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MEDICAL INTERPRETER'S EXPERIENCE WORKING WITH DISTRESSED FAMILIES IN PEDIATRIC SETTINGS

by

Paulina S. Lim

A Dissertation Submitted in
Partial Fulfillment of the
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ABSTRACT

MEDICAL INTERPRETERS' EXPERIENCE WORKING WITH DISTRESSED FAMILIES IN PEDIATRIC SETTINGS

by

Paulina S. Lim

The University of Wisconsin-Milwaukee, 2023
Under the Supervision of Professors Amy Olen and W. Hobart Davies

Effective communication between families and pediatric clinicians is essential for mitigating family stress and improving quality of care. Families who speak a primary language other than English must contend with the added stress of language barriers during stressful encounters, which could impact the quality of patient care and health outcomes. Trained medical interpreters facilitate communication, including distress expressions, during interpreted medical encounters (IME). Little is known about how interpreters identify distress and what factors impact distress identification during IME. This project describes how interpreters identify distress of families during IME, and how they identify cultural nuances in distress expression and communication of families during IME. Special attention is placed on factors that influence why and how interpreters identify distress expression, such as their intersecting social identities and lived personal and professional experiences. Interpreters from the current study collectively reported that families in IME expressed distress in various ways: through visual, auditory, interpersonal, and contextual cues. Interpreters also perceived that distress expression among Spanish-speaking families in IME is diverse and simultaneously culture-specific and universal, influenced by cultural norms specific to the families' intersecting social identities. Therefore, cultural concepts of distress and more covert culture bound expressions of distress (e.g., withdrawal) should be considered when evaluating family distress. Medical care teams inclusive of health care clinicians and medical interpreters should continue to cultivate their own cultural and emotional intelligence to better understand cultural concepts of distress among families from multiply minoritized backgrounds in the health care system. Clinicians and medical interpreters may benefit from collaboratively working together to better identify and respond when families are distressed.

Keywords: *distress, cultural expression of distress, interpreted medical encounters, medical interpreting, pediatric care*

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LIST OF ABBREVIATIONS

ACA	Affordable Care Act
CHIA	California Healthcare Interpreting Association
CSHCN	Children with Special Health Care Needs
DOJ	Department of Justice
EP	English Proficient
HCP	Health Care Provider
IME	Interpreted Medical Encounter
IMIA	International Medical Interpreters Association
LEP	Limited English Proficiency
PICU	Pediatric Intensive Care Unit

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To my parents,
Thank you for your unwavering support and strength.
I am proud to be your daughter.

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Introduction

Medical Interpreters' Experience Working with Distressed Families in Pediatric Settings

The United States Census Bureau (2018) estimates that 65 million (21.5%) United States residents speak a language other than English at home, with 26 million (8.5%) individuals speaking English “less than very well.” Individuals who speak English “less than very well” have historically been labeled as individuals with limited English proficiency (LEP), defined by the US Department of Justice (DOJ) as “individuals who do not speak English as a primary language and who have a limited ability to read, speak, write, or understand English” (DOJ, 2005). The DOJ further notes that “LEP” individuals “may be entitled to language assistance with respect to a particular type or service, benefit, or encounter” (DOJ, 2005).

However, the term “limited English proficiency” has been considered problematic since the label does not fully encapsulate the complexity of individuals’ cultural identities, linguistic abilities, and linguistic preferences, and it emphasizes a deficit framework rather than highlighting the cultural wealth and knowledge of linguistically minoritized individuals (Oropeza et al., 2010). Despite these criticisms, health care research and practice and the United States Census Bureau continue to use the term “LEP”. Although the term “LEP” is more commonly used in research and literature, the term *families in interpreted medical encounters (families in IME)* will be used in this study to describe patients and families who speak a language other than English as their primary language and use interpretation services in pediatric medical settings. The term “LEP” will only be used when citing or referring to official documents or sites such as the Affordable Care Act or the United States Census Bureau.

Brief history of linguicism

Throughout US history, migration from foreign nations to the United States has spurred movements advocating for the legal protection of English as the national language, and legal restrictions of other languages (i.e., Official English movement; Crawford, 2000). The perceived rising “threat” of bilingualism and immigration eventually resulted in the declaration of English as the official language of state governments in 31 states (U.S English, 2020). In 1996, a bill titled “English Language Empowerment Act” was voted on by Congress and approved by the House of Representatives to designate English as the federal government’s sole language of official business (H.R. 123, 1996). However, the bill never became law since it did not receive adequate support in the Senate. It was reintroduced to the House of Representatives as the “English Unity Act” (H. R. 997) in 2007, in 2011, and again in 2019, and to the Senate in 2019 (S. 678). The reintroduction of HR 997 speaks to the persistence of non-English linguicism in the US, the desire for English to be the official language, and the perceived threat to the status of English as the imagined official language. To date, the United States federal government does not specify an official language; however, all official documents in the US are written in English, though some are published in other languages.

Linguistic discrimination (i.e., linguicism) is defined as unfair treatment based on use of language and characteristics of speech, including first language, accent, size of vocabulary (e.g., whether the speaker uses complex and varied words), modality, and syntax. Linguicism and the influence of the so-called "English-only" movement may play a role in contributing to disparities in access to medical information for families who speak languages other than English. Additional factors, which may serve as proxies for language discrimination, should be considered as well, such as a lack of adequate funding allocated by medical institutions or the federal government to support meaningful language access services (Crawford, 2000).

Linguistic minoritization and health outcomes in pediatric settings

By 2060, it is estimated that one in six individuals (69 million) in the United States will be foreign born (i.e., anyone who is not a US citizen at birth). Most foreign-born individuals are expected to be characterized as “LEP” (US Census, 2020). According to the United States Census, categorization as foreign born includes “naturalized U.S. citizens, lawful permanent residents (i.e., immigrants), temporary migrants (i.e., foreign students), humanitarian migrants (i.e., refugees and asylees), and unauthorized migrants” (US Census, 2020).

According to the Healthcare Cost and Utilization Project, there were approximately 5.5 million hospital stays in community hospitals (i.e., short-term, non-Federal, general and specialty hospitals, excluding hospital units of other institutions) for children under 17 years of age in 2016 (Freeman et al., 2006). To date, there is no known nationwide statistical data on the actual number of families affected by the hospital stays, as families may experience multiple admissions in a year. Similarly, no known nationwide statistical data can be found for families who speak a primary language other than English and require interpretation services during medical visits. However, given the increased rate of families who speak a primary language other than English living in the United States, it is likely that many children from families that require interpreting services will encounter the health care system, with some requiring high intensity inpatient care (e.g., pediatric intensive care unit, neonatal intensive care unit, or emergency department), or experiencing high stress medical encounters (e.g., end-of-life discussions, family conferences).

Disparities in child health outcomes associated with race and ethnicity are well researched, with evidence suggesting that linguistically minoritized families experience health disparities independent of social determinants of health such as race, ethnicity, socioeconomic status, and perceived discrimination (Eneriz-Wiemer et al., 2014). Physically healthy children with families in IME are less likely to be insured, to have a patient or family centered medical home [i.e., an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families (Pediatrics, 2002)], or to receive specialty referrals. Additionally, physically healthy children with families in IME are more likely to experience serious medical errors compared to children with English-proficient (EP) parents (Cohen et al., 2005; Flores et al., 2005).

The added linguistic barrier also contributes to serious medical events during hospitalization and poorer health quality and status (Cohen et al., 2005; Eneriz-Wiemer et al., 2014; Flores et al., 2005). Disparities in assessment, communication, and parent satisfaction between families in IME and families who do not require medical interpretation services (i.e., EP parents) have also been documented in the literature. Specifically, families in IME received fewer pain assessments compared to EP patients (Jimenez et al., 2014), received less information during family conferences in the PICU (Thornton et al., 2009), experienced suboptimal communication due to shared decision making and heightened imbalance between physician and family speech (Van Cleave et al., 2014) and were less likely to report patient-centered care satisfaction (Zurca et al., 2017) compared to EP parents.

A systematic review conducted by Eneriz-Wiemer and colleagues (2014) evaluated the relationship between families in IME and health outcomes for children with special health care needs (CSHCN). Similar to families with healthy children, findings indicated that parents of children with CSHCN who were in IME: 1) have poorer health care access [e.g., were uninsured, had no usual source of care or medical home, had limited after-hours care, were less likely to access electronic health information (Blumberg et al., 2005; Singh et al., 2009; Yu & Singh, 2009)]; 2) have unmet mental health care needs (Inkelas et al., 2007); and 3) have increased costs associated with health care utilization [e.g., missing or stopping work, paying out of pocket (Yu et al., 2004; Yu & Singh, 2009). Families in IME were also more likely to receive poorer quality of care, such that families in IME were less likely to receive family centered care (Coker et al., 2010; Yu & Singh, 2009); have health care providers (HCP) who are sensitive to the family's values and customs (Coker et al., 2010); and have HCP who treat parents as partners in their child's care (Kenney et al., 2011) or engage in discussion with the family about transition from child to adult medical care (Lotstein et al., 2009).

