A Review of Internet Resources Related to Spoken Language Intervention for Spanish-Speaking Parents of Children who are Deaf or Hard of Hearing

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Abstract

Objective: The purpose of this study was to identify website information related to hearing loss, hearing technology, and spoken language development available to Spanish-speaking parents of children who are deaf or hard of hearing (DHH).
Design: An exploratory, descriptive design was used to determine the presence or absence of parent education information on a variety of websites.
Study Sample: The study explored Internet resources provided by national, state, and parent support organizations in the United States.
Results: A total of 53 organization websites were identified that had information for parents of children who are DHH and learning spoken language, eight of which were international. Fifteen content areas were reviewed for each website. Of the 53 websites, 25 had information in Spanish.
Conclusions: Results of the current study revealed website resources are often fragmented and less in-depth for Spanish speaking parents with children who are DHH and learning spoken language.

Key Words: hearing, website, Internet, children, Spanish

Acronyms: DHH = Deaf or Hard of Hearing; EHDI = Early Hearing Detection and Intervention; FM = Frequency Modulation; JCIH = Joint Committee on Infant Hearing

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Introduction

Hearing loss in early childhood is often unexpected and 95% of children who are deaf or hard of hearing (DHH) have hearing parents (Mitchell & Karchmer, 2004) who want their child to learn spoken language (Alberg, Wilson, & Roush, 2006). For many parents, identification of hearing loss not only alters their vision of their child's future, but their confidence in how to support their child's development and overcome obstacles that may impact their access to or understanding of pertinent information related to their child's diagnosis (Cole & Flexer, 2015). Upon learning their child is DHH, parents often seek information about hearing loss (e.g., cause, type, degree) and hearing technology (e.g., hearing aids, cochlear implants, assistive technology); many parents are unfamiliar with available services and have financial questions or concerns (DesGeorges, 2003). In addition, social and emotional support, including accessing parent-to-parent connections can be critical for many families (Henderson et al., 2014).

When hearing loss is identified, and early intervention provided, child developmental outcomes can be optimized. Tomblin, Oleson, Ambrose, Walker, and Moeller (2014) found that when children had early and consistent audibility with hearing aids, their language outcomes were better than children without access to consistent intervention. Parents, however, face numerous challenges in learning

how to secure and navigate daily management of hearing technology and language intervention (Moeller, Hoover, Peterson, & Stelmachowicz, 2009; Muñoz et al., 2015; Muñoz, Preston, & Hicken, 2014; Muñoz, Blaiser, & Barwick, 2013; Sjoblad, Harrison, Roush, & McWilliam, 2001). In fact, studies have shown significant variability in hearing aid use for young children (Jones, 2013; Jones & Launer, 2010; Muñoz et al., 2014; Walker et al., 2013), a factor that can influence spoken language development. Parents face a steep learning curve related to intervention, and access to information (e.g., various Internet resources) can offer opportunities for parents and other caregivers to gain essential knowledge.

The importance of culturally and linguistically family centered services for effective intervention is identified in professional practice guidelines (Joint Committee on Infant Hearing [JCIH] Supplement, 2013), and includes provision of materials for families in their home language. In the United States, by 2050, it is projected that 82% of population growth will be from immigrants and U.S.-born minorities, with Hispanics representing one of the fastest growing segments of the population (Passel & Cohn, 2008). Given these data, the number of potential Spanish speakers would rise to about 62 million people in the U.S. (Instituto Cervantes, 2015). In a country where English is the dominant language it is important to ensure that health care information is available and accessible to *all* families

regardless of their home language. A language barrier can increase the risk of having limited access to information and resources (Steinberg, Bain, Li, Delgado, & Ruperto, 2003), reducing a person's ability to clearly understand information that is important for making educated decisions about health care. Furthermore, parents can experience challenges accessing information and support from experienced providers. In the U.S., state Early Hearing Detection and Intervention (EHDI) coordinators have reported significant shortages in pediatric audiologists (Muñoz, Bradham, & Nelson, 2011). There are also shortages of speech-language pathologists and deaf educators with expertise in listening and spoken language (Nelson, Lenihan, & White, 2014). In addition, hearing loss is relatively low incidence and many families live in disperse geographical locations. Together these factors further increase challenges for Spanish-speaking families in the U.S.

