

# Hispanic Parents' Beliefs, Attitudes, and Perceptions Toward Pediatric Hearing Loss: A Comprehensive Literature Review

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**Abstract: Objective:** The purpose of this review was two-fold: (a) to understand research findings about Hispanic parents' beliefs, attitudes, and perceptions related to hearing loss after having children who are deaf or hard of hearing, and (b) to inform future research needs that could expand audiologists' ability to provide patient-centered care with this population.

**Design:** A comprehensive review of the literature was used to identify relevant articles for the review.

**Study Sample:** Five research articles met the inclusion criteria.

**Results:** Three primary themes emerged: (1) deafness causality, parents tended to describe the cause of the hearing loss in terms of religion and folk beliefs; (2) cultural attitudes, parents reported having paternalistic views related to the care of their child and experiencing community stigma, and (3) cultural values, parents described how personalism, familism, fatalism, and respect informed their perspectives.

**Conclusions:** This comprehensive literature review found that limited research has been done to understand beliefs, attitudes, and perceptions of Hispanic parents toward pediatric hearing loss. Synthesis of five studies revealed important cultural factors for audiologists to consider in the provision of patient-centered care. Beliefs related to the cause of hearing loss, cultural values, and integration of children within the Hispanic community, may be critical elements for audiologists to address when promoting parental engagement.

**Key Words:** Hispanic, beliefs, attitudes, perceptions, hearing loss

**Acronyms:** ASHA = American Speech-Language-Hearing Association; DHH = deaf or hard of hearing; JCIH = Joint Committee on Infant Hearing; PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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## Introduction

Hispanic people constitute 18% (58 million) of the population in the United States. The Hispanic population increased by over 40% between the years 2000 and 2010 and is expected to be at 119 million by 2060 (Colby & Ortman, 2015). Many (72%) Hispanics report Spanish as the primary language they use at home (U.S. Census Bureau, 2017), an important factor when considering educational supports for parents with a child who is deaf or hard of hearing (DHH). Based on the shift in demographics, it can be anticipated that audiologists will be offering services to this population more frequently.

Best practice guidelines for working with children who are DHH indicate the importance of providing services that are family-centered and culturally sensitive (Joint Committee on Infant Hearing [JCIH], 2013) to support family engagement in all aspects of service delivery (American Speech-Language-Hearing Association [ASHA], 2004). Language barriers and cultural differences between the provider and patient can compromise patient satisfaction, and possibly treatment outcomes, if patients feel their needs are not being addressed in a manner that acknowledges their cultural perspective (Abreu, Adriático, & DePierro, 2011). It is estimated that 13% of families living in the United States speak Spanish in the home

as a primary language, but only 3.7% of audiologists in the United States report being Spanish-English bilingual (ASHA, 2017). Audiologists may find it challenging to navigate cultural differences in addition to language barriers in the delivery of services, requiring intentional efforts on the part of audiologists to adequately address the needs of Hispanic families.

Few studies have explored perspectives, experiences, and needs of Hispanic parents of children who are DHH. Research in pediatric audiology has primarily focused on the experiences of families from the majority culture with higher socioeconomic status (Muñoz, Blaiser, & Barwick, 2013; Muñoz, Preston, & Hicken, 2014; Muñoz et al., 2015; Moeller, Hoover, Peterson, & Stelmachowicz, 2009; Sjoblad, Harrison, Roush, & McWilliam, 2001; Walker et al., 2013). One study, conducted by Caballero et al. (2017), explored hearing aid management challenges and support needs of Hispanic parents (N = 42) of children birth to five years of age. Findings revealed that parents wanted more support from their audiologist than they were receiving, wanted more information and training, and that they experienced challenges that interfered with how much their child used their hearing aids. Given the importance of family-centered care and the projected growth of the Hispanic population in the United States, understanding research findings related to the perspectives, beliefs, and attitudes of Hispanic parents would benefit audiologists. The purpose of this review was two-fold: (a) to understand research findings about Hispanic parents' beliefs, attitudes, and perceptions related to hearing loss after having children who are deaf or hard of hearing, and (b) to inform future research needs that could expand audiologists' ability to provide patient-centered care with this population.