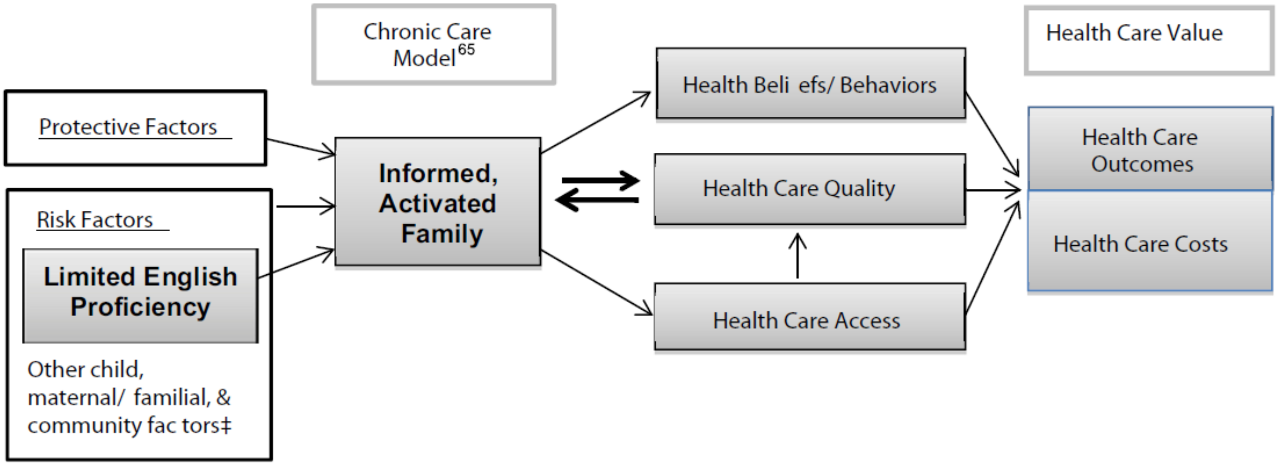

Figure 1. Theoretical model for association between parental LEP and health care access.
Note: Eneriz-Weimer and colleagues use the term parents with Limited English Proficiency to refer to families in IME (Eneriz-Wiemer et al., 2014; Karliner et al., 2007)

The quality of parent-provider communication, and whether it is viewed as family-centered, has been identified as a contributing factor to child health outcomes for families in IME. Specifically, the Chronic Care Model (Karliner et al., 2007) adapted for pediatric care (Wagner, 1998) of families in IME (Eneriz-Wiemer et al., 2014) further describes the causal pathways that could result in improved health outcomes (see Figure 1 above). In this model, language is a risk factor that impacts the degree to which families are informed (via the quality of parent-provider communication during medical encounters) and activated (i.e., manage health and health care needs) to advocate for their child's care needs (Eneriz-Wiemer et al., 2014). An informed and activated family system could potentially facilitate productive interactions between families and HCP, which should ultimately lead to improved health outcomes and lower health costs.

For family systems in IME, trained medical interpreters who facilitate communication between families and clinicians are a crucial link that is expected to result in improved health care outcomes. Since studies have indicated that language interpreting is a high cognitive load process which draws from a finite store of interpreters' cognitive resources (Bistra, 2014; Liu et al., 2004; Pöchhacker, 2011), others within the medical care team may adopt strategies that facilitate the interpreting process and result in higher quality communication within IME (Hsieh 2006; Lehna, 2005; Hudelson 2005). Therefore, the medical care team, including the interpreter, and the families should all contribute and collaborate effectively to result in positive health outcomes.

Interpreted Medical Encounters

Effective communication between families and clinicians is essential for establishing trust, decreasing family stress, and improving quality of care (Levetown, 2008; Ranjan et al., 2015; Studdert et al., 2003). For families in IME, spoken language interpreters could help facilitate effective communication. The Affordable Care Act (ACA) Section 1557 "requires covered entities to take *reasonable steps* to provide meaningful access" to individuals with limited English proficiency, which "may include the use of provisional language assistance services" such as oral language assistance through interpreters or written translation (Patient

Protection and Affordable Care Act, 2016). Multiple studies have highlighted the importance of using spoken language interpreters during IME since it results in improved clinical care, increased patient involvement, and increased patient safety in all medical settings, including pediatrics (Dunlap et al., 2015; Eneriz-Wiemer et al., 2014; Firew et al., 2020; Flores et al., 2005; Jungner, 2018; Karliner et al., 2007; Zurca et al., 2017).

Although the use of medical interpreters has been instrumental in bridging cultural and linguistic gaps and providing effective health care to families in IME, studies indicate that access to interpreters alone does not sufficiently result in effective communication (Abbe et al., 2006; Arthur et al., 2015; Zurca et al., 2017). For example, although access to professional interpretation services during IME may mitigate disparities in care experiences, parents continue to report increased problems with communication in various high stress pediatric departments including the emergency departments (ED; Arthur et al., 2015), the pediatric intensive care unit (PICU; Zurca et al., 2017), the neonatal intensive care unit (NICU; Obregon et al., 2019), and during various points in medical encounters, including during the medical appointment (Riera et al., 2015), family centered rounds (Levin et al., 2015; Rea et al., 2018) and at discharge (Jimenez et al., 2020; Obregon et al., 2019).

For example, families in IME during family centered rounds were less likely to correctly name a diagnosis or understand the medical plan (Lion et al., 2013; Zurca et al., 2017) and were less likely to understand discharge goals compared to English proficient (EP) families (Subramony et al., 2012). In the pediatric ED setting, parent perceived inaccuracies in interpretation were associated with increased reported problems understanding the information provided, including access/coordination of care (e.g., perceived wait times) and information about a child’s illness and care compared to EP parents (Arthur et al., 2014). Another study conducted by medical providers noted that “alterations” in communication occurred in 56% of interpreted statements, characterized by “additions, omissions, substitutions, editorializations, answering for the patient/clinician, confessions, and patient advocacy”, underscoring provider perspectives that “inaccuracies during IME happen frequently” (Sinow et al., 2017). Outside of IME (i.e., when interpreters are unavailable), families might be reluctant to request interpreter services even when gaps in communication were present (Rea et al., 2018; Riera et al., 2015; Seltz et al., 2011; Zurca et al., 2017) or during discharge when gaps in provision of written instructions in the family’s preferred language such as medication instructions and educational resources were provided in English (Jimenez et al., 2020).

Communication Factors

Interpreters’ perceived roles may impact how they manage the communication between families and clinicians in IME. Likewise, clinician views of interpreter roles may impact whether and how they address the family when interpreters are involved in the child’s care.

Interpreter Perspectives on Interpreter Roles

Spoken language interpreters are expected to adhere to industry-defined codes of ethics and assume an appropriate interpreter role during medical encounters [International Medical Interpreter Association (IMIA), 2007; California Health Interpreters Association (CHIA), 2002]. Roles for medical interpreters are described as *message converter, message clarifier, cultural clarifier*, and *patient advocate*. These roles fall along a continuum describing what has been referred to as interpreter *visibility* or *invisibility* among all participants in the IME. On the invisible end is the *conduit* or *message converter role*, in which the interpreter is solely responsible for conveying an exact linguistic interpretation of content from one language to another, without intervening in any way in the communication [i.e., the interpreter is an “interpreting machine” (Fatahi et al., 2008)] and without additions, omissions, or changes in meaning.

On the visible end, interpreters may intervene in IME to, among other objectives, clarify meaning; advocate for patients; explain contextual, cultural or technical concepts; and soften inflammatory language (Hsieh, 2007). In the *message clarifier* role, interpreters monitor for possible words or concepts that might lead to misunderstanding and clarify possible sources of confusion for the patient, clinician, or interpreter. The *cultural clarifier* role goes beyond clarification of linguistic messages and involves facilitating communication (e.g., communicating cultural beliefs about health and illness that may vary from the biomedical perspective) between individuals who do not share a common culture. Finally, the *advocate* role involves active intervention in the interpreted communication on behalf of the well-being of an IME stakeholder, for example, advocating in the interest of the patient’s health and well-being. Some examples of advocacy include suggesting interpreter services in follow-up visits or educating patients about their right to linguistically accessible services and about healthcare culture. Communication of patient distress might be one example of an aspect of medical encounters in which interpreters adapt a more visible role (i.e., message clarifier, cultural clarifier, patient advocate) in the communication exchange compared to an invisible role (e.g., message converter).

