provision of culturally competent care

Practitioners were asked to rank how often they used pre-specified strategies for ensuring the provision of culturally competent care, including selecting culturally relevant materials; encouraging all family members to attend the therapy; using some of the family’s home language (e.g., words, phrases you have learned); using interpreters or having a family member, friend, or colleague translate; modifying assessments (administering subsets of a standardized assessment or assessing language abilities through checklists, vocabulary lists, etc.); and modifying interventions to reflect the home environment. Only some professionals answered this question, as some indicated it was not applicable to them. Of those who responded, using interpreters or having a family member, friend, or colleague translate was the most used strategy by audiologists (90.7%), encouraging all family members to attend sessions was the most used strategy by AVTs (75%), and selecting culturally relevant materials was the most used strategy by SLPs (80%).

Practitioners from each profession also provided an account of other alternative strategies, such as providing privacy when needed (e.g., removal of religious garments), using lots of examples during discussions, and asking the families how they would modify activities to be more representative of their home environments.

Strategies for learning about cultures

Practitioners were asked to report how important they believed pre-specified strategies are for learning about cultures (essential, very important, somewhat important, or not important). Table 4 summarizes the proportions of practitioners who viewed a strategy to be ‘essential’ or ‘very important’. Strategies were: attending workshops, lectures, training, and/or courses on cultural sensitivity; asking caregivers questions about home

life (e.g., caregiver roles, routines, etc.); asking caregivers about how hearing loss is perceived in their culture; and scheduling home visits.

Practitioners reported all strategies to be important to varying degrees with the exception of home visits, which fewer than 20% of audiologists found to be essential or very important. Practitioners from each profession also provided an account of other strategies, such as doing research on cultures and culturally competent practices (e.g., internet, news, books, etc.), talking to coworkers about their experiences and/or multicultural friends, and talking to cultural interpreters.

Table 4
Proportion of practitioners who viewed strategies as important

Facilitators: proportion of practitioners who viewed strategies as “essential” or “very important”	Audiologists n (%)	Auditory-verbal therapists n (%)	Speech-language pathologists n (%)
Strategies for learning about cultures			
Attend workshops, lectures, training on cultural sensitivity	53/80 (66.2)	8/12 (66.6)	14/15 (93.3)
Ask caregivers questions about home life	65/80 (81.2)	12/12 (100)	14/15 (93.3)
Ask caregivers about cultural perceptions of hearing loss	62/79 (78.4)	12/12 (100)	14/15 (93.3)
Schedule home visits	11/66 (16.6)	7/12 (58.3)	11/15 (73.3)

Characteristics of a culturally competent practitioner

Practitioners were asked to rank the importance of pre-specified characteristics of a culturally competent practitioner (e.g., essential, very important, somewhat important, not important). The first three categories were collapsed into one category: ‘important’. Many key characteristics were reported as important by audiologists, AVTs, and SLPs, including being open-minded, respectful, and knowledgeable of different cultures. Table 5 provides an overview of the proportion of professions who reported on important characteristics of a culturally competent practitioner.

Cultural competence training and barriers to providing services to minority culture families

We hypothesized that if practitioners received cultural competence training, they would experience fewer barriers when working with diverse populations. A Chi-square test for independence reporting Fischer’s exact probability test revealed no association between those who received training in cultural competence and barriers to service provision. Barriers occurred whether professions reported experiencing challenges due to culture during audiological testing, during discussions of diagnosis, during discussions of amplification, during assessments, and during interventions.

Table 5

Proportion of professions who reported on important characteristics of a culturally competent practitioner

Facilitators: professions who reported on important characteristics of a culturally competent practitioner	Audiologists n (%)	Auditory-verbal therapists n (%)	Speech-language pathologists n (%)
Has knowledge of different cultures	79/79 (100)	12/12 (100)	17/17 (100)
Is open-minded	82/82 (100)	12/12 (100)	18/18 (100)
Uses an interpreter	81/81 (100)	12/12 (100)	18/18 (100)
Is respectful of the need to preserve home language(s)	80/80 (100)	11/11 (100)	18/18 (100)
Uses communication strategies when needed	82/82 (100)	11/11 (100)	18/18 (100)
Is flexible with scheduling appointments	78/81 (96.3)	12/12 (100)	16/18 (88.9)
Engages in multicultural events	50/80 (62.5)	9/11 (81.8)	18/18 (100)
Modifies sessions and/or content when needed	81/81 (100)	12/12 (100)	18/18 (100)
Is aware of social issues that may interact with cultural identity, such as low income	78/79 (98.7)	12/12 (100)	18/18 (100)
Is aware of discriminatory policies	75/78 (96.1)	12/12 (100)	18/18 (100)
Is someone who is reflective of their own cultural identity, prejudices, biases, and/or assumptions	76/77 (98.7)	11/12 (91.7)	18/18 (100)
Explains session in advance to check with caregiver regarding if practice/content is appropriate	79/79 (100)	12/12 (100)	18/18 (100)
Enquires about life at home	78/80 (97.5)	12/12 (100)	18/18 (100)
Connects families of similar cultures and/or languages	71/80 (88.8)	12/12 (100)	16/18 (88.9)

An examination of specific training locations (e.g., university/college, employment training, courses/webinars) indicated no association between training location and barriers to service provision with the exception of training received from place of employment and cultural challenges experienced during audiological testing and discussing the diagnosis. Table 6 provides an overview the proportions of training status (e.g., received training, did not receive training) and barriers experienced. Of the 23 respondents who received cultural training at work, 22 reported experiencing cultural challenges during audiological testing (96%); however, of the 62 respondents who did not receive cultural training at work, 38 reported experience cultural challenges during audiological testing (61%). A Chi-square test for independence reporting Fischer's exact probability test indicated an association between training received from place of employment and experiencing cultural challenges during audiological testing ($p=0.001$).

Table 6

Proportions of practitioners with and without cultural competence training who experienced cultural barriers

Cultural challenges:		Audiologic testing ^b	Discussing diagnosis ^c	Discussing amplification ^d	Conducting language assessments ^e	Providing interventions ^f
Training status: ^a		n (%)	n (%)	n (%)	n (%)	n (%)
Received any training	Yes	30/37 (81.1)	39/44 (88.6)	40/44 (90.9)	33/46 (71.7)	25/34 (73.5)
	No	30/47 (63.8)	31/50 (62.0)	40/51 (78.4)	36/47 (76.6)	26/36 (72.2)
Location of training:						
University/college	Yes	2/4 (50.0)	7/7 (100.0)	8/8 (100.0)	7/8 (87.5)	7/9 (77.8)
	No	58/81 (71.6)	64/88 (72.7)	72/88 (81.8)	62/86 (72.1)	44/62 (71.0)
Place of employment	Yes	22/23 (96%)	26/28 (92.8)	25/27 (92.6)	14/19 (73.7)	15/19 (78.9)
	No	38/62 (61%)	45/67 (67.2)	55/69 (79.7)	55/75 (73.3)	36/52 (69.2)
Courses	Yes	9/12 (75.0)	15/16 (93.8)	14/16 (87.5)	3/3 (100.0)	12/16 (75.0)
	No	51/73 (69.9)	56/79 (70.9)	66/80 (82.5)	66/91 (72.5)	39/55 (70.9)
Other	Yes	2/3 (66.7)	2/3 (66.7)	3/3 (100.0)	3/3 (100.0)	1/1 (100.0)
	No	58/82 (70.7)	69/92 (75.0)	77/93 (82.8)	66/91 (72.5)	50/70 (71.4)

^aThe comparison group for those who received any training is the group of respondents who reported no training (n= ##); for specific training locations, the comparison group includes both those respondents who reported no training and those respondents who received training but not in this specific location (training locations were not mutually exclusive).

^bFisher's exact test p-values for barriers in audiologic testing (in group who received training vs comparison group): received any training (p=0.094); university/college (p=0.577); place of employment (p=0.001); courses (p=1.0); other location (p=1.0).

^cFisher's exact test p-values for barriers in discussing diagnostic (in group who received training vs comparison group): received any training (p=0.004); university/college (p=0.186); place of employment (p=0.009); courses (p=0.063); other location (p=1.0).

^dFisher's exact test p-values for barriers in discussing amplification (in group who received training vs comparison group): received any training (p= 0.157); university/college (p=0.345); place of employment (p=0.221); courses (p=1.0); other location (p=1.0).

^eFisher's exact test p-values for barriers in conducting language assessments (in group who received training vs comparison group): received any training (p= 0.641); university/college (p=0.677); place of employment (p=0.614); courses (p=1.0); other location (p=0.562).

^fFisher's exact test p-values for barriers in providing interventions (in group who received training vs comparison group): received any training (p= 1.0); university/college (p=1.0); place of employment (p=0.556); courses (p=1.0); other location (p=1.0).

Similarly, of the 28 respondents who received cultural training at work, 26 reported experiencing cultural challenges during discussions of the diagnosis (93%); however, of the 67 respondents who did not receive cultural training at work, 45 reported experiencing cultural challenges during discussions of the diagnosis (67.2%). A Chi-square test for independence reporting Fischer's exact probability test indicated an association between training received from place of employment and experiencing cultural challenges during discussions of diagnosis (p=0.009).

Discussion

The goal of this study was to explore practitioners' experiences with offering early hearing loss services to minority culture families. Challenges were encountered during every stage of service delivery. There were no statistically significant associations between professional role type (e.g., audiologist versus AVT) and experiences of cultural barriers. The most important challenges across these professional groups were language barriers, cultural stigma of hearing loss, and a lack of culturally appropriate assessments.

Some significant associations between the location of cultural competency training and some cultural barriers experienced were identified. Specifically, the findings suggest practitioners who reported receiving cultural training at work were much more likely to

report that they experienced cultural challenges related to audiologic testing and discussions of diagnosis relative to those who did not receive such training. One potential explanation is that it is possible that workplace training in cultural competence is offered in response to cultural barriers experienced by practitioners – i.e., this finding could reflect the provision of training to those professionals for whom it is most needed. However, the amount of training was not quantified in the survey and would be helpful to further interpret our findings.

During audiological testing, the majority of audiologists experienced challenges due to language barriers; specifically, the child/parent did not understand the instructions. In many rehabilitation fields such as speech language pathology, physical therapy, and occupational therapy, language barriers consistently present challenges to therapists when providing services (Drolet et al., 2014; Dressler & Pils, 2009; Guiberson & Atkins, 2012; Lindsay, Tetrault, Desmaris, King, & Pierart, 2014).

During discussions of the hearing loss diagnosis, the majority of practitioners reported encountering unexpected reactions due to culture, such as stigma and believing the diagnosis was a consequence of the parents' actions (or lack thereof). This aligns with another study investigating parents' experiences with childhood hearing loss that also reported diagnosis results in cultural stigma and a source of shame upon the parents (Jackson et al., 2008; Lindsay et al., 2014).

Practitioners frequently experienced cultural challenges when discussing amplification, particularly audiologists, 82.9% of whom had experiences such challenges. Practitioners reported that parents were sometimes in denial or dismissive of the diagnosis (due to stigma), preferred to keep hearing loss hidden, or refused intervention because they thought hearing loss could be cured through alternative medicines and/or prayer. This finding is consistent with our previous findings, as well as existing literature (Bernstein & Eriks-Brophy, 2010; Grandpierre et al., under review; Grandpierre et al., 2018; Jackson et al., 2008).

Assessments were challenging due to the lack of culturally appropriate tests or the unavailability of tests in the child's language. Interventions were also difficult due to the lack of culturally appropriate materials, cultural norms dictating minimal interactions between parents and children, and caregivers having differing expectations of who should conduct the intervention. Studies have similarly reported how minority culture children are at a disadvantage when undergoing language assessments (Ball & Bernhardt, 2008; Peltier, 2014), as these tests are typically developed for the majority population (Choi & Pak, 2005). Such assessments can potentially lead to misdiagnosis (Ball, 2009; Eriks-Brophy, 2014; O'Hara, Rolandson, & SAC, 2010) and difficulty determining whether a language disorder is truly present (Ball & Bernhardt, 2008).

Practitioners used a variety of strategies to facilitate communication when working with families with minimal language proficiency. These included using simple language, using an interpreter/translator, writing out key words, learning key phrases in their patient's language, and using pictures, diagrams, videos or the internet to aid communication. Practitioners from all three professions reported using simple language as the most common strategy for facilitating communication. Auditory-verbal therapists used visual aids more than audiologists and speech-language pathologists to facilitate communication. Results from other rehabilitation studies report these strategies are helpful (Lindsay et al., 2014; Yeowell, 2010) but also state that talking slowly can help to

ensure comprehension. In addition, it is important to ensure families understand the content of each appointment and how the Canadian health care system works (e.g., perception of disability, support availability), which may be different from what is available in their home countries (Grandpierre et al., under review; Grandpierre et al., 2018; Lindsay, King, Klassen, Esses & Stachel, 2012; Lindsay et al., 2014). Although this finding was not reported in our study, ensuring families understand what is available to them and how disability is perceived in Canada (e.g., children with disabilities are often integrated into public schools) may facilitate service experiences.

Practitioners who wanted to learn more about different cultures reported attending workshops, lectures, or training events, asking families about their home life (e.g., caregiver roles, routines), scheduling home visits, and learning how hearing loss is perceived in their patient's culture. All professions reported all strategies were important; the exception was home visits, which less than half audiologists identified as important. This may relate to the fact that audiologists typically do not provide home visits. Other studies in rehabilitation also suggest community engagement, reaching out to cultural agencies, and/or attending cultural events as other ways to learn about different cultures (Maul, 2010; Munoz, 2002; Nelson, Allison, & Copley, 2007; Nelson et al., 2011). Ongoing training in cultural competence may also ensure the provision of appropriate care (Douglas et al., 2014).

Strategies for ensuring the provision of culturally competent care include the selection of culturally relevant materials, encouraging all caregivers to attend therapy sessions, using interpreters/translators, and modifying assessments and interventions when needed. While auditory-verbal therapists and speech language pathologists reported using all strategies to ensure the provision of culturally competent care, audiologists most often used the two strategies: having someone available to translate (e.g. interpreter, family members, friends, etc.), and modifying assessments when deemed necessary. Creating a diverse workforce (Kirkham et al., 2009), providing flexibility (Lindsay et al., 2014; Nelson & Allison, 2007), and having training and/or education on cultural sensitivity (Centeno, 2009; Dogan, Tschudin, Hot, & Ozkan, 2009) can also help to ensure culturally competent care.

There were several noticeable differences in reported barriers and facilitators between audiologists and therapists (both auditory-verbal therapists and speech language pathologists). Audiologists experienced less barriers during language assessments (e.g., due to a lack of culturally appropriate assessments) and interventions (e.g., due to variances in levels of family verbal interactions according to culture, as well as different listening and language expectations) in comparison to therapists. This may be attributed to differences in professions; audiologists provide diagnostic and hearing-technology services whereas therapists provide support for improving language outcomes. Depending on the needs of the child, parents may engage with therapists up to a weekly basis which may also explain why these clinicians experience more of these barriers.

Noticeable differences in facilitators between audiologists and therapists (e.g., learning key phrases in patient's home language) can also be attributed to the differences in the level of interactions between the patients' families and the professions. Interestingly, audiologists reported using interpreters more often than therapists. A possible explanation for this finding is audiologists provide extensive sensitive information which requires families to understand all the information in order to make

informed decisions on treatments. Although these differences haven't been statistically evaluated, it's important to note that the interpretations are exploratory, since the sample size outside of audiologists was relatively small.

Findings stemming from this study can be used to inform practitioners seeking to provide culturally competent care. However, the majority of the perspectives in this study were provided by audiologists. The lack of insight from practitioners who provide long-term services (e.g., language therapy or home/school support) is a limitation of this study. In addition, therapists used one form of therapy: the spoken language approach.

Future studies seeking to investigate multiple perspectives should disseminate the survey during the school year to increase response rates. In addition, data from Canadian territories that feature large Indigenous populations would greatly increase insight into the provision of culturally competent care. Another limitation was the lack of quantification of cultural competence training. Such data would provide insight into whether training reduces experiences of cultural barriers. Nonetheless, this study is one of the first to capture barriers and facilitators experienced by early hearing loss practitioners when providing services to minority culture families.

