Pediatric Feeding Disorders:

Caregiver Perspectives on Child Healthcare in the Latino Population

by

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ABSTRACT

Latino parents of children with feeding disorders completed a survey about their experiences accessing support and the cultural competence of their providers. This work is a follow-up project to a presented American Speech and Hearing Association Conference poster (Stats-Caldwell, Lindsay, Van Vuren, 2017). That project revealed caregivers' use of social media and indicated an overall perceived lack of support from providers. In the present survey, Latino caregivers identified the resources they consult and rated the level of helpfulness in addition to the types of supports they sought and received from these resources. Results indicate a considerable reliance on pediatricians in both frequency of consultation and helpfulness ratings. No significant difference was seen between the frequency of consultation between pediatricians, speech-language pathologists and other service providers. No significant difference was found in the helpfulness ratings between speech-language pathologists and topic-specific social media pages, nor speech-language pathologists and grandmothers. Participants indicated reliance on social media for informational resources. The influence of social media is discussed. The cultural implications of treating this population are also reviewed.

DEDICATION

To the caregivers and the underserved, and to the professionals who strive to provide culturally competent services, may we work together to serve our youth.

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Introduction

It is conservatively estimated that nearly one million children below the age of five are affected by pediatric feeding disorders (PFDs) in the United States (Barkmeier-Kraemer, Linn, Thompson, Byrd, Steinfeld, Hoffmann, Silverman, 2016). Although there is no single definition of PFDs, Feeding Matters (2017) described PFDs as “a severe disruption to eating, drinking, or digesting that may cause medical problems and compromise growth and development.” Symptoms of PFDs may include food refusal, less than optimal growth, inability to master developmentally-appropriate feeding skills, disruptive mealtime behavior, choking, gagging, vomiting, excessive meal time duration, or food selectivity by type and/or texture (Arvedson, 2008; Manikam & Perman, 2000). PFDs can be categorized into four different domains to better describe the source of dysfunction. The four domains are: medical, nutrition, skill, and psychological. In the medical domain, dysphagia is a type of feeding disorder characterized by difficulty swallowing food or liquid due to anatomical or neural abnormalities. As a PFD with physiological etiology, dysphagia must be given special consideration during intervention (Kakodkar & Schroeder, 2013).

Over three hundred conditions contribute to the four PFD domains (Feeding Matters, 2017) and many conditions affect multiple domains. Conditions contributing to PFDs include environmental disruption as a result of negative interactions with foods that may lead to aversive reactions, gastroenterological and digestive problems, developmental delay, or diagnoses such as Autism, cerebral palsy, Down Syndrome, failure to thrive, Eosinophilic esophagitis and more (Manikam & Perman, 2000).

The complexity of PFDs can have a significant impact on mealtime routines, family dynamics, and parent-child interactions. PFDs have an innate ability to disrupt mealtimes which can impact the cultural dynamics of mealtime and other cultural-rich routines surrounding feeding practices. Therefore, cultural differences are an important aspect to consider when providing intervention for PFDs. In addition, intervention for PFDs can be affected by cultural traditions, acculturation, and assimilation.

Cultural Implications

Davis-McFarland (2008) defined culture as the filter through which people view the world and evaluate all aspects of their existence. Food has important cultural implications for treatment of children's oral motor, swallowing, and feeding disorders, therefore interventions should be tailored to account for differences in culture and acculturation (Davis-McFarland, 2008; Kittler, Sucher, & Nahikian-Nelms, 2012). Acculturation is the capability to function within a dominant culture while maintaining important aspects of the original culture. Assimilation is the adaption of a dominant culture's customs. This study is a report on the cultural characteristics of the Latino population as they relate to food and mealtimes and the implications for providing feeding treatment and intervention.

Barriers to Healthcare

Outside factors such as geographical location, accessibility to healthcare, and socio-economic status will be discussed, as these factors may impact tendencies of varying cultural groups and are relevant considerations that influence intervention. It should be noted that providers and professionals are used interchangeably throughout this paper to refer to medical personnel providing care.

A differentiation between the terms Latino and Hispanic should be made. Latino refers to anyone of Latin American origin. Hispanic is derived from the term Hispania, which refers to the geographical location of the Iberian Peninsula, which is present day Spain and Portugal. Frequently, Hispanic is used in statistics to represent a larger population, while Latino is a more specific representation of a subset of Hispanics. In addition, Latino and Hispanic are used interchangeably due a lack of differentiation between the two in current literature. The United States Census Bureau (2016) reported the Hispanic population is roughly 56.6 million within the United States and accounts for 17.6% of the nation's population. Noteworthy statistics also reported by the United States Census Bureau (2016) indicated 21.4% of Hispanics live at or below the poverty line and 16.2% lack healthcare insurance. The Latino population is commonly unable to access adequate resources for intervention as a result of socioeconomic status.

A cross-sectional survey of families' access to health care revealed poverty, lack of health insurance, and transportation difficulties as major barriers (Flores, Abreu, Olivar, & Kastner, 1998). Parents reported limited access was due to the inability to afford visits and lack of health insurance. Distance from clinics and the expense or inconvenience of public transportation impacted access as well. Another study indicated 40% of uninsured participants reported not having a regular source of medical care due to cost and legal status (Valdez, Giachello, Rodriguez-Trias, Gomez, & De La Rocha, 1993). Undocumented Latinos are unlikely to seek out care in fear of deportation (Castañeda & Melo, 2014; Ransford, Carrillo, & Rivera, 2010). This may indicate Latino families are relying on other channels for medical care and advice.

Flores et al. (1998) revealed differences in language are the greatest barrier to receiving health care for children and reported a “high proportion of parents said that problems with culture and language had caused them to not bring their child in for health care.” Valdez et al. (1993) continued the conversation on language barriers, stating poor communication can inhibit quality care. It should be noted that many Latinos may not participate in care coordination with the belief that their linguistic diversity will impede the process (Davis-McFarland, 2008) or because professionals do not understand Latino culture (Flores et al., 1998).

Latino Cultural Considerations

Cultural considerations in the Latino population that should inform professionals’ recommendations include the concept of *respeto,* family dynamics, traditional foods, as well as views on healthcare and the influence of alternative medicines. *Respeto* is the concept of mutual respect or respect for those in authoritative roles. Flores et al. (1998) indicated that Latinos expect the same level of respect they give to professionals. A professional’s inability to demonstrate respect can negatively impact perceptions and satisfaction. This level of respect leads Latinos to view professionals as authoritative figures. This could explain why caregivers may not appear actively involved in the child’s care and do not feel comfortable questioning or disagreeing with professionals (Davis-McFarland, 2008). As a form of respect, many Latinos may remain silent or avoid eye contact (Sanjur, 1995). Professionals may view this as a lack of understanding or indifference to treatment. Therefore, caregivers may not challenge suggestions made by professionals in order to show respect rather than demonstrate misunderstanding.

Latino Food Culture

Traditionally, women are typically identified as the lead role in the kitchen when discussing nutrition and cooking (Janer, 2008; Sanjur, 1995). However, acculturation has changed this significantly in that now men and women tend to share these duties equally. Despite these changes, women experience obstacles and pushback from family members when making healthy eating changes (Kittler et al., 2012). Status is related to their ability to cook and work in the kitchen, thus they are likely to identify strongly with suggestions made about food, ingredients, and techniques. Any nutrition intervention and advice may be perceived as an accusation of inadequacy (Kittler et al., 2012). This is an important cultural component professionals should note when making recommendations for PFDs.

Professionals should be knowledgeable about typical ingredients found in Latino cuisine such as maize, beans, rice, squash, plantains, yucca, and chilies. Common techniques typically include frying, baking, and boiling (Janer, 2008). Ingredients and techniques may vary among families, and a greater level of acculturation may coincide with a more standard American diet of quick breakfasts and lunches (Janer, 2008). Breastfeeding practices may vary across cultures as well. It is reported that breastfeeding is not the sole source of nutrition in the Mexican culture and that herbal teas and commercially prepared milk formulas may be introduced within the first week of life because they are thought to provide additional nutrients (Davis-McFarland, 2008). When delivering intervention for PFDs, providing textures and consistencies of traditional foods is an important consideration. Implementation of traditional ingredients in intervention may be greatly received by clients and caregivers and increase client compliance.

An emphasis in conversation is an important dynamic to consider when discussing the Latino food culture. Cooking and mealtimes become a way for Latinos to affirm their cultural identity and family history (Janer, 2008). Latinos are ten times more likely to emphasize eating together than American families and set their tables to prepare for a social experience (Allende-Fite, 2013). Due to acculturation, dinners are more likely to adhere to the traditional culture of long conversations, while weekday breakfasts or lunches may be shorter (Janer, 2008). It is important for healthcare professionals to note that meal times may extend in duration and expand beyond the simple engagement of eating. Conversation and active participation in meal preparation may be encouraged for children. PFDs can greatly impact the cultural components of meal time and impact familial relationships. Therefore, recommendations for the home may need to focus on making children active participants during mealtime to account for the social dynamic in this culture.

Although varying across cultures, food and feeding practices are deeply rooted in culture and reflect beliefs about nutrition and health needs. Views on healthcare, traditional medicine, and western medicine can dictate compliance in intervention and should be considered when making recommendations.

Many Latino families use western medicine, while some rely on traditional beliefs and use home remedies or folk healers (*curanderos*) (Sanjur, 1995). Some Latinos believe there are three primary forces that cause illness: hot-cold imbalance, drafts or winds, and undigested foods (Sanjur, 1995). A common practice is the hot-cold dichotomy. The hot-cold dichotomy classifies foods and beverages as hot or cold. An illness is viewed as an imbalance of the body’s homeostasis. Food is used to restore the body to homeostasis. For example, rashes or fevers are considered hot conditions and are treated with cold foods such as vegetables, fruits, or dairy products. As a result, almost any degree of illness leads to a withdrawal of certain foods in the Latino culture (Sanjur, 1995). Therefore, children are not forced to eat foods they resist which can have a direct implication on their nutritional status and affect intervention considerations when consulting children with PFDs. This tradition may not be understood by professionals, but is an important aspect to consider and respect when treating feeding disorders in the Latino population (Davis McFarland, 2008; Sanjur, 1995) as the belief of the cause of PFDs may vary by family.

Cultural Considerations for Consulted Resources and Perceived Helpfulness

An extremely important consideration for feeding practices is the variance between what resources different cultures consult and where value is placed. Intervention for PFDs is a complex pathway that includes numerous factors and encompasses a multi-disciplinary team. However, cultural values and customs or outside factors such as socioeconomic status may impact where caregivers seek help and advice for care.

One study surveyed parents of children with feeding disorders to assess their experiences accessing support and services (Stats-Caldwell, Lindsay, Van Vuren, 2017). The survey was originally deployed to drive the development of an online educational module for caregivers of children with PFDs. Parents identified which resources they consulted and rated the helpfulness of these resources. Results indicated a heavy reliance on social media for information and caregivers reported finding topic-specific social media more helpful than physicians and nearly as helpful as speech-language pathologists.

While it is important to note that socio-economic status is a factor in accessing this platform of information, Korda & Itani (2013) indicated that more than half of U.S.

adults across all age and ethnic/racial groups use the internet to search for health information. The convenience of these platforms makes healthcare readily available for patients and have benefits for providers as well.

The Latino population may also rely on family members as a resource for care. Minimal to no research was found specifically on PFDs in the Latino population. However, some articles discussed feeding practices within the Latino population in infancy. Many Latina mothers adopt infant feeding practices that have been recommended by relatives, friends, or neighbors rather than professionals (Bryant, 1982). Because family, friends, and neighbors are a primary support system, it can be beneficial to include these members of kin in treatment education. Mothers are responsible for feeding and caring for children, although fathers are commonly the dominant member of the nuclear unit and are responsible for every day decisions.

In a study that examined cultural differences on the influence of family members on mothers' feeding practices, Latina mothers were found to be more likely to rely on family members' recommendations than were Anglo-American mothers (Bryant, 1982). Proximity of supportive networks such as friends and family in relation to the geographical location of health care professionals greatly influenced the likelihood of using a healthcare professional as a resource for infant feeding practices (Davis-McFarland, 2008).

There is heavier reliance on female members as opposed to male members as it relates to feeding practices. Mothers report they compare their infant's development to neighbors, but do not rely on neighbors as a resource for information. Although mothers may not respect neighbors' advice, information is transmitted through these channels

(Bryant, 1982). Puerto Rican and Cuban mothers turn to extended family frequently for advice and assistance and some even live with their mother during the perinatal period (Bryant, 1982). Sussner, Lindsay, & Peterson (2008) indicated grandmothers may greatly influence early child feeding practices. Family education may be an important component when providing intervention for children with feeding disorders in the Latino population because extended family members have a strong influence on feeding practices (Houston, Waldrop, & Mccarthy, 2011). Professionals should provide education to the nuclear and extended family to increase the likelihood of compliance while also considering levels of acculturation and assimilation.

Davis-McFarland (2008) stated levels of acculturation and assimilation impact duration of breastfeeding and as a result, feeding practices vary within this population. The extent to which recommendations are consistent with the family’s cultural values may determine the extent to which the family will understand, accept, and comply with therapeutic programs (Davis-McFarland, 2008). Caregivers will hear and understand the instructions and explanations through their cultural antenna (Davis-McFarland, 2008). Caregivers may feel professionals are unlikely to understand their culture and will not make recommendations that align with the beliefs and traditions of their culture. This further validates the importance of cultural competence among service providers. Understanding feeding practices within the Latino population may support and increase service satisfaction and provision.