Traditionally, the conduit role has been favored as the interpreter’s primary role by interpreters and national licensing agencies (Angelelli, 2004). However, interpreting literature has challenged the appropriateness of interpreters functioning solely in the message converter role, with some interpreting scholars claiming an ethical obligation for interpreters to play a more visible role, which may include ensuring that emotional expressions and affective content is appropriately rendered (Angelelli, 2004; Hsieh, 2007; Hsieh & Nicodemus, 2015; Schwei et al., 2019). IMIA and CHIA have noted in their standards of practice that an interpreter must know how to engage both clinician and patient effectively and efficiently in accessing the nuances and hidden socio-cultural assumptions embedded in each other's language (CHIA, 2002; IMIA, 2007). Further, interpreter roles may be fluid and may change based on the ongoing conversation, as speakers and contextual factors of IME impact interpreter communicative strategies and management of their roles (Hsieh, 2007; Llewellyn-Jones & Lee, 2013).

Clinician Perspectives on Interpreter Roles

Studies suggest that clinicians prioritize the message converter role for interpreters (Hsieh, 2007; Hsieh & Hong, 2010; Rosenberg et al., 2007) and highlight the lack of trust between clinicians and interpreters due to confusion of role expectations (Dysart-Gale, 2007; Williams et al., 2018). Qualitative data also points to clinicians' concerns that interpreters overstep their professional roles, contributing to a lack of trust between medical clinicians and interpreters due to confusion of role expectations and boundaries when interpreters assume roles other than message converter. For example, a more visible interpreter role is seen as problematic when clinicians perceive it to diminish patient-provider communicative autonomy or overlap with clinicians' responsibilities and functions (Fatahi et al., 2008; Hsieh & Hong, 2010; Rosenberg et al., 2007; Schwei et al., 2019; Zendedel et al., 2016). However, evidence also suggests that some pediatric clinicians believe a medical encounter with high quality interpretation involves multiple interpreter roles that transcend message conversion, such that interpreters act as cultural brokers or patient advocates (Schwei et al., 2019). During these IME, clinicians recognize the value of interpreters who communicate subtlety and with nuance, help clinicians build rapport with patients, and explain culture-specific content (Schwei et al., 2019; Tam et al., 2019).

Despite availability of published guidelines about the appropriate use of medical interpreter services (Association of American Medical Colleges, 2019; Juckett & Unger, 2014), the degree to which medical clinicians adhere to these guidelines has not yet been explored. Additionally, and perhaps due to the variety of roles and real-life interpreter practices, role confusion among interpreters and clinicians is wide-spread and persistent (Hsieh, 2007). It is also likely that role confusion might manifest during IME, especially when interpretation of a patient or family's distress or cultural expressions of distress are taken into consideration. Finally, it is unknown how different interpreter roles impact interpreters' identification and communication of patient and family distress, and interpreter-clinician communication effectiveness in IME.

Family Distress in Pediatrics

Pediatric medical encounters can be stressful and frightening, and could result in distress for many parents and families (Nelson & Gold, 2012; Stremler et al., 2017). For the purposes of this study, distress is defined as experience of traumatic stress, anxiety, and/or depression. Among EP families, factors that contribute to parent distress in pediatrics include the frequency of the child's invasive procedures (De Young et al., 2014), a child's illness severity, and the long term nature of the child's condition (Mattson & Kuo, 2019), suggesting that family distress is associated with the child's condition. Additionally, admission to pediatric hospitals has multiple associated financial and emotional costs and could impose a burden on the family (Rosenberg et al., 2013). Families in IME must contend with the added stress of language barriers in addition to stressors associated with their child's medical hospitalization (Stephen & Zoucha, 2020; Stevenson et al., 2017). Thus, it is important to address the identification and communication of patient and family distress during IME to potentially decrease psychological stress and improve overall quality of care.

To date, there is limited research about how families in IME express distress in medical settings. However, studies have suggested that cultural and religious considerations play a role in family medical decision making, such as end-of-life decisions or pediatric palliative care (Wiener et al., 2013). Culture and faith play a role in the involvement of clergy, communication with children about death (e.g., acceptability of disclosure of life threatening diagnosis to the child), the meaning of pain and suffering, the meaning of death and dying, and location of end-of-life care (Wiener et al., 2013). Thus, cultural influences might impact how, why, and whether families express distress during IME.

Cultural expression of distress

Cultural concept of distress was newly added to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and refers to "ways that cultural groups experience, understand, and communicate suffering, behavioral problems, or troubling thoughts and emotions" (APA, 2013; Kohrt et al., 2014). There are three main types of cultural concepts of distress, including *cultural syndromes*, *cultural idioms of distress*, and *cultural explanations or perceived causes*. *Cultural syndromes* refer to "symptoms and attributions that tend to co-occur among individuals in specific cultural groups, communities, or contexts and are recognized locally as coherent patterns of experience" (APA, 2013; Kohrt et al., 2014). The syndrome may or may not be recognized as an illness within the culture, but such cultural patterns of distress and features of illness may nevertheless be recognizable by an outside observer. *Cultural idioms of distress* refer to "ways of expressing distress that may not involve specific symptoms or syndromes, but that provide collective, shared ways of experiencing and talking about personal or social concerns." Finally, *cultural explanation* refers to "a label or feature of an explanatory model that provides a culturally conceived cause for symptoms, illness, or distress". Culture plays a significant role in the vulnerability to, experience of, and recovery from distress (Bryant-Davis, 2005). Thus, understanding of cultural concepts of distress can enhance detection of mental health problems, reduce cultural bias in diagnostic research, and increase cultural salience of intervention trial outcomes (Kohrt et al., 2014). Lack of cultural understanding of distress could also result in over-pathologizing or missing distress cues when present (Fogel et al., 2019; Lewis-Fernández & Kirmayer, 2019).

It is also important to consider the complexities of cultural identities by addressing intersecting identities in the context of distress expression. *Intersectionality* was originally coined by Crenshaw (1991) to address the exclusion of the experiences of women of color in antisexist and antiracist activism and scholarship. Contemporary application of intersectionality refers to the way in which individuals with multiple minoritized identities experience oppression qualitatively differently from individuals from the dominant cultural group due to multiple identities and social locations (Bryant-Davis, 2019; Crenshaw, 1991). Intersectional oppression may include the combined and/or simultaneous experience of racism, heterosexism, sexism, linguicism, classism, ageism, xenophobia, immigration status, transphobia, religious intolerance, and/or able-bodism. Families from linguistically minoritized backgrounds might contend with intersectional oppression in medical settings or have different world views about distress expression and communication.

In accordance with cultural concept of distress, it is likely that families in IME express distress in differing ways. According to the Health Care Toolbox (2014), significant cultural variations exist in a child's or family's expression of distress:

> Pain, fear, worry, or hyperarousal are sometimes expressed somatically. Traumatic stress reactions can be extremely subdued, can appear to be over-magnified, or can even mimic psychotic reactions. Often, family and cultural factors combine to define what is considered an appropriate reaction to illness or trauma. Some families and cultural groups are less comfortable responding to personal questions about emotional distress. They may think that being distressed means that there is something mentally wrong (Health Care Toolbox, 2014, Attending to Distress).

Intersecting identities add a layer of complexity to cultural and identity-based expressions of distress and should be considered individually and in the context of the family system in IME.

Interpreter Identification of Distress in IME

Literature on interpreter strategies for identifying emotion and distress is limited to mental health care interpreting, with articles focusing on psychiatric disorders, types of encounters [e.g., mental health settings, conflict zones and with crime victims (Bancroft et al., 2016)], and how mental health therapists consider non-verbal communication and inflection (Bot, 2005; Doherty et al., 2010; Resera et al., 2015; Vernon & Miller, 2001). When patients are in emotional distress, Bancroft and colleagues recommend that interpreters should follow the caregiver's (i.e., clinician, mental health practitioner) lead, as interpreters lack the formal training to handle emotional distress (Bancroft et al., 2018). It is also likely that interpreter's perceived roles, industry defined standards of practice and codes of ethics impact whether and how interpreters communicate distress during IME (IMIA, 2007; CHIA, 2002). Specifically, role boundaries, confusing role expectations among the parties interpreters serve (Hsieh, 2007), and IME stakeholder expectations of interpreter objectivity and neutrality may impact distress communication. Interpreters may choose to convey the family's distress without intervening in any way in the communication or may choose to intervene by clarifying and advocating for the family. However, it is unknown whether and how interpreters communicate and respond to family distress in the context of IME.