## Method

A comprehensive review of the literature was conducted to identify peer-reviewed journal articles published on the beliefs, attitudes, and perceptions of Hispanic parents related to pediatric hearing loss. The search for relevant studies followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) approach (Liberati et al., 2009), which consists of four phases: (a) identification of research papers through database searching; (b) screening of the articles identified in the first phase; (c) eligibility of the articles after full-text readings, and (d) inclusion in the review of the articles that fit the criteria.

### Procedures

Database searches were completed (CINAHL, ERIC, PsychINFO, Medline, Psychology and Behavioral Science, MedicLatina, and Fuente Académica) using English search terms (“Hispanic OR Spanish OR latin\*”) AND (“believe OR belief\* OR attitude\* OR perception\*”) AND (“Hearing loss OR deaf\* OR hearing impair\* OR hard of hearing”), and Spanish search terms:

(“Hispanic\* OR Latin\*”) AND (“creencia OR percepción\* OR actitud\*”) AND (“pérdida auditiva OR sordera OR trastorno auditivo”). Articles were included if they met the following criteria: (a) peer-reviewed research published from 1985 through 2017, (b) participant sample included Hispanic parents of children who are deaf or hard of hearing, and (c) research addressed attitudes, beliefs, or perceptions about hearing loss.

The database search identified 170 unduplicated journal article abstracts. Title and abstract screening excluded 136, and full-text review excluded an additional 29 articles. Of those excluded by full-text review, 10 did not include Hispanic participants, 7 did not include hearing loss, 8 were not research studies, and 4 did not address cultural beliefs, attitudes, or perceptions. The complete search resulted in five peer-reviewed articles that met the inclusion criteria. A qualitative assessment was completed for all eligible articles, emergent themes related to beliefs, attitudes, and perceptions of Hispanic parents related to pediatric hearing loss were synthesized, and a narrative summary was generated.

## Results

All of the studies were published in English, and the same author (Steinberg) wrote three of the five articles. Three primary themes emerged (see Table 1): (a) deafness causality, parents tended to describe the cause of the hearing loss in terms of religion and folk beliefs; (b) cultural attitudes, parents reported having paternalistic views related to the care of their child and experiencing community stigma, and (c) cultural values, parents described how personalism, familism, fatalism, and respect informed their perspectives. A discussion of the five articles that met our inclusion criteria follows.

### Steinberg and colleagues (1997)

The authors interviewed nine Hispanic families (the majority were of Puerto Rican origin) to identify their perceptions, attitudes, and beliefs about deafness and disability. The interviews were conducted orally, in either Spanish or English, based on the participant's language preference; most reported coming from large families and having family support to raise their children. Sixty-seven percent ( $n = 6$ ) of the families referred to God when explaining why their child or other children were deaf. Other beliefs were related to the fact that God had chosen their family to raise a child with hearing loss or that God would restore the child's hearing whenever he might think it is the right time. Besides the belief that God caused the child's deafness, other causes of hearing loss reported were noise from a plane or hereditary causes when another diagnosis was provided by the physician.

Parents described experiencing public stigma, feeling as though their child was losing their identity in the Hispanic community because others would refer to