Summary and Purpose of Study

This report provides a brief introduction to PFDs, the barriers to healthcare Latinos face, the customs found in Latino food culture, and highlight the importance of the assimilation and acculturation impacts on the traditional customs of feeding practices in the Latino culture. Research indicated Latinos put an emphasis on conversational exchange and family during meal time and women are likely to take on nutritional and cooking duties. Common utilized resources, behaviors demonstrated in consultation, and healthcare practices found in the Latino population are discussed.

Further exploration of which resources Latinos consult and where they garner information is needed. This will provide professionals the knowledge to share evidence-based practice and information with this population. Understanding the importance of typical traditional medicines, family members, and cultural practices will provide relevant information for providers. The frequency of use of various resources consulted by this population in addition to the type of support they receive from these resources will be beneficial for providers, clients, and their families. Furthermore, understanding effective means of communication between professionals and parents in the Latino community may increase care coordination, overall satisfaction, and client compliance.

Betancourt et al. (2005) discusses the importance of cultural competence between healthcare professionals. As the diversity in the United States increases, clinicians and providers face a broad range of perspectives that are influenced by cultural backgrounds. Expectations for care vary by culture and are influenced by belief systems which may impact their desire to adhere to professionals' recommendations. Further discussed in this paper, is that provider-patient communication and a general understanding and respect for cultural differences suggests improved patient satisfaction and health outcomes.

To broaden our understanding of these issues, a survey was deployed to parents of Latino ethnicity who have children with PFDs to gain insight on where this population turns for support and their views on the cultural competency of their providers. This information may lead to increased support, communication, care coordination, and a comprehensive understanding of the cultural implications of feeding practices as it relates to Latino families with PFDs.

Method

All procedures and materials involved in this study were approved by Arizona State University's Institutional Review Board (IRB) before data were collected. Notification from the IRB indicated this project was labeled exempt due to the nature of this study. See Appendix A for a copy of this notification.

Participants

Thirty-two Latino caregivers of children with feeding difficulties completed the survey. Inclusion criteria were: 1) self-identification as Latino/a, 2) age at least 18 years, 3) caregiver of a child who has difficulty feeding. Twenty participants completed the survey in-person at a local clinic or support group in Phoenix, Arizona. Twelve other participants completed the survey online through Qualtrics.

Eight monolingual Spanish speakers completed the survey and eight monolingual English speakers completed the survey. The remainder of participants reported being bilingual in Spanish and English, accounting for 47%. Seventy-five percent reported being of Mexican descent. Ninety-three percent of participants reported they have lived in the United States for 10 years or more.

For the purposes of this survey, 'child' was defined as anyone under the age of 18 years. Caregivers reported the following medical diagnoses as contributing to their child's feeding difficulty: Autism (57%), Reflux (14%), and cleft lip or palate (7%). The other category accounted for 22%, which included diagnoses of intellectual disability, cerebral palsy, hydrocephalus, epilepsy, Down Syndrome, and tracheoesophageal fistula. The reported mean age of the child was 7;0 years, with a range between 5 months and 17;5 years.

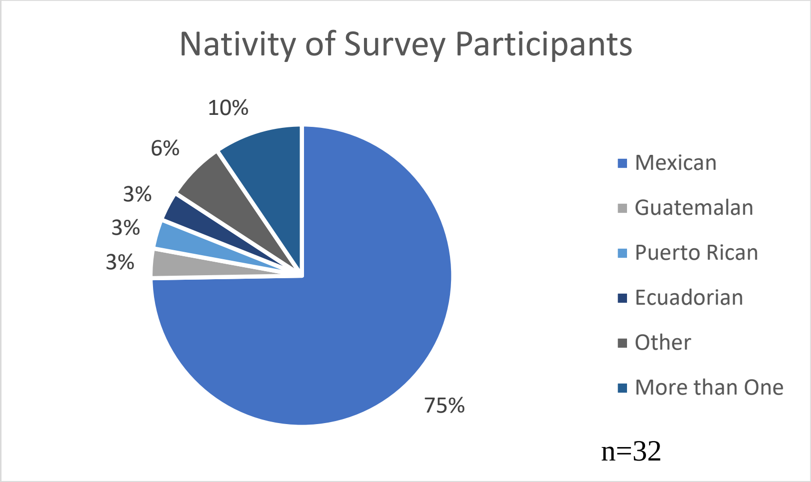


Figure 1: Nativity of survey participants.

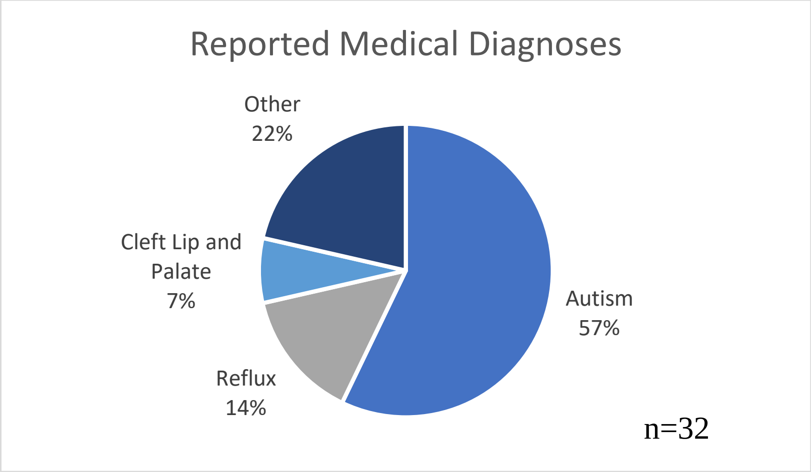


Figure 2: Reported medical diagnoses of participants' children

Materials

The content of this survey was adapted from the work of Stats-Caldwell, Lindsay, and Van Vuren (2017), but also included several dimensions reflecting cultural considerations of the Latino population. The survey was adjusted and altered considerably to include questions that assessed cultural considerations providers should note when providing intervention to Latinos with feeding difficulties.

The survey was divided into four parts as described in Table 1. An open-ended question was provided at the end of the survey for participants to leave comments that were not covered in the survey questions.

Prior to survey deployment, all content was back translated to ensure translation accuracy (Appendix B). A consent form outlining the purpose of the survey, risks, benefits, and contact information for the investigators accompanied all surveys. Participants were required to acknowledge they had read the consent form prior to completing the survey if completed online. Participants who completed the survey in-person placed an X in a box to acknowledge they had read the consent form. Both the survey and consent forms were provided in both Spanish and English for participants. The survey and consent forms are provided in Appendix C and D.

Procedure

Online Survey. The survey was deployed online through topic-specific social media pages using an IRB-approved recruitment flyer (Appendix E), provided in both languages, with links to the Spanish and English versions of the survey created on Qualtrics. Topic-specific social media pages provide support for users to share stories and information to best support their children who share similar diagnoses. These pages included some of the following diagnoses: Autism, Pierre-Robin Syndrome, cerebral palsy, acid reflux, and feeding tubes. A list of the topic-specific social media pages used to support the deployment of the survey can be found in Appendix F.

Administrators of the topic-specific social media pages granted admission to the pages prior to survey deployment. The investigators shared the purpose of the survey and informed administrators the survey was voluntary, anonymous, and for research purposes prior to sharing the Qualtrics links. Administrators were notified they could remove the survey links if the survey did not appear appropriate for their page. Participants who chose to complete the survey were redirected to Qualtrics through the provided link where they were presented with the consent form. Participants were required to acknowledge they had read the consent form prior to completing the survey. If desired, participants could print the consent form for their records. Participants were required to input the month and year of the child’s birthdate. All other questions were voluntary. It should be noted that the IP address function was disabled on Qualtrics to prevent any identifying information from being gathered during data collection.

In-person survey. In-person participants were recruited in the Greater Phoenix Arizona area at local clinics, parent support groups, and local advocacy groups. Providers were given the recruitment flyer to share with participants that met the criterion. However, the only person to administer the in-person survey was the co-investigator (Van Vuren). At no time did other individuals administer the survey. Participants who chose to complete the survey in-person were first provided a consent form in their preferred language. Participants were instructed to mark an X in a box on the consent form for acknowledgement as to reduce possibility of collecting any potentially identifying information. Participants were then provided the survey in their preferred language. Upon completion of the survey, a copy of the consent form was given to participants for their records, and the original consent form and survey were kept by the investigators. The survey was voluntary, and as such, participants could elect not to answer one or more questions. This is further reported and explored in the results and discussion sections of this paper.

Table 1

Overview of Survey Sections

Section	Title	Relevant Information	Sample Questions
Part One	Demographic Information of Child	• Age • Ethnicity • Identify caregivers involved in care • Medical diagnosis (if applicable)	• Which descent does the child *most* identify with? • Who makes most of the decisions about the child's medical care? • If known, what is the child's medical diagnosis?
Part Two	Demographic Information of the Caregiver	• Ethnicity • Language Preferences • Time spent in the United States	• Which descent do you *most* identify with? • Do you live near people who have similar background and cultural traditions?
Part Three	Primary Service Provider	• Cultural competence of service providers • Cultural implications for care • Barriers to health care	• How important is it to incorporate alternative medicine into the child's care? (natural remedies, herbs, etc.) • Do you feel there is a language barrier between you and the child's primary service provider?
Part Four	Resources	• Identify consulted resources rate level of helpfulness • Types of support	• Please indicate how **often** you use the following resources when you have questions or need help regarding your child's feeding disorder. • Please indicate what type of support you **hope** to receive when you consult the following service providers

Data Analysis

Demographic information was analyzed using frequency count and percentages to determine the distribution of nativity and percent of respondents who self-identified as bilingual, as well as the average age and range of the participants' children.

Three Likert scales were used to assess participants' responses throughout the survey (Table 2). Likert Scale 1 was used to determine the frequency of participants' behavior. Likert Scale 2 was used to determine the level of helpfulness for each consulted resource. Likert Scale 3 was used to determine the importance of cultural considerations in care.

A Wilcoxon signed-rank test was conducted to assess whether the ratings in frequency of consultation of each resource differed as well as if helpfulness ratings differed significantly between resources. This test was also used to assess the significance of cultural considerations. A correlational analysis was conducted to compare the frequency and helpfulness of each resource. A Wilcoxon signed-rank test was conducted to assess whether cultural considerations differed significantly.

Table 2

Overview of Likert Scales

Ratings	Likert Scale Questions
	Likert Scale One
Always Most of the Time Half of the Time Sometimes Never	- How often do you use techniques recommended by a family member? - How often do you use techniques recommended by a professional? -Please indicate how **often** you use the following resources when you have questions or need help regarding your child's feeding disorder.
	Likert Scale Two
Extremely Helpful Helpful Somewhat Helpful Not Helpful	-Please indicate how **helpful** you find the following resources when you have questions or need help regarding your child's feeding disorder.
	Likert Scale Three
Extremely Important Important Somewhat Important Not Important	- How important is it to incorporate alternative medicine into the child's care? (natural remedies, herbs, etc.) - How important is it to include other family members when making decisions about the child's care? - How important is it that you maintain practices from your cultural heritage when you eat?

Results

This study was conducted to gain information about three main areas:

1. Resources
    a. What resources do Latinos value most when seeking care for their children with feeding difficulties?
    b. How often do they consult these resources?
    c. How helpful are these resources?
2. Support
    a. How often do Latino caregivers feel supported by professionals?

    b. What types of support do Latino families seek when consulting resources?
    c. Do they report obtaining the support they seek?
3. Cultural factors
    a. What cultural factors should providers consider when working with Latino families?
    b. How do cultural values and perspectives differ among Latino families?

Resources

Feeding disorders require a collaborative team approach with multiple professionals involved in care. To better understand where Latino families seek care participants identified which resources they value most, the frequency they consult each resources, and rated the helpfulness of each resource. Participants reported the top three most valued resources are pediatricians, grandmothers, and speech-language pathologists. Eighteen participants indicated they most value pediatricians. Fourteen participants valued grandmothers, while thirteen participants valued speech-language pathologists. Other valued resources are shown in Figure 3. Topic-specific social media pages are forums for people who identify with a specific population or cause to collaborate and share. General social media is considered someone’s personal page and community. Investigators then identified the frequency participants consult each resource in addition to how helpful participants perceive each resource.

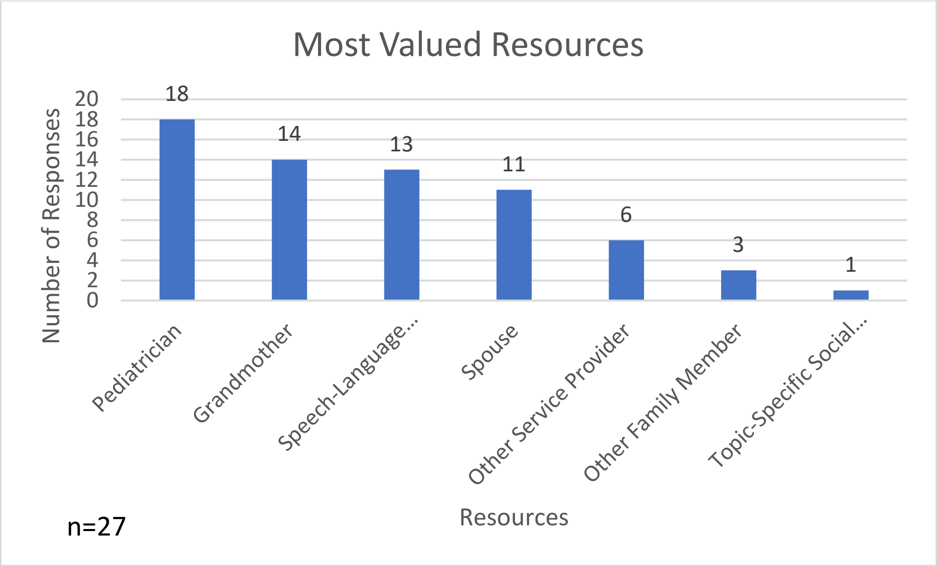


Figure 3: The reported most valued resources.