In medical settings, clinicians are the primary communicative partners of patients and families during IME. Interpreters may defer to medical clinicians to identify and address patient and family distress due to perceived interpreter roles during IME (see section on communication factors). However, clinicians may have difficulty identifying distressed patients due to challenges with simultaneously providing effective medical care and supporting distressed families. Previous studies support the hypothesis that clinicians may have difficulty identifying distressed families. They might rely on illness severity cues (e.g., mechanical ventilation, disease progression) rather than the patient or family’s emotional expression or body language (Rothschild et al., 2020). Indeed, among EP families, PICU clinicians were more likely to rate family anxiety as high when the child was on mechanical ventilation (Needle et al., 2009) and oncologists’ recommendations for supportive counseling has relied more heavily on progressive disease rather than patient distress (Söllner et al., 2001).

Summary

Effective communication between families and pediatric clinicians is essential for mitigating family stress and improving quality of care, especially during distressing pediatric medical encounters. Families who speak a primary language other than English must contend with the added stress of language barriers and intersectional systemic oppression in addition to their child’s hospitalization, which could further impact the quality of patient care and health outcomes. Trained medical interpreters facilitate communication between patients/families and clinicians during IME. Spoken language interpreters adhere to industry-defined codes of ethics and assume an appropriate interpreter role during medical encounters that fall along a continuum describing interpreter visibility or invisibility in IME: *message converter, message clarifier, cultural clarifier,* and *patient advocate*. During distressing encounters, interpreters may adapt a more visible (i.e., message clarifier, cultural clarifier, patient advocate) to communicate patient and family distress. However, there is limited understanding about how families in IME express distress and what cultural factors are salient during distress expression. Thus, this study aims to describe 1) how interpreters identify distress of families during IME, and 2) how they identify cultural nuances in distress expression and communication of families during IME. Special attention is placed on factors that influence why and how interpreters identify distress communication, such as their intersecting social identities and lived personal and professional experiences.

Methods

Positionality Statement

Positionality refers to the "stance or positioning of the researcher in relation to the social and political context of the study—the community, the organization or the participant group" (Coghlan & Brydon-Miller, 2014). Positionality influences the assumptions, research design, and methods of a study (Creswell & Creswell, 2014) and is interconnected with the personal and philosophical views (i.e., worldview) of the researcher. In this sense, researchers are co-creators of meaning with participants, given their lived experiences and the lenses through which they interpret data.

Statement of Positionality

I have actively considered my assumptions and reflected on my lived experiences, and how that has impacted my alignment throughout the research process: from inception of the research question to dissemination of results to the interpreting community. While I have lived experience with intersectional systemic oppression related to xenophobia, immigration and linguicism as an Asian-American woman, I am an outsider to the interpreting community central in this study: I am neither a trained medical interpreter nor a monolingual Spanish speaker receiving medical care at a children's hospital. One way I have navigated my concerns related to being an outsider to the community is by collaborating with Amy Olen, a trained medical interpreter and professor in Translation and Interpreting Studies, consulting the interpreters about the findings and conclusions of the study, and actively and authentically amplifying the voices of the interpreters who participated in the study. My intentions are to amplify the voices of the medical interpreters and ensure that data interpretation reflects the voices and perspectives of the participants as closely as possible. This study is a product of our collective collaboration, and without their trust, guidance, and knowledge, I am unable to do this work.

Participants

Participants were recruited from a large, free-standing children's hospital in a major metropolitan area in the United States. The hospital serves as a level 1 trauma center and contains a level IV neonatal intensive care unit (NICU) and large pediatric intensive care unit (PICU). Thirteen spoken language interpreters participated in the study; 6 out of 13 participants participated in the member checks. All interpreters reported Spanish/English as their interpreting language pair. Most participants were female and identified as Hispanic, Latino/Latina/Latinx. Interpreters who were employees of the children's hospital and those who were hired through a contractor as members of an in-house contract group participated in the study. Six participants were employees and seven were members of the in-house contract group. Professional interpreting experience ranged from 2 to 20 years, with pediatric interpreting experience ranging from 2 to 13 years. Almost all interpreters have worked in “Level 3” clinics, which are high-intensity or acuity clinics (e.g., surgery, transplant, cancer care, end of life, etc.).

Procedures

The procedure for participant recruitment and data collection was approved by the University of Wisconsin-Milwaukee Institutional Review Board (IRB; IRB # 20.124). All participants were provided with an informed consent. Due to COVID-19 mandates encouraging physical distancing, all recruitment, interviews, and survey completion were conducted virtually via video or phone conferencing (e.g., Microsoft Teams or Zoom). Participants were able to choose which platform to use for the interview.

All voiced language, in-person interpreters of all language pairs in the large midwestern pediatric hospital were invited to participate in the study. Interpreters who were at least 18 years old, who were working at the children’s hospital, and who had worked in at least one pediatric care setting (e.g., primary care, asthma, pediatric intensive care unit, gastroenterology) were invited to participate in the study. Prospective participants were required to have access to a phone or device that could connect to the internet, as the survey and interview were conducted via online survey and virtual interview. Participants were given the option of interviewing in Spanish or English. All participants opted to complete the interview in English.

Co-PIs (Paulina Lim and Amy Olen) and graduate students with experience in qualitative interviewing conducted and audio recorded the interviews. Interviews and survey completion lasted approximately 90 minutes. Audio recordings were deidentified prior to transcription by undergraduate research assistants and a transcription agency and were deleted once transcription was complete.

Recruitment

Interpreters were recruited from the Language Services department via a monthly newsletter and a recorded video that summarized the aims of the projects. Interested participants signed up for an interview via a Qualtrics link shared in the monthly newsletter. All recruitment materials were shared via email. The study had obtained support from the manager of Patient Amenities and Family Services to encourage participation for these group. The manager of Language Services at the children's hospital for full time interpreters and the manager of an in-house contract interpreting services agency for contract interpreters were contacted to facilitate monthly distribution of the recruitment materials. Prospective participants were provided with an informed consent detailing the risks and benefits of the study, that participation was voluntary, and that interviews would be audio recorded.

Data Collection

Once participants signed up for an interview via a Qualtrics link, they were contacted by the principal investigator to schedule a virtual interview via their preferred platform (e.g., Microsoft Teams, Zoom, or over the phone). Upon confirmation of the scheduled interview, participants were provided with a link to join the virtual interview and access the online survey.

Graduate students with experience in conducting qualitative interviews under the supervision of Drs. W. Hobart Davies (Psychology) and Amy Olen (Translation & Interpreting Studies) conducted and audio record the interviews. Interviews and survey completion lasted approximately 90 minutes. Participants spent 5 minutes on the informed consent, 5 to 10 minutes for the demographics survey, approximately 60 minutes for the interview, and 10-15 minutes for the online survey. Audio recordings were deidentified prior to transcription by the graduate and undergraduate students and were deleted once transcription was complete.

Materials

Measures

All participants were asked to complete a demographics survey and a semi-structured interview as part of the study.

Survey Development

An interdisciplinary team of experts in Pediatrics, Pediatric Psychology, Language Services, and Translation and Interpreting Studies collaboratively developed a demographics survey and semi-structured interview (i.e., initial interview) that asked spoken language medical interpreters about identification and communication of patient and family distress to pediatric clinicians, the impact of disclosing intense or traumatic information to families, and available resources for medical interpreters. Sections related to identification and communication of distress will be the primary focus of this project. The full interview guide and the demographics survey is presented in Appendix 1.

Cognitive Interview Phase

Three medical interpreters were independently interviewed and asked to complete a cognitive interview to assess the feasibility and acceptability of the project (Beatty & Willis, 2007; Willis, 2005). The cognitive interview is presented in Appendix 2. Interpreters who participated in the pilot interview had clinical experience in pediatric care settings and were not currently contracted by the hospital at the time of the interview. Two former pediatric interpreters and one medical interpreter and translator with experience working with both pediatric and adult populations were asked to complete pilot interviews. The interview guide was edited based on pilot interview responses.