**Table 1**  
**Summary of Research Articles Included in the Review**

Author (Year)/country	Design	Participants	Education Level	Deafness causality	Cultural Attitudes	Cultural values	Focus
Steinberg et al. (1997), USA	Interviews	9 Hispanic Families	NR	God's will; divine will	Community stigmatization Paternalistic attitude	Familism Respect Fatalism	Gain insight into perceptions and beliefs about deafness by exploring the experiences and responses of Hispanic families in discovering and adjusting to a child's hearing loss.
Steinberg et al. (2003), USA	Questionnaires and interviews	29 Hispanic Families	Low	Religion and God's will influenced their decisions	Paternalistic attitude	Familism Respect Fatalism	Examine the decision-making process of Hispanic families living in the US who have a child with hearing loss.
Palmer et al. (2008), USA	Longitudinal/prospective	139 Families (56 Caucasian, <b>59 Hispanic</b> , 29 Asian)	Low	God's will	NR	Familism	Examine parental reasons for, and beliefs about, genetic testing for deafness in early-identified infants, and to determine if they differ as a function of ethnicity.
Steinberg et al. (2007), USA	Interviews	24 Parents (16–Hearing English Speakers <b>5–Hearing Spanish speakers</b> 3–Deaf parents)	Low	Divine will vs hereditary vs physical insult	NR	Fatalism	Identify attitudes toward the use of parental narratives on genetic testing for children with hearing loss.
Guiberson (2013), Spain	Survey	71 Spanish parents	High	NR	Community stigmatization	Familism Personalism	Describe factors and trends associated with Spanish parents' choice of communication modality and spoken language bilingualism for children who are DHH; identify if bilingual variables predict children's bilingual status in a country where bilingualism is common.

Note. DHH = deaf or hard of hearing; NR = not reported

their child as the “deaf one,” the “mute one”, or use the diminutive “little deaf one”. Some mothers reported that deaf children were viewed with pity by the Hispanic people they encounter (e.g., attaching the diminutive “-ito” or “-ita” when referring to the deaf child: “sordita”, “pobrecito” [little deaf one, poor little one]). Another element shared by the parents was that other Hispanics in the community tend to assume that hearing loss is associated with intellectual disabilities: “*there are people who think that he is retarded because they don't know him...*” (p. 211).

### Steinberg and colleagues (2003)

The researchers interviewed 29 Hispanic families living in four states (i.e., Pennsylvania, Texas, Central Florida, and Northern California) to explore their decision-making process after the identification of deafness. All parents had at least some high school education. Eighty percent of the children ( $n = 23$ ) had severe to profound

hearing loss, and three had known hereditary deafness. Four children (14%) had cochlear implants; technology use was not reported for the remaining children. The authors explored the impact of culture, language, and access to available information and services. Approximately half were given written materials about communication opportunities. The authors found that Hispanic parents' decisions were often complicated by language and cultural barriers, as well as limited access to information in Spanish at an appropriate educational level. Parents reported that even when they expressed their desire to have their children learn Spanish, most followed the professional's recommendations when making decisions about communication, with a combination of sign language and spoken English most often recommended by professionals. The study also found that mothers were the most involved in the decision-making process, followed by fathers, family doctor, grandparents, and friends. Findings related to

attitudes and beliefs about deafness showed 96% of the Hispanic families agreed with the statement, “Children should be taught sign language so they can talk to deaf people” (p. 6). Also, less than half of the participants agreed with the statement: “Deaf children should go to ordinary schools” (p. 6).

### **Palmer and colleagues (2008)**

The authors presented baseline data collected from 139 parents of deaf children participating in a longitudinal, prospective study on genetic testing for connexin-related deafness. Forty-two percent ( $n = 59$ ) of the parents were Hispanic living in Southern California, with the majority having a high school diploma or higher. The purpose of this study was to examine ethnic differences in parental perceptions of genetic testing for deaf infants. All parents in this study consented to genetic testing to understand the cause of their child’s deafness. Asians and Hispanic parents were more likely to perceive genetic testing in harmful terms (e.g., harmful effects on family, harmful to child, emotionally difficult to receive genetic information). Hispanic participants reported the most common reasons for genetic testing were related to etiology: to learn more about the baby’s deafness, to know the cause of the baby’s deafness, and to find out if the cause of the baby’s deafness was genetic. Furthermore, Hispanic parents attached more importance to family planning as a reason for genetic testing than did Caucasian parents, with the majority of the Hispanic parents (60%) feeling that a “very important” reason for their child to have genetic testing was for making decisions about whether to have more children in the future.