Consulted resources. Using a Likert scale, participants indicated how often they consult each resource. Table 3 shows the percent of participants who selected each level of the Likert scale, from Always to Never, indicating most people consult professionals most often. Percentages of those that did not respond is displayed in Table 3. Results of the Wilcoxon-signed rank test indicated that pediatricians, speech-language pathologists, and other service providers are consulted significantly more often than all other resources. There was no significant difference in frequency with which pediatricians, speech-language pathologists and other service providers were consulted; each of these resources was consulted with about the same level of frequency. Grandmothers and topic-specific social media are rarely consulted. There was no significant difference in the frequency with which grandmothers and social media resources (general social media p=.465, and topic-specific p=.661) were consulted. Significant difference was seen between the frequency topic-specific social media was consulted and all three providers.

A pairwise comparison is shown in Table 5 to further present the relationship among resources.

Perceived Helpfulness. Participants rated the helpfulness of each resource using a Likert scale. Most participants found professionals most helpful. Percentage of participants who did not respond to this question is presented in Table 4. A Wilcoxon signed-rank test was conducted to assess whether the population mean ranks differ in helpfulness for each resource (Table 6). A comparison was conducted between pediatricians, speech-language pathologists, and other providers. Results indicated there was no significant difference in the helpfulness of these resources. Furthermore, none of these professionals had higher helpfulness ratings than the spouse. Pediatricians were significantly different from grandmothers (p=.026) in helpfulness ratings. No difference was seen when comparing helpfulness ratings of grandmothers to speech-language pathologists (p=.082) and other providers (p=.093). Pediatricians were significantly different from topic-specific social media pages (p=.023). However, speech-language pathologists (p=.102) and other providers (p=.128) had helpfulness ratings that were not significantly different from topic-specific social media pages. Topic-specific social media had higher helpfulness ratings than general social media. Except for grandmothers and other family members, all resources had a significant difference when compared to general social media.

A correlational analysis was conducted to examine the relationship between frequency of consultation and perceived helpfulness for each resource (Table 7). For all resources except neighbor/friend, there was a significant positive correlation between frequency of consultation and helpfulness ratings.

Table 3

Frequency of resource consultation

Resources (n=32)	Likert Scale					
	Always	Most of the Time	Half of the Time	Sometimes	Never	No Response
Pediatrician	30%	25%	3%	6%	3%	33%
SLP	25	15	6	8	11	36
OSP	28	17	0	5	8	42
Grandmothers	14	0	8	20	25	33
TSSM	5	3	3	17	25	47

Note: Speech-Language Pathologist (SLP); Other Service Provider (OSP); Topic-Specific Social Media (TSSM)

Table 4

Helpfulness ratings of resources

Resources (n=32)	Likert Scale				
	Extremely Helpful	Helpful	Somewhat Helpful	Not Helpful	No Response
Pediatrician	36%	19%	11%	3%	31%
SLP	25	19	11	6	39
OSP	22	22	6	8	42
Grandmothers	22	11	17	14	36
TSSM	8	17	11	14	50

Note: Speech-Language Pathologist (SLP); Other Service Provider (OSP); Topic-Specific Social Media (TSSM)

Table 5

Pairwise comparisons of frequency of resource consultation

Resources	Resources Z-Value p-value								
	Pediatrician	OSP	SLP	Spouse	Grandmother	TSSM	General SM	Other Family Member	Neighbor / Friend
Pediatrician	X	-.850 .395	-1.594 .111	-2.215 .027*	-3.187 .001*	-3.370 .001*	-3.457 .001*	-3.412 .001*	-3.572 .000*
OSP		X	-1.121 .262	-1.568 .117	-3.291 .001*	-2.948 .003*	-3.215 .001*	-3.220 .001*	-3.325 .001*
SLP			X	-.862 .389	-2.490 .013*	-2.915 .004*	-3.008 .003*	-2.866 .004*	-3.088 .002*
Spouse				X	-2.286 .022*	-2.015 .044*	-2.401 .016*	-2.455 .014*	-3.092 .002*
Grandmother					X	-.439 .661	-.731 .465	-1.00 .317	-1.809 .070
TSSM						X	-2.070 .038*	-.942 .346	-2.326 .020*
General Social Media							X	-.306 .760	-1.265 .206
Other Family Member								X	-1.291 .197
Neighbor/ Friend									X

Note: Asterisks indicate a statistically significant difference at p=.05. Speech-Language Pathologist (SLP); Other Service Provider (OSP); Topic-Specific Social Media (TSSM); General Social Media(General SM).

Table 6

Pairwise comparisons of helpfulness ratings of resources

Resources	Resources Z-Value p-value								
	Pediatrician	OSP	SLP	Spouse	Grandmother	TSSM	General SM	Other Family Member	Neighbor/ Friend
Pediatrician	X	-.942 .346	-1.403 .161	-1.842 .066	-2.226 .026*	-2.269 .023*	-2.803 .005*	-3.146 .002*	-3.585 .000*
OSP		X	-.264 .792	-1.155 .248	-1.741 .082	-1.637 .102	-2.709 .007*	-2.638 .008*	-3.236 .001*
SLP			X	-.924 .356	-1.681 .093	-1.523 .128	-2.553 .011*	-2.602 .009*	-3.384 .001*
Spouse				X	-1.387 .166	-1.052 .293	-2.588 .010*	-2.181 .029*	-3.002 .003*
Grandmother					X	-.145 .884	-1.897 .058	-1.356 .175	-2.484 .013*
TSSM						X	-.835 .404	-1.983 .047*	-1.717 .086
General Social Media							X	-.537 .591	-1.508 .132
Other Family Member								X	-.183 .855
Neighbor/ Friend									X

Note: Asterisks indicate a statistically significant difference at p=.05. Speech-Language Pathologist (SLP); Other Service Provider (OSP); Topic-Specific Social Media (TSSM); General Social Media (General SM).

Table 7

Correlational analysis of frequency of consultation to reported helpfulness

Resource	Correlation Coefficient	p-value
Pediatrician	r(23)=.728	p= .000*
Speech-Language Pathologist	r(22)=.778	p= .000*
Other Professional	r(20)=.725	p= .000*
Spouse	r(19)=.496	p= .031
Grandmother	r(22)=.748	p= .0001*
Topic-Specific Social Media	r(18)=.729	p= .001*
Other Family Member	r(18)=.649	p= .004*
General Social Media	r(18)=.867	p= .000*
Neighbor/Friend	r(18)=.327	p= .185

Note: Asterisks indicate statistically significant data at p=.01.

Support

Participants indicated how often they feel supported by the professionals involved in their care. Sixty-four percent of participants indicated they feel supported by professionals always or most of the time. Figure 4 displays the distribution of all responses for this question.

Participants indicated the type of support they anticipated when consulting different resources by selecting whether they sought medical, emotional, or informational support. The total number of participants who indicated a desire of any type of support from the displayed resources is reflected in Figure 5. As shown in Figure 5, participants sought medical support primarily from pediatricians. Emotional support was sought from all three resources about equally. Participants indicated seeking informational support from topic-specific social media pages. Participants were allowed to select more than one type of support per resource. As a result, some participants reported seeking medical support from both pediatricians and SLPs. Some participants sought emotional support from all three resources. Most participants sought informational support from all three.

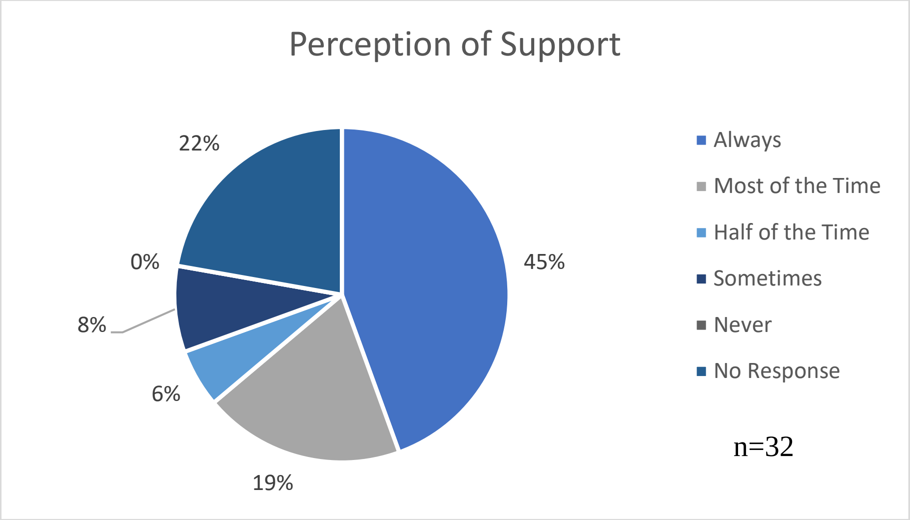


Figure 4: The percentage of participants indicating the frequency of provider support.

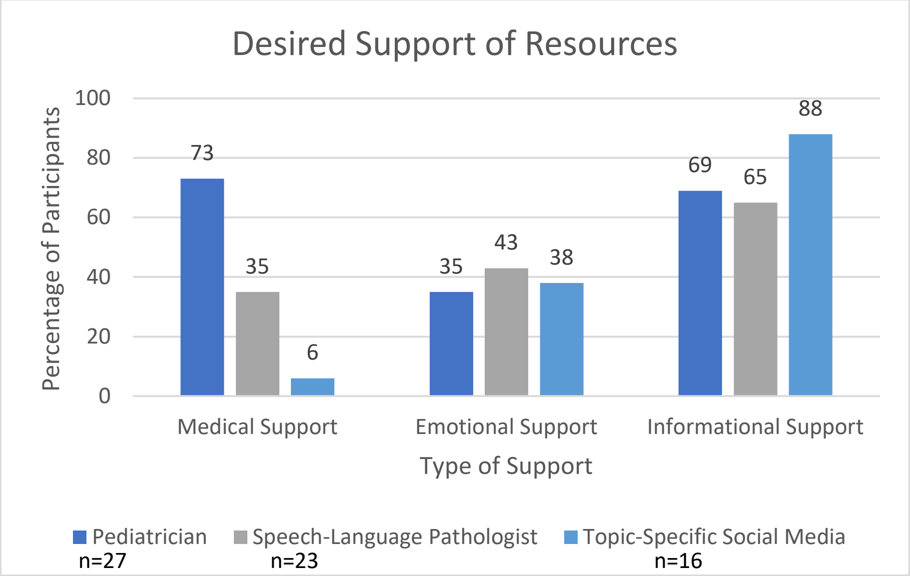


Figure 5: A comparison of the desired types of support among resources.

Nine participants indicated a desire for receiving emotional support from pediatricians while 10 participants indicated the same support from speech language pathologists and 6 participants indicted the same desire from topic-specific social media pages. Figure 6a reflects the percentage of participants who received the emotional support they desired. Of the total number of participants who indicated desiring emotional support from pediatricians, fifty-six percent of participants indicated receiving such support. Forty percent of participants who indicated a desire for emotional support from speech-language pathologists received such support. Sixty-seven percent of participants who indicated a desire for emotional support from topic-specific social media pages reported receiving such support.

The total number of participants who indicated a desire of receiving informational support is as follows: pediatrician $n=18$, speech-language pathologist $n=15$, topic-specific social media $n=14$. Figure 6b reflects the percentage of participants who received the informational support they desired. Fifty-six percent of participants who indicated a desire for informational support from their pediatricians also reported receiving such support. Eighty-seven percent of participants who indicated a desire for informational support from speech-language pathologists reported receiving such support. Ninety-three percent of participants who indicated a desire for informational support from topic-specific social media pages reported receiving such support.

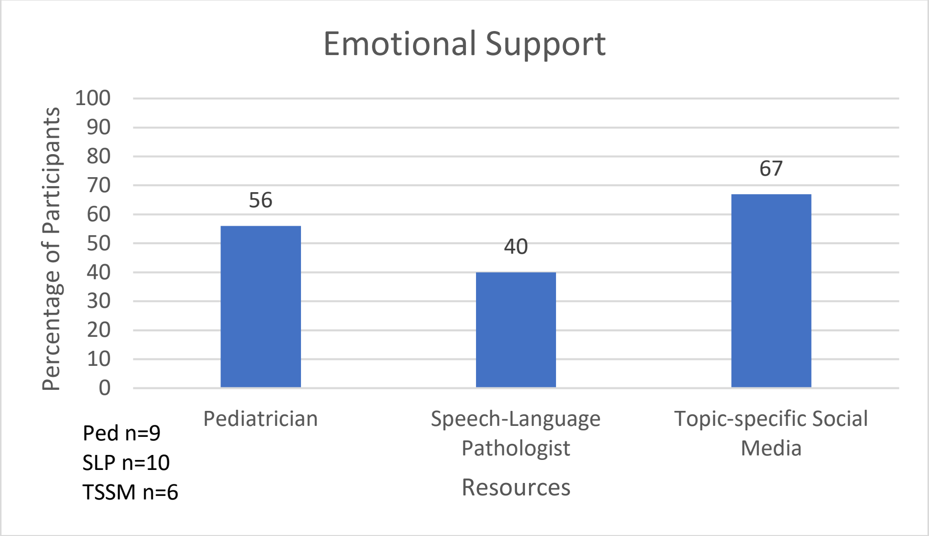


Figure 6a: The percentage of participants who received the emotional support they sought from various resources.