Overall, medical interpreters who completed the cognitive interview rated the interview questions as somewhat easy to listen to and understand. They shared that they felt comfortable answering the questions and that the interview was “non-threatening”. While the interpreters who participated in the cognitive interview unanimously reported that there were no other topics to include or exclude in the interview guide, they suggested that defining “distress” might be helpful in answering the question. Since the research team believed it is important to receive broad perceptions relating to the concepts of distress, we refrained from defining this term and instead provided the prompt: “If participants ask what we mean by distress, say “what does distress mean for you? What did it distress look like to you when you’ve interpreted for families?”.

Potential Risk

Medical interpreters who participated in this study might have been subjected to potential discomfort due to discussion of past and current distress. To mitigate participant risk, during the informed consent process (i.e., before the interview), all interpreters were informed that participation was voluntary, they could stop the study at any time, and they could skip any questions they were uncomfortable answering. All interpreters were provided a document outlining available mental health providers should they need or want to seek mental health services. Any interviewer with concern about the participant’s distress or potential self-harm would contact W. Hobart Davies, a licensed clinical psychologist, who was on call for consultation during active interviews.

Data Analysis

Qualitative Coding

Qualitative coding of data began when initial transcripts were received. All transcripts were coded using a thematic analysis approach, which allowed for inductive identification of practices around distress communication (Elo et al., 2014; Saldaña, 2016). Transcripts were transferred to QSR NVivo Software, a qualitative software package, for thematic analysis. Paulina Lim and Amy Olen (primary coders) read all transcripts in depth and coded them independently. Codes and operational definitions were discussed and modified, if necessary, after every three transcripts until all transcripts were coded. Disagreements on codes and operational definitions were discussed in person until agreement was achieved. For example, a difference in coder interpretation of results related to differences due to their distinct fields and disciplines, such that what was understood to be perceived as avoiding feeling an emotion from a psychological standpoint may have been viewed from an interpreting studies vantage point as interpreter adherence to the impartiality tenet of medical interpreter codes of ethics. A codebook was created based on the initial codes, which included the code names and operational definitions. The primary coders updated the codebook to address coding discrepancies and added new codes identified in the data. A provisional list of codes was provided, but researchers flexibly applied analytic methods during and after, depending on the data (Saldaña, 2016). Documentation of team meetings and consensus on themes during coding were used to ensure qualitative credibility, dependability, and confirmability, which parallel quantitative validity and reliability (Nowell et al., 2017).

Member check

Following the coding of all available data from the initial interview, codes were arranged into provisional themes by the primary coders (Saldaña, 2016). The primary coders discussed themes related to distress expression and how lived experience might have influenced distress identification with the interpreters through member checking. Member checking is used to validate, verify, or assess the trustworthiness of qualitative results (Birt et al., 2016; Doyle, 2007). The interview for the member check was drafted by the primary coders. The primary coders consulted with Jacqueline Nguyen, a professor in Educational Psychology and expert in qualitative analysis, to check for biases, clarify the contents of the member check guide, and prioritize which themes to present to the participants. Both interview and interpreted data were returned to the participants, such that each participant was able to read their own transcript and the aggregated codes and themes analyzed by the primary coders. Participants were also encouraged to add comments to the interpreted data to enhance the credibility of the results. The member check interview guide is in Appendix 4.

All thirteen participants were invited to participate in member checks. Interpreters were asked if they were interested in participating in a follow-up interview so that the research team could ensure that they understood interpreters' experiences and could hear interpreters' feedback about the research team's interpretation of what they have shared. Six interpreters (all identified as Latina with 2-13 years of experience in pediatrics) volunteered to participate in member checks.

Member checking data was coded similarly to the initial interview transcripts outlined above. Data from the member check was integrated into the findings by the primary coders. Codes and operational definitions were modified based on information gleaned from the member check. Codes relating to the indicators of distress and cultural observations related to distress (i.e., aims 1 and 2) emerged from the initial interview and were clarified through the member checks; codes relating to lived experience and positionality (aim 3) emerged from the member checks.

Thematic analysis

Following the coding of all available data from member checks, codes were independently incorporated into existing themes by the primary coders. The primary coders discussed themes related to lived experience and distress identification and communication until consensus was reached. After member checking data was incorporated into the themes, the primary coders presented thematic results to individuals (Charles Rothschild, MD and Hobart Davies, PhD) who have research or clinical expertise in medical communication, distress in pediatric clinical care, and/or working with interpreters. Unanimous group consensus was required to finalize themes.

Results

Results are organized into themes related to distress expression and cultural concepts of distress in IME: indicators of distress, contributors to distress, cultural observations about distress, and lived experience.

Indicators of distress

When asked “what indicates to you that a family is distressed?”, interpreters described instances when a family *requested more* of something, had *difficulty with communication,* and *emotional expression. Verbal cues, body language and appearance,* and their *interactions with others* were also indicators of distress. Table 1 summarizes interpreters’ observations about indicators of distress in pediatric IME.

Table 1. Interpreters’ observations about indicators of distress

Theme	Code	Operational Definition
Requests more	Family asks for more	Family requests for second opinion, more options, information or help for child; family asks multiple questions
	Sense of urgency	Family doesn’t want to wait for results; demands to see clinician; wants answers immediately

Difficulty with communication	Difficulty communicating	Family is mumbling, stuttering, finding the right words; difficulty expressing verbally
	Difficulty understanding	Family asks questions that have already been answered or doesn't understand the information being discussed
Verbal cues	Family verbalizes	Family comments or verbalizes their distress and/ or dissatisfaction
	Tone of voice	Family's tone of voice (e.g., being short)
Body Language and appearance	Mannerism	Walking around/pacing, tapping fingers, wringing hands
	Facial expression	Facial expression is blank, family appears "lost"
	Disheveled / frazzled	Caregivers appear disheveled or messy in appearance; frazzled
	Appears distracted	Family's mind appears to be wandering, not present, mental avoidance
Emotional expression	Express emotions	Family express distress, anger, sadness, upset, nerves, anxiety, shock during IME
	Crying	Tearing up, crying
	Withhold emotions	Family holds emotions in; family is quiet
Interaction with others	Tension between family members	Family has a hard time managing child's behaviors; family arguing among themselves
	Dismiss interpreter	Family does not want an interpreter present

Requested more. Some interpreters noticed distress when a family *requested more,* characterized by the *family asking for more* (e.g., a second opinion, more options, more help, more answers, more time or asking multiple questions). Participant 106 shared, "they're just not happy with what the providers is giving them, and they try to ask for more options or like just looking for more help for their kids." Participant 107 noted:

> I guess then at least the patient is more direct with their questions and then the provider has to be more direct in their answers. And then patients feel like they kind of remove their shyness and feel open to ask for more clarification, because sometimes some patients won't ask for any clarification about anything. They just agree with everything that the provider's saying, but then when they're a little bit more emotional they'll ask for more things like, "what's gonna happen?" and "what are they gonna be looking at?", and

> "when are they gonna bring things?" and then the provider does more of telling them what's going on and then what they're planning to do and when they're planning to do it.

Interpreters also shared that some families came to encounters with a *sense of urgency*, described as instances when a family had difficulty waiting for results or answers, or would request to see the provider immediately. Participant 102 commented, "Sometimes when they're really anxious or they want an answer-- they don't wanna wait for test results to come back-- and they're asking, 'Why is it taking so long?' or 'Why they haven't do this or that?'" Participant 103 shared, "When they … demand to see the provider because we'll go sometimes and do rounds and then the family will say, 'we need the provider now because something happened right now.'"

Difficulty with communication involved two elements related to speaking and understanding. *Difficulty expressing* was characterized by family members "mumbling" (Participants 101), "stuttering" (Participant 107), difficulty finding the right words, and difficulty expressing selves verbally. Participant 103 shared: "They raise their voices or they mumble things. They're not being really clear or they contradict themselves." Interpreters also reported that some families had *difficulty understanding* the information discussed or asking questions that have already been answered. Participant 101 reported: "Well, you know you see them arched up, a little bit more leaned forward like they kind of squint a little, 'What are you saying?' And, you know they're more like, 'What's going on?'".

Verbal cues included instances when a *family verbalized* or expressed their dissatisfaction with the medical care vocally. Participant 106 shared: "when the families just start to be more verbal about how unhappy they are with the situation or what the options the doctors are giving them", while Participant 102 reported: "people are going to bring them up to the table. They are going to say them…a lot of people when they're stressed and they're really worried, you know, their whole language comes out.” Interpreters also noted that they perceived distress due to the family’s *tone of voice,* including “how [the family is] saying things” (Participant 103), “speaking very softly” (Participant 107), or “being short with the provider” (Participant 115). Additionally, Participant 112 reported: “you tell them the news and you can hear the same regular tone, I don't know when you told the news. Their tone tends to kind of sometimes-- they drop, or they get higher or they use-- even sometimes you hear their voice cracking and they're about to cry.”