### **Steinberg and colleagues (2007)**

The authors interviewed 24 parents whose children had been referred for genetic testing (but had not yet been tested) for hearing loss. Parents recruited for this study included 16 hearing, English-speaking parents; 5 hearing, Spanish-speaking parents; and three deaf parents. Participants represented a diverse range of ethnic, racial, and socioeconomic groups. The Spanish-speaking parents recruited for this study had a lower educational level compared to the English-speaking parents. The interview included asking parents questions related to their knowledge of genetics (e.g., “What did you think was the reason for getting genetic testing?”), questions specific to hearing loss and experiences with healthcare professionals (e.g., “What were you told at the time about the results of the testing?”), values regarding the presence of hearing loss in their children (e.g., “How do you think being deaf or hard of hearing is different from having a different kind of disability?”). Several themes emerged from parental narratives, such as misconceptions and limited knowledge about genetics and the nature of hearing loss being transmitted genetically, and perspectives on genetic testing. Parents also reported wanting to know the cause of their children’s hearing loss (e.g., feeling relief or responsible). All of the Hispanic parents in the

study speculated divine intervention as the cause of hearing loss. Some parents considered their children’s hearing loss as a punishment from God while others considered the belief that God had chosen them as parents of a child with hearing loss, for a special purpose.

### **Guiberson (2013)**

The author surveyed 71 highly educated Hispanic parents of children who are DHH from Spain, to obtain information related to four specific areas: (a) family supportiveness and involvement, (b) accessibility to services and information; (c) professional involvement and supportiveness, and (d) bilingual variables. The majority of children had severe-to-profound hearing loss, were using cochlear implants, and their parents had selected an oral-only mode of communication; approximately one-third of the parents chose to raise their children to be spoken-language bilingual (English/Spanish). Most parents indicated they believed it was beneficial for their child to be bilingual, and that children who are DHH are capable of becoming bilingual in spoken languages. Parents reported that their partners/spouses and the extended family were their major support system and were involved in the decision-making process. Regarding professional support and involvement, parents indicated that the highest level of support and involvement was from speech-language pathologists, audiologists, and deaf educators. Half of the parents reported they struggled and had to work hard to obtain information about their children’s options, and more than half said they wished professionals had provided more resources and offered more communication opportunities (e.g., oral vs. American Sign Language vs. cued speech) for their child.

## **Discussion**

Given the importance of patient and family-centered care and the projected growth of the Hispanic population in the United States, audiologists can benefit from understanding how Hispanic parents of children who are DHH view hearing loss. This comprehensive literature review identified five studies that explored Hispanic parents’ beliefs, attitudes, and perceptions toward pediatric hearing loss. Three primary themes emerged from the review: deafness causality (cause of the hearing loss in terms of religion and folk beliefs); cultural attitudes (e.g., paternalistic views and community stigma); and cultural values (e.g., personalism, familism, fatalism, and respect. These themes offer insights that can help audiologists consider questions that may be important to raise with Hispanic parents of children who are DHH.

### **Deafness Causality: Religious and Folk Beliefs**

How the cause of a chronic illness or disability is perceived culturally can have a significant impact on other aspects of the family’s and the community’s

attitudes toward the child with the disability. Hispanics are more likely to associate chronic diseases (e.g., hearing loss) with God's will or a divine intervention (Groce, 1987). Chronic illness and disability is seen by many cultures as a form of punishment. Religion and God were reported as the main cause of hearing loss (e.g., divine will, God's punishment, lack of faith in God) among children in all of the studies in this review (Guiberson, 2013; Palmer et al., 2008; Steinberg, Bain, Li, Delgado, & Ruperto, 2003; Steinberg, Davilla, Collazo, Loew, & Fischgrund, 1997; Steinberg et al., 2007). Inherited disorders are frequently seen as being caused by a family curse, and a clinician's suggestion to determine who is the carrier for a particular gene, could be interpreted as an attempt to identify who is at fault. Such interpretations from families, may further complicate attempts to encourage families to continue getting assistance (Steinberg et al., 2007). In this literature review, however, two studies (Palmer et al., 2008; Steinberg et al., 2007) found that parents wanted to identify the cause of the disability, and the authors indicated the importance parents placed on understanding their children's cause of deafness, regardless of their religion, hearing status, or ethnic background.