References

- Ball, J. (2009). Supporting young Indigenous children's language development in Canada: A review of the research on needs and promising practices. *Canadian Modern Language Review*, 66(1), 19–47. DOI: 10.3138/cmlr.66.1.019
- Ball, J., & Bernhardt, B. M. (2008). First Nations English dialects in Canada: Implications for speech-language pathology. *Clinical Linguistics and Phonetics*, 22(8), 570–588. DOI: 10.1080/02699200802221620.
- Ball, J., & Lewis, M. (2014). First Nations elders' and parents' views on supporting their children's language development. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 224–237.
- Baydala, L., Rasmussen, C., Birch, J., Sherman, J., Wikman, E., Charchun, J., . . . Bisanz, J. (2009). Self-beliefs and behavioral development as related to academic achievement in Canadian Aboriginal children. *Canadian Journal of School Psychology*, 24(1), 19–33. DOI: 10.1177/0829573509332243
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Owusu Ananeh-Firempong, I. I. (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118:293-302. DOI: 10.1093/phr/118.4.293
- Bernstein, A., & Eriks-Brophy, A. (2010). Supporting families. In E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.225–257). Springfield, IL: Charles C Thomas Publisher.
- Choi, B., & Pak, A. (2005). A catalog of biases in questionnaires. *Prevention of Chronic Diseases*, 2(1), 1–13.
- Centeno, J. (2009). Issues and principles in service delivery to communicatively impaired minority bilingual adults in neurorehabilitation. *Seminars in Speech and Language*, 30:139-52. DOI: 10.1055/s-0029-1225951
- Crago, M. (1990). Development of communicative competence in Inuit children: Implications for speech-language pathology. *Journal of Childhood Communication Disorders*, 13(1), 75–83. DOI: 10.1177/152574019001300108
- Dogan, H., Tschudin, V., Hot, I., & Özkan, I. (2009). Patients' transcultural needs and carers' ethical responses. *Nursing Ethics*, 16(6), 683-696. DOI: 10.1177/0969733009341396
- Douglas, M. K., Rosenkoetter, M., Pacquiao, D. F., Callister, L. C., Hattar-Pollara, M., Lauderdale, J., ... & Purnell, L. (2014). Guidelines for implementing culturally competent nursing care. *Journal of Transcultural Nursing*, 25(2), 109-121. DOI: 10.1177/1043659614520998
- Dressler, D., & Pils, P. (2009). A qualitative study on cross-cultural communication in post-accident in-patient rehabilitation of migrant and ethnic minority patients in Austria. *Disability and rehabilitation*, 31(14), 1181-1190. DOI: 10.1080/09638280902773786
- Drolet, M., Savard, J., Benoît, J., Arcand, I., Savard, S., Lagacé, J., ... & Dubouloz, C. J. (2014). Health services for linguistic minorities in a bilingual setting: Challenges for bilingual professionals. *Qualitative Health Research*, 24(3), 295-305. DOI: 10.1177/1049732314523503
- Eriks-Brophy, A. (2014). Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language*

- Pathology and Audiology*, 38(2), 152–173.
- Fairgray, E., Purdy, S. C., & Smart, J. L. (2010). Effects of auditory-verbal therapy for school-aged children with hearing loss: an exploratory study. *Volta Review*, 110(3), 407-433.
- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, 17(1), 38-49.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*, 18(1), 23. DOI: 10.1186/s12913-017-2811-1
- Grandpierre, V., Fitzpatrick, E., Thomas, R., Mendonca, O., Sikora, L., Potter, B. (Submitted with revisions). Barriers and facilitators to cultural competence in rehabilitation services: A qualitative inquiry. *Canadian Journal Of Speech-Language Pathologists and Audiologists*.
- Grandpierre, V., Fitzpatrick, E., Thomas, R., Sikora, L., Potter, B., Thomas, O. Perspectives of parents of minority culture backgrounds on pediatric hearing loss services: A qualitative inquiry. (Submitted). *Canadian Journal Of Speech-Language Pathologists and Audiologists*.
- Guiberson, M., & Atkins, J. (2012). Speech-language pathologists' preparation, practices, and perspectives on serving culturally and linguistically diverse children. *Communication Disorders Quarterly*, 33(3), 169-180. DOI: 10.1177/1525740110384132
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377-381. DOI: 10.1016/j.jbi.2008.08.010
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82–98. DOI: 10.1177/1525740108314865
- Kaipa, R., & Danser, M. L. (2016). Efficacy of auditory-verbal therapy in children with hearing impairment: A systematic review from 1993 to 2015. *International Journal of Pediatric Otorhinolaryngology*, 86, 124-134. DOI: 10.1016/j.ijporl.2016.04.033
- Kirkham, E., Sacks, C., Baroody, F., Siddique, J., Nevins, M. E., Woolley, A., & Suskind, D. (2009). Health disparities in pediatric cochlear implantation: An audiologic perspective. *Ear and Hearing*, 30(5), 515-525. DOI : 10.1097/AUD.0b013e3181aec5e0
- Lindsay, S., Tétrault, S., Desmaris, C., King, G. A., & Piérart, G. (2014). The cultural brokerage work of occupational therapists in providing culturally sensitive care. *Canadian Journal of Occupational Therapy*, 81(2), 114-123. DOI: 10.1177/0008417413520441.
- Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with

- immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*, 34(23), 2007-2017. DOI: 10.3109/09638288.2012.667192
- Nelson, A., Allison, H., & Copley, J. (2007). Understanding where we come from: Occupational therapy with urban Indigenous Australians. *Australian Occupational Therapy Journal*, 54(3), 203-214. DOI: 10.1111/j.1440-1630.2006.00629.x
- Maul, C. (2010). *Identifying culturally competent clinical skills in speech-language pathologists in the central valley of California*. (Doctoral dissertation) University of California, USA.
- Munoz, J. (2002). *Culturally responsive caring in occupational therapy: A grounded theory*. (Doctoral dissertation). University of Pittsburgh, Pittsburgh, USA.
- Nelson, A., Gray, M., Jensen, H., Thomas, Y., McIntosh, K., Oke, L., & Paluch, T. (2011). Closing the gap: Supporting occupational therapists to partner effectively with First Australians. *Australian Occupational Therapy Journal*, 58(1), 17-24. DOI: 10.1111/j.1440-1630.2010.00912.x
- O'Hara M, Rowlandson, J, Canadian Association of Speech-Language Pathologists and Audiologists. (2010). Speech, language and hearing services to First Nations, Inuit, and Metis children in Canada, with a focus on children 0 to 6 years of age. Retrieved from <http://sac-oac.ca/sites/default/files/resources/Complete%20report%20-%20English.pdf>.
- Peltier, S. (2014). Assessing Anishinaabe children's narratives: An ethnographic exploration of elders' perspectives. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 174-193.
- Phillips, R., Worley, L., & Rhoades, E. (2010). Socioemotional considerations. In, E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.187-223). Springfield, IL: Charles C Thomas Publisher.
- Prelock, P. A., Hutchins, T., & Glascoe, F. P. (2008). Speech-language impairment: how to identify the most common and least diagnosed disability of childhood. *The Medscape Journal of Medicine*, 10(6), 136.
- Rhoades, E. A. (2008). Working with multicultural and multilingual families of young children. In, J. Madell & C. Flexer (Eds.), *Pediatric audiology: Diagnosis, technology, and management* (pp. 262-268). New York, NY: Thieme Medical Publishers.
- Rhoades, E. A., Price, F., & Perigoe, C. B. (2004). The changing American family & ethnically diverse children with hearing loss and multiple needs. *Volta Review*, 104(4), 285-305.
- Rhoades, E. (2013). Working with multicultural and multilingual families of young children with hearing loss. In J. F. C. Madell (Ed.), *Pediatric audiology: Diagnosis, technology, and management*. (pp. 262-268). New York: Thieme Medical Publishers.
- Santilli, V., & Miller, A. N. (2011). The effects of gender and power distance on nonverbal immediacy in symmetrical and asymmetrical power conditions: A cross-cultural study of classrooms and friendships. *Journal of International and Intercultural Communication*, 4(1), 3-22. DOI: 10.1080/17513057.2010.533787
- Sjogblad, S., Harrison, M., Roush, J., & McWilliam, R. A. (2001). Parents' reactions and

- recommendations after diagnosis and hearing aid fitting. *American Journal of Audiology*, 10(1), 24-31. DOI: 10.1044/1059-0889(2001/004)
- Spahn, C., Richter, B., Burger, T., Löhle, E., & Wirsching, M. (2003). A comparison between parents of children with cochlear implants and parents of children with hearing aids regarding parental distress and treatment expectations. *International Journal of Pediatric Otorhinolaryngology*, 67(9), 947-955. DOI: 10.1016/S0165-5876(03)00160-5
- Sterzuk, A. (2008). Whose English counts? Indigenous English in Saskatchewan schools. *McGill Journal of Education/Revue des sciences de l'éducation de McGill*, 43(1):9-19.
- Statistics Canada. (2011). *Population by mother tongue and age groups (total), 2011 counts, for Canada, provinces and territories*. Retrieved from <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/hltfst/lang/Pages/highlight.cfm?TabID=1&Lang=E&Asc=1&PRCode=01&OrderBy=999&View=1&tableID=401&queryID=1&Age=1>.
- Statistics Canada. (2017). Study: A look at immigration, ethnocultural diversity and languages in Canada up to 2036, 2011 to 2036. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/170125/dq170125b-eng.htm>. Retrieved June 1, 2017 <http://www.statcan.gc.ca/daily-quotidien/170125/dq170125b-eng.htm>
- United States Census Bureau. (2017). New Census Bureau report analyzes U.S. population projections 2015. Available from: <https://www.census.gov/newsroom/press-releases/2015/cb15-tps16.html>.
- Yanbay, E., Hickson, L., Scarinci, N., Constantinescu, G., & Dettman, S. J. (2014). Language outcomes for children with cochlear implants enrolled in different communication programs. *Cochlear Implants International*, 15(3), 121-135. DOI: 10.1179/1754762813Y.0000000062
- Yeowell, G. (2010). What are the perceived needs of Pakistani women in the North west of England in relation to physiotherapy, and to what extent do they feel their needs are being met?. *Physiotherapy*, 96(3), 257-263. DOI: 10.1016/j.physio.2010.01.003
- Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, 12(2), 209-220. DOI: 10.1093/deafed/enl033

Chapter 6: Integrated discussion

Background

This program of research explored the influence of culture in the context of pediatric hearing loss services from both practitioner and caregiver perspectives. The objectives were: 1) to review and assess the state of knowledge with respect to barriers and facilitators of cultural competence in rehabilitation services; 2) to explore practitioners' experiences with providing services to minority culture families who have children with hearing loss; and 3) to explore the experiences of minority culture families receiving services for their child's hearing loss.

Context

Despite considerable literature on cultural competence in various medical fields, there is a paucity of research in the field of pediatric hearing loss (Ball & Lewis, 2014; Eriks-Brophy, 2014; Grandpierre et al., 2018). Western-influenced early hearing loss services were developed based on data normed on the majority population. As a result, families of minority culture backgrounds might not be receiving appropriate care (Rhoades, 2013), which could limit language outcomes. This is concerning due to the substantially increasing diversity of Canada's population. Consequently, there is an important need for empirical research to inform the best standards of care for minority culture families.

Theoretical framework

This program of research was informed by Bronfenbrenner's (1977) bioecological systems theory. This theory considers an individual's development to be influenced by the multilayered contexts of his/her surrounding environment (in order): the microsystem (e.g., home, school, work), mesosystem (interrelations between microsystems), exosystem (e.g., extensions of the mesosystem such as neighborhoods, media, government), macrosystem (e.g., culture, society), and chronosystem (e.g., dimension and evolution of time).

This program of research revealed a variety of environmental contexts influencing the development of the individual. Contextualizing this theory within this dissertation revealed the child with hearing loss is positioned at the core (Figure 3). The caregivers and the family's culture are in the child's immediate environment. Surrounding this layer is the early hearing loss services seeking to address the hearing loss. With culturally competent care, the environmental layers can seamlessly work together to ensure optimal language outcomes for the child. Without cultural competence, the child may experience some unnecessary difficulties achieving this goal (e.g., stigma left unaddressed can lead to the rejection of interventions so as to keep the hearing loss hidden).

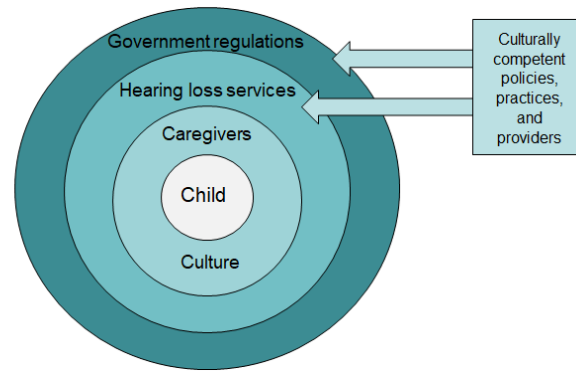


Figure 3. Bronfenbrenner's bioecological systems theory in a pediatric hearing loss context

Bronfenbrenner's framework successfully guided this program of research with its conceptualization of multiple environmental contexts surrounding a developing individual that are interconnected and require investigation from multiple perspectives.

Method

The sequential nature of the mixed methodology used for this program of research helped to complement, strengthen, and confirm the findings. The topic of this dissertation had received little prior attention and for this reason, could not be investigated through a singular method. As result, both qualitative and quantitative inquiries were required. This research therefore employed an exploratory sequential mixed methods design (Creswell, 2013) whereby the researcher investigates the objectives using a qualitative approach. Findings from this approach are then used to develop a quantitative phase.

The scoping review (Chapter 2) provided direct guidance for shaping the content of the interview protocols with practitioners (Chapter 3) and families (Chapter 4). The findings of the scoping review substantially contributed to the development of these protocols, as only one empirical study offered minimal insight into facilitators to promoting cultural competence in a pediatric hearing loss service setting. Utilizing the findings on known barriers and facilitators in other rehabilitation fields (e.g., speech language pathology, physiotherapy, and occupational therapy) successfully enabled the exploration of this topic in pediatric hearing loss services. Findings from the practitioner interviews were used to revise the interview protocol for the families. Specifically, the focus was to explore consistent commonalities in terms of whether the challenges practitioners encountered were also experienced by families. In addition, we also wanted to learn if the strategies practitioners used to provide culturally competent care were considered by the caregivers to be effective. Table 1 provides a visual representation of the methods used throughout this dissertation.

Table 1
Dissertation methodology

Approaches	Study
Qualitative	Scoping Review, Chapter 2
	Practitioner Interviews, Chapter 3
	Caregiver Interviews, Chapter 4
Quantitative	Practitioner Survey, Chapter 5

Ultimately, the mixed methodology approach enabled an analysis of existing literature in rehabilitation services (as no prior systemic approaches to data consolidation had been conducted on this topic), and was used to guide the investigation of practitioners' and caregivers' experiences of service delivery/reception. The sequential nature of the methodology used in this dissertation was salient to successfully exploring a topic for which minimal empirical evidence had been collected.

Summary and Interpretation of Findings

Inquiry 1 – Scoping Review

The first inquiry involved a scoping review to explore existing literature on cultural competence in rehabilitation services. This review was undertaken to explore the state of knowledge on this topic by identifying barriers and facilitators experienced by practitioners and minority culture patients. The overall goal of this literature review was to inform the content for the interviews and survey while addressing potential gaps in the literature.

Results confirmed a research gap in the field of audiology. Only one article in this field explored cultural competency in service provision (Kirkham et al., 2009) and, notably, this topic was not the objective of the study. The minimal relevant findings from this study provided suggestions for facilitators to cultural competence, specifically fostering culturally competent work environments (e.g., increasing diversity in the workforce, cultural competence training, and using cultural liaisons).

The literature search (see Appendix A) was therefore expanded to include other rehabilitation fields (e.g., speech language pathology, occupational therapy, physiotherapy, and nursing within these fields) due to the pilot search yielding few studies in audiology. Findings from these other rehabilitation fields indicated consistency in the barriers (e.g., language barriers, limited culturally appropriate resources) and facilitators (e.g., cultural awareness in practitioners and services, and explanations of services and health care system) experienced by both practitioners and caregivers.

This scoping review provided the first account to summarize the experiences of rehabilitation practitioners providing services to diverse patients, as well as minority culture patients' experiences with receiving services. Article retrieval was limited to English studies and as a result the findings are not globally representative. In addition, there is a possibility that articles were missed as the literature review was restricted to the search strategy and scanning the reference list of included articles. These results provided

the foundation for further investigation in the pediatric audiology field in the remaining inquiries (Chapters 3-5). Alone, this scoping review provides practitioners with knowledge to increase culturally competent services by providing a summary of facilitators to cultural competence (e.g., communication strategies, explanations of services and the health care system) and barriers (e.g., stigma, lack of culturally appropriate materials, etc.).

Inquiry 2 – Interviews with Practitioners

The interview guide for practitioners was based on findings from the scoping review. The interview guide (Appendix D) was designed to explore practitioners' experiences with providing services to minority culture families through the use of semi-structured interviews. A secondary goal for this study was to inform the interview guide for Inquiry 3 (Appendix E), the study completed with minority culture caregivers.

Inquiry 2 findings indicated barriers occurred at each stage of service delivery, from diagnostic services to treatment. Barriers included those related to language, gender (e.g., preference for male practitioners), and lack of culturally appropriate materials (e.g., assessments, therapy content). Strategies described as facilitators to help provide culturally competent care included communication strategies (e.g., repetition, simple language, speaking slowly, and visual aids), learning about cultural differences, explaining the health care systems to families, and modifying assessments and interventions as needed.

Interviews with practitioners from various provinces using different intervention approaches (e.g., oral, visual, and/or total communication approaches to therapy) might have strengthened the study. However, this study was nonetheless able to address a critical research gap by contributing empirical data on cultural competence in an unexplored professional field. To the best of our knowledge, no studies to date have explored service provision to minority culture families of children with hearing loss. This study therefore provides a first step towards exploring challenges experienced by these service providers and the strategies they used to increase culturally competent care.

Inquiry 3 – Interviews with Caregivers

The interview content for parents with minority culture backgrounds with children receiving services for hearing loss was based on findings from the scoping review (Inquiry 1) and the practitioner interviews (Inquiry 2). The sequential nature of the methodology informed the interview guide (Appendix E) as no existing empirical studies on parental perspectives were sufficient to address this dissertation's focus on barriers and facilitators to culturally competent care.

Parents reported experiencing difficulties when learning of their child's hearing loss, which centered around four primary issues: stigma, preservation of home language, additional support, and explanations of services and health care system. Discussions about perceptions of hearing loss in their home country revealed stigmas that sometimes resulted in the need to hide disabilities; this is an important finding, and practitioners must be aware of this issue in order to address it. While conversations about Canadian health services were quite positive, parents expressed the need for practitioners to encourage the preservation of their home language. In addition, extra and ongoing support, such as access to the same translator, was highlighted by parents as an important

need in addition to explanations of what each session entails. Finally, explanations of health care systems were viewed as crucial for culturally competent care as many parents stated the health care systems in their home country were quite different.

To our knowledge, this study is the first of its kind to explore the experiences of parents of a minority culture with receiving early hearing loss services for their children. Findings from this study can help practitioners gain valuable insight into the possible challenges that parents of minority culture backgrounds encounter. The findings also capture various strategies that can improve the provision of culturally competent care. Although the study featured only a few participants who recently moved to Canada, this limitation provides direction for future studies. An additional key recommendation is that researchers seeking to investigate cultural competence in pediatric hearing loss services should select participants receiving services from different service models.