Body language and appearance. Interpreters mentioned several characteristics, including *mannerisms* such as “pacing the room” (Participant 101), “tapping” (Participant 103), “wringing hands” (Participant 113), *facial expression* (e.g., withdrawal or face going blank), *appearing disheveled* or “frazzled” (Participant 105), and *appearing distracted* or “mentally not there” (Participants 108). Participant 104 shared:

> Many things among body language. If I see pacing back and forth, angry faces, sad faces, tears. I sometimes look to the hands if they're you know creating a fist. I actually look at everything. Their lips if they’re quivering, if they're ready to just burst out into tears, I can usually tell before that happens too. If they change colors, like you can see that they get flushed in the face. All those things.

Participant 112 shared:

> They're going to look like they're gone from there. Their facial expression is going to look different than before that situation happened. So you also need to be paying attention to their faces, to the movement of their hands. Sometimes when people get really nervous, they become antsy. You know how when you get nervous or you just start getting anxious, your feet start moving. Maybe it's not their face, it's also the whole body.

Finally, Participant 105 commented about *appearance*, “Culturally I feel like if you go out, you’re put together, so some of the parents, you know, they come in a little more disheveled”.

Emotional expression. Many interpreters commented that an indicator of distress is when families *expressed emotions* such as “anger”, “sadness”, “upset”, “nerves”, “anxiety”, or “shock” during or after an encounter. Participant 102 shared, “the way they say things. Like there's more like anger in the voice or sadness versus just regular talking voice.” *Crying* is also an indicator of distress. Participant 110 shared:

> When I see, for instance, Mom, when see her crying all by herself … this happened a lot in the oncology unit. So I'm telling you, this is in the inpatient ward. It's in the floors in the hot [hematology/oncology/transplant] unit, the oncology area. So that's where we see moms spend time. Sometimes it depends on the treatment. It can be for a month in the hospital. And if I see Mom by herself and crying, and I notice that something is bothering her, I kind of just mention a little bit to the nurse because if I see the family always participating in things with her son and always walking out in the hallway with them and then all of a sudden, I see her eyes later, crying.

Other interpreters shared that an indicator of family distress is when families *withheld emotions,* defined as times when interpreters perceived families were refraining from expressing emotions or were quiet during the encounter. For example, Participant 103 noted, “A lot of times it is withdrawal. It’s where they just go blank and they just don’t say anything,” while Participant 109 shared, “Sometimes they don't wanna talk”.

Interactions with others. *Tension between family members* and being *dismissive of the interpreter* were also indicators of distress. Regarding *tension between family members,* Participant 108 shared, “If they start like having a discussion between them, you know between the mom and dad, or if the parent starts mistreating the child like yelling at them or you know, ‘stop doing that!’ or I mean just your typical signs of distress.” Regarding *dismissive of interpreter*, Participant 110recounted:

> I try not to judge, I noticed when I interpret, it's not the nicest everytime. We have different encounters. I mean, different families that could be very understandable. They're very nice. But some other time, they come upset. They're mad, I mean, because they hear a big surgery or they got really bad news. So I think when-- this is when I know that, if they're upset, they could say, "I don’t want an interpreter," or, "I don't need you." But I was with them before, so I know they need us. And sometimes I just try to talk to them very politely and respectful and professionally, tell them, "I'm here. I know you're under stress. I'm here to be your voice. I'm your interpreter. Just allow me to be there for you, just to be your interpreter, and deliver all the message," and just to explain that we're here just to communicate-- I mean, to help them with the communication.

Contributors to distress

Some interpreters noted that the *family’s situation*, the *child’s medical situation,* and *providers* contributed to distress. Table 2 summarizes interpreters’ observations about contributors to distress in pediatric IME.

Table 2: Interpreter observations about contributors to distress

Code	**Operational Definition**
Providers	Providers contribute to distress
Medical situation	Medical circumstance or diagnosis (e.g., trauma, oncology, end of life, surgery, new diagnosis, emergency)
Family’s situation impacts distress	Family’s experiences in the past (e.g., trauma, medical encounters) impacts distress

The *family’s situation* or experiences in the past (e.g., trauma, current circumstances, previous encounters in the medical system) could impact distress. Participant 109 noted:

> It's difficult based on the way they are saying their emotions. It could be difficult because they are not very clear, or you don't know what happened in the past that is making this situation get out of control. Usually, something that is out of control has a back picture, right, like a background, kind of. And you don't know it. And it's kind of hard sometimes to get to that.

Participant 112 described a scenario that could heighten distress:

> … they're driving as fast they can, and they get there, and that morning the person got fired and you don't understand it…. Wisconsin, sun shining outside, it's 80 degrees outside, and you're driving normal. And you have a work, you have a job, or you have food in your home instead of getting that news, or bad news, or whatever. That's gonna affect that a lot. And not only in Spanish speaking [language] -- in any language, and we need to be aware of that.

Interpreters also reported that the *child's medical situation* contributes to distress, especially during care conferences, new diagnoses, critical situations, death and dying, surgery, accidents, and trauma or in the oncology or emergency department. Participant 112 further explained with an encounter in the trauma center:

> We have a trauma situation. Everybody is talking at the same time. … We have an accident and this patient recently came from Puerto Rico. He doesn't speak English, and somebody stabbed him and he doesn't know what's going on. And it's 10 people trying to get him. You check his situation and put those cables and everything at the same time, and put IVs at the same time, and he doesn't know what's going on.

Finally, Participant 104 described how *providers* contribute to distress:

> Sometimes, even in some cultures, just speaking to the-- and this is tricky right, because we don't know in some cultures if you don't look directly in their eyes or to-- you know at them, then it may be disrespectful. Sometimes if you --if there's two or three family members in that consult room but you're focusing in one person more than the other, that can also create distress with them because then you're being disrespectful and you know in not looking at the parents or whatever the case is too. So it's really-- culture is really tricky. It's really hard to know so…yes there's ways that providers can create distress, we can create distress with families and not even know it.

Cultural observations about distress

When asked "Do you notice cultural differences when families express distress? If so, what have you noticed?", interpreters shared observations related to distress expression, including *distress is obvious*, *distress is universal*, *distress is diverse*, and *distress is culture-specific,* including observations related to the family's *country of origin*, *education-geographic location*, *practices about caring for sick family members* and *cultural/systemic differences.* Themes related to cultural observations of distress are summarized in Table 3.

Table 3. Interpreter's cultural observations about distress

Theme	**Code**	**Operational Definition**
	Obvious	Can easily tell families/ patients are distressed
	Diverse	Interpreter sees many ways family express distress
	Universal	Distress expression is the same cross-culturally
Culture Specific	Education – Geographic Location	Family's education is a factor in distress expression; perceptions about family's health literacy; class; relating to geographic location (e.g, rural, urban)
	Country of origin	Distress expression is based on country of origin
	Cultural differences in caring for sick	Considerations for rituals or care process that contribute to distress
	Systemic cultural difference	Systemic differences between the United States and other culture (e.g., medical systems)

Some interpreters reported that *distress is obvious* since distress is "apparent or visible" (Participant 104). Participant 115 further expanded on this idea and stated:

> If the patient is distressed, it's going to be very obvious to the provider. I don't know. Yeah. I mean, if it's not obvious to the provider, I don't think that I would know either. You know what I mean? In my mind, the stress is very visual. You can see it. Somebody who's hysterical, crying, screaming, the sadness just shows. If they don't show it, I don't know that I can-- I don't read signs. Unless somebody tells me or shows it physically, I can't really say you're one way or the other. So in my mind, if a patient is distressed, it would be very obvious to everybody in the room.

A few interpreters reported that *distress is universal,* indicating that distress expressions are expressed similarly across cultures. Participant 109 stated, "I mean, it can be in different forms, but I feel that the emotions are pretty much the same in any culture. They come up, be very upset or very angry, the same way everybody else" while Participant 108 reported: "some things are universal. Some stress signs are universal."

Some interpreters reported that *distress is diverse* since there are many ways that patients and families express distress. Participant 110 shared:

> I notice a lot in the families that they kind of want to be left alone. Sometimes, at the moment, they don't want to talk or they don't want an interpreter. And sometimes they can be angry. They can be angry at the providers. Sometimes it's simple as just-- we see them cry. We see them sad. But other times, they can also be angry, mad … And in the culture sometimes, they don't want to say anything because they don't want to bother people. … Sometimes we just kind of don't want to bother people. And then we just keep it in and don't let anyone know.