Research shows that when people are faced with a new diagnosis, such as hearing loss, they turn to the Internet for education (Rice, 2006). In fact, the Internet is now nearly ubiquitous in the U.S., with 90% of people ages 25 years and older (U.S. Department of Commerce, 2014) utilizing the Internet as a primary source of information. Having access to accurate and complete information via the Internet can help parents of children who are DHH effectively understand and manage their child's hearing loss, support their child's developmental progress, and identify potential emotional and financial support services.

Given the disperse population, challenges accessing professionals with specialized expertise in pediatric hearing loss, and the increase in Spanish language families in the U.S., there is a need for Internet resources in Spanish to support parent learning related to spoken language development for children who are DHH. For these reasons, this study was completed to determine what information is available electronically via the Internet by Spanish-speaking parents of children who are DHH and communicate using spoken language.

Method

National, state, and parent support organization websites in the U.S. that address pediatric hearing loss were included in the review if the scope of their website addressed topics related to intervention for spoken language acquisition in children who are DHH. Websites from private clinics and hospitals, and websites that addressed only newborn hearing screening were excluded from the review. The first author and an assistant jointly conducted the website review in June 2015 in two phases.

Procedure
Phase 1 included a broad Internet search of national, state, and parent support organizations in the U.S. using the Google Chrome search engine. State EHDI

websites that included information related to intervention for spoken language development after diagnosis of hearing loss were also included. Links embedded within the initial sites and hyperlinked to outside websites were also evaluated.

Content Areas
The content area topics deemed important for families seeking information about hearing loss, hearing technology, and spoken language intervention were determined using an iterative process. As websites were reviewed, main topics were identified and added to a list. As new topics were identified, previously reviewed websites were checked again to see if the topic area was overlooked during the initial review of content. The sites were searched for presence or absence of content areas; 15 areas were identified (see Table 1).

Website Features and Social Media
Various social media and website features were noted as present or absent. The features were determined using an iterative process. As websites were reviewed, features (e.g., newsletters, blogs, videos) and social media were added to a list as they were identified. As new features and social media were identified, previously reviewed websites were checked again to see if the feature was overlooked during the initial review.

Table 1. Content Areas Included in the Website Review

Foundational knowledge (e.g., type of hearing loss)	Advocacy and education
Hearing aids	Hearing assessment
Cochlear implants	Parent-to-parent support
Early intervention	Glossary
Medical referrals after diagnosis (e.g., otolaryngology)	Social-emotional
Assistive technology (generally)	Financial assistance
FM systems	Additional disabilities
Parent-professional collaboration (working with professionals)	

Note. FM = Frequency Modulation

Table 2. Social Media and Website Features included in the Website Review.

Google+	Videos	Newsletter	Contact us
Facebook	Blog	Rich Site Summary (RSS)	Chat
Twitter	YouTube	Pinterest	Parent distance education

Twelve features and social media options were identified (see Table 2).

Phase 2 included an in-depth review of the written content on the websites that included information in Spanish. Websites from Phase 1 that only had information in English were excluded. The content in Spanish for each website was subjectively rated by the first author and the research assistant jointly using a 3-point scale (*1 = no information; 2 = some information; 3 = extensive information*). This scale was used to broadly categorize websites rather than to determine specific differences between them.

For example, www.babyhearing.org, provides in-depth information (e.g., hearing aids and cochlear implants) in English and Spanish, and was categorized as having *extensive information*, whereas, http://www.parentcenterhub.org/repository/auditiva provides basic descriptions on some topics (e.g., Early Intervention and educational considerations) and was categorized as having *some information*.

Analysis

The assistant entered ratings into an Excel spreadsheet. For Phase 1, a code was entered to indicate the presence or absence for each content area. When information was present the assistant indicated whether it was in English, Spanish, or both English and Spanish. For Phase 2, the same content areas (Table 1) were reviewed using the 3-point Likert scale for the websites that provided information in Spanish. The ratings data from Phase 2 were also entered into the spreadsheet. Descriptive statistics were used to identify frequencies and trends noted across the websites.

Results

The website review revealed a total of 53 websites with information about hearing loss, hearing technology, and spoken language intervention. For the 15 content areas identified (Table 1), five were found on more than 50% of the websites: cochlear implants, foundational knowledge (e.g., type of hearing loss, causes of hearing loss), early intervention, hearing aids, and hearing assessment. Less

than 20% of the websites addressed parent-professional collaboration and additional disabilities (see Figure 1).