Inquiry 4 – Survey of Practitioners

The final inquiry involved the development and distribution of a survey designed for practitioners who have provided early hearing loss services to minority culture families. The goal of this survey was to explore the experiences of practitioners providing services to minority culture families within Canada. Survey development was informed by the findings stemming from the first three inquiries. Piloting the survey amongst practitioners providing services in a large multicultural city as well as among international graduate students helped improve the relevance and readability of the survey.

As was the case for the interviews, results indicated practitioners experienced challenges during each stage of service delivery. However, the survey involved a much larger sample of practitioners responding from various Canadian provinces. Key challenges included language barriers, stigma, and the lack of culturally appropriate materials. However, numerous strategies were also reported and used to ensure the provision of culturally competent care. Key strategies were communication strategies, learning about cultural differences, selecting culturally appropriate materials, and modifying intervention content when needed.

The results of this study contribute to a research field that has received little attention. The greatest strength of this study was the large sample of audiologists who responded to the survey. In addition, the survey was developed from previous findings stemming from this dissertation (Chapters 2-4). Combined with consistent findings from the preceding studies, this final chapter contributes foundational knowledge of barriers and facilitators to providing culturally competent pediatric hearing loss services.

Future studies seeking to expand on this literature should seek insight from practitioners providing ongoing care. Practitioners such as language therapists or itinerant teachers of the deaf and hard of hearing would be able to provide insight as they have more opportunities to get to know the families of their pediatric patients. Audiologists, the main profession that responded to this survey, typically see their patients less and only provide diagnostic and/or technological support. Studies should also seek insight from practitioners who have provided services to Canada's Indigenous population, given they represent a significant portion of Canada's overall population and culturally competent care could address noted health inequities for this group.

In summary, the results of this study contribute to a research field that has received little attention. The findings can be used to improve culturally competent care in early hearing loss services amongst Canada's increasingly diverse population.

Integration of findings

A synthesis of the findings across all four studies reveals common themes regarding barriers and facilitators and their connections to the provision of culturally competent care.

Barriers to cultural competence in pediatric hearing loss services

A review of all inquiries confirms the occurrence of cultural barriers at each stage of service delivery, from diagnostic testing to the provision of treatment, suggesting room for intervention development at all stages of the treatment trajectory. Language barriers and stigma were consistently shown to be key challenges experienced both by practitioners and families. Practitioners unable to converse in a given family's dominant language were seen as a particularly notable challenge. Caregivers provided a different insight: the need to preserve their home language. Caregivers repeatedly stated how important it was to them to raise their children with their home language, and also with both official languages in Canada. While the practice to promote multilingualism for children with hearing loss in Canada has become more common, the promotion of unilingualism for a multicultural child with hearing loss does not align with culturally competent care, except perhaps in instances where the child has additional health issues (e.g., other illnesses, disease, syndromes, learning disabilities, etc.).

Stigma, while reported as a challenge for both practitioners and caregivers alike, was discussed in depth by caregivers who provided insight into why hearing loss and disabilities were taboo in their home countries. Specifically, caregivers pointed to a prevailing lack of knowledge surrounding hearing loss and limited instances where they encountered children with this disability and/or children using hearing aids. This lack of knowledge might have contributed to children with disabilities being sent away to 'special schools'. The anxiety surrounding the possibility of stigma might also account for family members' doubts about diagnosis. This new insight can better prepare practitioners who provide services to families of minority culture backgrounds as they will be able to better understand why stigma exists, address it with explanations of hearing loss, discuss the benefits of hearing technology, and describe options for mainstream schools. Limited culturally appropriate materials such as language assessments were also consistently noted to be problematic. However, this view was only reflected by practitioners in both interviews and the survey; caregivers might have experienced these challenges, but this theme did not emerge in their interviews. Given the small sample of caregivers in addition to having only a few recent immigrant participants, future work should seek to interview more recent immigrant families and/or families with Indigenous heritage to seek their perspectives. Exploration of this topic would be of benefit as it would provide insight into how to develop culturally appropriate materials.

Practitioners in both interviews and surveys consistently reported gender as a barrier for various reasons (e.g., caregivers were not receptive to information provided by a female practitioner or female children being asked to remove religious attire (their hijab) by a male practitioner). Caregivers did not mention this concern, but this could be

due to the small sample size and limited number of recent immigrant participants; this barrier might also be experienced by caregivers and therefore requires further investigation in future studies.

Facilitators to cultural competence in pediatric hearing loss services

A wide range of facilitators to providing culturally competent care was reported in the studies within this dissertation. Knowledge of cultural differences was viewed as an important characteristic by both practitioners and families. Caregivers also reported the desire to have practitioners with more experience serving families of minority culture backgrounds as they would be better able to tailor care to meet families' needs. Gaining knowledge on different cultures can involve attending cultural competence training events and asking families about their home life (e.g., roles of family members, daily routines). Services that incorporate such cultural knowledge are another important feature to cultural competence in a healthcare context. According to results from caregiver interviews, this can be achieved with the promotion of the preservation of home language, the provision of culturally appropriate materials (e.g., translated documents, tailored assessments and intervention sessions), and the use of communication strategies (e.g., simple language, pictures, or videos) to ease language barriers.

Caregivers also exclusively commented on the need for and importance of translators. While practitioners reported the benefit of translators and interpreters, caregivers provided additional insight on the benefits of having access to the same translator. This would save time and reduce frustrations experienced by families with respect to the need to repeat background information to provide context to the translator.

Finally, both practitioners and families consistently reported the benefits of detailed explanations. Specifically, explanations of the diagnosis, perceptions of disabilities in Canada, interventions, and available support were deeply appreciated by families and reported to be important by practitioners. Caregivers explained that the health care system in Canada is often quite different to what they were accustomed to in their home country. Clear explanations of hearing loss diagnosis, treatment plans, and the health care system can contribute to ensuring the provision of culturally competent care.

Revisiting Bronfenbrenner's Bioecological Systems Theory

Revisiting the conceptual framework used to guide this program of research, the findings from this dissertation suggest that culture affects each environmental context, particularly if the family has recently immigrated. This insight also supports the notion of the chronosystem, as environmental contexts change over time. For example, a new arrival may experience more cultural challenges as opposed to someone who has lived in Canada for many years and acclimated; in other words, the more acclimatized the family, the fewer cultural barriers might be experienced in service provision. This insight also applies to the practitioner who is providing services to newcomers or to rural Indigenous populations.

Summary

Canadian populations are becoming increasingly diverse. Early hearing loss practitioners need to be aware of possible barriers to care during service provision to minority culture families and the strategies that can be used ensure the provision of culturally competent care.

The early stages of this research indicated an apparent lack of studies on cultural competence in the field of audiology. This was apparent in a preliminary literature review (Chapter 1) that detailed reports from experts who stated available research on this topic was often dated and anecdotal (Ball & Lewis, 2014; Eriks-Brophy, 2014). The first level of inquiry, a scoping review (Chapter 2), provided confirmation of the lack of empirical evidence on this topic in the context of hearing loss services. Chapters 3-5 addressed the research gap by investigating the perspectives of both practitioners and families of children with hearing loss. Findings from qualitative and quantitative inquiries reiterated the concerns of experts who brought attention to the fact that pediatric hearing loss services are tailored to meet the needs of the majority culture. While this was not directly confirmed by practitioners participating in this dissertation, the vast majority of the study participants reported experiencing various barriers due to culture at each stage of service delivery. This finding suggests the need for improvement to better ensure the provision of care that addresses the needs of our multicultural populations. Improving cultural competence is especially important considering the influence culture can have on families with children of hearing loss. For instance, and as noted in Chapter 1, the diagnosis of hearing loss in a child can result in extended family members severing all ties with the child and his/her parents (Jackson, Traub, & Turnbull, 2008). A similar finding emerged from interviews with caregivers (Chapter 4) in this dissertation. Specifically, some families hid the loss from relatives or the general public in their home countries because the stigma associated with disability was so strongly held.

A limitation in this research program was that half the studies (e.g., interviews with practitioners and caregivers) were contextualized to the Ottawa region. In addition, there was minimal insight from families and limited insight from therapists (e.g., survey). Nonetheless, this dissertation was able to provide insight into a topic that has not received attention.

Addressing common challenges reported by practitioners and families alike is important for improving cultural competence in pediatric hearing loss services. The preliminary search (Chapter 1) suggested practitioners use strategies such as simple language, providing translators/interpreters, becoming familiar with different cultural practices, and modifying assessments when needed (Bernstein & Eriks-Brophy, 2010; Kay-Raining Bird, 2014; Eriks-Brophy, 2014). Findings from all inquiry levels supported all of these strategies; however, the latter strategy was not confirmed in interviews with caregivers. It is possible caregivers are not aware assessments can be culturally adapted. An additional survey developed for caregivers could further investigate whether modifying assessments and/or tailoring care is a beneficial strategy for providing culturally competent care.

Future research

Additional research in culturally competent pediatric hearing loss services is still required. Specifically, more research is needed into caregivers' experiences from the perspective of recent immigrants as well as Canadian Indigenous families. Future studies should also investigate this topic by exploring the experiences of different professions within this field (e.g., itinerant teachers of the deaf and hard of hearing, language therapists, etc.) and those who use different services models (e.g., other language therapy approaches) as this dissertation mainly focused on the spoken-language approach.

Conclusion

This research provides a foundational understanding of possible challenges and strategies to culturally competent practices in the field of pediatric hearing loss. Additionally, it contributes to the field of rehabilitation sciences by investigating the state of knowledge on this topic in various fields of rehabilitation (e.g., speech pathology, occupational therapy, and physiotherapy). While the scoping review confirmed the topic of cultural competence has been explored in many rehabilitation fields (not including pediatric hearing loss), it also highlighted a need for future studies to explore the perspectives of patients and caregivers receiving services from all of these fields. It is the hope of this author that the research findings of this dissertation can be used to provide improved standards of care specific to minority culture populations.

References

- Ball, J., & Bernhardt, B. M. (2008). First Nations English dialects in Canada: Implications for speech-language pathology. *Clinical Linguistics and Phonetics*, 22(8), 570–588.
- Ball, J., & Lewis, M. (2014). First Nations elders' and parents' views on supporting their children's language development.
- Bernstein, A., & Eriks-Brophy, A. (2010). Supporting families. In, E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Toward a family-centered approach* (pp.225–257). Springfield, IL: Charles C Thomas Publisher.
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513–531.
- Creswell, J. W. (2014). *Research Design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Eriks-Brophy, A. (2014). Assessing the language of Aboriginal Canadian children: Towards a more culturally valid approach. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 152–173.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., & Potter, B. (2018). Barriers and facilitators to rehabilitation services: A scoping review. *BMC Health Services Research*, 18(23). doi: 10.1186/s12913-017-2811-1.
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82–98.
- Kay-Raining Bird, E. (2014). A resource kit to assist speech-language pathologists and audiologists in providing informed services to first nations, Inuit, and Métis people. *Canadian Journal of Speech-Language Pathology and Audiology*, 38(2), 238–250.
- Kirkham E, Sacks C, Baroody F, Siddique J, Nevins ME, Woolley A, et al. Health disparities in pediatric cochlear implantation: An audiologic perspective. *Ear and Hearing*. 2009;30(5):515-25.
- Rhoades, E. A. (2013). Working with multicultural and multilingual families of young children. In, J. Madell & C. Flexer (Eds.), *Pediatric audiology: Diagnosis, technology, and management* (pp. 262-268). New York, NY: Thieme Medical Publishers.

Statement of Contributions

Scoping review (Chapter 2): With assistance from Lindsey Sikora in performing the strategy, all screening, data abstraction, analysis, synthesis, and original draft of the paper was performed by Viviane Grandpierre. Victoria Milloy, the second author, provided secondary screening and verified the abstraction. All coauthors provided support regarding the research design and provided feedback for edits to the manuscript.

Practitioners' interview (Chapter 3): Viviane Grandpierre is responsible for developing the interview protocol, testing the protocol, conducting the interviews, transcribed, analyzing, synthesizing, and preparing the original draft. Viviane Grandpierre performed the majority of transcriptions, with several transcribed by Oreen Mendonca. All transcriptions were verified by Viviane Grandpierre. Roanne Thomas reviewed and provided feedback on the coding. All coauthors provided support regarding the research design and provided feedback for edits to the manuscript.

Caregivers' Interview (Chapter 4): Viviane Grandpierre is responsible for developing the interview protocol, testing the protocol, conducting the interviews, transcribed, analyzing, synthesizing, and preparing the original draft. Ovini Thomas performed several transcriptions, though the vast majority was conducted by Viviane Grandpierre. All transcriptions were verified by Viviane Grandpierre. Roanne Thomas reviewed and provided feedback on the coding. All coauthors provided support regarding the research design and provided feedback for edits to the manuscript.

Survey Manuscript (Chapter 5): Viviane Grandpierre is responsible for developing a draft survey and piloting the survey. She is responsible for integrating feedback and revising the survey, dissemination, data collection, analyses, and drafting the original manuscript. Beth Potter provided feedback on the initial and finalized surveys, and also provided assistance with analyses and interpretation. JoAnne Whittingham reviewed the data dictionary developed by Viviane. Flora Nassrallah translated the survey into French and disseminated the survey to French respondents. She also assisted with performing statistical analyses. Jen Taylor performed data entry, 12% of which was verified by Viviane Grandpierre. All coauthors provided support regarding the research design and provided feedback for edits to the manuscript.

Knowledge Translation

Oral Presentations

Viviane Grandpierre. (2017). Barriers and Facilitators to Cultural Competence in Rehabilitation Services. 19th Annual Rehabilitation Research Colloquium Organizing Committee, Ontario, Canada.

Main Audience: Researcher

Viviane Grandpierre. (Oral presentation accepted). Barriers and Facilitators to Cultural Competence in Pediatric Hearing Loss Services. SAC Conference. Edmonton, Alberta, May, 2018.

Poster presentations

Viviane Grandpierre, Elizabeth Fitzpatrick, Roanne Thomas. (2017). Barriers and facilitators to cultural competence in early hearing loss services: A qualitative analysis. Canadian Association of Audiology, Ottawa, Canada.

Main Audience: Researcher

Journal articles

Viviane Grandpierre, Victoria Milloy, Lindsey Sikora, Elizabeth Fitzpatrick, Roanne Thomas, Beth Potter. (2018). Barriers and facilitators to cultural competence in rehabilitation services. BMC Health Services. 18:23. doi: 10.1186/s12913-017-2811-1 Research.

First Listed

Viviane Grandpierre, Elizabeth Fitzpatrick, Roanne Thomas, Oreen Mendoca, Beth Potter, Lindsey Sikora. (Under review). Barriers and facilitators to cultural competence in early hearing loss services: A qualitative analysis. Canadian Journal of Speech Pathology and Audiology.

Appendix A

Scoping review, Chapter 2 – Search strategy

Medline

1. Cultural Competency/
2. Culturally Competent Care/
3. Minority Health/
4. (Cultur* adj2 competen*).tw.
5. (cultur* adj2 sensitiv*).tw.
6. (cross cultur* adj2 care).tw.
7. (transcultural adj2 care).tw.
8. (minority adj1 health).tw.
9. (multicultur* adj2 health*).tw.
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. exp Rehabilitation/
12. "Physical and Rehabilitation Medicine"/
13. Physical Therapy Modalities/
14. Occupational Therapy/
15. Audiology/
16. Speech-Language Pathology/
17. Nursing/
18. Transcultural Nursing/
19. Nursing Care/
20. rehabilitation.tw.
21. physiotherap*.tw.
22. (physical adj1 therap*).tw.
23. (occupational adj1 therap*).tw.
24. audiolog*.tw.
25. (speech adj1 language adj1 patholog*).tw.
26. nurs*.tw.
27. or/11-26
28. exp Socioeconomic Factors/
29. Healthcare Disparities/
30. Racism/
31. Social Discrimination/
32. Health Services Accessibility/

33. Prejudice/
34. Xenophobia/
35. Minorities Groups/
36. "Emmigrants and Immigrants"/
37. "Transients and Migrants"/
38. Vulnerable Population/
39. Refugees/
40. (sociocultur* adj2 barrier*).tw.
41. (health care adj2 dispar*).tw.
42. (racial adj2 disparit*).tw.
43. (ethic* adj2 disparit*).tw.
44. racism.tw.
45. (social adj2 discrimination).tw.
46. (cultur* adj2 responsiv* adj2 care).tw.
47. (Health adj2 service* adj2 accessib*).tw.
48. prejudice.tw.
49. xenophon*.tw.
50. minorit*.tw.
51. immigrant*.tw.
52. refugee*.tw.
53. transient*.tw.
54. or/28-53
55. 10 and 27 and 54

psycINFO

1. Cultural Sensitivity/
2. Cross Cultural Differences/
3. Cross Cultural Treatment/
4. (Cultur* adj2 competen*).tw.
5. (cultur* adj2 sensitiv*).tw.
6. (cross-cultur* adj2 difference*).tw.
7. (cross-cultur* adj2 treatment).tw.
8. (transcultural adj2 care).tw.
9. (minority adj1 health).tw.
10. (multicultur* adj2 health*).tw.
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. rehabilitation/