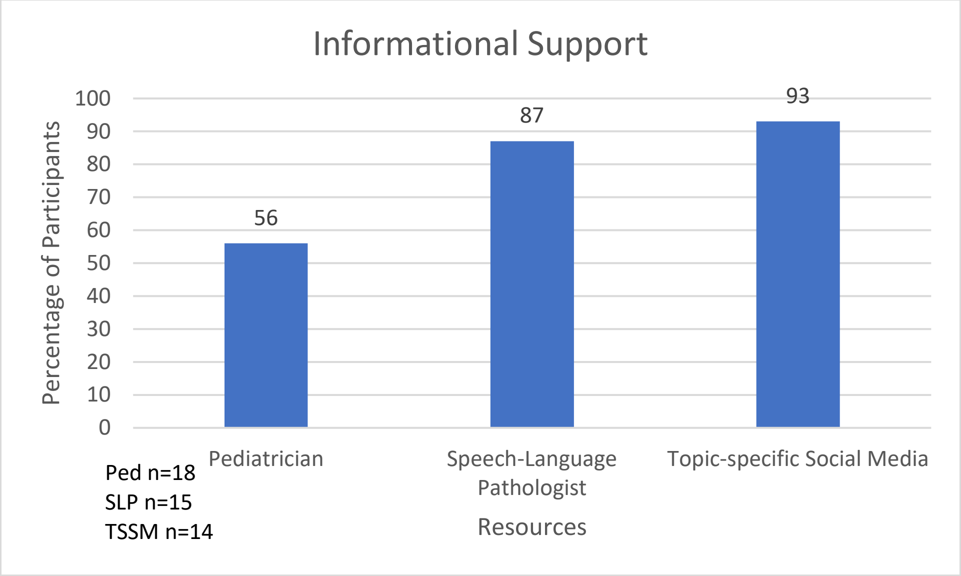


Figure 6b: The percentage of participants who received the informational support they sought from various resources.

Cultural Considerations

This survey was deployed to identify cultural considerations providers should be aware of when providing feeding intervention for the Latino population.

Influence of family members. Caregivers ranked how often they implement recommendations made by professionals and family members using a Likert scale, from Always to Never. Three participants did not respond to this question. Shown in Figure 7, nearly 100% of participants that responded to this question indicated they implement recommendations made by their professionals always or most of the time. Shown in Figure 8, forty-five percent of participants indicated implementing recommendations made by their family members always or most of the time. A Wilcoxon signed-rank test was conducted to identify a significant difference between implementation of recommendations made by professionals or family members. Results indicated professional recommendations are implemented significantly more frequently than family member recommendations (z=-3.409, p=.001).

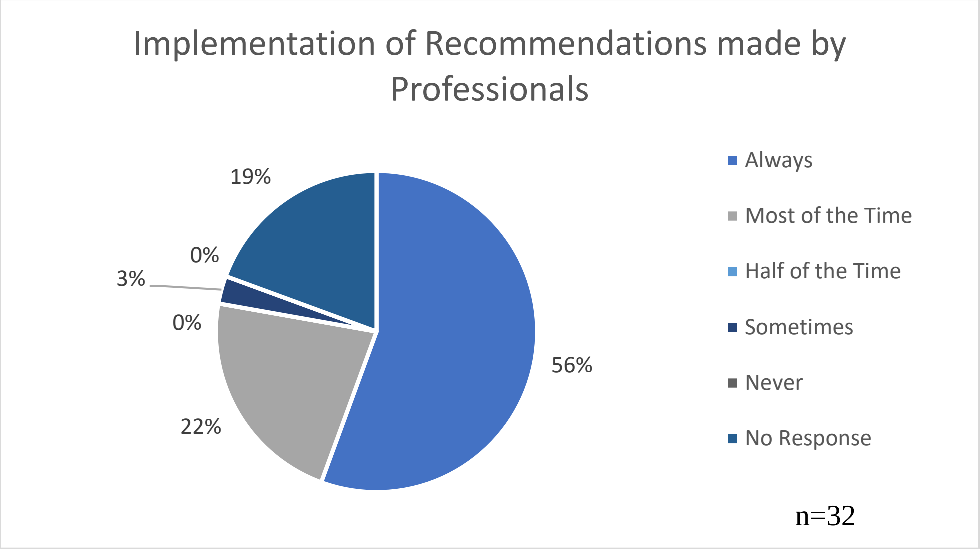


Figure 7: The frequency in which participants indicated implementing recommendations made by professionals.

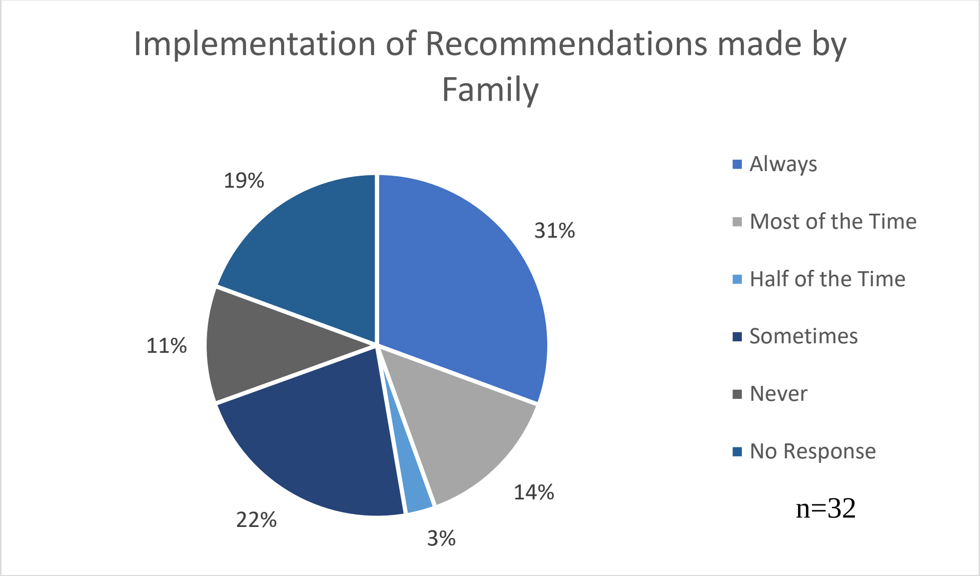


Figure 8: The frequency in which participants indicated implementing recommendations made by family.

Using a Likert scale from extremely important to not important, participants indicated the importance of including family members in decision making, use of alternative medicine during intervention, and maintaining cultural traditions during mealtime. Table 8 shows that 50% of participants indicated it is extremely important or important to include family members in decision making, while 31% indicated it is extremely important or important to incorporate alternative medicine in care. Forty-two percent of participants indicated it is extremely important or important to maintain cultural practices during mealtime.

A Wilcoxon signed-rank test was conducted to identify a significant difference in importance of these cultural considerations (Table 9). Results indicated no significant difference between including family members and use of alternative medicine (z=-1.605, p=.109), nor use of alternative medicine or maintaining cultural traditions during mealtime (z=-.036, p=.971). There was a significant difference between including family members and maintaining cultural practices during mealtime (z=-2.159, p=.031). Results regarding cultural considerations are further discussed later in this paper.

Table 8

Importance ratings of cultural considerations

n=32	Extremely Important	Important	Somewhat Important	Not Important	No Response
Inclusion of Family Members	31%	19%	17%	8%	25%
Use of Alternative Medicine	14	17	33	11	25
Maintaining Cultural Practices	14	28	17	19	22

Table 9

Pairwise comparisons of cultural considerations

Topics	Topics Z-Value p-value		
	Maintaining Cultural Practices	Use of Alternative Medicine	Inclusion of Family Members
Maintaining Cultural Practices	X	-.036 .971	-2.159 .031*
Use of Alternative Medicine		X	-1.605 .109
Inclusion of Family Members			X

Note: Asterisks indicate a statistically significant difference

Cultural implications for professionals. Participants indicated topics they want providers to advance their knowledge on to better support Latino customs. Participants could indicate more than one response for this question. As a review, forty-seven percent of participants reported being bilingual in Spanish and English and 11% of participants indicated there is a language barrier between the caregiver and service providers. Fifty-six percent of participants indicated professionals involved in their child's care always communicate in their preferred language (Figure 9). Figure 10 displays cultural considerations for providers to note when implementing care. However, nearly 35% of the respondents indicated they wish providers had the ability to speak in their native language. Sixty-five percent of participants indicated they wish providers knew more about traditional mealtime routines, while 31% of participants indicated they wish providers were aware of typical foods in Latino culture and alternative or complementary treatments.

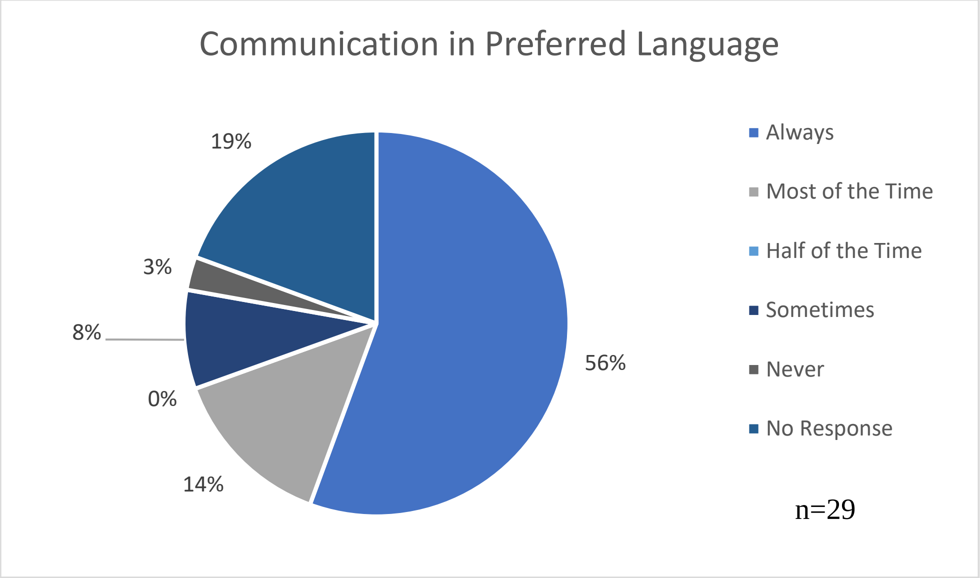


Figure 9: Participants' response to the frequency in which professionals communicate in a client's preferred language.

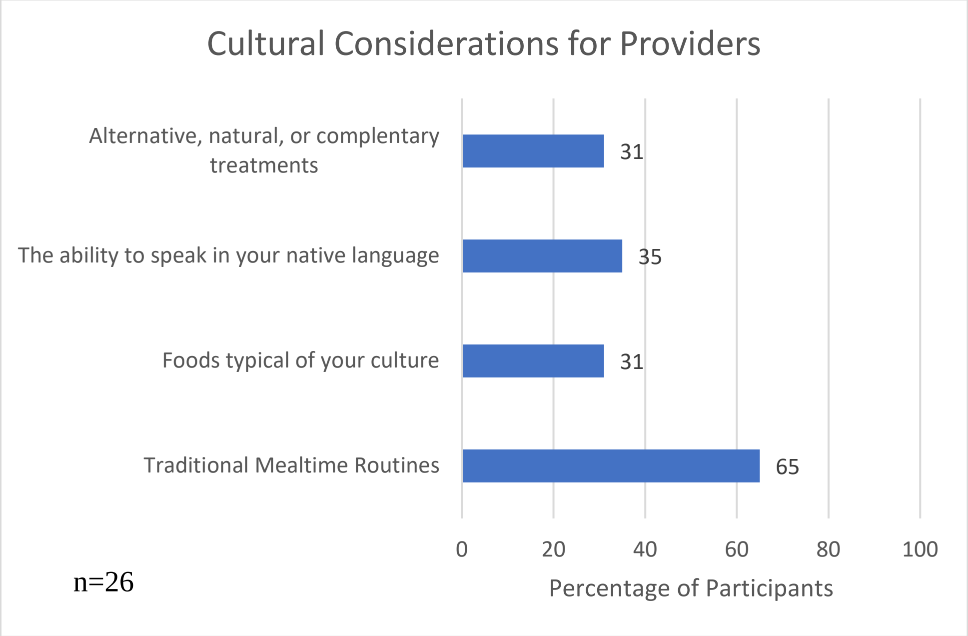


Figure 10: Distribution of topics providers should consider when providing feeding intervention.

Discussion

This study was designed to garner information about the frequency Latinos consult resources, the perceived helpfulness of these resources, the types of support Latinos seek when consulting these resources, and the cultural considerations providers should note when providing intervention to families of the Latino population.

Resources

Results indicated Latino caregivers value pediatricians most above all other resources (Figure 3). In the Latino culture, the concept of *respeto* indicates authority figures are taught to be awarded respect and as a result, pediatricians may be treated and viewed with high regard (Flores et al., 1998; Gonzalez-Ramos, G., Zayas, L., Cohen, E., & Deleon, Patrick H., 1998). Sanjur (1995) indicated that Latinos are unlikely to disagree or question recommendations made by providers and their regard for positions of authority may be deeply rooted in their culture. According to Arvedson & Brodsky (2002), pediatricians typically manage a feeding team and may serve as a central point of contact for families. As a vital role in care, pediatricians should encourage family engagement during consultation to ensure appropriate care coordination among all providers that also includes family preferences.

Despite high regard for professionals, grandmothers are reported as the second most valuable resource above speech-language pathologists and other service providers. As previously mentioned, Sussner et al. (2008) indicated there is heavy reliance on grandmothers, specifically when the focus is caring or feeding for an infant. A grandmother's role may be of high value due to their maternal experience. Further conversation regarding grandmother's role in this culture is discussed later in this paper.