Distress is culture specific. Other interpreters shared observations across and within groups since families either *expressed emotions* or *withheld emotions*. Participant 102 noted,

> Normally Latin or Hispanic families are more apprehensive. They don't show their emotions as easily but there are some that really do show their emotions, that are more open to say what they're feeling versus others don't really say much.

Additionally, some interpreters reported that families from specific *countries of origin* either *expressed emotions* or *withheld emotions* during stressful situations. Participant 108 shared:

> Probably the American culture has the tendency to be more polite probably. For example, someone from [country][1] will start yelling, you know, and making a big fuss out of something because they are so worried about the child. But on the other hand, someone from a very small town from [country] will thoroughly withdraw, be quiet or don't say anything. So, it depends on-- because if you think about it, Spanish is used in a lot of different countries. So, it depends also on that country of origin.

Additionally, Participant 101 noted:

> Some cultures are very, very quiet, very humble and they listen and regardless of what the news are saying, they're getting, um, they just sometimes just depending on the news they can cry of happiness or fear or upset but yeah there's some cultures are or that are, um you know, they'll throw themselves on the floor and just cry and yell and, and others that will hold it in as much as they can--and they'll just keep telling you, "I'm OK."

Interpreters also considered how the intersection between the family's *education-geographic location* impacts distress expression. During the member check interview, Participant 101 expanded on cultural observations related to distress:

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[1] Countries of origin were removed from the text to reduce harm and minimize generalizations about individuals from particular countries of origin

> **Interpreter**: Yes. Culturally, you can notice right away how they're dressed, how they stand, how insecure they look, their accent, their tone. Coming from [country], you can tell pretty fast into your encounter what-- do they come from the city, do they come from a rural area, do they come from little towns with very small population? You can sense that. If you listen and you pay attention, you can understand.
>
> **Interviewer**: Do you think that impacts how they show or express when they're feeling distressed or stressed during an encounter?
>
> **Interpreter**: Yes, because usually the less education you have or the less exposed that you've been, the more fearful you show. You're fearful of a medication, you're fearful of an IV, you are fearful to come into the hospital. You're afraid for them to see a doctor so you rather not bring them to the hospital. So yeah, it totally impacts and that reflects on their behavior, how they foresee, how they express.

Similarly, during the member check interview, Participant 104 further expanded:

> I have found that rural versus urban families are-- and, yeah, I think education and a lot of that plays a role in this, of how comfortable they are expressing this, and how they view the role of a doctor. Right? So the more rural indigenous families, whether that is from any country in Latin America, I feel they are more apt not to say much and deal with their distress and not ask any questions. Then, a family that is more urban or more educated, no matter what the country is from, I feel like they feel more comfortable in asking questions or dealing with their distress or showing their distress or talking about their distress. Our other families, more rural, more indigenous, sort of sit there and accept anything that comes their way. Even if they don't feel right about it, because of their view of how they view the doctors as not necessarily gods, but the ones who have the last

> word, the ones who are the most educated, and their word it is what it is, it's exactly whatever they say they follow. No questions asked. So that's the difference that I see. I've seen it in my own experience, in my background with the elderly, in my community. They go to the doctor. They don't ask any questions. I'm, "Why didn't you ask for this? Why didn't you?" "No. Because that's what the doctor said, so that's what I have to do." That's other families more educated that will question things, "Well, why do I have to take that when that makes me feel this way? Is there anything else I could take?" There's a little bit more communication there. Or if they feel distress, "Well, this is how I feel about this. This is making me nervous," or "This is making me angry," or, "Why is it that I can't be seen?" That kind of thing. As other families just won't say much.

Interpreters also described *cultural differences in caring for sick*, defined as culture-bound rituals or care practices, that factors that influence distress expression. Participant 104 described:

> Perhaps they have a religious belief or something that…or the child is going through some kind of care process here that it's against our beliefs, I don't know. Diet maybe sometimes it's against their beliefs, right, they believe that sometimes when you're sick and you have a cold you have to eat certain things. Certain cultures believe that. You know, it's either chicken and soup, it depends and so I feel it does happen, I don't always feel the families share specifically what it is.

Participant 115 shared:

> This is very Hispanic culture-specific. I'm trying to find an example to explain it. So say that the provider is speaking to the patient who's a Spanish speaker and say that that patient's daughter or son is in the room as well and they understand what the provider is saying because they speak English and understand it but the parent doesn't. There may be

> a tendency for even within family members to say, "Oh, no, don't tell them the bad news because that's going to upset them," when in fact it's something that they need to hear because they need to understand what's going on with their health. But because it's bad news, the culture is more of a, "Oh, let's not tell him because we don't want to worry him or we don't want him to get stressed out about it." It's just that mentality of being very careful about when and how to relay bad news to family members or within family members even because there's that thing about, "Oh, we don't want to worry them or stress them out,"

Finally, interpreters described *systemic cultural differences* between United States and Hispanic culture [e.g., "in Latin America, a doctor is seen as almost like a god" (Participant 108), emergency services, surgery] that could influence distress expression. Participant 104 explained the difference between emergency services in the US with Hispanic culture:

> In some cultures, there is no wait in an emergency room, you are seen right away so when they come here and they sit for an hour or two to be seen, they believe they are being disrespected, you know, their time is being disrespected but it's not the case.

Participant 103 shared an experience during a care conference and described:

> There are families that we go through a whole care conference to explain everything to them and the end they're completely blank. I mean a lot of times it's not even—it's not even the language barrier, a lot of times it's the emotional barrier too. Because, I mean if it's something really stressful they're not going to hear. There was an experience that I had with an ENT doctor, he was known to be very energetic, and he was always fast about everything and he was sometimes mean to the families too. So, I was interpreting and he was going fast as usual and I was interpreting they needed to do surgery on their

> child because his tonsils were too big, he was snoring a lot, and he needed ear tubes – he was having a lot of ear infections. And he went through the whole spiel about what they were going to do. They're like, "we're going to do surgery," and then he went on to explain the surgery and whatnot and what was gonna happen afterwards, and at the end, the family is like, "So why are you doing surgery?" and he got angry. He said, "we just went through all of this," and, "aren't you paying attention?". So, I took him outside and I told him it's like, 'with our families when the first time that you mention surgery they're going to block themselves because in our country there's no such thing as preventive care. We usually whenever we go to the doctor is because someone is really sick and usually when they say surgery it's usually it's been so long and the problem is so chronic that usually they don't come out of surgery alive. So, in their mind, they're thinking, "Oh my god it's surgery, they're gonna die, they're gonna get anesthesia," and they're just going to die and they just block themselves,' and he's like, "that makes so much sense. Because I've had this with so many of my families," and I'm like, "that's what it is."

Member check. When asked for their thoughts regarding the statements related to distress ("It sounds like interpreters notice cultural features or features of the families' identity like education that impact how families show or express their distress. It also sounds like interpreters see a lot of diversity in how families from different cultures show their emotions and distress"), all six participants reported that they agreed with the statement. Many further expanded on cultural observations related to distress and emphasized how families present to encounters uniquely based on their intersecting identities. Participant 108 shared:

> Every family is different because it depends on where they're coming from, how long they've been living in this country, if they understand a little bit of English or nothing, if

they're well-educated, if their financial situation is very bad or very good. There's just so many factors.

Lived experience

Themes related to the interpreter's lived experience are summarized on Table 4.

Table 4. Interpreters' lived experience and positionality

Theme	Code	Operational Definition
	Bicultural	Interpreter understands both American and Latin American culture
Lived experience	Professional	Relating to length of interpreting, education, on the job experience
	Personal	Relating to early experience such as immigration, being an interpreter for their family; personality
	Cultural intelligence	Interpreter possesses nuanced understanding of individuality and cultural similarity

Interpreters described the importance of being *bicultural* and having cultural understanding of both American and Hispanic cultures and cultural elements of communication. For example, Participant 108 shared during the member check interview:

> **Interpreter**: Something that is very cultural, that comes from a cultural point of view. And for me, it's just natural that they're saying that. And then, for example, whenever I walk barefoot because when I get a cold, for example. And the provider's like, "What are they talking about? You get cold because you get a virus not because you're walking on cold floor." And, of course, I understand that that's not part of the American culture. So I have the knowledge of both cultures and that's when I know that I need to be a cultural broker and explain to provider why mom is saying that.
>
> **Interviewer**: What I hear you say, really, it's not just because you understand one culture, you understand both cultures, and that's really important.
>
> **Interpreter**: Correct. So, if I have been in the United States for only six months, I will not understand that the American providers doesn't know about that, you know? But

> because I do understand the American culture because I have lived here for over 20 years, I know it's a matter of fact that they have no idea why the person is saying that.