13. Physical Therapy/
14. Occupational Therapy/
15. Audiology/
16. Speech Language Pathology/
17. Nursing/
18. rehabilitation.tw.
19. physiotherap*.tw.
20. physical therap*.tw.
21. occupational therap*.tw.
22. audiolog*.tw.
23. speech language patholog*.tw.
24. nurs*.tw.
25. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26. sociocultural factors/
27. health disparities/
28. racism/
29. social discrimination/
30. minority groups/
31. immigration/
32. refugees/
33. at risk populations/
34. (sociocultur* adj2 barrier*).tw.
35. (health care adj2 dispar*).tw.
36. (racial adj1 discrimination).tw.
37. (ethic* adj2 disparit*).tw.
38. racis*.tw.
39. discrimination.tw.
40. (cultur* adj2 responsiv* adj2 care).tw.
41. minorit*.tw.
42. immigrant*.tw.
43. refugee*.tw.
44. transient*.tw.
45. (vulnerable adj1 population*).tw.
46. (at risk adj1 population*).tw.
47. 26 - 46
48. 11 and 25 and 47

EMBASE

1. cultural competence/
2. cultural sensitivity/
3. transcultural care/
4. minority health/
5. (Cultur* adj2 competen*).tw.
6. (cultur* adj2 sensitiv*).tw.
7. (cross cultur* adj2 care).tw.
8. (transcultural adj2 care).tw.
9. (multicultur* adj2 health*).tw.
10. (minority adj1 health).tw.
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. exp rehabilitation care/
13. rehabilitation/
14. physiotherapy/
15. occupational therapy/
16. audiology/
17. speech disorder/
18. nursing/
19. nursing practice/
20. rehabilitation.tw.
21. audiolog*.tw.
22. physiotherap*.tw.
23. physical therap*.tw.
24. occupational therap*.tw.
25. speech language patholog*.tw.
26. nurs*.tw.
27. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. health care disparity/
29. racism/
30. Social discrimination/
31. minority group/
32. minority health/
33. immigrant/
34. refugee/

35. vulnerable population/
36. (sociocultur* adj2 barrier*).tw.
37. (health care adj2 dispar*).tw.
38. (racial adj1 discrimination).tw.
39. (ethic* adj2 disparit*).tw.
40. racis*.tw.
41. discrimination.tw.
42. (cultur* adj2 responsiv* adj2 care).tw.
43. minorit*.tw.
44. immigrant*.tw.
45. refugee*.tw.
46. transient*.tw.
47. (vulnerable adj1 population*).tw.
48. 28 - 47
49. 11 and 25 and 47

AMED

1. (Cultur* adj2 competen*).tw.
2. (cultur* adj2 sensitiv*).tw.
3. (cross cultur* adj2 care).tw.
4. (transcultural adj2 care).tw.
5. (minority adj1 health).tw.
6. (multicultur* adj2 health*).tw.
7. 1 or 2 or 3 or 4 or 5 or 6

CINAHL

1. (MH "Cultural Competence")
2. (MH "Cultural Sensitivity")
3. (MH "Transcultural Care")
4. (Cultur* N2 competen*)
5. (cultur* N2 sensitiv*)
6. (cross cultur* N2 care)
7. (transcultural N2 care)
8. (minority N1 health)
9. (multicultur* N2 health*)
10. 1-9
11. (MH "Rehabilitation+")
12. (MH "Physical Therapy+")

13. (MH "Occupational Therapy")
14. (MH "Audiology")
15. (MH "Speech-Language Pathology")
16. (MH "Nursing Staff, Hospital")
17. (rehabilitation)
18. (physiotherap*)
19. (physical therap*)
20. (occupational therap*)
21. (audiolog*)
22. (speech language patholog*)
23. (nurs*)
24. 11-23
25. (MH "Healthcare Disparities")
26. (MH "Racism")
27. (MH "Discrimination")
28. (MH "Minority Groups")
29. (MH "Immigrants")
30. (MH "Refugees")
31. (MH "Transients and Migrants")
32. (MH "Special Populations")
33. (sociocultur* N2 barrier*)
34. (health care N2 dispar*)
35. (racial N1 discrimination)
36. (ethic* N2 disparit*)
37. (racis*)
38. (discrimination)
39. (cultur* N2 responsiv* N2 care)
40. (minorit*)
41. (immigrant*)
42. (refugee*)
43. (transient*)
44. (vulnerable N1 population*)
45. 25-44
46. 10 AND 24 AND 45

LLBA

1. Cultur* competen*

2. cultur* sensitiv*
3. cross cultur* care
4. transcultural care
5. minority health
6. multicultur* health*

ComDisDome

1. Cultur* competen*
2. cultur* sensitiv*
3. cross cultur* care
4. transcultural care
5. minority health
6. multicultur* health*

OTSeeker

1. Cultur* competen*
2. cultur* sensitiv*
3. cross cultur* care
4. transcultural care
5. minority health
6. multicultur* health*

PEDro

1. Cultur* competen*
2. cultur* sensitiv*
3. minority health
4. multicultur* health*

Appendix B

Scoping review, Chapter 2 - Data abstraction form

DATA EXTRACTION PILOT

Study Characteristics

- Author:
- Year:
- Title:
- Journal:
- Sub-study (yes/no, author, year & title):
- Country in which the study was conducted:
- Rehab field:
- Ethics:

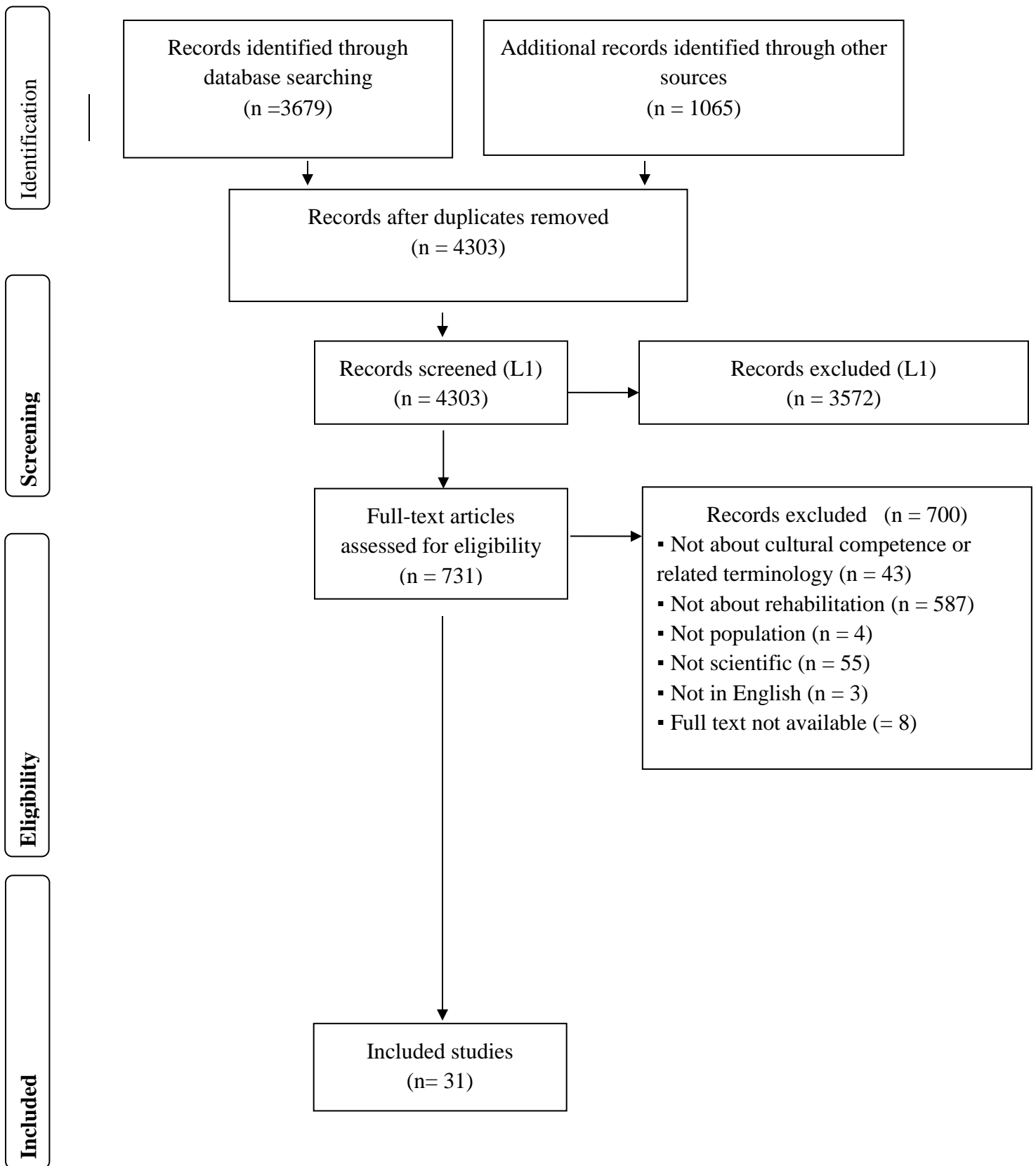
Study Data

- Study objective(s):
- Study design:
- Sample size / Participant characteristics (e.g. languages, cultural background, age, gender, disease, SES):

Outcomes

- Barriers, Facilitators in delivery/reception of rehabilitation services (e.g. parent/patient/practitioner views; recommendations for practitioners/services):

Appendix C
 Scoping review, Chapter 2 - PRISMA Flow Chart



Appendix D

Practitioner Interview, Chapter 3 – Interview Protocol

Purpose of interview: I am meeting with practitioners who are or have provided services to minority culture caregivers of children with hearing loss in order to better understand service needs. I am defining ‘minority cultures’ as any cultural groups that are not representative of the majority culture in Canada (e.g. caregivers that do not identify as primarily French or English Canadian). I am interested in learning about your experiences with servicing minority culture families. For example, I would like to hear about whether the delivery of care to this population is a smooth process or whether there are challenges. I would also like to hear about if/how you tailor care to suit the needs of minority culture families.

Procedure: I will ask you questions to guide our conversation but feel free to talk about your experiences and to add any information you feel is relevant and important. Please don’t hesitate to ask questions. I’m going to start off by asking you some background questions, then I’ll ask questions about your interpretation of culturally competent care. I’ll then move on to asking you about your experiences servicing minority culture families and strategies that you might use to help improve service delivery.

Definitions: Cultural competence in a health care context has been defined as “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 et al., p.293).

General information:

Location of interview: Clinic Other: _____

Gender:

Informant: Audiologist AVT Other: _____

Education:

Years of practice:

Background questions

1. What is your position title?
2. How long you have been working in this field?
3. Please tell me about your cultural heritage and the languages you speak.

Cultural competence questions

4. I’m looking for some information on the proportion of cultural minority families you service. In your current caseload, how often do you work with minority culture families? (e.g. most of the time, half of the time, some of the time, etc.)

Prompt:

In the past year, what percent of your patients are cultural minorities? What are the most common cultural groups serviced?

Again, cultural minority families are defined here as any cultural groups that are not representative of the majority culture in Canada.

5. What does the phrase ‘culturally sensitive care’ mean to you?

Prompt: In your opinion, what are key characteristics of a culturally sensitive practitioner?

6. Have you attended any courses or training on cultural competence?

Prompt: Did you receive any training in your degree? From your job?

Questions on servicing minority culture families: from diagnosis to intervention

Note: Some of these questions might be more relevant for a particular position in Audiology – if it's not part of your job, please describe any relevant encounter.

7. Did you encounter surprising reactions to the diagnosis? If you have, tell me about it.

Prompt: Did some cultural minority families perceive disability as something to be ashamed of or something to be concealed or as a gift?

8. Did you encounter challenges when discussing amplification options? If you have, tell me about it.

Prompt:

Did you have to use any strategies for hearing aid use? Did you feel that you had to do anything differently?

Were some opposed to amplification for cultural reasons?

Are there difficulties with achieving consistent amplification use?

Do some families seem to feel they need more guidance with amplification usage?

9. Did you experience challenges when providing therapy? If you have, tell me about it.

Prompt: Were some aspects of the therapy not applicable to the child's home environment?

10. Did you encounter challenges when filling out language assessment questionnaires? If you have, tell me about it.

Prompt: Were some aspects of the questionnaires not applicable to the child's home environment?

Personal strategies for working with minority culture families

11. What are some of the methods you use when providing services to minority culture families?

Prompt: Do you modify standardized assessments such as administering a subset as opposed to a complete battery of assessments?

Prompt: Do you tailor therapy sessions in order to better reflect the patient's home environment?

12. Do you use any methods to help improve communication with minority culture families? If so, what are some examples? If not, please explain why.

Prompt: Did you try different strategies to improve communication like simplifying language?

13. What would you say is the most important factor in culturally appropriate care?

Prompt: Here are some examples: knowledge of cultural differences, knowledge of culturally sensitive practices, having culturally appropriate assessments and interventions, etc.

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

Appendix E

Caregiver Interview, Chapter 4 – Interview Protocol

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
 Cochlear implants Left ear Right ear

Age of amplification: _____

Background

1. Have you always lived in Canada?
2. Tell me a little bit about your family.
Prompt: Are your kids in school yet?
3. Tell me about your family’s cultural background.
Prompt: What is your child’s/children’s cultural heritage?
Prompt: Do you have any cultural traditions?
Prompt: Tell me about something about the customs of your culture (e.g. meals).
Prompt: Are there any differences in the health care system?
4. What languages do your family speak?

Hearing loss history

5. Tell me about how you found out about your child’s hearing loss.
Prompt: Was your child screened at birth?
Prompt: Tell me about the process from screening to when your child’s hearing loss was confirmed. How many visits?

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

6. 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?
Prompt: What information or guidance did you need after the diagnosis (e.g. after confirmation)?
Prompt: What kind of supports did you need, e.g. social worker, therapist, family?
Prompt: What supports/information did you receive?

Cultural information

7. How is hearing loss regarded in your family's culture?
Prompt: Is hearing loss viewed as a disability? Is it viewed negatively or positively?
Prompt: How are disabilities viewed/seen in your culture?
8. 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?
Prompt: 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

9. 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?
10. How did you feel about using English/French in your hearing loss appointments?
Prompt: Would you have wanted an interpreter?
Prompt: Were you encouraged to use your language with your child? How did you feel about that?
11. 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?
Prompt: What would be the best way to be told about your child's hearing loss?
12. 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?
Prompt: Was your health care practitioner sensitive to your values?
Prompt: If you could improve this experience, what would be different?
13. 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?
Prompt: What did you think of the therapy that you needed to continue at home?

Prompt: What are some recommendations for improvement?

14. 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?

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

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

Appendix F

Practitioner Interview, Chapter 3 – Consent form

INFORMATION LETTER / CONSENT FORM Health care practitioner version

Investigating barriers and facilitators to cultural competence in early hearing loss interventions

CHEO Principal Investigator: Ms. Kelley Rabjohn

Principal Investigator: Elizabeth Fitzpatrick, Ph.D.

Co-investigator: Viviane Grandpierre, Ph.D.(c)

Address:

CHEO Research Institute,
401 Smyth Road,
Ottawa, ON
K1H 8L1

Telephone Number: (613) 738-3907

The purpose of this study is to investigate whether early hearing loss services are culturally sensitive to minority culture families. Specifically, we are interested in learning about whether we need to tailor care to meet the needs of minority culture families (e.g. families that don't identify themselves as primarily English or French Canadian).

Researchers at the University of Ottawa and the Children's Hospital of Eastern Ontario Research Institute (CHEO) are conducting this research project. Before agreeing to take part in this study, it is important that you read and understand this document.

Why is this study being done?

This study is being conducted because Canada's population is becoming increasingly multicultural. The problem is that experts have stated that hearing loss interventions are tailored to meet the needs of the majority populations' cultural values, and as a result, may not equally serve all cultural groups. Additionally, there seems to be very little research on how cultural diversity impacts hearing loss services. The little research that we have found to date suggests that available information is dated and usually stereotypical. For these reasons, this study is being conducted to get information from minority culture caregivers (e.g. people who do not identify their culture as English or French Canadians) of children with hearing loss about their experiences receiving care

and the experiences of pediatric hearing loss practitioners delivering care to this population.

The information from the interviews will be used to help describe possible limitations and successes in hearing loss services for minority culture children. These results will also be used to help determine the need for improving cultural sensitivity in pediatric hearing loss interventions.

How many people will participate?

At CHEO, we expect to have 12 caregivers and 12 hearing loss practitioners to participate. We expect to invite eligible participants in the study for the next year. The study is expected to be active until summer, 2018.

What does participation involve?

You have been selected because you have provided services to cultural minority families. We will be interviewing select families and practitioners simultaneously to document possible instances where care is affected by cultural differences and instances where care has been tailored to meet the needs of these families.

Interviews

If you agree to participate, we will ask you to part take in a single interview. In this interview, we will ask you questions about your experience in servicing culture minority families, from the time of hearing loss identification to intervention. In addition, we would also like to know about what you think is important for servicing these families.

If you agree to participate, we will meet with you at a convenient time and place for a 45 to 60 minute interview. This can be during work time or off work time according to your preference. The interviews will be audio-recorded.

Benefits, Risks and Inconvenience

Benefits

There are no anticipated benefits from participating in this study; however, our hope is to change clinical practice if the results indicate a need or to take better care of pediatric hearing loss patients in the future.

Risks/Inconvenience

We know of no harm that taking part in this study could cause you. Participation in this study may cause you some inconvenience because of the time involved for completing the interviews.

Will I be paid to participate?

You will not be paid to take part in this study.

Will I be told about new information?

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study. At the conclusion of the study, you can receive a copy of the results.

What about confidentiality and privacy?

The decision to participate or not in the research will be kept confidential. You may withdraw from participation at any time during this study. All information will be kept strictly confidential. We might quote some comments from the interviews however your name will not be disclosed.

All copies of the audio recording of the interview and interview notes will be carefully stored with password protection on a restricted computer securely stored in the Audiology Lab at the Children's Hospital of Eastern Ontario Research Institute. Only our team members will have access to the interview information, however members from the CHEO research Ethics Board may also look at the site where your records are held to check that our study is following the proper laws and guidelines. Any information from the interviews will be destroyed (e.g. shredded, deleted) 7 years after publication of the results.

Is the research team benefiting from the study (i.e., real or perceived conflict/competing interests)?