Understanding parent perspectives on genetic testing for deafness is an important consideration within a patient-centered care model (Palmer et al., 2008). Furthermore, Steinberg et al. (2007) emphasized the need for audiologists to be sensitive to parents' personal and sociocultural backgrounds when discussing genetic testing. Audiologists should provide emotional and educational support when parents are facing the possibility of having their child identified with a genetic cause for the hearing loss.

### **Cultural Attitudes**

**Paternalistic views.** In Hispanic families, parents often overprotect their children with a disability, even when the person with a disability wants independence and to be included in society (Steinberg et al., 2003). Two studies in this review (Steinberg et al., 1997; Steinberg et al., 2003) found evidence of paternalistic attitudes, in which parents feel the disability is unacceptable, or they experience negative social pressure. Such feelings and experiences can interfere with their participation in programs and their engagement in the intervention process. Hispanic parents of young children may prefer to keep the child at home, unseen even by close family and neighbors, for various reasons such as embarrassment about their children's condition or the desire to protect their children from being teased or insulted by others (Groce, 1987; Steinberg et al., 1997). These perspectives may represent a mismatch between the majority and minority cultures on the views of disabilities. How parents are supported in this process, including feeling respected, can influence their engagement in the process. Their willingness to explore opportunities to learn how to support their children and

how to advocate for their children should be addressed in a way that incorporates their potential paternalistic tendencies.

**Community Stigma.** Within the Hispanic community, disability can be seen as a divine punishment, an inherited evil, or as a result of family impurity. This can cause the family to feel deeply ashamed or even interfere with their ability to cope (Steinberg et al., 1997). Two of the studies in this review found parents experienced difficulty dealing with the community's stigmatization (e.g., children referred to as "sordo" [the deaf one] rather than using their name), and cases in which the child's own identity was lost due to the existence of the hearing loss (Steinberg, et al., 1997; Guiberson, 2013).

### **Cultural Values**

**Familism (Familismo).** The Hispanic community places a strong importance on close family relationships. The extended family plays an important role in decision-making, whereas within the U.S. society, the nuclear family is more often primarily involved in making treatment decisions for their child. Hispanic parents, conversely, often make key decisions in consultation with older relatives, grandparents, uncles, and aunts. This is a critical factor to consider within service delivery, as it is also common for extended family members to have a primary role in the day-to-day care of the child, including emotional support and financial assistance (Groce, 1987). Four of the studies in this literature review found the family and extended family members were an important part of their social support (Guiberson, 2013; Palmer et al., 2008; Steinberg et al., 1997; Steinberg et al., 2003).

**Personalism (Personalismo).** Development of a personal relationship with the health provider (e.g., audiologists) is often desired, and also includes the physical space between patient and provider—body language is important (Christensen, 1992). A desire for this relationship preference was described by parents in relation to the management of their children's hearing aids (Caballero et al., 2017). Guiberson (2013) detailed how parents reported the professional involvement; specifically, how the speech-language pathologists, audiologists, and deaf/special educators were highly involved, supportive, and their personal relationship helped them engage in making shared decisions regarding the children's treatment.

**Fatalism (Fatalismo).** Hispanics are more likely than the majority culture to believe that all events are predetermined and inevitable because it is part of their destiny. When parents hold this belief, they may think chronic illnesses are determined by God, and therefore must be accepted and considered as a *castigo divino* (punishment) for personal or family members' sins (Baquet & Hunter, 1995). Fatalism was a common

cultural value found in three of the articles included in this review (Steinberg et al., 1997; Steinberg et al., 2003; Steinberg et al., 2007). Audiologists need to take into consideration this cultural value because it might interfere with treatment adherence.

**Respect (*Respeto*).** Hispanics place importance on showing respect to authorities or knowledgeable figures, including healthcare providers. They are often presumed to know the answers, and because of this they will tend to follow whatever recommendations are suggested, even when it goes against their will. Two of the articles included in this review (Steinberg et al., 1997; Steinberg et al., 2003) reported on the importance of the value of respect within the treatment process. Steinberg et al. (2003) reported that even when parents had expressed their desire to have their children learn Spanish, most followed the professional's recommendations (respect) when making decisions about communication, agreeing to intervention that included spoken English and sign language. When audiologists are working with parents, they can support parent engagement by acknowledging and discussing what values are important to the family and letting those values guide the process.