The 12 website features (e.g., FaceBook, Twitter, blog), embedded in the 53 websites, were evaluated to identify if they were present or absent (see Figure 2). More than 50% of the websites contained contact information, a FaceBook link, and Twitter account link. Approximately one-third of the websites offered a newsletter. Less than 10% of the websites offered educational modules or a chat feature to ask a question.

Of the 53 websites, 25 had information in Spanish in at least one of the 15 content areas (see Figure 3). The websites with Spanish language information included four national, seven state, six parent support, and eight international websites (for a list, see Appendix). More than 50% of the websites had some information in Spanish on the following eight content areas: foundational knowledge, cochlear implants, early intervention, hearing aids, hearing assessment, Frequency Modulated (FM) systems, assistive technology, and advocacy/education. Approximately one-third of the websites had extensive information in three areas: foundational knowledge, hearing aids, and a glossary. Less than 10% of the websites had extensive information in Spanish related to parent-to-parent support,
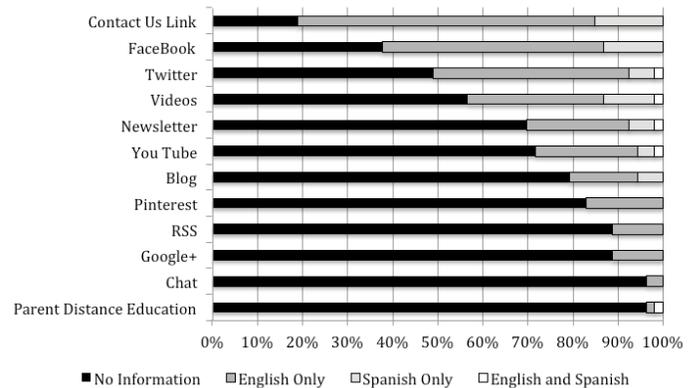

■ No Information   ■ English Only   □ Spanish Only   □ English and Spanish

Figure 2. Additional Website Features Present in English, Spanish, or English and Spanish (*N* = 53).

■ No Information   ■ English Only   □ Spanish Only   □ English and Spanish
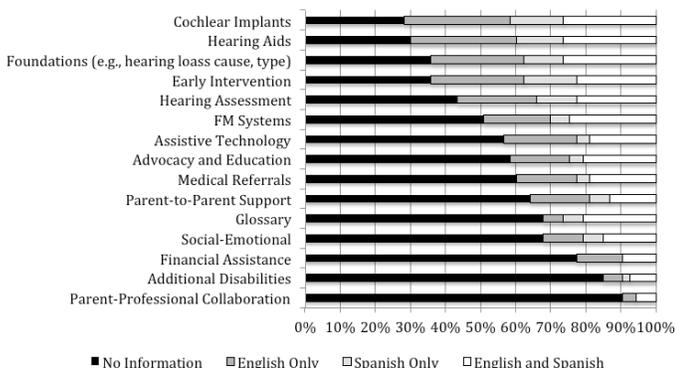
Figure 1. Website Content Present in English, Spanish, or English and Spanish (*N* = 53).

■ No Information   ■ Some Information   □ Extensive Information
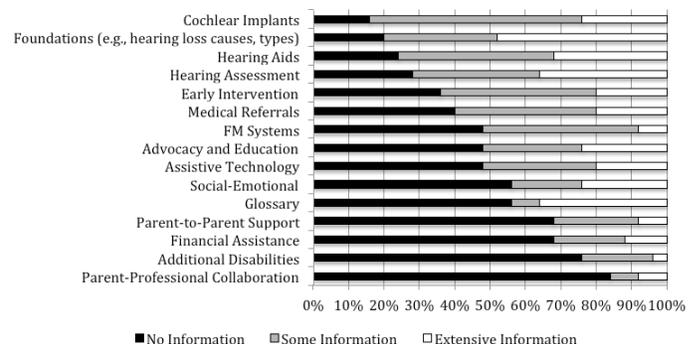
Figure 3. Extent of Spanish Language Information Provided on Websites (*n* = 25).

parent-professional collaboration, additional disabilities, and FM systems.

Discussion

This website review investigated the extent of healthcare information about hearing loss, hearing technology, and spoken language intervention available for families of children who are DHH and speak Spanish. Findings from this study revealed 53 websites with healthcare information in English and/or Spanish. Of those, 25 websites had information in Spanish, and very few provided in-depth information for parents. Information was often fragmented on websites with only some content areas (Table 1) included. For websites that provided information in both English and Spanish, the information in Spanish was often more limited than that provided in English; for example, FaceBook pages were only in English and videos were often only in English. The gaps that exist for Spanish-language Internet resources further limit how families can gain needed knowledge to help their children.