The research team members are not benefiting personally, financially or in some other way from this study.

What if I have questions?

If you have any questions concerning participation in this study, contact Viviane Grandpierre (the study's co-investigator) at 613- 738-3907.

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

CONSENT

I acknowledge that the research procedures described above, and of which I have a copy, have been explained to me. I understand that I am voluntarily agreeing to participate in this research study. I have been given an opportunity to ask questions concerning the study process and the questions have been adequately answered. In addition, I know that I may contact the investigators (whose contact information is below) if I have further questions either now or in the future. I have been assured that personal records relating to this study will be kept confidential. I understand that my identity will not be disclosed to any person, except if there is a medical emergency or if required by law. I understand that I can withdraw from the study at any time and for any reason. I understand that if any knowledge gained from this study becomes available that could influence my decision to continue in this study, I will be promptly informed.

I, _____, consent to the participation of myself in the study described above.

Name of witness

(printed)

Signature _____ Date _____

I have explained this study to the participant and I am satisfied that it is understood

Name and Title

Signature _____ Date _____

Research Team:

Principal Investigator: Elizabeth Fitzpatrick, PhD, AUD(C); Faculty of Health Sciences, University of Ottawa, CHEO Research Institute; tel. 613-562-5800, ext. 4545; email: elizabeth.fitzpatrick@uottawa.ca.

Co-Investigator Viviane Grandpierre, PhD; Faculty of Health Sciences, University of Ottawa, CHEO Research Institute; tel. 613-738-3907; email: vgrandpierre@cheo.on.ca

Appendix G

Caregiver Interview, Chapter 4 – Consent to contact form

Investigating barriers and facilitators to cultural competence in early hearing loss interventions

Family Consent to Contact

You are being invited to join a research study that is looking to learn about whether child hearing loss services are appropriate for minority culture families (e.g. people who do not identify themselves as mainly French or English Canadian). You are being invited to join this study because your child has been getting services for his/her hearing loss. Researchers at the University of Ottawa and the Children's Hospital of Eastern Ontario Research Institute (CHEO) are running this research study. Before agreeing to take part in this study, it is important that you read and understand this document.

Please see the attached information letter for detailed information.

If you are interested in learning more about the study, the researchers would be happy to contact you to answer any questions that you have. If you agree to have us call or e-mail you please complete this form. You will be contacted by Viviane Grandpierre, the study's co-investigator.

This study has been approved by the CHEO Research Ethics Board.

What is your child's cultural heritage? _____

Your Name: _____

Telephone: _____

Please see the back of this consent for cautions about using e-mail for communication. In our e-mail communications with you, we will not use your child's name or date of birth.

E-mail address - please write clearly: _____

What is the best time of day to call you:

morning afternoon evening

I, _____ have read and fully understand this consent form. I give permission for the researchers to contact me to answer any questions I may have about this study.

Signature of Parent/Caregiver: _____

Appendix H

Caregiver Interview, Chapter 4 – Consent form INFORMATION LETTER / CONSENT FORM

Caregiver version

Investigating barriers and facilitators to cultural competence in early hearing loss interventions

Principal Investigator: Elizabeth Fitzpatrick, Ph.D.

Co-investigator: Viviane Grandpierre

Address:

CHEO Research Institute,
401 Smyth Road,
Ottawa, ON
K1H 8L1

Telephone Number: (613) 738-3907

You are being invited to join a research study that is looking to find out about whether hearing loss services for children are appropriate for minority culture families. Researchers at the University of Ottawa and the Children's Hospital of Eastern Ontario Research Institute (CHEO) are running this research study. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to participate or not in this study will not affect the care you receive at CHEO. You are free to withdraw from the study at any time and there will be no penalty to you or your child.

Why is this study being done?

This study is being done because Canada's population is becoming more and more multicultural. The problem is that hearing loss services typically use tools that were made based on information about people who represent the majority population (e.g. English or French Canadians). There is very little research about cultural diversity in hearing loss services and how appropriate these services are for minority culture families. The little research that we have found suggests that available information is old and usually stereotypical. For these reasons, this study is being done to get information from culturally diverse parents/caregivers of children with hearing loss (e.g. people who do not

identify their culture as English or French Canadians). We want to know about what your experiences were like when your child was getting care for his/her hearing loss. We want to know if you thought that the service your child received were culturally sensitive. For example, we'd like to know if you found that some of the information used in language therapy sessions were appropriate or fitting of your home environment.

The results of this study will help to us find out ways to improve hearing loss services for culturally diverse children and their families.

How many people will participate?

At CHEO, we expect to have 12 parents/caregivers participate. We expect to invite people to participate in the study for the next year. The study is expected to be active until summer, 2018.

What will I have to do?

Interviews

If you agree to take part in our study, we will ask you to participate in a single interview. In this interview, we will start by asking you basic questions about your family's cultural background, the languages you speak at home, education, and employment. This information will help us understand the data we are collecting. We will then ask about your child's hearing loss, how you learned about it, what your experience was like when you were told about the treatments available, and what your experience was like with your child's language therapy sessions. Also with your consent, we will ask your child's audiology center to provide us with information about your child's hearing loss including the cause, degree of hearing loss, age of diagnosis, hearing aid recommendations, and rehabilitation services. If you agree to take part, we will meet with you either at the audiology clinic or your place of residence at a convenient time for a 45 to 60 minute interview. With your permission, the interviews will be audio-recorded.

Questionnaire feedback

Based on the results from these interviews, we will develop a short questionnaire that we will ask culturally diverse parents of children with hearing loss to complete. Before we send out these questionnaires to other families, we may ask you to look over this questionnaire to help us make sure that it is understandable. Your feedback can help us improve this questionnaire since most families who will be filling it out will not have English as their first language. This can be done either in person or over the phone, at your convenience. It is estimated that this questionnaire will take 20-30 minutes.

Benefits, Risks and Inconvenience

Benefits

You/your child will not benefit directly from participating in this study. We can share the results of the study with you.

Risks/Inconvenience

You might experience discomfort during the interview. This may include you feeling uncomfortable with some of the questions being asked if they are sensitive. If you feel uncomfortable, you may choose not to answer a question. You may also stop the interview at any time.

Will I be paid to participate?

You will not be paid to take part in this study.

Will I be told about new information?

We will tell you about any new information that might change your decision to participate. If this happens, we will ask you again if you still want to be in the study.

Once the study is finished, you can receive a copy of the results.

What about confidentiality and privacy?

The information from the interviews will be used to help describe possible troubles in hearing loss services for culturally diverse families. All information will be kept confidential. Your identity will not be given to any person, except if there is a medical emergency or if we legally need to. We won't release your name or your child's in any publication, report or presentation. We might quote some comments from the interviews but we will never give you or your child's name.

If you choose not to participate or decide to stop participating in this study at any time, this will not affect the care your child will receive in the clinical or community program. At any time during the interview you can choose to not answer a question. You can also take back your answer, or stop the interview.

The information we will get from your interview will be carefully stored with password protection on a restricted computer. All copies of the audio recording of the interview and interview notes will be securely stored in the Audiology Lab at the Children's Hospital of Eastern Ontario Research Institute. Only our team members will have access to the interview information, however members from the CHEO research Ethics Board

may also look at the site where your records are held to check that our study is following the proper laws and guidelines. Any information from the interviews will be destroyed (e.g. shredded, deleted) 7 years after publication of the results.

Is the research team benefiting from the study (i.e., real or perceived conflict/competing interests)?

The research team members are not benefiting personally, financially or in some other way from this study.

What if I have questions?

If you have any questions concerning participation in this study, contact Viviane Grandpierre (the study's co-investigator) at 613- 738-3907.

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

CONSENT

I acknowledge that the research procedures described above, and of which I have a copy, have been explained to me. I understand that I am voluntarily agreeing to participate in this research study and that I allow access to my medical records and/or personal information as described in this consent form. I have been given an opportunity to ask questions concerning the study process and the questions have been adequately answered. In addition, I know that I may contact the investigators (whose contact information is below) if I have further questions either now or in the future. I have been assured that personal records relating to this study will be kept confidential. I understand that my identity will not be given to any person, except if there is a medical emergency or if required by law. I understand that I can remove my consent and stop my participation in the study at any time and for any reason. I have been reassured that this will not affect the quality of care that I or any member of my family receives at CHEO. I understand

that if any knowledge gained from this study becomes available that could influence my decision to continue in this study, I will be promptly informed.

I, _____, consent to the participation of myself and my child, in the study described above.

_____ Date _____
Signature of person authorized to sign on behalf of the subject (e.g., parent or guardian)

Name of witness

(printed)

Signature _____ Date _____

I have explained this study to the participant and I am satisfied that it is understood

Name and Title

Signature _____ Date _____

Appendix I

Caregiver Interview, Chapter 4 – Caregiver demographics form

Interviewer-assisted Child and Family Information Questionnaire

To help us understand the data we are collecting we would like to ask you to provide some information about your child and your family. Your answers will be completely confidential and your identity will not be revealed to any person. This information will only be reported as group summaries

Date: ____/____/____
DAY MONTH YEAR

Name of person answering this questionnaire:

Relationship to the child: Mother Father Other _____

Your Child

Child's Name	Last: _____	First: _____
Partial date of birth	____/____ MONTH YEAR	Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female

Mother's Name	Last: _____	First: _____
e-mail:	_____	
Father's Name	Last: _____	First: _____
		Initial: _____

Your Child's Health History

Is your child being followed by a professional for medical or developmental concerns?

YES

NO

Please describe:

Are you aware of any children or adults in your family who have a hearing loss, e.g. brothers, sisters or cousins of your child or yourself?

YES

NO

Please describe:

Your Family

How many children do you have? _____

How many of your children have hearing loss? _____

Besides your child/children, who else lives with you (including in laws)?

- Parents
- Grandparents
- Uncles
- Aunts
- Cousins
- Children

Hearing Health

What degree of hearing loss does your child have?

Left Side

Normal

Mild

Moderate

Severe

Profound

Don't know

Right Side

Normal

Mild

Moderate

Severe

Profound

Don't know

Child #2: Left side:

Right Side:

Child #3: Left side:

Right Side:

Your Child's Amplification

What hearing aid(s) does your child use?

- Cochlear implant
- Hearing aid
- FM system

Child #2: _____

Child #3: _____

Therapy services

1. What type of rehabilitation program is your child in for hearing loss?

- Auditory-based: emphasizes oral speech
- Sign: emphasizes signed language
- Total communication: combines oral and signed speech

Child #2:

Child #3:

2. Does your child receive any other services?

- Physiotherapy
- Occupational therapy
- Child development services
- Family Support Worker
- Other: _____

Child #2:

Child #3:

Please describe your family's cultural heritage:

What language(s) are spoken most often to your child/children at home?

Family's Education

What is the highest level of education of any adult living in your household?

- None
- Secondary (high) school graduation certificate or equivalent
- Diploma or certificate from at a trade, technical or vocational school, etc.
- Bachelors or undergraduate degree(s) (for example, B.A., B.Sc., LL.B.)
- Post graduate degree(s), for example, a Master's degree(s), a Doctorate or a degree in medicine, dentistry, veterinary medicine or optometry
- Other: _____

What is your household income from all sources before taxes (for example, wages and salaries, income from self-employment, employment insurance, pensions, child support, etc.)?

- Below \$20,000
- \$20,000 to less than \$40,000
- \$40,000 to less than \$60,000
- \$60,000 to less than \$80,000
- \$80,000 to less than 100,000
- \$100,000 or more

Appendix J

Caregiver Interview, Chapter 4 – Consent to release form

CONSENT FOR DISCLOSURE

I hereby authorize: _____
(Name of Audiologist/Agency Releasing Information)

Address

City/Prov/Postal Code

To release to:

Viviane Grandpierre, PhD(c), Co-investigator
Audiology Research Lab, Children's Hospital of Eastern Ontario Research Institute
401 Smyth Rd., Room R1133
Ottawa ON K1H 8L1

This study has been approved by the CHEO Research Ethics Board.

The following information: *Information about my child's hearing loss including details of the diagnosis, the age of my child when diagnosed, the cause of the hearing loss, the degree of hearing loss, amplification recommendations, and intervention information.*

From the records of: _____
(Name of Child)

(Partial date of birth: mo/year)

I understand this information is to be used by the recipient for the purposes of data collection for the study "Barriers and facilitators to cultural competence in early hearing loss interventions". *This consent allows both written and verbal communication. It can be withdrawn at any time by notification in writing.*

Signature of person authorized to sign on behalf of the child

Date _____

Relationship to Child: _____

Name of witness

(printed)

Signature: _____ Date _____

Note: Authorization must be signed by the client if incapable, by the parent or legal guardian, whichever is the appropriate legal authority. In the case of a person who is physically or mentally disabled to such a degree as to be incapable of giving consent, the next-of-kin may authorize release of information.

Appendix K

Caregiver Interview, Chapter 4 – CHEO medical abstraction form

Unique ID:

Partial Date of Birth: ____/____/____
(MMM/YY)

Gender: Male Female

Date of Last Visit: ____/____/____

ROUTE TO REFERRAL	
<input type="checkbox"/> Screened	<input type="checkbox"/> Not screened (Referred)

SCREENING	
Date of Screening: ____/____/____	Location: _____
Outcome: <input type="checkbox"/> Pass <input type="checkbox"/> Refer <input type="checkbox"/> No Result/Incomplete <input type="checkbox"/> Did Not Test <input type="checkbox"/> Not Screened	

HEARING LOSS DIAGNOSIS	
Date of Referral: ____/____/____	
Date of First Assessment: ____/____/____	Location: _____
Hearing Loss: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Inconclusive; monitored	
Date of Hearing Loss Confirmation: ____/____/____	Location: _____

Notes on HL Diagnosis

RISK STATUS

At Risk

Not At Risk

Not at CHEO

ETIOLOGY

Known: YES NO

*Category *Etiology

- | | | |
|---|------------------------|-------|
| 1 | familial | _____ |
| 2 | defect ENT | _____ |
| 3 | syndromic | _____ |
| 4 | prenatal infection | _____ |
| 5 | NICU graduate | |
| 6 | meningitis | |
| 7 | middle ear disease | |
| 8 | ototoxic meds/oncology | |
| 9 | unknown | |

ONSET OF HEARING LOSS

Congenital	<input type="checkbox"/>	A PHL that is confirmed after a refer result on screening
Early onset	<input type="checkbox"/>	A PHL that is recognized in the neonatal period, defined for this study as including children referred and diagnosed before 6 months of age.
Late onset	<input type="checkbox"/>	A PHL that is diagnosed following screening pass and/or a least one diagnostic assessment with thresholds within normal limits
Progressive	<input type="checkbox"/>	A change in audiometric thresholds after diagnosis of ≥ 20 dB in the pure tone average
Unknown	<input type="checkbox"/>	A permanent hearing loss (PHL) diagnosed after infancy with no history of screening, no risk factors identified and unknown etiology

INTERVENTION: HABILITATION TYPE

A) Amplification

Amplification:

Hearing aids Left ear Right ear

Cochlear implants Left ear Right ear

INTERVENTION: HABILITATION TYPE			
Intervention Type	<input type="checkbox"/> AVT	<input type="checkbox"/> SLP services	<input type="checkbox"/> Other
Intervention Start	____/____/____	Intervention Discharge	____/____/____
Language	<input type="checkbox"/> ENGLISH	<input type="checkbox"/> FRENCH	Therapist: _____
Intervention Notes			

Is the patient receiving health care services other than for hearing loss?

Lastest Audiology Evaluations

Date	Loss Type		Click Threshold	250 Hz	500 Hz	1000 Hz	2000 Hz	3000 Hz	4000 Hz	6000 Hz	8000 Hz
		R									
			PTA/SRT								
		L									
			PTA/SRT								
			Rx and Amplification Use								

Appendix L

Caregiver Interview, Chapter 4 – Multi-center case report form

Unique ID

Date of Birth: ____/____/____

Gender: Male Female
(MM/YY)

Date of Report: ____/____/____

Primary Language(s) in the home

English French Sign Other _____

Primary Language of Service

English French Sign

ROUTE TO REFERRAL	
<input type="checkbox"/> Screened	<input type="checkbox"/> Not screened (Referred)

SCREENING	
Date of Screening: ____/____/____	Location: _____
Outcome: <input type="checkbox"/> Pass <input type="checkbox"/> Refer <input type="checkbox"/> No Result/Incomplete <input type="checkbox"/> Did Not Test <input type="checkbox"/> Not Screened	

HEARING LOSS DIAGNOSIS	
First Assessment: ____/____/____	Location: _____
DAY MONTH YEAR	
Hearing Loss: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Could not confirm	
Hearing Loss Confirmation: ____/____/____	Location: _____
DAY MONTH YEAR	

ONSET OF HEARING LOSS		
Unknown	<input type="checkbox"/>	A permanent hearing loss (PHL) diagnosed after infancy with no known etiology
Congenital	<input type="checkbox"/>	A PHL that is recognized at birth or that is believed to have been present at birth.
Early onset	<input type="checkbox"/>	A PHL that is recognized in the neonatal period, defined for this study as including children referred and diagnosed before 6 months of age.
Late onset	<input type="checkbox"/>	A PHL that is diagnosed following a least one normal BERA in the neonatal period.

Does this child have any other medical and/or developmental issues, e.g. medically fragile, CP, developmental delay or vision problems

Yes No If yes, describe briefly

Most current threshold information (Date: ____/____/____)

ABR (dB EHL) VRA (dB HL) Play (dB HL)

Ear	Thresholds					Tymps	OAEs	Nature of HL
	250 Hz	500 Hz	1000 Hz	2000 Hz	4000 Hz			

Has the hearing loss progressed since diagnosis, e.g., an increase in the pure tone average greater than 20 dB

Yes No If yes, describe briefly

INTERVENTION: RECOMMENDATIONS

Recommendations at Diagnosis	Monitor *	HA	FM only	FM System (w Has)	Habilitation
____/____/____ DAY MONTH YEAR					
____/____/____ DAY MONTH YEAR					
Follow-up Recommendations	Monitor *	HA	FM only	FM System (w HAs)	Other
____/____/____ DAY MONTH YEAR					
____/____/____ DAY MONTH YEAR					
Diagnosis Rx Notes					

* Children may be monitored when they are not a candidate for HA, medical follow-up is necessary (e.g. for middle ear issues) or when assessments are inconclusive (e.g. with incomplete thresholds, AN), a retest is recommended, etc.