There are limitations to this review; because of the scant research on this topic, findings should be interpreted with caution. The results of all the studies together represent 173 Hispanic families and cannot be generalized. Another limitation to highlight is that one study was primarily Puerto Rican parents, and another study was conducted in Spain. Furthermore, two of the studies were published more than ten years ago, and younger Hispanic parents' views may be different from older generations.

### **Implications for Practice and Future Research Needs**

Familiarization with characteristics of the Hispanic culture can offer benefits to audiologists in development of culturally competent practices. Even though differences exist among Hispanic families, there are four values that are common within the Hispanic culture that may be helpful to consider when providing audiology services to this population (Antshel, 2002; Calzada, Tamis-LeMonda, & Yoshikawa, 2013; Inclan, 1990; Irving, Benjamin, & San-Pedro, 1999; Rhoades, Price, & Perigo, 2004; Zea, Quezada, & Belgrave, 1994).

Health communication is an essential component of service delivery, and patient-centered care requires audiologists to consider needs on an individual basis. Patient and family factors can differ in multiple ways, such as culture, English proficiency, health literacy, socioeconomic status, or education level. There is a difference between the U.S. general population and Hispanics in educational attainment for individuals

25 years and older. According to the U.S. Census Bureau (2017), 66% of the population 25 years and over of Hispanic origin had at least a high school diploma; compared to 93% of Non-Hispanic Whites alone. In the Caballero et al. study (2017), 72% of the primary caregivers did not complete high school. In this review, three studies reported participants had a low educational level (less than high school) compared to other ethnicities. This has important implications regarding how professionals provide information and support parent learning.

Culturally competent practices can help reduce disparities through culturally sensitive and unbiased care. This involves understanding and respecting the language, religion, beliefs, and cultural values (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003); and taking time to learn more about each family's cultural background. The following suggestions may be helpful for audiologists when engaging families coming from a Hispanic background:

- Ask families their thoughts on the cause of their children's hearing loss: Sensitively challenge misconceptions, take time during the appointment to address the causes of hearing loss and compare it to the families' beliefs, and potentially incorporate information about the myths related to disabilities among the Hispanic community.
- Involve extended families and friends: Ask families how they would like their family members to be involved in the process (familism) and adjust the practices, to the extent possible, to reflect respect for their cultural preferences. For example, welcome extended family members *with permission* to the appointment, appointments can also be confirmed with extended family members (get their phone numbers as well) or teach other family members how to manage the children's hearing devices (e.g., how to change a hearing aid battery).
- Provide emotional support: For Hispanic families, close and warm relationships are important, even at a professional level. Address parents' emotional response to the hearing loss and treatment process. Families need to feel safe and free from judgment to share their challenges, beliefs, and thoughts.
- Education opportunities: Families vary in the extent they are aware of, know how to, and desire to take initiative to access educational resources. Having culturally appropriate resources in their native language can help families better understand the nature of hearing loss, treatment options, and communication opportunities available to their children; facilitating their ability to move forward.

Further research is needed that describes Hispanics beliefs, attitudes, and perceptions toward pediatric hearing loss in the United States. This information is important and can help audiologists improve service delivery for this population by providing a better understanding of parental experiences, beliefs about hearing loss, and important factors for making decisions for their children. Further, it would be beneficial to explore how audiologists are prepared to provide culturally competent services and opportunities to enhance training related to serving culturally and linguistically diverse families.

### Conclusion

This comprehensive literature review found that limited research has been done to understand beliefs, attitudes, and perceptions of Hispanic parents toward pediatric hearing loss. Synthesis of five studies revealed important cultural factors for audiologists to consider in the provision of patient-centered care. Beliefs related to the cause of hearing loss, cultural values, and integration of children within the Hispanic community, may be critical elements for audiologists to address when promoting parental engagement. Audiologists need to consider the patients' cultural background, and their level of education to implement shared treatment decisions.

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