Hearing loss identification and subsequent intervention can be overwhelming for parents. Parents and other caregivers are faced with learning new information and skills, as well as how to apply new learning in their daily lives. To compound the problem, when English is not the primary language in the home, parents may require an interpreter when communicating with the audiologist and other intervention providers. Having access to health information in a variety of formats (e.g., verbal, written, demonstration, video) can aid in retention of information and support the development of effective self-management in patients and their families (Rogo, 2014). Both mothers and fathers of children who are DHH reported that they want information in a variety of formats (verbal, written, video), and that access to accurate information is important for learning to integrate new skills into daily routines with their children (Muñoz et al., 2015). Hispanic parents of young children who are DHH specifically reported that they want more concrete resources (Caballero & Muñoz, 2015).

Children often have caregivers other than the mother, including the father, grandparents, other family members, and day care providers. Audiologists have reported that they most frequently instruct mothers (n = 332/343; 97%) on how to manage hearing aids (Meibos et al., 2015), yet mothers have reported that other individuals care for their children who are DHH during the day (Rusk & Muñoz, 2015). The mother then is often in the position of instructing other caregivers how to manage the child's hearing devices and auditory environment. Internet resources can aid instruction of other caregivers, reinforce parent learning, and support parents in gaining confidence with new knowledge and skills.

Access to accurate information via the Internet in the parents' primary language offers a mechanism to support parent learning in a flexible manner that can serve to reinforce and supplement information provided by the audiologist and other intervention providers. For information

to be accessible for learning, factors such as health literacy, computer access, readability of information on other devices (e.g. smart phones), and cultural sensitivity that can influence how effectively information reaches the intended audience should be considered (Cotton & Gupta, 2004). Additional research is needed to better understand factors that influence Hispanic parent access of information on the Internet, how it may need to be tailored to meet their access needs, and how delivery of information can provide action-oriented learning support.

Conclusions

Results of the current study revealed website resources are often fragmented and less in-depth for Spanish speaking parents with children who are DHH and learning spoken language. Current available resources in Spanish on national, state, U.S. parent organizations, and international websites primarily support awareness for the content in the hearing healthcare areas identified in this review. The present data reflect a need for more complete, in-depth information that is easily accessible on the Internet, to support parent learning and enhance parent confidence for managing their children's hearing loss effectively on a daily basis. Parents need access to complete and accurate information, regardless of their primary language.

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Appendix

Websites with Spanish language information related to hearing loss, hearing technology, and spoken language development for parents of children who are deaf or hard of hearing (DHH) as of June 2015.

Organization	Website URL
National (U.S.)	
Center for Disease Control and Prevention	
Center for Parent Information and	www.cdc.gov/ncbdd/hearingloss/
Resources	www.parentcenterhub.org/repository/auditiva
National Institutes of Health	
March of Dimes	www.nidcd.nih.gov/pages/default.aspx
	http://nacersano.marchofdimes.org/complicaciones/ perdida-de-la-audicion.aspx
State Early Hearing Detection and Intervention	
Florida	
	http://www.floridahealth.gov/programs-and-services/ childdrens-health/newborn-screening/nbs-hear.html
Iowa	http://idph.iowa.gov/ehdi/families
Kansas	http://www.soundbeginnings.org/
Wyoming	http://www.wyomingehdi.org/
Michigan	http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_21429---,00.html
Virginia	http://www.vdh.virginia.gov/livewell/programs/ehdi/home.html
New Mexico	http://archive.nmhealth.org/nbhs/
Parent	
Baby Hearing	www.babyhearing.org
AG Bell Listening and Spoken Language	www.listeningandspokenlanguage.org
Center	
Beginnings	www.ncbegin.org
Hands & Voices	www.handsandvoices.org
John Tracey	http://www.jtc.org
Hear-It	www.hear-it.org
International	
FIAPAS	www.fiapas.es
Fundacion ECO	www.ecodepadres.org
Oír es Clave	ww.oiresclave.org
t-oigo	www.t-oigo.com
Mas Que Padres	www.masquepadres.arrakis.es
Fundacion Amaoir	www.amaoir.org
Mi Hijo Sordo	www.mihijosordo.org
Fundacion CINDA	www.fundacioncinda.com