Appendix M

Practitioner survey, Chapter 5 – English questionnaire

Instructions: This questionnaire is designed for practitioners who are providing or have provided services to caregivers of children with hearing loss in order to better understand service needs, specifically for families from minority cultures. Even if you do not /have not provided services to minority-culture families, your feedback is still important. Thank you kindly for your participation.

Screening questions

1. **Are you a clinician currently providing/have provided early hearing loss services to children?**
 Yes (please continue to complete this questionnaire)
 No → *If you selected 'no', we value your participation however we are looking specifically for clinicians who are or have provided early hearing loss services. **We would greatly appreciate you returning this questionnaire or sending us an email to advise us that you are not currently practicing as it will help inform us about the reason for not completing the questionnaire.***

2. **Do you/have you worked with minority culture children?** *For the purposes of this survey, we are defining 'minority cultures' as any cultural groups that are not representative of the majority culture in Canada (e.g. does not identify as primarily English or French-Canadian).*
 Yes
 No → ***If no, please go to question #11.***

Providing services to cultural minority patients

3. **What is the approximate proportion of minority culture clients on your current caseload?**
 <10%
 10-19%
 20-39%
 40-59%
 60-79%
 >80%

4. **Have you ever received specific training (e.g. courses, workshops, etc.) related to the provision of cultural competent care or culturally appropriate care?**
 Yes → *If you answered yes, from where did you receive this training? Please check all that apply:*
 From university/college
 From work
 From additional courses, training, webinars, etc.
 Other: _____
 No

5. When the caregivers have limited proficiency in the service language, how often do you use the following strategies to facilitate communication?

	All of the time	Most of the time	Some of the time	Never
Use simple language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use an interpreter or someone proficient in the language of the caregivers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Write out key words	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use pictures, diagrams, videos, or the internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learn a few words or key phrases in the language of the caregivers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Not applicable (I have not worked with caregivers who have limited proficiency in the service language)

6. Have you ever experienced challenges when providing audiological testing due to cultural reasons?

Yes

If you selected yes, please select the reasons that apply (check all that apply):

- The child/parent did not understand the instructions for the assessment and/or intervention
- The caregivers preferred a practitioner of a different gender
- Testing was difficult due to religious attire (e.g. the sensitive nature of requesting hijabs to be removed)

Other:

No

Not applicable

7. In discussing the diagnosis of a permanent hearing loss, have you encountered any surprising reactions (from caregivers) that might be attributable to culture?

Yes

If you selected yes, please select the reasons that apply (check all that apply):

- Hearing loss is stigmatized in the caregiver's culture
- Hearing loss is perceived as a divine intervention or a gift
- Hearing loss is seen as a consequence of the caregiver's actions or lack thereof

Other:

No

Not applicable

8. When discussing amplification options and/or promoting consistent usage, have you encountered challenges for cultural reasons?

Yes

If you selected yes, please select the reasons that apply (check all that apply):

- Caregivers had dismissive attitude or denial of hearing loss due to cultural reasons (e.g. disability is stigmatized and/or seen as shameful)
- Caregivers preferred to keep hearing loss hidden from family and/or public
- Caregivers had concerns regarding amplification affecting marriageability
- Caregivers believed hearing loss can be cured through prayer, traditional medicines, and/or complementary and alternative medicines

Other:

No

Not applicable

9. Have you experienced challenges when conducting standardized assessments and/or parent questionnaires with multicultural families?

Yes

If you selected yes, please select the reasons that apply (check all that apply):

- Lack of culturally appropriate assessments (e.g. content is representative of majority culture)
- Lack of assessments available in the language of the child/family

Other:

No

Not applicable

*****CONTINUED ON NEXT PAGE*****

10. Have you experienced challenges when providing interventions (e.g. spoken language therapy) due to cultural reasons?

Yes

If you selected yes, please select the reasons that apply:

- Amount of interaction between caregivers and children varies across cultures (e.g. in some cultures, there is minimal interactions between parents and children)
- Lack of culturally appropriate materials (e.g. books, toys, etc.)
- Caregivers had different expectations regarding who conducts therapy (e.g. believes practitioner should be providing therapy, not themselves)
- Caregivers had different listening and language expectations than what practitioners expect to successfully conduct therapy
- Primary caregiver was not the person who attended the sessions (e.g. in some cultures, elders are the primary caregivers)

Other:

No

Not applicable

11. In your opinion how important are the following strategies for learning about cultures other than your own? Select all that apply to your position.

	Essential	Very important	Somewhat important	Not important
Attend workshops, lectures, training, and/or courses on cultural sensitivity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ask caregivers questions about home life (e.g. caregiver roles, routines, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ask caregivers about how hearing loss is perceived in their culture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Schedule home visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you use any other strategies? Please describe.

12. In your opinion, how important are the following strategies to be used during sessions to ensure the provision of culturally appropriate care? Select all that apply to your position.

	All of the time	Most of the time	Some of the time	Never
Select culturally relevant materials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encourage all family members to attend therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use some of the family's home language (e.g. words, phrases you have learned)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use interpreters, a family member or friend or a colleague (e.g., from your facility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modify assessments (e.g. administer subsets of standardized assessments or assess language abilities through checklists, non-standardized vocabulary lists, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modify intervention to reflect home environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Not applicable

Do you use any other strategies during sessions to ensure the provision of culturally appropriate care?

*****CONTINUED ON NEXT PAGE*****

13. In your opinion, how important are the following characteristics of a culturally appropriate practitioner?

	Essential	Very important	Somewhat important	Not important
Has knowledge of different cultures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is open-minded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uses an interpreter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is respectful of the need to preserve home language(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uses communication strategies when needed (e.g. simple language, pictures, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is flexible with scheduling appointments (e.g. to accommodate religious holidays and/or practices)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Engages in multicultural events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modifies sessions and/or content when needed (e.g. selects culturally appropriate materials or adapts materials where required)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is aware of social issues that may interact with cultural identity, such as low income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is aware of discriminatory policies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is someone who is reflective of their own cultural identity, prejudices, biases, and/or assumptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explains session in advance to check with caregiver regarding if practice/content is appropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inquires about life at home (e.g. caregiving roles, routines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Connects families of similar cultures and/or languages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Do you have any additional information regarding your experiences with providing services to multicultural families?

Yes: Please describe in the space below:

No

DEMOGRAPHICS

15. Gender:

- Male
- Female
- Other

16. What languages are you proficient in? Check all that apply.

- | | | |
|---|--|---|
| <input type="checkbox"/> English | <input type="checkbox"/> Greek | <input type="checkbox"/> Ukrainian |
| <input type="checkbox"/> French | <input type="checkbox"/> Hungarian | <input type="checkbox"/> Punjabi |
| <input type="checkbox"/> Arabic | <input type="checkbox"/> Italian | <input type="checkbox"/> Spanish |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Korean | <input type="checkbox"/> Tagalog (Filipino) |
| <input type="checkbox"/> Cree | <input type="checkbox"/> Persian (Farsi) | Other: _____ |
| <input type="checkbox"/> German | <input type="checkbox"/> Polish | |
| <input type="checkbox"/> ASL | <input type="checkbox"/> Portuguese | |
| <input type="checkbox"/> Signed English | <input type="checkbox"/> Vietnamese | |

17. How would you identify your ethnocultural background? (Categories as per Statistics Canada, 2011. Please check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Canadian (English / French) | <input type="checkbox"/> Portuguese |
| <input type="checkbox"/> French | <input type="checkbox"/> Irish |
| <input type="checkbox"/> British | <input type="checkbox"/> German |
| <input type="checkbox"/> Scottish | <input type="checkbox"/> Italian |
| <input type="checkbox"/> Ukrainian | <input type="checkbox"/> Dutch (Netherlands) |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Polish |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Latin American | <input type="checkbox"/> Other (please specify): _____ |
| <input type="checkbox"/> Japanese | |
| <input type="checkbox"/> South Asian (East Indian, Pakistani, Punjabi, Sri Lankan) | |
| <input type="checkbox"/> South East Asian (Cambodian, Indonesian, Laotian, Vietnamese) | |
| <input type="checkbox"/> Aboriginal | |
| <input type="checkbox"/> Arab / West Asian (Armenian, Egyptian, Iranian, Lebanese) | |

18. What is your highest attained educational degree?

- Bachelors degree
- Masters degree
- Doctoral degree

19. What is your profession title? Check all that apply.

- Audiologist
- Certified Auditory Verbal Therapist
- Speech-language pathologist
- Other: _____

20. Years of work experience in providing early hearing loss intervention services to children?: _____

21. What type of practice/s are you employed in? (If you are on leave, please answer according to your employment agreement)

- Private
- Public
- Both
- Other: _____

Appendix N

Practitioner survey, Chapter 5 – French questionnaire

Enquête – Questionnaire pour les cliniciens en soins de santé

Instructions : Ce questionnaire est conçu pour les cliniciens qui offrent (ou ont offert) des services aux parents/tuteurs d'enfants ayant une perte auditive afin de mieux comprendre les services requis, plus précisément pour les familles de minorité culturelle. Même si vous n'offrez pas (ou n'avez pas offert) des services à des familles appartenant à une minorité culturelle, vos impressions nous sont importantes. Nous vous remercions pour votre participation.

Questions de dépistage

1. Êtes-vous un(e) clinicien(ne) qui offre présentement des services d'intervention précoce en perte auditive à des enfants (p.ex. à temps plein, à temps partiel, ou en congé temporaire)?

Oui (veuillez continuer de remplir ce questionnaire)

Non → Si vous avez répondu "non", nous apprécions votre participation mais nous recherchons spécifiquement des cliniciens qui pratiquent présentement ou qui sont en congé temporaire. **Ce serait très apprécié si vous pourriez retourner ce questionnaire ou nous envoyer un courriel pour nous aviser que vous ne pratiquez pas présentement. Ceci nous permettra de justifier les questionnaires qui n'ont pas été répondus.**

2. Travaillez-vous/avez-vous travaillé avec des enfants de minorité culturelle? Pour ce questionnaire, nous définissons "une minorité culturelle" comme étant tout groupe culturel qui ne représente pas la culture majoritaire au Canada (p.ex. ne s'identifie pas culturellement comme étant principalement canadien français ou canadien anglais).

Oui

Non → Si vous avez répondu "non", veuillez passer à la question #11.

Offrir des services à des patients de minorité culturelle

3. Parmi votre liste de cas actuels, quelle est environ la proportion de patients/clients qui appartiennent à une minorité culturelle?

<10%

10-19%

20-39%

40-59%

60-79%

>80%

4. Avez-vous reçu une formation (p.ex. cours, séminaire, etc.) au sujet des soins démontrant une compétence culturelle et une sensibilisation aux différentes cultures?

Oui → Si vous avez répondu "oui", où avez-vous reçu cette formation? Veuillez sélectionner tous les énoncés pertinents :

À l'université/au collègue

Au travail

Avec des cours additionnels, des formations, des séminaires en ligne, etc.

- Autre(s): _____
- Non

5. Lorsque les parents/tuteurs ne sont pas à l'aise dans la langue de service, utilisez-vous les stratégies suivantes pour faciliter la communication?

	Toujours	Souvent	Parfois	Jamais
Utilisation d'un langage simplifié	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utilisation d'un interprète ou d'un individu qui maîtrise bien la langue des parents/tuteurs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utilisation de mots clés à l'écrit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utilisation d'images, de diagrammes, de vidéos, ou de l'internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apprentissage de quelques mots ou phrases clé dans la langue des parents/tuteurs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Sans objet (Je n'ai pas travaillé avec des parents/tuteurs qui ne sont pas à l'aise avec la/les langues parlée(s) par le clinicien.)

6. Avez-vous déjà fait face à des défis lors d'une évaluation audiolinguistique à cause de raisons culturelles?

- Oui

Si vous avez répondu "oui", veuillez sélectionner tous les énoncés pertinents:

- L'enfant/parent ne comprenait pas les instructions données lors de l'évaluation et/ou l'intervention
- Les parents/tuteurs préféraient un clinicien d'un autre sexe
- Le déroulement de l'évaluation était difficile à cause de vêtement(s) religieux (p.ex. la situation délicate de demander d'enlever le hijab)

Autre:

- Non
- Sans objet

7. En discutant le diagnostic d'une perte auditive permanente avec les parents/tuteurs d'un enfant, avez-vous observé des réactions surprenantes qui pourraient être associées à des facteurs culturels?

- Oui

Si vous avez répondu "oui", veuillez sélectionner tous les énoncés pertinents:

- La perte auditive est stigmatisée dans la culture du parent/tuteur
- La perte auditive est perçue comme étant une intervention divine ou un don
- La perte auditive est considérée une conséquence des actions, ou un manque d'actions, du parent/tuteur

Autre:

- Non
- Sans objet

8. Lorsque vous discutez les options d'amplification et/ou vous en promouvez l'usage continu, avez-vous fait face à des défis pour des raisons culturelles?

- Oui

Si vous avez répondu "oui", veuillez sélectionner toutes les raisons pertinentes:

- Les parents/tuteurs avaient une attitude méprisante ou démontraient du déni face à la perte auditive pour des raisons culturelles (p.ex. un handicap est stigmatisé et/ou perçu comme honteux)
- Les parents/tuteurs préféraient ne pas dévoiler la perte auditive à la famille et/ou au public
- Les parents/tuteurs avaient des inquiétudes concernant l'effet de l'utilisation de l'amplification sur le potentiel matrimonial
- Les parents/tuteurs croyaient que la perte auditive pourrait être guérie par la prière, la médecine traditionnelle, et/ou la médecine complémentaire et alternative

Autre:

- Non
- Sans objet

9. Avez-vous fait face à des difficultés lors du déroulement d'évaluations standardisées et/ou concernant des questionnaires pour parents avec des familles multiculturelles?

- Oui

Si vous avez répondu "oui", veuillez sélectionner toutes les raisons pertinentes:

- Un manque d'évaluations sensibles aux différences culturelles (p.ex. le contenu représente la culture majoritaire)
- Un manque d'évaluations disponibles dans la langue de l'enfant/de la famille

Autre:

- Non
- Sans objet

10. Avez-vous eu des difficultés à offrir des interventions (p.ex. thérapie auditive-verbale) à cause des raisons culturelles?

Oui

Si vous avez répondu "oui", veuillez sélectionner toutes les raisons pertinentes:

- La quantité d'interaction entre les parents/tuteurs et l'enfant varie selon la culture (p.ex. dans certaines cultures l'interaction entre les parents et l'enfant est minime)
- Il y a un manque de matériel culturellement adapté (p.ex. livres, jouets, etc.)
- Les parents/tuteurs avaient des différentes attentes concernant la personne qui devrait faire la thérapie (p.ex. ils croient que le clinicien est entièrement responsable de la thérapie et ne veulent pas s'impliquer)
- Les parents/tuteurs avaient des différentes attentes face à l'écoute et au langage comparativement à ce qui est attendu afin de mener des sessions de thérapies avec succès
- Les parents/tuteurs n'étaient pas présents aux sessions (p.ex. dans certaines cultures, les aînés ont le rôle du parent/tuteur)

Autre:

Non

Sans objet

11. Selon vous, quelle est l'importance des stratégies suivantes pour apprendre sur les différentes cultures autre que la vôtre? Veuillez sélectionner toutes celles qui sont pertinentes.

	Extrêmement important	Très important	Légèrement important	Pas du tout important
Participer à des séminaires, des conférences, des formations, et/ou des cours sur la sensibilité culturelle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Demander aux parents/tuteurs des questions sur leur vie à la maison (p.ex. le rôle des parents/tuteurs, la routine, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Demander aux parents/tuteurs comment la perte auditive est perçue dans leur culture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Planifier des visites à la maison	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Utilisez-vous d'autres stratégies? S'il vous plaît les décrire ci-dessous.

12. Selon vous, quelle est l'importance d'utiliser les stratégies suivantes durant les sessions de thérapie afin d'offrir des soins culturellement appropriés? Veuillez sélectionner toutes les stratégies ci-dessous qui sont pertinentes à votre position.

	Toujours	Souvent	Parfois	Jamais
Choisir du matériel culturellement pertinent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encourager tous les membres de la famille d'assister aux sessions de thérapie	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utiliser un peu de la langue parlée à la maison (p.ex. des mots, des phrases que vous avez apprises)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utiliser un interprète, un membre/un ami de la famille, ou un collègue (p.ex. un individu qui travaille avec vous)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapter les évaluations (p.ex. administrer des versions différentes des évaluations standardisées ou évaluer les capacités linguistiques avec une liste de critères ou de vocabulaire non-standardisée, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modifier l'intervention pour refléter l'environnement à la maison	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Sans objet

<p>Utilisez-vous d'autres stratégies durant les sessions de thérapie afin d'offrir des soins culturellement adaptés?</p>

13. Selon vous, quelle est l'importance des caractéristiques suivantes d'un clinicien sensible aux différentes cultures?

	Extrêmement important	Très important	Légèrement important	Pas du tout important
Connaître différentes cultures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être ouvert d'esprit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utiliser un interprète	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être respectueux du désir de préserver la langue parlée à la maison	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utiliser des stratégies de communication quand nécessaire (p.ex. langage simplifié, images, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être flexible avec la planification des rendez-vous (p.ex. pour accommoder les fêtes religieuses et/ou les pratiques religieuses)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S'impliquer dans des événements multiculturels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modifier des sessions et/ou le contenu des sessions si nécessaire (p.ex. choisir du matériel approprié pour les différentes cultures ou adapter le matériel lorsque nécessaire)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être au courant des problèmes sociaux qui pourraient interagir avec l'identité culturelle, telle que la pauvreté	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être au courant de politiques discriminatoires	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Être un individu qui réfléchit sur sa propre identité culturelle, sur les préjugés, et/ou sur les assumptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Expliquer les sessions en avance afin de vérifier avec les parents/tuteurs que le contenu et l'approche soient appropriés	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discuter de la vie à la maison (p.ex. rôles des parents/tuteurs, routines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mettre en contact des familles de cultures et/ou de langues semblables	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Avez-vous de l'information additionnelle sur vos expériences à offrir des services à des familles multiculturelles?