Consulted resources. Although this data set reports value is placed on pediatricians a Wilcoxon signed-rank test was conducted to identify the frequency all the resources were consulted (Table 4). Because feeding disorders require a team approach, it is vital to understand which providers and resources caregivers rely on. The results of this test give insight into which resources Latinos consult, regardless of where value is placed. Results showed no significant difference in the frequency all three professionals were consulted. These results indicated variance in which providers are frequently consulted for care and advice, which further encourages and supports the use of a collaborative approach for feeding care. This could also indicate that Latinos have high regard for all medical professionals and the concept of *respeto* is transferred amongst professionals. Furthermore, this suggests professionals should be aware of a potential hesitancy Latinos may have to engage in conversation and question recommendations.

Reassuring the importance of conversation and open dialogue can encourage families to actively participate in care and improve overall satisfaction and perhaps improve client compliance.

Although grandmothers were reported as being of value, results indicated grandmothers are consulted just about as frequently as topic-specific social media. In fact, the frequency of consultation between grandmothers and topic-specific social media did not significantly differ, indicating this population consults these resources equally. Despite grandmothers being highly valued, they rank equivalent to topic-specific social media pages. However, topic-specific social media had a significantly higher frequency of use ratings than general social media. As a review, topic-specific social media are forums for people who identify with a specific population or cause while general social media describes someone’s personal profile and community. This data suggests this population is consulting specific platforms and pages more often than utilizing their personal pages or community. A look into the influence of social media is discussed later in this paper.

Perceived helpfulness. In addition to analyzing the frequency of consultation, a comparison was made to assess the perceived helpfulness of each resource (Table 6). These findings, in conjunction with the frequency of consultations, give valuable insight on how professionals can improve interactions with families and caregivers when serving this population.

Similar to the frequency results, no significant difference was revealed between pediatricians, speech-language pathologists, and other professionals in helpfulness ratings which indicates this population does not perceive one professional as more helpful than any other when discussing feeding. It should be noted that none of the professionals had higher helpfulness ratings than the spouse. Although perhaps not surprising, this indicates spouses are viewed as equally as helpful as professionals regarding the child's care.

Pediatricians had a significantly different perceived helpfulness than grandmothers which indicates that this population finds pediatricians more helpful than grandmothers. However, no difference was seen between grandmothers, speech-language pathologists, and other providers. These results indicate that pediatricians are viewed as more helpful than grandmothers, yet speech-language pathologists and other professionals are equally as helpful as grandmothers. It is to be remembered that grandmothers were infrequently consulted while speech-language pathologists were consulted significantly more than grandmothers. Yet, results indicated no difference in the level of helpfulness between these two resources. These results indicate this population is not reaping the benefits from this resource, which strongly suggests speech-language pathologists need to improve strategies to provide more effective support. Although further research is necessary to determine why pediatricians are viewed as more helpful than other providers, these results suggest pediatricians are providing a type of support other providers are not. Further research is needed to identify how speech-language pathologists and other service providers can increase overall satisfaction.

As a review, grandmothers are valued for advice, but are rarely consulted for such advice and are not found more helpful than topic-specific social media. Although grandmothers were not frequently consulted, this value may be a cultural element and value may lay in the simplicity that they provide care for infants and are frequently involved in the nuclear family unit. Sussner et al. (2008) indicated grandmothers may greatly influence early child feeding practices. Because extended family members have a strong influence on feeding practices, family education is an important component when treating children with feeding disorders in the Latino population and may support modifying behaviors that in turn support the child (Houston, Waldrop, & Mccarthy, 2011). One article indicates Latina mothers conform to familial practices, similar to the concept of *respeto*, as a way to prevent family tension (Johnson, Clark, Goree, O'Connor, & Zimmer, 2008) because of the emotional and sometimes financial support provided by grandparents. Calzada, Fernandez, Cortes, & Zarate (2010) indicated that *respeto* emphasizes a strong consideration for adults and serves as a means of maintaining harmony with the extended family and mothers may stray from disregarding grandmother's advice to maintain this harmony (Marin & Marin, 1991). To sum up the importance of elders in the Latino culture is a quote from one mother that looked at the importance of *respeto* stating, "your parents are 'number one.' Your grandparents are even greater than 'number one'" (Calzada, Fernandez, Cortes, 2010). Although the concept of respect for elders is common in many cultures, Villarreal, Ricardo, Blozis, Shelly, & Widaman (2005) suggest the family is a more important value for the Latino population than other cultural groups. The current study and research could indicate that grandmothers play a strong cultural role for reasons outside of medical care, but should be involved in care.

In comparison to social media, results indicated pediatricians were significantly more helpful than topic-specific social media (Table 6). However, speech-language pathologists and other providers were not viewed as more helpful than topic-specific social media. As a review, topic-specific social media pages were one of the least frequently consulted resources. Discussion is needed to expand upon the role of social media in healthcare and the importance of utilizing this platform. Results indicated all resources except for grandmothers and other family members had a significant difference when compared to general social media. This indicates that general social media is not commonly utilized for care nor found helpful. Rather topic-specific social media pages are perceived as more helpful than general social media.

Minimal to no research has looked specifically at the implications of social media on feeding disorders, however some research has been published on how social media may impact service provision.

A poster was presented at the American Speech and Hearing Association Conference in 2017. This work, done by Stats-Caldwell et al., was a survey deployed to drive the content of an online educational module for parents who have children with feeding disorders. Although the demographics of this survey do not match the current study, the results of this survey indicated a strong reliance on social media. Specialized professionals such as speech-language pathologists, occupational therapists, or physical therapists were reported as the most frequently consulted followed by physicians and topic-specific social media pages. However, caregivers reported topic-specific social media pages were more helpful than physicians and nearly as helpful as specialized professionals.

Comparing the results of the current study and the previously mentioned survey indicates that culture, race, and other factors may greatly impact the way in which clients navigate the healthcare system and may impact who they consult. Although value is placed on grandmothers, a cultural factor, the current study indicated the helpfulness of grandmothers and topic-specific social media pages do not differ. This finding supports a shift in the use of social media platforms. Research indicates that socio-economic status is a barrier for the Latino population (Flores et al., 2008; Valdez et al., 1993; Castañeda & Melo, 2014; Ransford et al., 2010) which may impact access to social media therefore reducing the frequency topic-specific social media is consulted. The results of the comparison of frequency and helpfulness indicated pediatricians ranked the highest in both categories. Cultural considerations of grandmother's role should be used in conjunction with reliable topic-specific social media to provide support and resources. The following section discusses types of support provided by professionals in which the influence of social media is further explored.

Support

The research conducted by Stats-Caldwell et al. (2017) did not assess the type of support caregivers were searching for when consulting various resources. However, a better understanding of what support caregivers are seeking may support and improve the perceived level of helpfulness from various resources. Sixty-four percent of participants in the current study indicated they feel supported by their professionals.

Participants responded to a free response question in which caregivers indicated a desire to support parent knowledge, how to diversify tastes and textures, training parents how to teach other caregivers such a babysitters or family members, how to provide age appropriate support. Ultimately caregivers are indicating a need to understand what implementations are recommended and why. A quotation taken from a participant in the free response question directly sums up the feelings caregivers have surrounding caring for a child with feeding disorders; “at times, it feels like feedings alone are a full-time job.”

In this study, support was divided into three different types; medical, emotional, and informational resources. Noteworthy comparison is seen between pediatricians, speech-language pathologists, and topic-specific social media for emotional and informational support. Figure 6a displays the results of emotional support. Although relatively evenly distributed, 67% of participants indicated they received the emotional support they sought from topic-specific social media pages. Only 40% of participants indicated they received the emotional support they anticipated from speech-language pathologists. These results serve as a reminder to professionals that feeding disorders are a complex diagnosis that requires care in all aspects of both the client and the caregiver and encourages providers to attend to the impact this may have on caregivers’ emotional well-being. Due to the complex and ever-changing world of feeding disorders caregivers may be seeking emotional support from providers, but may not be direct in sharing this need or providers may feel unequipped to deal with such emotions. A closer look at the challenges and emotional support caregivers seek is discussed later in this paper using anecdotal evidence from topic-specific social media pages. Regardless, these results further support the need for an effective holistic multi-disciplinary approach in treatment of feeding disorders.

Figure 6b displays the results of informational support. Only 56% of participants indicated receiving the pursued informational support from pediatricians. Ninety-three percent of participants indicated receiving the informational support they sought from topic-specific social media. These results indicate this population is utilizing social media as a channel for information. Perhaps this is because they are not receiving the information from the providers, or it could be the convenience of these platforms. Discussion surrounding the reliability of this information exchanged on these pages is warranted as feeding disorders are complex in nature and require medical teams to collaborate to provide the best care for these children. However, topic-specific social media pages are rarely vetted, and frequently medical professionals are not allowed to participate in these pages. Discussion surrounding the types of information exchanges made on these platforms follows later in this paper.

When the results of Stats-Caldwell et al. (2017) and this current research project are considered, there is certainly a trend that shows people are consulting social media for support which indicates social media may be a cross-cultural means of communication. While it is important to note that socio-economic status is a factor in accessing this information, Korda & Itani (2013) indicate that more than half of U.S. adults across all age and ethnic/racial groups use the internet to search for health information. Although the debate on the type of support is still in question, nonetheless, these two studies argue the ever-growing presence of social media in healthcare. According to Fox (2011) 80% of adults online were searching for health information. However, social media is an important avenue for the 70% of adolescents who use this source because this source is an easy, cost effective way to reach many people (Korda & Itani, 2013). As this population ages, a further increase in social media may be seen which calls providers to utilize these platforms to exchange information with clients.

Using social media as a means to provide education extends the patient visit and improves information flow and consistency of care (Eckler, Worsowicz, & Rayburn, 2010). The convenience of these platforms makes healthcare readily available for patients, but also have benefits for providers.

Social media can reach broad audiences while enabling and supporting clients in health care-related interactions (Thackeray, Neiger, Hanson & McKenzie, 2008; Korda & Itani, 2013). This can improve patient education, encourage community outreach opportunities, and support patient compliance. “Research now shows that some online communications are effective at improving knowledge and understanding of specific health topics” (Korda & Itani, 2013, p. 16). Community outreach is a target of social media as well and can connect parents to community activities that provide support for caregivers in similar situations (Eckler et al., 2010). “Other studies show that patients may experience empowerment in decision making about their health through online learning, finding they have increased confidence in asking questions of providers and information to help them manage their conditions” (Korda & Itani, 2013, p. 19). This report supports Latino families in overcoming their fear of questioning authority figures and supports communication between caregivers and professionals. Prasad (2013) said social media “is about maximizing the relationships among patients [and] health care providers. Social media can be used to increase compliance with medication, patient support, and education, and links with patient support groups” p.492. Patients can retrieve information rather than receiving it which encourages an active participation in the management of their healthcare (Prasad, 2013), an important component for the currently discussed population.

The noteworthy highlight of the results of informational support lay in the satisfaction found in topic-specific social media pages. Ninety-three percent of participants who sought informational resources, reported finding informational sources on topic-specific social media pages. Providers are well-versed in analyzing current research and literature to determine the legitimacy of information. However, this is a specific skill and clients or caregivers who recently received a diagnosis may not understand jargon or know how to determine which sources provide legitimate information and may result in use of topic-specific social media pages due to the convenience of these platforms.

To further support the need for provider support and patient education are the following quotations taken from Facebook topic-specific social media pages (see Appendix F). These highlight the types of information that are exchanged on these platforms and call into question the validity of these sources, but also demonstrate the dire need of support these caregivers feel when caring for children with feeding disorders.

Example 1: Emotional Support and Informational Resources

> “I just lost my baby to acid reflux, she was 2mo 13 days. I just wish I knew more about this disease and what more I could have done to prevent it” (Acid Reflux Babies Support Group, 2018).

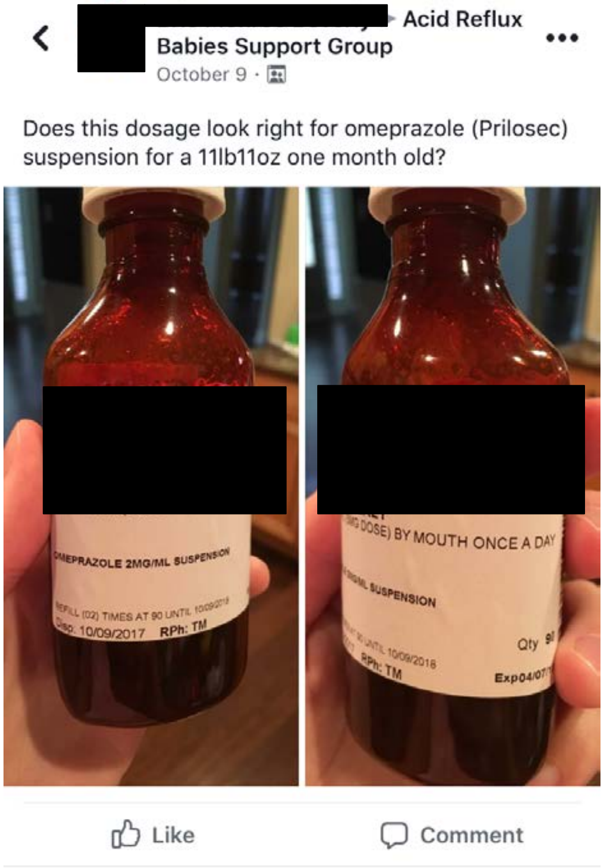
Example 2: Combination

> “I’m starting to feel burned out from all the feeding fights and medical tests that don’t lead to answers” (Bottle Aversion Support, 2018)

Example 3: Medical Support

“Does this dosage look right for omeprazole (Prilosec) suspension for a 11lb11oz one month old?”

Anecdotal Evidence of Desired Support



[redacted] Acid Reflux Babies Support Group

October 9 ·

Does this dosage look right for omeprazole (Prilosec) suspension for a 11lb11oz one month old?

[redacted]

[redacted]

Figure 11: Example of medical information exchanged on topic-specific social media pages (Acid Reflux Babies Support Group, 2017)

Example 4: Medical Support

“Please Help! My 5-year-old has had a fever of 102 since Sunday…we took him into the dr. and he has Strep throat. He needs to take 2 tsp of medicine twice a day and he is super oral defensive. I’ve spent the last hour with him screaming and throwing himself on the floor. He gags just looking at it…HOW in the world am I

> supposed to get him to take this? Nothing is working. NOTHING. Is there anything I can do" (Sensory Processing Disorder Advocacy, 2018).

Example 5: Combination

> "I have an awful time with feeds. My daughter keeps choking, so I try to pace her, keep her at the right angle…I keep being told she just has growing and learning to do but she is 4mo 31days…at my wits end" (NICU Mom Support Group, 2018).

An extremely important component to consider when consulting social media for advice is the regulation of this information. Discussed in Prasad (2013) is a study that indicated 30% of participants thought they were helped by the medical advice they found online, but nearly 70% said they were unsure. This indicates that much of the information found online "still originates from unregulated sources" (Prasad, 2013, p.494). Regardless, social media has begun a paradigm shift in healthcare, and "it is hard to ignore the momentum of this form of medium" (Prasad, 2013, p.492). At the end of the day, "social media has proven potential for health promotion and behavior change" (Korda & Itani, 2013, p.22) and "social media is where the future is, and most importantly, that's where our patients are going to be" (Prasad, 2013, p.494). It is the professional's responsibility to maintain and utilize the platforms patients are using. Based on the results of the current study professionals involved in feeding care need to use pediatricians as a point of contact, include spouses and grandmothers in discussion, and provide resources during consultation or direct caregivers to reliable online sources or educate them on the cautions of using topic-specific social media until those pages are backed by evidence or regulated by professionals. Furthermore, based off the anecdotal and research-based evidence presented in this discussion, it appears providers need to shift implementation of intervention to allow time to consult with parents and continue using a team approach and dynamic collaboration.

Further research is needed to identify how Facebook is vetted and how professionals can ensure informational support is evidence-based. Further research can examine whether providers should be using social media platforms as a service delivery method for such information, which could provide an increased satisfaction for providers.

Cultural Considerations

Villarreal et. al (2005) indicates family is an exceptionally important value in the Latino population. Therefore, a comparison was made between the frequency caregivers implement recommendations of professionals and family members (Figure 7 & 8). However, a significant difference revealed caregivers implement recommendations made by professionals more often than family members. This may indicate that although professional advice is implemented more often than family, including family members in discussions should still be considered when consulting with Latino families due to the strong background evidence regarding the importance of family.

Three other considerations were assessed for providers to be aware of when working with this population; the importance of including family members in decision making, use of alternative medicine in care, and maintaining cultural practices during mealtime. Contrary to Villarreal et. al (2005), results of this study indicated a significant difference between inclusion of family members and maintaining cultural practices. However, no difference was seen between the use of alternative medicine and maintaining cultural practices (Table 9). Investigators did not ask participants to identify what constitutes cultural practices. As a result, maintaining cultural practices may encompass including family member and use of alternative medicine in addition to other previously discussed cultural considerations. This may be why results demonstrated a significant difference. Regardless, these results encourage the discussion surrounding cultural competence of providers and calls providers to continue learning and expanding their understanding of differing cultures and the implications needed when consulting various populations. Although it is unclear why some considerations were found significant and others were not, it urges providers to engage in conversation to truly understand what aspects are important in care. Variance within this population is seen in this study and urges providers to consider other factors than strictly those limited to their specialty which further validates the use of a team approach.

Finally, this survey provided participants a list of cultural considerations participants wish providers knew more about (Figure 10). Of the participants that responded, traditional mealtime routines received the most responses. One limitation of this study is that investigators did not ask participants to indicate what constitutes traditional mealtime routines. However, background research previously discussed indicates mealtime as a social experience. Further research is needed to investigate how professionals can make recommendations for children with feeding difficulties that align with traditional mealtime routines and cultural aspects of food in the Latino population. Foods typical of Latino culture, the ability to speak in the native language, and the use of alternative medicine were among the next highest ranked topics for providers to increase knowledge. These results indicate the variance that lies within the Latino population and calls providers to individualize treatment plans and recommendations based on the beliefs of specific families.

Limitations

The limited number of participants, in addition to the fact that the study was released to potential participants in metropolitan Phoenix, could prevent this sample from representing a diverse population. Furthermore, participants online did not indicate their geographical region and prevents investigators from understanding what sample was represented. Age and gender of caregivers were not identified in this survey. However, replication of this study may focus on how variation in age and gender impacts results. No monolingual Spanish speakers completed the survey online. All eight participants who reported being monolingual Spanish speakers completed the survey in-person. This may have impacted results as monolingual Spanish speakers were not evenly distributed across both survey mediums. Because this survey was voluntary some participants did not answer every question. Despite the limitations presented in this research study, significant results are apparent and further research is warranted to continue to explore the presented topics.

Further Research

Further research is warranted to better understand the cultural considerations providers should note when serving this population. In addition, further exploration of the specific type of support caregivers seek is warranted which may increase overall satisfaction and encourage positive interactions between caregivers and providers. Feeding disorders are complex and require many professionals. Replication of this study could provide increased understanding of which professionals serve as a central point which could in turn streamline and promote effective communication among professionals. Further research is needed to identify specifically how professionals can increase their overall support and better understand where providers are lacking. This study is limited to the Latino population, therefore similar studies that target other cultures may provide significant information for providers. Cross-cultural comparisons may provide insight into the ever-growing need for culturally competent providers in the field of health care and specifically in those professions that support caregivers and children affected by feeding disorders.

Conclusion

This study indicates the importance of understanding what resources the Latino population places value on in addition to comparing which resources they consult and the overall perceived helpfulness of each resource. These results should motivate professionals to utilize the scope of their practice by providing effective intervention that encourages a holistic approach by including all aspects of care including counseling, education, as well as the required medical care. This study reveals the increasing use of social media and the role it will continue to play in healthcare and encourages professionals to utilize such platforms and educate caregivers and clients on the importance of understanding the source of information. More importantly, providers must integrate patient education into their sessions and provide the resources clients are seeking. Effective communication is an integral part of care and this study continues to support the notion of providing various types of support that are specific for each caregiver and client. Finally, this study presents cultural considerations for the Latino population and demonstrates the general trends of various cultural aspects but highlights the variance that lies within one specific population. This study should lead providers to recognize the complexity and immense impact feeding disorders have on caregivers and their customs and adapt the care they provide to the needs of each client and family.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD EXEMPT LETTER

ASU Knowledge Enterprise Development

EXEMPTION GRANTED

Augusta Helms Tillery
Speech and Hearing
480/727-4511
Kate.Helms-Tillery@asu.edu

Dear Augusta Helms Tillery:

On 10/13/2017 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Pediatric feeding disorders: Caregiver perspectives on child health care in the Latino community
Investigator:	Augusta Helms Tillery
IRB ID:	STUDY00006734
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Pediatric Feeding Consent Form_Spanish, Category: Consent Form; • Helms Tillery CITI training, Category: Other (to reflect anything not captured above); • Pediatric Feeding Survey_Spanish, Category: Translations; • Pediatric Feeding Survey_English, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Pediatric Feeding Translation Certification form, Category: Other (to reflect anything not captured above); • Pediatric Feeding_Social Behavioral_Revised, Category: IRB Protocol; • Pediatric Feeding Consent Form_English, Category: Consent Form; • Pediatric Feeding Recruitment Announcement_Revised, Category: Recruitment Materials;

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 10/13/2017.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc:
Augusta Helms Tillery
Katherine Van Vuren
Tamiko Azuma

APPENDIX B

BACK TRANSLATIONS

Conducted by Jose Heredia- Native Speaker of Mexican Descent

Consent Form:

Information sheet about participation in a research study IRB# ________________

Study Title: Pediatric Feeding Disorders: Caregiver Perspectives on Child Health Care in the Latino Community

Investigators: Kate Helms-Tillery, PhD, CCC-SLP; Katherine Van Vuren B.A., NTP; Tamiko Azuma, PhD

Purpose of the study: The purpose of this study is to survey Latino/a parents and caregivers of children with feeding or swallowing disorders. This survey asks about the feeding and swallowing services your child receives. The goal of the survey is to help practitioners learn about parent perspectives and to support their efforts to provide culturally sensitive services. Results from the survey will be shared with practitioners serving Latino families who have children with feeding or swallowing disorders. Results may also be used to guide educational materials for service providers or used in professional presentations and publications.

Participation in the research study: If you are Latino/a, at least 18 years old, and provide care to a child with a feeding or swallowing problem, you are invited to take this survey. If you agree to take this survey, you can choose to complete it online or on paper. If you are unable to complete the survey online or on paper, you may ask the researcher to make an audio recording of your answers. You will be given a consent form before you take the survey. After you consent to participate, the survey will ask you about your experiences with pediatric feeding disorders. We expect that the survey should last about 10 minutes or less.

Do you have to be in this study?
-You do not have to be in this study.
- Participation is voluntary
- You can agree to take part and later change your mind
- Your decision will not be held against you
- You can ask all the questions you want before you decide

Risks, benefits, costs, and compensation of participation: There are no risks, costs, or compensation associated with your participation in this study. We hope that the results of this study will help service providers give quality services to Latino/a children and their caregivers.

Participant privacy and research record anonymity: The survey results will be anonymous. We will collect general information about each caregiver and child (age range, gender, ethnicity, etc.), but we will not collect or share any information that could identify you or the child. Your survey responses may be reviewed by the ASU

Institutional Review Board. The data resulting from your participation may be used in publications and/or presentations but we will not share any information that could identify you or the child.
Contact Information: If you have questions, concerns, complaints, or think the research has harmed you, you may talk to the research team at: Arizona State University- Kate Helms-Tillery- ahelms@asu.edu; Katherine Van Vuren- katherine.vanvuren@asu.edu. Katherine speaks both Spanish and English.

This research is being overseen by the Arizona State University (ASU) Institutional Review Board (IRB). You may also talk to them at (480) 965-6788 or email research.integrity@asu.edu if you have questions regarding your rights as a research participant or other questions, concerns, or complaints.

By continuing, you agree to participate in this research study and consent to have read the above information.

If you are in agreement to participate, put an X in the box ☐

You are free to print or keep this page for your records.

Survey:
Part 1- Demographic Information of Child
1. What is the child's date of birth? Month____________ Year____________
2. Where is your family from?
a. Mexico
b. Cuba
c. Puerto Rica
d. Nicaragua
e. Honduras
f. Peru
g. Ecuador
h. Colombia
i. Guatemala
j. Dominican
k. Other_____
l. More than one ____
3. Who makes most of the decisions about the child's medical care?
a. Both parents
b. Mother only
c. Father only
d. Grandparent(s)
e. Foster parent(s)
f. Professional caregiver
g. Other ____
4. Who takes care of the child most of the time?
a. Both parents

b. Mother only
c. Father only
d. Grandparent(s)
e. Foster parent(s)
f. Professional caregiver
g. Other _______________________
5. Who was the first to suspect a feeding/swallowing issue with the child?
a. Child's primary caregiver
b. Child's physician
c. Family member
d. Other _____________________________
6. If known, what is the child's medical diagnosis? (For example: Down Syndrome, Autism, Gastroesophageal Reflux Disease (GERD)) _____________________________

Part 2- Demographic Information of the Caregiver
1. Where is your family from?
a. Mexico
b. Cuba
c. Puerto Rica
d. Nicaragua
e. Honduras
f. Peru
g. Ecuador
h. Colombia
i. Guatemala
j. Dominican
k. Other_____
l. More than one ____
2. How much total time have you spent in the United States?
a. 0-1 year
b. 1-5 years
c. 6-10 years
d. 10+ years
3. Do you live near people who have similar background and cultural traditions? a. Yes b. No
4. Are you bilingual? (Can you speak and understand more than one language?) a. Yes b. No
5. Which languages do you speak? ________________________________
Part 3- Primary Service Provider

1. If your child receives services from a speech-language pathologist (SLP), do you feel the SLP is sensitive to your culture? A. Yes b. No c. Not Applicable- a SLP is not currently providing treatment

2. Which professional is most involved in the child's care.
a. Speech Language Pathologist
b. Occupational Therapist

c. Physical Therapist
d. Pediatrician
e. Gastroenterologist
f. Neurologist
g. Cardiologist
h. Pulmonologist
i. Ear-Nose-Throat Specialist
j. Dietician
k. Psychologist
l. Other ____________________

Please keep in mind the primary service provider selected in the previous question when you respond to the following questions:

	Always	Most of the time	Half of the time	Sometimes	Never
How often do you feel supported by the child's primary service provider when you raise concerns or ask questions about the child's feeding habits?					
How often does the professional use your preferred language?					
How often do you use the recommendations made by a family member?					
How often do you use recommendations made by the professional?					
If you don't use techniques made by the professional, why not?					

Please indicate how important the following practices are in your family.

	Extremely Important	Very Important	Somewhat Important	Not Important
How important is it to incorporate alternative medicine into the child's care? (natural remedies, herbs)				
How important is it to include other family members when making decisions about the child's care?				
How important is it that you maintain practices from your cultural heritage in mealtime?				

Do you feel a language barrier impacts effective communication between you and the child's primary service provider?

a. Yes b. No

From the list below, please select the topics you believe service providers should consider when consulting with families.
a. Traditional mealtime routines
b. Foods typical of your culture
c. Signs of respect for those in authoritative roles
d. The ability to speak in your native language
e. Alternative or complementary treatments
f. The importance of extended family
g. Religious beliefs and practices
h. Other. ________

Part 4- Resources

From the list below, please select the people whose advice about feeding you value the most. Select as many as you wish.
a. Child's grandmother
b. spouse
c. other family member
d. neighbor/friend
e. Speech Language Pathologist
f. Pediatrician

g. Other Service Provider ____
h. Social Media specific pages (i.e.; Facebook groups or pages about feeding or other issues)
i. Social Media

For the following questions please indicate how **often** you use the following resources when you have questions or need help regarding your child’s feeding disorder.