Oui: Veuillez décrire dans l'espace ci-dessous.

Non

DEMOGRAPHIE

15. Sexe :

- Masculin
 Féminin
 Autre

16. Quelle(s) langue(s) maîtrisez-vous? Veuillez sélectionner toutes celles qui sont pertinentes.

- | | | |
|--|---|---|
| <input type="checkbox"/> Anglais | <input type="checkbox"/> Grec | <input type="checkbox"/> Ukrainien |
| <input type="checkbox"/> Français | <input type="checkbox"/> Hongrois | <input type="checkbox"/> Pendjabi |
| <input type="checkbox"/> Arabe | <input type="checkbox"/> Italien | <input type="checkbox"/> Espagnol |
| <input type="checkbox"/> Chinois | <input type="checkbox"/> Coréen | <input type="checkbox"/> Tagalog (Filipino) |
| <input type="checkbox"/> Cri | <input type="checkbox"/> Persan (Farsi) | Autre: _____ |
| <input type="checkbox"/> Allemand | <input type="checkbox"/> Polonais | |
| <input type="checkbox"/> ASL | <input type="checkbox"/> Portugais | |
| <input type="checkbox"/> Langue des signes britannique | <input type="checkbox"/> Vietnamien | |

17. A quel(s) groupe(s) ethnoculturel(s) vous identifiez-vous? (Les catégories sont basées sur celles de Statistiques Canada, 2011. Veuillez sélectionner tous les groupes pertinents.)

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Canadien (Anglais / Français) | <input type="checkbox"/> Portugais |
| <input type="checkbox"/> Français | <input type="checkbox"/> Irlandais |
| <input type="checkbox"/> Britannique | <input type="checkbox"/> Allemand |
| <input type="checkbox"/> Écossais | <input type="checkbox"/> Italien |
| <input type="checkbox"/> Ukrainien | <input type="checkbox"/> Hollandais |
| <input type="checkbox"/> Chinois | <input type="checkbox"/> Polonais |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Noir |
| <input type="checkbox"/> Latino-Américain | <input type="checkbox"/> Coréen |
| <input type="checkbox"/> Japonais | <input type="checkbox"/> Autre: _____ |
- Asie du sud (Indien de l'est, Pakistanais, Punjabi, Sri Lankais)
 Asie du sud-est (Cambodgien, Indonésien, Laotien, Vietnamien)
 Aborigène (Indien de l'Amérique du nord, Métis, Inuit, Esquimau)
 Arabe / Asie de l'ouest (Arménien, Égyptien, Iranien, Libanais)

18. Quel est votre plus haut niveau de scolarité atteint?

- Baccalauréat
- Maîtrise
- Doctorat

19. Quel est le titre de votre profession? Veuillez sélectionner tous ceux qui sont pertinents.

- Audiologiste
- Thérapeute auditivo-verbale certifiée
- Orthophoniste
- Autre: _____

20. Combien d'années d'expérience avez-vous à offrir des services d'interventions précoces en perte auditive à des enfants? _____

21. Dans quel type de pratique travaillez-vous? (Si vous êtes en congé, veuillez répondre selon votre contrat d'embauche)

- Privée
- Publique
- Les deux
- Autre: _____

Appendix O

Practitioner survey, Chapter 5 – English Information Letter

Questionnaire Survey

Barriers and Facilitators to Early Hearing Loss Interventions

Investigators: *Elizabeth Fitzpatrick (PhD), *Viviane Grandpierre (PhDc)
(*University of Ottawa; Children’s Hospital of Eastern Ontario)

HEALTH CARE PRACTITIONER INFORMATION FORM

You are invited to participate in a research project. This participation information form describes the study and outlines what will be asked of you if you decide to take part.

Purpose of this Research Study:

The purpose of this study is to investigate whether early hearing loss services are culturally sensitive to minority culture families. Specifically, we are interested in learning about whether we need to tailor care to meet the needs of minority culture families (e.g. families that don’t identify themselves as primarily English or French Canadian).

Researchers at the University of Ottawa and the Children’s Hospital of Eastern Ontario Research Institute (CHEO) are conducting this research project. Before agreeing to take part in this study, it is important that you read and understand this document.

This study is being conducted because Canada’s population is becoming increasingly multicultural. The problem is that experts have stated that hearing loss interventions are tailored to meet the needs of the majority populations’ cultural values, and as a result, may not equally all cultural groups. Additionally, there seems to be very little research on how cultural diversity impacts hearing loss services. The little research that we have found to date suggests that available information is dated and usually stereotypical. For these reasons, this study is being conducted to get information from minority culture caregivers (e.g. people who do not identify their culture as English or French Canadians) of children with hearing loss about their experiences receiving care and the experiences of pediatric hearing loss practitioners delivering care to this population.

The information from the questionnaires will be used to help describe possible limitations and successes in hearing loss services for minority culture children. These results will also be used to help determine the need for improving cultural sensitivity in pediatric hearing loss interventions.

Participants:

This study will invite a minimum of 100 practitioners working in Canada. We are specifically looking for practitioners with the following characteristics:

- Certified audiologists, speech language pathologists, and/or auditory verbal therapists;
 - Are currently providing/ have provided early hearing loss services (e.g. diagnostic and therapy-related services) to children with permanent hearing loss; and
 - Are currently providing/ have provided treatment to minority culture children.

If we have contacted you in error we apologize and ask that you notify us so we can remove your name from the mailing list.

Procedures:

This study consists of a questionnaire survey. The questionnaire is included with this package and should take no longer than 30 minutes to complete. If you would like to participate, please fill in the questions in English and mail it back to the Audiology Research Lab at the Children's Hospital of Eastern Ontario's Research Institute (CHEO RI) using the postage-paid envelope.

We understand that you may prefer not to take part in this study. If this is the case you may do one of the following things:

1. Return a blank questionnaire in the postage-paid envelope provided – we will immediately remove you from the mailing list for this study.
2. Call the Audiology Research Lab at CHEO [613-738-3907] and leave a voicemail message with the identification number that appears on the front page of your questionnaire – we will immediately remove you from the mailing list for this study.
3. Ignore this letter. The Audiology Research Lab will contact you up to 5 times in total about this study. This is done to try to get as many responses as possible so that we can be more confident of the results. If you ignore all five of the contacts you will be removed from the mailing list for this study.

Benefits, Risks and Inconvenience

Benefits

There are no anticipated benefits from participating in this study; however, our hope is to change clinical practice if the results indicate a need or to take better care of pediatric hearing loss patients in the future.

Risks/Inconvenience

We know of no harm that taking part in this study could cause you. Participation in this study may cause you some inconvenience because of the time involved for completing the questionnaires.

Voluntary Participation and Withdrawing from this Study:

You are under no obligation to participate in this study. You are free to withdraw from the study at any time.

Compensation

You will not be paid to take part in this study.

New information

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

At the conclusion of the study, you can receive a copy of the results.

Confidentiality:

You may withdraw from participation at any time during this study. All information will be kept strictly confidential. We might quote some comments from the questionnaire however your name will not be disclosed.

If you choose to participate, when your questionnaire is received, your replies will be entered onto a computer database for analysis. Your name or other identifying information will not appear on your questionnaire or on the computerized data file. The identification number on the front of your questionnaire will be used only by the Audiology Research Lab to track whether you have responded to the study. This is done so that we know whether to send you a reminder letter and so that we can keep track of the total number of responses.

The questionnaires will be kept in a secure location, only accessible to the investigators of this study. Once the study is complete, and no further analyses are required, the identification numbers will be permanently removed from computerized data so that they cannot be linked with individual participants.

Is the research team benefiting from the study (i.e., real or perceived conflict/competing interests)?

The research team members are not benefiting personally, financially or in some other way from this study.

Questions?

If you have any questions concerning participation in this study, contact Viviane Grandpierre (the study's co-investigator) at 613- 738-3907.

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

Enquête - Questionnaire

Barrières et facilitateurs aux interventions précoces en perte auditive

Chercheurs: *Elizabeth Fitzpatrick (PhD), *Viviane Grandpierre (PhDc)
(*Université d'Ottawa; Centre hospitalier pour enfants de l'est de l'Ontario)

FORMULAIRE D'INFORMATION POUR LE CLINICIEN EN SOINS DE SANTÉ

Vous êtes invité à participer à un projet de recherche. Ce formulaire de participation décrit l'étude et ce qu'on demandera de vous si vous décidez d'en prendre part.

But de l'étude:

L'objectif de cette étude est d'investiguer si les services précoces en perte auditive sont culturellement sensibles aux familles appartenant à une minorité culturelle. Plus précisément, nous sommes intéressés de savoir si nous devons adapter les soins pour répondre aux besoins des familles de minorité culturelle (p.e. les familles qui ne s'identifient pas culturellement comme étant principalement canadiennes françaises ou canadiennes anglaises).

Des chercheurs à l'Université d'Ottawa et au Centre hospitalier pour enfants de l'est de l'Ontario (CHEO) mènent ce projet de recherche. Avant d'accepter de participer à cette étude, il est important de lire et de bien comprendre ce document.

Cette étude est en cours parce que la population canadienne devient de plus en plus multiculturelle. Par contre, les experts ont déclaré que les interventions ciblant les pertes auditives sont adaptées pour répondre aux besoins des valeurs culturelles de la population majoritaire et conséquemment pas nécessairement à ceux de tous les groupes culturels. De plus, il n'y a pas beaucoup de recherche sur l'effet de la diversité culturelle sur les services en perte auditive. Le peu de recherche que nous avons trouvé jusqu'à présent suggère que l'information additionnelle est désuète et elle est habituellement basée sur des stéréotypes. Cette étude est donc menée pour obtenir des renseignements des parents/tuteurs des enfants de minorité culturelle (p.e. venant d'une famille qui ne s'identifie pas culturellement comme principalement canadienne française ou canadienne anglaise) qui ont une perte auditive. Nous sommes intéressés d'en savoir plus sur leurs expériences avec les soins reçus ainsi que sur les expériences des cliniciens pédiatriques en perte auditive qui offrent des soins à cette population.

Les renseignements obtenus avec ce questionnaire seront utilisés pour décrire les limites et les succès que présentent les services en perte auditive aux enfants de minorité culturelle. Les résultats seront aussi utilisés pour déterminer le besoin d'améliorer la sensibilité culturelle en interventions pédiatriques en perte auditive.

Participants:

Cette étude invitera un minimum de 100 cliniciens travaillant au Canada. Nous cherchons plus précisément des cliniciens ayant les caractéristiques suivantes:

- Des audiologistes certifiés, des orthophonistes, et/ou des thérapeutes auditifs-verbaux;
- Offrent présentement des services précoces en perte auditive (p.e. diagnostique, service de thérapie) à des enfants avec une perte auditive permanente; et
- Offrent présentement des traitements à des enfants appartenant à une minorité culturelle.

Pardonnez-nous si nous vous avons contacté par erreur. Nous vous demandons de nous informer si c'est le cas pour que nous puissions enlever votre nom de la liste de diffusion.

Protocole:

Cette étude consiste d'une enquête par questionnaire. Le questionnaire est inclus dans ce document et devrait prendre au plus 30 minutes à compléter. Si vous êtes intéressé à participer, veuillez compléter le questionnaire en français et le retourner par la poste dans l'enveloppe préaffranchie au Laboratoire de recherche en audiologie à l'Institut de recherche au Centre hospitalier pour enfants de l'est de l'Ontario (IR CHEO).

Nous comprenons que vous ne préférez peut-être pas participer à cette étude. Si c'est le cas, vous pouvez soit :

4. Retourner le formulaire vierge dans l'enveloppe préaffranchie fournie – nous vous enlèverons de la liste de diffusion pour cette étude immédiatement.
5. Appeler le Laboratoire de recherche en audiologie à CHEO [613-738-3907] et laisser un message sur la boîte vocale avec le numéro d'identification qui apparaît sur la première page du questionnaire – nous vous enlèverons de la liste de diffusion pour cette étude immédiatement.
6. Ignorer cette lettre. Le Laboratoire de recherche en audiologie vous contactera 5 fois en tout pour cette étude. Cette approche nous permet d'obtenir le plus de réponses possible pour que nous soyons plus confiants de nos résultats. Si vous choisissez d'ignorer les 5 tentatives de contact, nous vous enlèverons de la liste de diffusion pour cette étude.

Avantages, risques, et inconvénients

Avantages

Il n'y a pas d'avantages anticipés découlant de votre participation à cette étude; par contre, nous espérons changer la pratique clinique si les résultats en indiquent le besoin, ou d'offrir de meilleurs soins aux patients ayant une perte auditive pédiatrique dans le futur.

Risques/Inconvénients

La participation à cette étude ne vous causera aucun mal. Le seul inconvénient qui se présente en participant à cette étude est le temps nécessaire pour remplir le questionnaire.

Participation volontaire, et retrait de l'étude:

Vous n'êtes aucunement obligé de participer à cette étude. Vous êtes libre de vous retirer à n'importe quel moment.

Compensation

Vous ne serez pas payé pour participer à cette étude.

Nouvelles informations

Les nouvelles informations que nous obtiendrons au courant de cette étude pourraient affecter votre décision d'y participer. Si c'est le cas, nous partagerons ces nouvelles informations avec vous et nous vous demanderons de nouveau si vous voulez toujours participer à l'étude.

A la fin de l'étude, vous pourrez recevoir une copie des résultats.

Confidentialité:

Vous pouvez vous retirer de cette étude à n'importe quel moment. Toute information sera gardée strictement confidentielle. Nous citerons possiblement certains commentaires du questionnaire mais votre nom ne sera pas divulgué.

Si vous choisissez de participer, lorsque votre questionnaire est reçu, vos réponses seront entrées sur un ordinateur dans une base de données pour des fins d'analyse. Votre nom et toute autre information qui pourrait vous identifier n'apparaîtront pas sur votre questionnaire, ni sur les données mises dans l'ordinateur. Le numéro d'identification sur la première page de votre questionnaire sera utilisé seulement par le Laboratoire de recherche en audiologie pour voir si

vous avez répondu au questionnaire. Ceci nous permet de savoir si nous devons vous envoyer une lettre de rappel et de déterminer le nombre total de réponses.

Les questionnaires seront conservés dans un endroit sécuritaire, accessible seulement aux chercheurs impliqués dans cette étude. Une fois que l'étude sera terminée, et quand ce sera déterminé qu'aucune autre analyse ne soit requise, les numéros d'identification électroniques seront effacés de façon permanente pour que ce soit impossible de les associer aux participants individuels.

Est-ce que l'équipe de recherche bénéficie de cette étude (c-à-d, conflit d'intérêt)

Les membres de l'équipe de recherche ne bénéficient pas personnellement, financièrement, ou d'une autre façon de cette étude.

Questions?

Si vous avez des questions au sujet de la participation à cette étude, veuillez contacter Viviane Grandpierre (la co-chercheuse de l'étude) au 613- 738-3907.

Cette étude a été révisée et approuvée par le comité de déontologie de CHEO. Le comité de déontologie de CHEO inclut des individus de professions diverses. Le comité révisé tous les projets de recherche qui prennent place à l'hôpital impliquant des sujets humains afin de protéger les droits et le bien-être des individus participant à la recherche. Le comité ne remplace pas le jugement d'un parent ou d'un enfant en terme de déterminer ce qu'est la meilleure décision pour eux. Vous pouvez contacter le directeur du comité de déontologie pour des renseignements additionnels sur les droits du patient dans les projets de recherche au (613) 737-7600 (3272). Toutefois, cette personne ne pourra pas vous donner des renseignements pertinents à l'étude qui porte sur les éléments en santé.