	Always	Most of the time	Half of the time	Sometimes	Never
Child’s Grandmother					
Spouse					
Other Family Member					
Neighbor/Friend					
Speech Language Pathologist					
Pediatrician					
Other Provider (PT, OT, etc.)					
Topic Specific Social Media (Facebook pages that are specific to Autism, Cerebral Palsy, or another diagnosis)					
General Social Media (Posting on your individual page to receive support)					

For the following questions please indicate how **helpful** you find the following resources when you have questions or need help regarding your child's feeding disorder

	Extremely Helpful	Helpful	Somewhat Helpful	Not Helpful
Child's Grandmother				
Spouse				
Other Family Member				
Neighbor/Friend				
Speech Language Pathologist				
Pediatrician				
Other Provider (PT, OT, etc.)				
Topic Specific Social Media (Facebook pages that are specific to Autism, Cerebral Palsy, or another diagnosis)				
General Social Media (Posting on your individual page to receive support)				

For the following questions, please indicate what type of support you ***hope*** to receive when you consult the following service providers.

	Emotional Support	Medical Support	Informational Resources	Not Applicable- do not use this provider
Speech Language Pathologist				
Pediatrician				
Family Member				
Topic Specific Social Media or General Social Media				

For the following questions, please indicate what type of support you ***actually*** receive when you consult the following service providers.

	Emotional Support	Medical Support	Informational Resources	Not Applicable- do not use this provider
Speech Language Pathologist				
Pediatrician				
Family Member				
Topic Specific Social Media or General Social Media				

Please leave any other thoughts or comments about what parents would like to know about pediatric feeding disorders or what they would like providers to know.

____

____

____

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Recruitment Material: Arizona State University’s (ASU) Department of Speech and Hearing Science is interested in learning more about the perspectives of Latino(a) parents of children with difficulty eating, the resources they consult to best support their children, and the cultural implications of care for their children. The information collected in this survey will give service providers valuable information to best support culturally sensitive practices. All responses are anonymous but may be shared outside of ASU’s Department of Speech and Hearing Science.

APPENDIX C

ENGLISH AND SPANISH SURVEY

Part 1- Demographic Information of Child

1. What is the child's date of birth?

   Month ____ Year ____
2. Which descent does the child *most* identify with?
   - a. Mexican
   - b. Cuban
   - c. Puerto Rican
   - d. Nicaraguan
   - e. Honduran
   - f. Peruvian
   - g. Ecuadorian
   - h. Colombian
   - i. Guatemalan
   - j. Dominican
   - k. Other ________________
   - l. More than one ____
3. Who makes most of the decisions about the child's medical care?
   - a. Both parents
   - b. Mother only
   - c. Father only
   - d. Grandparent(s)
   - e. Foster parent(s)
   - f. Professional caregiver
   - g. Other ______________
4. Who feeds the child most of the time?
   - a. Both parents
   - b. Mother only
   - c. Father only
   - d. Grandparent(s)
   - e. Foster parent(s)
   - f. Professional caregiver
   - g. The child self-feeds
   - h. Other _______________
5. Who was the first to suspect a feeding issue with the child?
   - a. Child's primary caregiver
   - b. Child's physician
   - c. Family member
   - d. Other _______________________________
6. If known, what is the child's medical diagnosis? (For example: Down Syndrome, Autism, Gastroesophageal Reflux Disease (GERD))
   - a. _______________________________

Part 2- Demographic Information of the Caregiver who is filling out this survey

1. Which descent do you *most* identify with?
   - a. Mexican
   - b. Cuban
   - c. Puerto Rican
   - d. Nicaraguan
   - e. Honduran
   - f. Peruvian
   - g. Ecuadorian
   - h. Colombian
   - i. Guatemalan
   - j. Dominican
   - k. Other _______________
   - l. More than one _______

2. How much total time have you spent in the United States?
    a. 0-1 year
    b. 1-5 years
    c. 6-10 years
    d. 10+ years
3. Do you live near people who have similar background and cultural traditions?
    a. Yes
    b. No
4. Are you bilingual? (Can you speak and understand more than one language?)
    a. Yes
    b. No
5. Which languages do you speak?

    ____

Part 3- Primary Service Provider

If your child receives services from a speech-language pathologist (SLP), do you feel the SLP is sensitive to your culture?

a. Yes
b. No
c. Not applicable-a SLP is not providing services

Please identify which service provider is **most** involved in the child's care.

a. Speech Language Pathologist
b. Occupational Therapist
c. Physical Therapist
d. Pediatrician
e. Gastroenterologist
f. Neurologist
g. Cardiologist
h. Pulmonologist
i. Ear-Nose-Throat Specialist
j. Dietician
k. Psychologist
l. Other ___________

Please keep in mind the primary service provider selected in the previous question when you respond to the following questions:

	Always	Most of the time	Half of the time	Sometimes	Never
How often do you feel supported by the child's primary service provider when you raise concerns or ask questions about the child's feeding habits?					
How often does the child's primary service provider communicate with you in your preferred language?					
How often do you implement recommendations about feeding given by the primary service provider?					
How important is it that you maintain practices from your cultural heritage in your daily life?					
If you don't use techniques recommended by the professional, why not?					

Please indicate how important the following practices are in your family.

	Extremely Important	Very Important	Somewhat Important	Not Important
How important is it to incorporate alternative medicine into the child's care? (natural remedies, herbs, etc.)				
How important is it to include other family members when making decisions about the child's care?				
How important is it that you maintain practices from your cultural heritage in your daily life?				

Do you feel a language barrier impacts effective communication between you and the child’s primary service provider?

a. Yes
b. No

From the list below, please select the topics you believe service providers should consider when consulting with families.

a. Traditional mealtime routines
b. Foods typical of your culture
c. Signs of respect for those in authoritative roles
d. The ability to speak in your native language
e. Alternative or complementary treatments
f. The importance of extended family
g. Religious beliefs and practices
h. Other. ________

Part 4- Resources

From the list below, please select the people whose advice about feeding you value the most. Select as many as you wish.

a. Child’s grandmother
b. Spouse
c. Other family member
d. Neighbor/friend
e. Speech Language Pathologist
f. Pediatrician
g. Other Service Provider ____
h. Social Media specific pages (i.e.; Facebook groups or pages about feeding or other issues)
i. Social Media (i.e.; posting questions to your own social media community)
j. Other _________

For the following questions please indicate how **often** you use the following resources when you have questions or need help regarding your child's feeding disorder.

	Always	Most of the time	Half of the time	Sometimes	Never
Child's Grandmother					
Spouse					
Other Family Member					
Neighbor/Friend					
Speech Language Pathologist					
Pediatrician					
Other Provider (PT, OT, etc.)					
Topic Specific Social Media (Facebook pages that are specific to Autism, Cerebral Palsy, or another diagnosis)					
General Social Media (Posting on your individual page to receive support)					

For the following questions please indicate how **helpful** you find the following resources when you have questions or need help regarding your child's feeding disorder

	Extremely Helpful	Helpful	Somewhat Helpful	Not Helpful
Child's Grandmother				
Spouse				
Other Family Member				
Neighbor/Friend				
Speech Language Pathologist				
Pediatrician				
Other Provider (PT, OT, etc.)				
Topic Specific Social Media (Facebook pages that are specific to Autism, Cerebral Palsy, or another diagnosis)				
General Social Media (Posting on your individual page to receive support)				

For the following questions, please indicate what type of support you ***hope*** to receive when you consult the following service providers.

	Emotional Support	Medical Support	Informational Resources	Not Applicable- do not use this provider
Speech Language Pathologist				
Pediatrician				
Family Member				
Topic Specific Social Media or General Social Media				

For the following questions, please indicate what type of support you ***actually*** receive when you consult the following service providers.

	Emotional Support	Medical Support	Informational Resources	Not Applicable- do not use this provider
Speech Language Pathologist				
Pediatrician				
Family Member				
Topic Specific Social Media or General Social Media				

Please leave any other thoughts or comments about what parents would like to know about pediatric feeding disorders or what they would like providers to know.

____

____

Spanish Survey

Parte 1- Información demográfica del niño/a

1. ¿Cuál es la fecha de nacimiento del niño(a)?
   Mes______
   Año ______
2. ¿De donde es su familia?
   a. México
   b. Cuba
   c. Puerto Rico
   d. Nicaragua
   e. Honduras
   f. Perú
   g. Ecuador
   h. Colombia
   i. Guatemala
   j. Dominicana
   k. Otro(a) _______________
   l. Más de uno(a) ___________
3. ¿Quién hace la mayoría de las decisiones sobre el cuidado médico del niño(a)?
   a. Los padres
   b. Solo la madre
   c. Solo el padre
   d. Los abuelos
   e. Los padres legales
   f. Un cuidador profesional
   g. Otro(a) __________________

4. ¿Quién cuida al niño(a) la mayor parte del tiempo?
    a. Los padres
    b. Solo la madre
    c. Solo el padre
    d. Los abuelos
    e. Los padres legales
    f. Un cuidador profesional
    g. Otro(a) ________________

5. ¿Quién fue la primera persona en notar el problema de comer con el niño(a)?
    a. La persona que cuida el niño(a) la mayor parte del tiempo
    b. El médico del niño(a)
    c. Una miembro familia
    d. Otro(a) ____________________

6. Si sabe, ¿cuál es el diagnóstico médico del niño(a)? (Por ejemplo; Autismo, síndrome de Down, La enfermedad por reflujo gastroesofágico)
    a. ___________________________

Parte 2- Información demográfica del cuidador/a

1. ¿De donde es su familia?
    a. México
    b. Cuba
    c. Puerto Rico
    d. Nicaragua
    e. Honduras
    f. Perú
    g. Ecuador
    h. Colombia
    i. Guatemala
    j. Dominicana
    k. Otro(a) _____________
2. Más de uno(a) _________ ¿Cuánto tiempo ha vivido en los Estados Unidos?
    a. 0-1 año
    b. 1-5 años
    c. 6-10 años
    d. 10+ años
3. ¿Vive cerca de personas que comparten sus tradiciones culturales?
    a. Sí
4. No ¿Es bilingüe? (¿Puede hablar y entender dos idiomas?)
    a. Sí
    b. No
5. ¿Cuáles idiomas habla?
    a. ________________________

Parte 3 – El Profesional Principal

1. Si el niño(a) recibe servicios de un profesional del habla y lenguaje, ¿Es sensible a sus valores familiares?
    a. Sí
    b. No
    c. No aplica- no usa un profesional del habla y lengua
2. ¿Cuál profesional participa más en el cuidado del niño(a)?
    a. Terapeuta del habla y lenguaje
    b. Terapeuta ocupacional
    c. Terapeuta físico
    d. Pediatra
    e. Gastroenterólogo
    f. Neurólogo
    g. Cardiólogo
    h. Neumólogo
    i. Especialista en oídos nariz y garganta (Otorrinolaringólogo)
    j. Nutriólogo
    k. Psicólogo
    l. Otros(as) ____________________

Considere <u>el profesional principal</u> elegido en <u>la pregunta anterior</u> cuando responda las siguientes preguntas:

	Siempre	A menudo	A veces	Raramente	Nunca
Cuando tiene preocupaciones o preguntas sobre los hábitos de comer del niño(a), ¿Con qué frecuencia se siente apoyado por el profesional principal del niño(a)?					
¿Con qué frecuencia usa el profesional su idioma preferido?					
¿Con qué frecuencia usa las recomendaciones de la familia cómo darle de comer al niño(a)?					
¿Con qué frecuencia usa las técnicas que el profesional le recomienda?					
Si no usa las técnicas que el profesional le recomienda, ¿porque no?					

Por favor, indica la importancia de las siguientes prácticas en su hogar.

	Extremadamente útil	Útil	Algo útil	No es útil
¿Qué tan importante es usar tratamientos alternativos o complementarios en el cuidado del niño(a)? (Por ejemplo, hierbas, remedios naturales)				
¿Qué tan importante es incluir a otros miembros de la familia al tomar decisiones sobre el cuidado del niño?				
¿Qué tan importante es mantener sus tradiciones culturales a la hora de comer?				

¿Siente que hay una barrera del idioma entre usted y el profesional principal del niño(a)?

a. Si
b. No

De la siguiente lista, seleccione lo que considera que los profesionales deben tener en cuenta cuando hablen con familias.

a. Rutinas tradicionales de las comidas
b. Comidas típicas de su cultura
c. Señales de respeto a los que desempeñan funciones autorizadas
d. La capacidad de hablar en su idioma preferido
e. Tratamientos alternativos o complementarios
f. La importancia de la familia lejana
g. Creencias y prácticas religiosas
h. Otro(a) ___________

Parte 4- Recursos

1. De la siguiente lista, seleccione las personas cuyos consejos acerca de comer valora más. Seleccione cuantas desee.
   a. Abuela de niño
   b. Esposo(a)
   c. Otro miembro de la familia
   d. Vecino/ amigo
   e. Terapeuta del habla y lenguaje
   f. Pediatra
   g. Otro profesional
   h. Páginas específicas de las redes sociales (por ejemplo, grupos de Facebook o páginas sobre problemas específicos)
   i. Medios de comunicación social (por ejemplo, publicar preguntas a su propia comunidad de redes sociales)
   j. Otro(a) _______________

Cuando tiene preguntas o necesita ayuda o tiene dificultades al dar comer, ¿con qué **frecuencia** utiliza los siguientes recursos.

	Siempre	A menudo	A veces	Raramente	Nunca
Abuela de niño(a)					
Esposo(a)					
Otro miembro de la familia					
Vecino o amigo					
Profesional del habla y lenguaje					
Pediatra					
Otro profesional (Terapista de ocupación, terapista de física, etc.)					
Páginas específicas de las redes sociales (grupos de Facebook o páginas sobre problemas específicos)					
Medios de comunicación social (publicar preguntas a su propia comunidad de medios sociales)					

Para las siguientes preguntas, ¿Qué tan **útil** ha sido estos recursos cuando ha tenido preguntas sobre su niño(a) problemas para comer?

	Extremadamente útil	Útil	Algo útil	No es útil
Abuela de niño(a)				
Esposo(a)				
Otro miembro de la familia				
Vecino o amigo				
Profesional del habla y lenguaje				
Pediatra				
Otro profesional (Terapista de ocupación, terapista de física, etc.)				
Páginas específicas de las redes sociales (por ejemplo, grupos de Facebook o páginas sobre problemas específicos)				
Medios de comunicación social (por ejemplo, publicar preguntas a su propia comunidad de medios sociales)				

Cuando consulta los siguientes recursos sobre el problema de comer del niño(a), ¿qué tipo de apoyo **espera** recibir? Seleccione todas las que correspondan.

	Apoyo emocional	Atención médica	Recursos informativos	No aplica- no usa este profesional
Professional del habla y lenguaje				
Pediatra				
Un miembro de familia				
Páginas sociales o medios sociales				

Cuando consulta los siguientes recursos sobre el problema de comer del niño(a), ¿qué tipo de apoyo recibe **actualmente**? Seleccione todas las que correspondan.

	Apoyo emocional	Atención médica	Recursos informativos	No aplica- no usa este profesional
Professional del habla y lenguaje				
Pediatra				
Un miembro de familia				
Páginas sociales o medios sociales				

Por favor, escriba otras sugerencias o comentarios sobre que les gustaría que padres conocieran o profesionales conocieran acerca del problema de comer de los niño/as.

APPENDIX D

ENGLISH AND SPANISH CONSENT FORMS

Consent Form

Information sheet about participation in a research study IRB#STUDY00006734

Study Title: Pediatric Feeding Disorders: Caregiver Perspectives on Child Health Care in the Latino Community

Investigators: Kate Helms-Tillery, PhD, CCC-SLP; Katherine Van Vuren B.A., NTP, Tamiko
Azuma, PhD

Purpose of the study: The purpose of this study is to survey Latino/a parents and caregivers of children with feeding or swallowing disorders. This survey asks about the feeding and swallowing services your child receives. The goal of the survey is to help practitioners learn about parent perspectives and to support their efforts to provide culturally sensitive services. Results from the survey will be shared with practitioners serving Latino families who have children with feeding or swallowing disorders. Results may also be used to guide educational materials for service providers, and may be used in professional presentations and publications.

Participation in the research study: If you are Latino/a, at least 18 years old, and provide care to a child with a feeding or swallowing problem, you are invited to take this survey. If you agree to take this survey, you can choose to complete it online or on paper. If you are unable to complete the survey online or on paper, you may ask the researcher to make an audio recording of your answers. You will be given a consent form before you take the survey. After you consent to participate, the survey will ask you about your experiences with pediatric feeding disorders. We expect that the survey should last about 10 minutes or less.

Do you have to be in this study?

-You do not have to be in this study.
- Participation is voluntary
- You can agree to take part and later change your mind
- Your decision will not be held against you
- You can ask all the questions you want before you decide

Risks, benefits, costs, and compensation of participation: There are no risks, costs, or compensation associated with your participation in this study. We hope that the results of this study will help service providers give quality services to Latino/a children and their caregivers.

Participant privacy and research record anonymity: The survey results will be anonymous. We will collect general information about each caregiver and child (age range, gender, ethnicity, etc.), but we will not collect or share any information that could identify you or the child. Your survey responses may be reviewed by the ASU Institutional Review Board. The data resulting from your participation may be used in publications and/or presentations but we will not share any information that could identify you or the child.

Contact Information:
If you have questions, concerns, complaints, or think the research has harmed you, you may talk to the research team at: Arizona State University: Kate Helms-Tillery ahelms@asu.edu; Katherine Van Vuren- katherine.vanvuren@asu.edu. Katherine speaks both Spanish and English.

This research is being overseen by the Arizona State University (ASU) Institutional Review Board (IRB). You may also talk to them at (480) 965-6788 or email research.integrity@asu.edu if you have questions regarding your rights as a research participant or other questions, concerns, or complaints.

By continuing with the survey, you agree to participate in this research study and consent to have read the above information. If you agree to participate, please check this box: ☐

You are free to print or keep this page for your records.

Formulario de consentimiento

Hoja informativa sobre la participación en un estudio de investigación IRB # STUDY00006734

Título del estudio: Trastornos alimentarios pediátricos: Perspectivas de los cuidadores sobre la atención de la salud infantil en la comunidad latina

Investigadores: Kate Helms-Tillery, PhD, CCC-SLP; Katherine Van Vuren B.A., NTP; Tamiko Azuma, PhD

Propósito del estudio: El propósito de este estudio es para preguntar a padres latinos de niños con problemas de comer sobre los servicios que recibe. Los resultados de este estudio serán compartidos con los profesionales que sirven a familias latinas que tienen niños con problemas de comer. El objetivo de este estudio es ayudar a los profesionales a aprender sobre los puntos de vistas de los padres. Este estudio apoyara las habilidades profesionales a dar servicios culturalmente sensibles. Los resultados pueden usarse para crear materiales educativos para profesionales o usa en presentaciones profesionales y publicados.

Participación en el estudio de investigación: Si usted es latino/a, tiene por lo menos 18 años y le da cuidado a un niño con un problema de comer, lo invitamos a tomar esta encuesta. Si acepta tomar esta encuesta, puede elegir por completarla por internet o en papel. Si no puede completar la encuesta por internet o en papel, puede pedirle al investigador que haga una grabación de audio de sus respuestas. Se le dará un formulario de consentimiento antes de tomar la encuesta. Después de dar su consentimiento para participar, la encuesta le preguntará sobre de sus experiencias con problemas de comer. Esperamos que la encuesta dure 10 minutos o menos.

¿Tiene que participar en este estudio?
- No tiene que participar en este estudio.
- La participación es opcional.
- Puede aceptar participar y luego cambiar de opinión.
- Su decisión no se tomará en su contra.
- Puede hacer todas las preguntas que quiera antes de decidir.

Riesgos, beneficios, costos y compensación de participación: No hay riesgos, costos o compensación asociados con su participación en este estudio. Esperamos que los resultados de este estudio ayuden a los profesionales dar servicios de calidad.

La privacidad y la investigación del participante anonimizan: Los resultados de la encuesta serán anónimos. Recogimos información general sobre cada padre y cada niño (rango de edad, género, origen étnico, etc.), pero no recogimos ni compartiremos ninguna información que pueda identificar a usted ni al niño/a. La Junta de Revisión Institucional de ASU puede ver las respuestas de la encuesta. Las respuestas pueden ser usados en publicaciones y/o presentaciones, pero no compartiremos ninguna información que pueda identificarlo a usted o al niño.

Información del contacto: Puede hablar con el equipo de investigación si tiene preguntas, preocupaciones, quejas o piensa que la investigación le ha hecho daño: Arizona State University- Kate Helms-Tillery- ahelms@asu.edu; Katherine Van Vuren- katherine.vanvuren@asu.edu. Katherine habla español e inglés.

La Junta de Revisión Institucional de la Universidad Estatal de Arizona (ASU) está supervisado esta investigación. Puede hablar con ellos al (480) 965-6788 o envía un correo electrónico a research.integrity@asu.edu si tiene preguntas sobre sus derechos como participante en la investigación u otras preguntas, preocupaciones o quejas.

Si continua, acepta participar en este estudio de investigación y acepta haber leído la información anterior. Si está de acuerdo a participar, ponga X en la caja.

☐

Puede imprimir o guardar esta página para sus registros

APPENDIX E

RECRUITMENT MATERIAL

Are you the caregiver of a child with feeding difficulties?

ASU College of Health Solutions
ARIZONA STATE UNIVERSITY

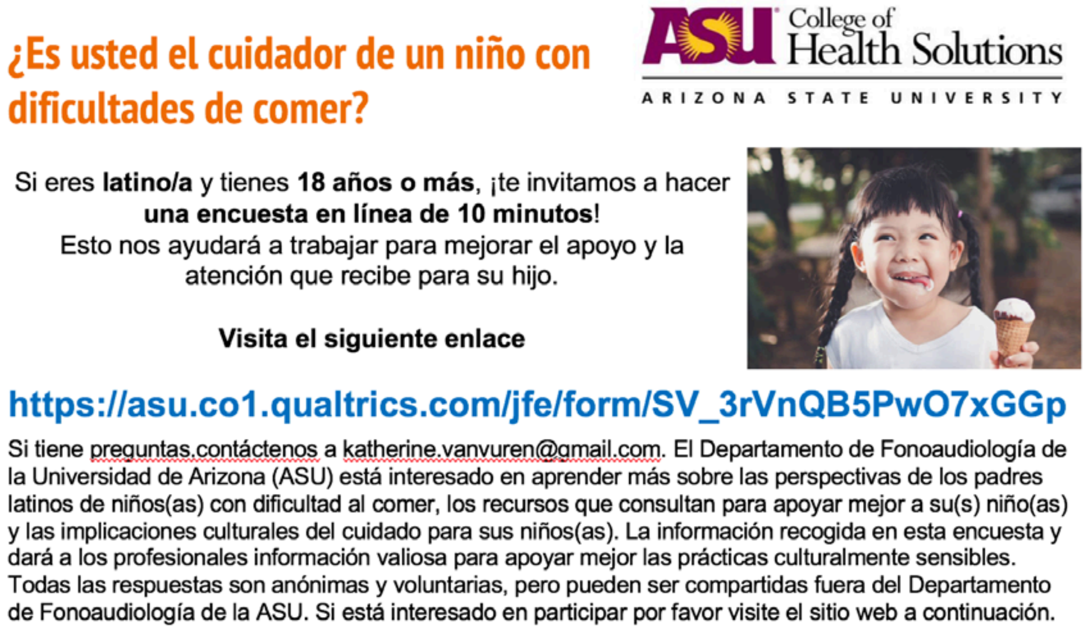
If you're Latino/a and 18 or older, you're invited to take a 10 minute online survey!

This will help us work to improve the support and care you receive for your child.

Visit the link below

https://asu.co1.qualtrics.com/jfe/form/SV_d5w5wbIPCMISuW1

Please email katherine.vanvuren@gmail.com for questions. Arizona State University's (ASU) Department of Speech and Hearing Science is interested in learning more about the perspectives of Latino(a) parents of children with difficulty eating, the resources they consult to best support their children, and the cultural implications of care for their children. The information collected in this survey will give service providers valuable information to best support culturally sensitive practices. All responses are anonymous and voluntary but may be shared outside of ASU's Department of Speech and Hearing Science. If you are interested in participating please visit the website above.



¿Es usted el cuidador de un niño con dificultades de comer?

ASU College of Health Solutions
ARIZONA STATE UNIVERSITY

Si eres **latino/a** y tienes **18 años o más**, ¡te invitamos a hacer **una encuesta en línea de 10 minutos**!
Esto nos ayudará a trabajar para mejorar el apoyo y la atención que recibe para su hijo.

Visita el siguiente enlace

https://asu.co1.qualtrics.com/jfe/form/SV_3rVnQB5PwO7xGGp

Si tiene preguntas,contáctenos a katherine.vanvuren@gmail.com. El Departamento de Fonoaudiología de la Universidad de Arizona (ASU) está interesado en aprender más sobre las perspectivas de los padres latinos de niños(as) con dificultad al comer, los recursos que consultan para apoyar mejor a su(s) niño(as) y las implicaciones culturales del cuidado para sus niños(as). La información recogida en esta encuesta y dará a los profesionales información valiosa para apoyar mejor las prácticas culturalmente sensibles. Todas las respuestas son anónimas y voluntarias, pero pueden ser compartidas fuera del Departamento de Fonoaudiología de la ASU. Si está interesado en participar por favor visite el sitio web a continuación.

APPENDIX F

CONSULTED TOPIC-SPECIFIC SOCIAL MEDIA PAGES

The following table lists the topic-specific social media pages the survey was deployed on and the number of members in each group.

Facebook Page Title	Number of Members
Acid Reflux Babies Support Group	6,373
Autism Society of Greater Phoenix	1,217
Babies with Feeding Aversion	95
Babies with Silent Reflux	3,406
Bottle/Infant Feeding Aversion Support	293
Cerebral Palsy	7,719
Cerebral Palsy Support Group	3,617
Families of NICU and Premature Babies	9,963
Feeding Matters	Followed by 7,398
FeeDR Pediatric Dysphagia	5,261
G-Tube Babies (G/J),(J),(N/G), and (N/J)	12,616
Gastroschisis babies	4,545
NFOSD Pediatric Support Group: Babies with Swallowing/Feeding Disorders	719
NICU Moms Support Group	3,079
Parents of Children with Multiple Food Allergies	5,222
Parents of Kids with Developmental Delays	2,295

Pediatric Communication and Feeding Development	1,272
Pediatric feeding disorders / FTT/ GERD/and kiddos with feeding tubes	16,900
Pierre Robin Sequence	3,419
Preemie Parents Club	6,431
Reflux Rebels	7,348
Sensory Processing Disorder (SPD) Support	83,665
Sensory Processing Disorder Advocacy	24,258
The Feeding Flock	281
Tubie Tips and Tricks	3,033