Appendix Q

Practitioner survey, Chapter 5 – List of contacts

The Ear Institute Audiology Clinic
ATTN: MOHAMMAD S ASGHAR
3030 Lawrence Ave E,
Scarborough, ON
M1P 2T7
Canada

Bentley Hearing Services Ltd.
ATTN: Barbara Taylor
460 Springbank Drive,
Suite 108
London, ON,
N6J 0A8
Canada

Listen Up Canada
ATTN: Allison C De La Lis
149 Brock Street
Kingston ON
K7L 1S2 Canada
Canada

The Hearing Outlet
ATTN: Errol R. Davis
210 Dundas St E Suite 302
Belleville, ON
K8N 5G8
Canada

Bentley Hearing Services Ltd.
ATTN: BARBARA D. BENTLEY
460 Springbank Drive,
Suite 108
London, ON,
N6J 0A8
Canada

Bentley Hearing Services Ltd.
ATTN: Jennifer Saunders
460 Springbank Drive,
Suite 108
London, ON,
N6J 0A8
Canada

In Touch Hearing
ATTN: Diane L. Webber-Hamilton
531 Davis Drive,
Suite 409,
Newmarket, ON, L3Y 6P5
Canada

Advanced Hearing Aid Clinic Inc.
ATTN: Rodney Taylor
1657 Carling Avenue
Ottawa, Ontario,
K2A 1C4
Canada

The Audiology Centre
ATTN: Rosanne Chan
Toronto Hearing Services
340-1333 Sheppard Ave E.
North York, Ontario M2J 1V1
Canada

Ethier Hearing Clinic
ATTN: Manon Yolande Ethier
Timmins and District Hospital
700 Ross Ave E,
Timmins, ON
P4N 8P2
Canada

Audiology and Hearing Aid Dispensing
Services
ATTN: Susan Thomsen
Halton Healthcare 7030 Derry Road
Milton, ON
L9T 7H6
Canada

Hearing Freedom
ATTN: Rosanne Mcnamee
5528 Ann St,
Manotick, ON
K4M 1A2
Canada

Elgin Audiology Consultants
ATTN: David Pfingstgraef
66 West Avenue,
St. Thomas, Ontario
N5R 5H7
Canada

Ethier Hearing Clinic
ATTN: J. Mark Gulliver
Timmins and District Hospital
700 Ross Ave E,
Timmins, ON
P4N 8P2
Canada

Hearing Assessment Services
Carolyn D Jones
717 Richmond St.
Suite 205
London, ON
N6A 1S2
Canada

Hearsay Speech And Hearing Centre
ATTN: Rui M Oliveira
6941 Derry Rd.,
Suite 203
Milton, ON,
L9T 7H5
Canada

Hearsay Speech And Hearing Centre
ATTN: Yvonne Oliveira
6941 Derry Rd.,
Suite 203
Milton, ON,
L9T 7H5
Canada

Heritage Hearing Care
ATTN: Andrea J. Graham
239 Pembroke St. West
Pembroke, Ontario
K8A 5N3
Canada

Listen Up Canada
ATTN: Barbara A. Sudeyko
118 Holland Avenue
Ottawa ON
K1Y 0X6
Canada

London Audiology Consultants
ATTN : Catherine A. Moore
387 Burwell Street
London, ON
N6B 2W3
Canada

Helix Hearing Center
ATTN: Leigh Ann M Forrest
147 Pinnacle Street
Belleville, ON,
K8N 3A5

K & H Audiology
ATTN : Karen P Kahansky
Champagne Centre
2 Champagne Dr, Unit B12, East Entrance
North York, Ontario
M3J 2C5
Canada

London Audiology Consultants
ATTN : Margaret Brac
387 Burwell Street
London, ON
N6B 2W3
Canada

London Health Sciences Centre
Victoria Hospital
ATTN: Denise M. Lewis
800 Commissioners Road East,
PO Box 5010
N6A 5W9
Canada

Markham Hearing Center
ATTN: Stephanie Mariasine-Bergman
110 Copper Creek Dr #105,
Markham, ON
L6B 0P9
Canada

Markham Hearing Center
ATTN: Vahideh Bosaghzadeh
110 Copper Creek Dr #105,
Markham, ON
L6B 0P9
Canada

Louise Tanaka
Markham Stouffville Hospital
Audiology Services
13175 Yonge Street
Richmond Hill, ON
L4E-0G6

Brian G. Field
Meridian Hearing Wortley
190 Wortley Road – Suite 105
London, ON
N6C 4Y7

Hish Husein
Auburn & Mountain Hearing Center
350 Conestoga Blvd Unit B3
Cambridge, Ontario,
N1R 7L7

Iola Preeti Sen Nichol
Muskoka Audiology Clinic
256 James St,
Bracebridge, ON
P1L 1S2

Catherine E. Payne
North Bay Audiology Clinic
164 Lakeshore Drive,
North Bay, Ontario,
P1A 2A8

David W. Gordey
Oticon Canada
6950 Creditview Rd #1,
Mississauga, ON
L5N 0A

Suzanne M. Vanden Heuvel
Carling-Broadview Medical Centre
Ottawa-Carleton Hearing Aid Dispensary
770 Broadview Avenue, Suite 100,
Ottawa, Ontario
K2A 3Z

Nancy Zantinge
Owen Sound Audiology
1240 2nd Ave E #2,
Owen Sound, ON
N4K 2J3

Heather V Holliday
Owen Sound Audiology
1240 2nd Ave E #2,
Owen Sound, ON
N4K 2J3

Norman H. Mele
Sense of Hearing Canada
11 – 1960 Appleby Line,
Burlington, ON
L7L 0B7

Brian A. Morassutti
Sound Speech & Hearing
345 8 St. E,
Owen Sound, ON
N4K 1L3

Susan Schlacht
Sound Therapy
44A Newgate Street
Goderich, ON
N7A 1P1

Suzanne E. Melanson
St. Joseph's Healthcare Hamilton
Charlton Campus
50 Charlton Avenue East
Hamilton, Ontario
L8N 4A6

Linda F. Hollingham
St. Joseph's Healthcare Hamilton
Charlton Campus
50 Charlton Avenue East
Hamilton, Ontario
L8N 4A6

Lorrie Lynn Matarazzo
The Canadian Hearing Society
1233 Paris St,
Sudbury, ON
P3E 3B6,
Canada

Judith A. Heal
The Hearing Rehab Centre
952 Jones Road, Suite B3,
Midland, ON
L4R 0G1

Lorraine A. Kennedy-Vosu
Toronto Hearing Services
377 Church Street
Suite #203
Markham, ON
L6B 1A1,
Canada

Jane M Steinberg
Total Hearing Centre
504 Dundas St,
Woodstock, ON
N4S 1C5

Christine L. Brown
H.A. Leeper Speech and Hearing Clinic
The University of Western Ontario
1201 Western Road
Elborn College, Room EC1501A
London, Ontario, Canada
N6G 1H1

Janet Witherspoon
Advanced Hearing Ontario Inc
75 Bayly St. West Unit 5
Ajax, ON
L1S 7K8

April Malandrino
Markham-Stouffville Hospital
Child Development Program- Audiology
13175 Yonge Street
Richmond Hill, Ontario
L4E 0G6

Sandra Lynn DeKok
Canadian Hearing Society
Windsor Regional Office - Private Practice
300 Giles Blvd East, Unit A3
Windsor, Ontario
N9A 4C4

L White
Elgin Audiology Consultants
66 West Ave., Suite 101
St. Thomas, ON
N5R 5H7

Sharon Woodcox
Grandview Children's Centre – Audiology
600 Townline Rd. S.
Oshawa, ON
L1H 7K6

Stella Maschas-Wong
Sick Kids Hospital – Audiology
555 University Avenue
6th Floor, Burton Wing
Toronto, ON
M5G 1X8

Vicky A Papaioannou
Sick Kids Hospital – Audiology
555 University Avenue
6th Floor, Burton Wing
Toronto, ON
M5G 1X8

Lauren D. Schofield
Sick Kids Hospital – Audiology
555 University Avenue
6th Floor, Burton Wing
Toronto, ON
M5G 1X8

Kelly Jellous
Sick Kids Hospital – Audiology
555 University Avenue
6th Floor, Burton Wing
Toronto, ON
M5G 1X8

Ashley Howarth
Hotel Dieu Shaver
541 Glenridge Ave.
St. Catharines, Ontario, Canada
L2T 4C2

Gina Oh
Sound Advice Hearing Clinic
685 Sheppard Ave., E. Suite 402
Toronto, ON
M2K 1B6

Allison Stevenson
South Windsor Hearing Centre
6-350 Cabana Rd.,
Windsor, ON
N9G 1A3

Carol Pavey
Ron Joyce Children's Health Centre
Hamilton Health Sciences Audiology Clinic
237 Barton St. E.
Hamilton, ON
L8L 2X2

Paula Varette-Cerre
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Charalee Smith
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Paul Stevenson
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Patricia Lee
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Susan Eitutis
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Bonnie Cooke
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Emily Rosen
Audiology – Hotel Dieu
Murray Building,
144 Brock St.,
Kingston, ON
K7L 5G2

Karin T Bork
Hearing Services
Alberta Children's Hospital,
2888 Shaganappi Trail NW,
Calgary, AB
T3B 6A8
Canada

Rhys J Kooistra
Professional Audiology Clinic // Hy's Centre
Main Floor
11010 101 Street NW,
Edmonton, AB,
T5H4B9

Jason T. Schmiedge
Expert Hearing Solutions
134 Primrose Dr,
Saskatoon, SK
S7K 5S6

Marina A. Walls
Yorkton Hearing Services
18 1 Ave N,
Yorkton, SK
S3N 1J3

Caryn A Woods
Cypress Audiology Centre
350 Cheadle St W,
Swift Current, SK
S9H 4G3

Montreal Children's Hospital (X8)
Speech-Language Pathology department
Attn: Clinicians
1001 Décarie Boulevard,
Room: A04.3140
Montreal, Quebec
H4A 3J1

Montreal Children's Hospital X8
Audiology Department
Attn: Clinicians
1001 Décarie Boulevard,
Room:
Montreal, Quebec
H4A 3J1

Doris B. Piplica
Glenrose Rehabilitation Hospital
Cochlear implant service
10230 111 Avenue NW
Edmonton, Alberta
T5G 0B7

Brian A. Schmidt
Glenrose Rehabilitation Hospital
Cochlear implant service
10230 111 Avenue NW
Edmonton, Alberta
T5G 0B7

Michael Vekasi
Glenrose Rehabilitation Hospital
Cochlear implant service
10230 111 Avenue NW
Edmonton, Alberta
T5G 0B7

Penny A.C. Gosselin
Audiology and Children's Allied Health –
Lethbridge Centre
Suite 120B, Main Floor
200 4 Avenue S
Lethbridge, Alberta
T1J 4C9

Laura Hudema
Community Audiology Services
Misericordia Community Hospital
16940 87 Avenue
Edmonton, Alberta
T5R 4H5

Danielle A. Stewart
Audiology Services
Grande Prairie Virene Building
10121 97 Avenue
Grande Prairie, Alberta
T8V 0N5

Katherine E. Kvile
Glenrose Rehabilitation Hospital
Cochlear implant service
10230 111 Avenue NW
Edmonton, Alberta
T5G 0B7

Kathy J. Packford
Glenrose Rehabilitation Hospital
Cochlear implant service
10230 111 Avenue NW
Edmonton, Alberta
T5G 0B7

Tania L. Gora
Living Sounds Hearing Centre
Village Park Medical
102, 937 Fir Street
Sherwood Park, Ab
T8A 4N6

Koren Rae Wasilka
L.A. Audiology Clinic Ltd.
#40-5201
50 St.
Leduc, AB
T9E 6T4

James L. Werner
Early Hearing Detection and Intervention
Medicine Hat Regional Hospital
666 5 Street SW
Medicine Hat, Alberta
T1A 4H6

Anne Elizabeth Woolliams Ross
Soundwave Hearing Care
701 14 Street Nw
Calgary, AB,
T2N 2A4

Charlotte M. Ellis
Soundwave Hearing Care
701 14 Street Nw
Calgary, AB,
T2N 2A4

Margaret Anne Korble
Westside Audiology
Hearing Clinic Calgary
Unit 202,
555 Strathcona Boulevard SW Calgary, A
T3H 2Z9

Nicuta Gairns
Wild Rose Audiology Clinic
Westgrove Medical Building
14211-103 Avenue NW
Edmonton, AB T5N 0S9

Marion E. Zeeman
Zeeman Audiology Hearing Clinic
2801 13 Ave SE,
Medicine Hat, AB
T1A 3R1

Brian Holmes
Expert Hearing Solutions
104 - 2205 Louie Drive
Westbank, BC,
V4T 3C3

Kristina L. Plewes
McNeill Audiology
1463 Hampshire Rd.
Victoria, BC
V8S 4T5

Carolyn E Hawrish
BC Family Hearing Resource Centre
15220 92 Ave,
Surrey, BC
V3R 2T8

Ning Y. Hu
Children's Hearing and Speech Centre of
3575 Kaslo St,
Vancouver, BC
V5M 3H4

Nichole L Sorensen
Expert Hearing Solutions
9685 BC-97,
Lake Country, BC
V4V 1P5

Jeff Naka
Expert Hearing Solutions
4900 27 St #20,
Vernon, BC
V1T 7G7

Robert D. Reiter
Expert Hearing Solutions
130-1835 Gordon Dr.,
Kelowna, BC,
V1Y 3H4

Cheryl N. Lane
Surrey Memorial Hospital
Audiology department
13750 96 Ave,
Surrey, BC
V3V 1Z2

Cindy R. Schubert
Abbotsford Regional Hospital and Cancer
Centre
Audiology Department
32900 Marshall Rd,
Abbotsford, BC
V2S 0C2

Laura L Curran
Northern Health
Terrace Health Unit
Audiology
3412 Kalum Street
Terrace, BC
V8G 4T2

Tosha Hodgson
Rockwell Audiology Inc.
Sun Valley Mall - 2nd Floor
204 - 3334 30th Avenue
Vernon BC V1T 2C8

Grace M. Shyng
Western Institute For The Deaf & Hard Of
Hearing
2125 W 7th Ave,
Vancouver, BC
V6K 1X9

Amir Hossein Soltani
NexGen - (Formerly Mainland Hearing)
404 -1200 Burrard Street,
Vancouver, BC
V6Z 2C7

Dr. Joyce Chen
Okanagan Hearing Centre
(Guisachan Village Mall)
115-2365 Gordon Dr.
Kelowna, BC

Mark Hansen
Sound Hearing Clinic
#207-1160 Burrard Street,
Vancouver, BC
V6Z 2E8

Sandra M Baker
Western Institute For The Deaf & Hard Of
Hearing
2125 W 7th Ave,
Vancouver, BC
V6K 1X9

Irene F. Scarrow
Bethesda Regional Health Centre
Audiology Department
316 Henry St,
Steinbach, MB
R5G 0P9

Wendy L Frenette
Chaleur Regional Hospital
Audiology Department
1750 Sunset Dr,
Bathurst, NB
E2A 4L7

Nadine A Jacob
Avenir Hearing
181 rue Wellington Street
Miramichi, NB,
E1N 1M2

Laudia J. Leblanc
Avenir Hearing
1888 Mountain Road
Moncton New Brunswick
E1G 1A9

Chantale Melanson
Audiology Department
Moncton Hospital
81 Albert St,
Moncton, NB
E1C 1B3

Amanda G. Reindorp-Young
Chaleur Regional Hospital
Audiology Department
1750 Sunset Dr,
Bathurst, NB
E2A 4L7

Anouk Elizabeth Roy
Dr Georges-L.-Dumont
University Hospital Centre
Audiology Department
330 Université Ave,
Moncton, NB
E1C 2Z3

Joe L. Gedge
Beltone Audiology and Hearing Clinic
16 Pinsent Dr,
Grand Falls-Windsor, NL
A2A 2R6

Jane A Bowering
Audiology Department
Janeway Children's Health and Rehabilitation
Centre
300 Prince Phillip Drive
St. John's, NL A1B 3V6

Beverley King
James Paton Memorial Regional Health Ce
Audiology Department
125 TCH
Gander, NL
A1V 1P7

Tawfik A.H. Shabaka
Labrador West Health Centre
Audiology
1700 Nichols-Adam Highway
Labrador City, NL
A2V 0B2

D. Scott Bonnell
Connect Hearing Kentville
100 - 70 Exhibition St.
Kentville, NS
B4N 4K9

Michel G. Comeau
Nova Scotia Hearing and Speech Centres
5657 Spring Garden Rd,
Halifax, NS
B3J 3R4

Adrienne M Comeau-Grandy
Nova Scotia Hearing and Speech Centres
45 Alderney Dr,
Dartmouth, NS
B2Y 2N6

Allison J Debow
Nova Scotia Hearing and Speech Centres
5657 Spring Garden Rd,
Halifax, NS
B3J 3R4

Ruth Evans
Nova Scotia Hearing and Speech
112 Provost St,
New Glasgow, NS
B2H 2P6

Sheila V. Fortier
Nova Scotia Hearing and Speech Centres
5657 Spring Garden Rd,
Halifax, NS
B3J 3R4

Heather L. Grant
Nova Scotia Hearing and Speech Centres
Health Park
45 Weatherbee Road, Suite 106
Sydney, NS
B1M 0A1

Scott P. Johnson
Nova Scotia Hearing & Speech Clinic
Town Square
10 Webster Street
Kentville, NS B4N 1H7

Tim P. Lushington
Nova Scotia Hearing & Speech Clinic
18 South Albion Street
Amherst, NS
B4H 2W3

Odilia M. Macdonald
Marco Hearing Health Centre
80 Crescent St,
Sydney, NS
B1S 2Z7

Sheila M. Nichols
Hearing Health Care Unit Of Southwest Nova
Limited
3 Lovitt St #103,
Yarmouth, NS
B5A 3C1

Greg A. Noel
Nova Scotia Hearing And Speech Centres
Queen Square
45 Alderney Drive, Suite 606
Dartmouth, NS
B2Y 2N6

Maureen Heather Scott-Popovich
Nova Scotia Hearing And Speech Centres
Harbour View Hospital
22 Richard Street
Sydney Mines, NS
B1V 2H7

Nadia S Tymczyszyn
Highland Hearing Clinic Ltd
3988 South River Rd, Hwy. 4,
Antigonish, NS
B2G 2H4

Jolene D Haberstock
Carlton Trail Hearing Clinic
2995 2 Ave W,
Prince Albert, SK
S6V 5V5

Barbara E. Bond
Audiologie West Island
3400 Rue du Marché,
Dollard-des-Ormeaux, QC
H9B 2Y1

RICHARD C. KENT
Nepean Hearing Clinic
2039 Robertson Rd
Ottawa, ON
K2H 8R2

Ann Yuile-Campbell
Centre D'audiologie Du Lakeshore
189 Hymus Blvd,
Pointe-Claire, QC
H9R 1E9

Debbie L. Davis
Eastside Audiology & Rehabilitation
2190 Victoria Ave E,
Regina, SK
S4N 7B9

Charlotte M. Douglas
Royal University Hospital
Audiology
Room 25 Ground Floor - Ellis Hall
103 Hospital Drive,
Saskatoon, SK
S7N 0W8