Interpreters also shared their *professional experience* (e.g., education, training, “on the job experience”, and length of interpreting) and *personal experience* (e.g., childhood, interpersonal relationships, personality) as important to their work as an interpreter. Participant 101 shared a *personal experience* related to their personality:

> **Interviewer**: It seems like being non-judgmental is really important for you, and I'm wondering where that comes from for you in particular?
>
> **Interpreter**: I guess that I've been misjudged. I have a strong tone of voice when I'm worried, I don't smile, I'm very straight to the point. And I've been misjudged to think that I'm rude or I'm stuck up. And I'm really not. But that's how many even of my own co-workers see me that I'm stuck up or I'm just rude or I don't care about people, you know? So maybe that's why I am so set in giving others-- being judgmental. Avoiding being judgmental because you never know who you're coming in across. You never know what that person's going through. I treat others as I want myself to be treated. I think that's the best way of describing what I'm trying to say. I treat all the elders as I want my parents to be treated. I treat all the kids as they wish they'll treat my kids. That would be the best way of describing my sense of doing my work, my code of ethics.

Finally, interpreters discussed their cultural awareness related to *cultural intelligence and humility* when identifying distress. Interpreters described how individuality and the personality of the person should be considered along with cultural similarities within people from the same background. For example, Participant 115 shared:

> I may be sitting next to a mom who's also from Puerto Rico but may have different-- I mean, we're two different people. So maybe the way she reacts to that news will be different to the way I react to bad news. So that would be where the individual differences would come in. We can't really generalize that everybody from San Juan, Puerto Rico, is going to react in exactly the same way in every situation because that's just not the way the world works. But there's cultural similarities within people in that same culture. But there's always going to be those individual differences to a certain extent because that's-- we're people. We're all people with different-- there's different experiences. There's no two me. There's no two of you.

Overall, interpreters described how their own background and personal stories, personal and professional experiences, and intersecting social identities, influence their approach to interpreting, including how they identify distress expression and cultural concepts of distress expression of families in IME.

Discussion

Statement of positionality

As a graduate trainee in clinical psychology with an emotion-focused and cultural-systems theoretical orientation, my intention was to understand how interpreters identified, conceptualized, and contextualized distress through a cultural framework. My training in pediatric psychology and lived experience allowed me to be more attuned to my own and other's cultural and emotional intelligence. These perspectives complemented Amy's framework when interpreting data since she highlighted whether, when, and how interpreter's role, ethical codes, and standards of practice arose in the transcripts. Consultation with the interpreters about the findings and conclusions of the study were integral to the process. Given my intentions to amplify the voices of the medical interpreters and ensure that data interpretation reflected their voices and perspectives, we paid special attention to craft a more holistic and nuanced narrative of distress expression, cultural observations about distress, and lived experience.

This study is truly a product of mutual respect and collaboration. Without collective trust, guidance, and knowledge, we are unable to do this work.

Discussion and Clinical Implications

The primary aims of the study were to describe how interpreters identify distress of families during IME, and how they identify cultural nuances in distress expression and communication of families during IME. Special attention is placed on factors that influence why and how interpreters identify distress communication, such as their intersecting social identities and lived personal and professional experiences. Ultimately, results from the study provide guidance for medical care teams, including behavioral health professionals, health care professionals, and interpreters on how to identify and conceptualize distress of families in IME through a cultural lens.

Distress is multifaceted

Interpreters from the current study collectively reported that families in IME expressed distress in various ways through a combination of visual cues (e.g., body language and appearance, facial expressions), auditory cues (e.g., verbalizations, emotional expression, tone of voice), interpersonal cues (e.g., interactions with others, communication difficulties), and contextual cues (e.g., medical situation, past experiences). These findings extend current conceptualizations regarding distress. Although distress expression during intense or challenging encounters are well documented in the literature (Abela et al., 2020; Balistreri et al., 2021; Yagiela et al., 2019), these studies typically include medical status (e.g., illness severity, admission type), communication style, previous mental health concerns, and lack of social support as contributors to distress and only include health care clinician perspectives about distress. The inclusion of interpreter perspectives regarding distress expression results in increased and more nuanced understanding of contextual and environmental considerations, nonverbal cues, and most importantly, cultural observations related to distress expression.

These ways of expressing distress are also consistent with indicators of distress that have been observed by health care clinicians among English-speaking families in the United States (Balistreri et al., 2021), suggesting that there may be commonalities in distress expression across families who speak different languages and across racial/ethnic backgrounds. Commonalities in describing distress may also indicate that clinicians and interpreters are attending and responding to similar cues during IME (Rothschild et al., 2020). However, despite commonalities in identifying distress expression among English-speaking and non-English speaking families, families who do not speak English continue to receive lower quality care (Eneriz-Wiemer et al., 2014). It would be beneficial to further explore why distressed families in IME receive lower quality care and lower referrals to psychosocial support. It is plausible that intersectional systemic oppression, difficulty understanding cultural concepts of distress, or clinicians relying on interpreters to manage patient and family distress during IME could be factors that impact distress identification and management for families in IME.

Although interpreters collectively described a diversity of distress cues and behaviors, there is also individual diversity in the range and combination of distress cues and behaviors that interpreters reported in the study. Individual interpreters provided a range of indicators, ranging between two and seven and in different combinations, such that some interpreters were more attuned to body language and tone of voice, while others were more attuned to emotional expression or how families interacted with each other and the care team. This pattern of response suggested that there may be individual differences among interpreters related to distress cues threshold or distress sensitivity since individual interpreters may be sensitive to *some*, but not all cues and indicators outlined in the study. Thus, medical interpreters likely have individual distress sensitivities or thresholds for determining family distress, which could be attributed to professional or personal experiences with distress or emotional states, cultural intelligence, or other factors that contribute to nuanced understanding of distress expressions. Interpreter roles (e.g., message converter), ethical codes and standards of practice (e.g., objectivity and neutrality) likely also play a role in distress identification.

Additionally, interpreters may be cued to several components of emotions, including the subjective experience of feeling states, behavioral (purposeful behavior, facial expression, nonverbal postures), psychological, and cognitive components (Persons, 2008; Persons & Hong, 2015). Since emotions evoke emotions in others (e.g., anger tends to elicit fear, sadness elicits sympathy), interpreters may also be experiencing emotional states during these encounters which might help cue them to the family's emotional state (Dimberg & Öhman, 1996; Gross & Muñoz, 1995; Keltner & Kring, 1998). This has been documented in other medical team populations, including nurses and physicians, such that patient expressions of sadness result in affective responses (e.g., express concern, emphasize partnership in care), while expressions of anger or neutral emotions elicited more instrumental behaviors (e.g., counsels medical or therapy) than sadness (Sheldon et al., 2009). Therefore, it might be beneficial for training agencies to include content related to emotional intelligence in their training materials so that medical interpreters can continue to develop emotional intelligence (Mayer et al., 2004; Mayer & Salovey, 1993). It would be beneficial to incorporate topics such as: fostering the ability to identify and regulate interpreters' own emotions (self-awareness and self-regulation, respectively), recognizing the emotions of other people and feeling empathy toward them (social awareness), and using these abilities to communicate effectively (conflict management skills). Since interpreters in this study described an ability to recognize and manage their own and others’ emotions during stressful IME, it is plausible that interpreters entered the field with inherent emotional intelligence that was cultivated through experiences in emotional IME. Consideration of how ethical codes and standards of practice could be incorporated with emotional intelligence training is also warranted.

Interpreters also indicated that some families expressed distress through the absence of emotions (e.g., withdrawal, saying “I’m ok”), which also aligns with PICU medical clinicians perceptions regarding distress expression (Balistreri et al., 2021). Withdrawal or remaining quiet during distressing encounters might get lost during the interpretation process due to language and emotion transfer from one party (i.e., the family to the interpreter) to another (i.e., the interpreter to the clinician) and may result in decreased ability of health care teams to pick up distress cues of families in IME. It is also plausible that families in IME who are perceived to be more expressive are more likely to be referred to psychosocial support or medical attention compared to families who are quiet or withdrawn due to perceptions that they are coping well, potentially resulting in inequities in access to behavioral health care. Additionally, interpreters also attributed withdrawal and refrain from expressing emotions due to families in IME from rural and/or indigenous backgrounds, an intersection of identities already minoritized in the medical system. Therefore, while previous studies have documented disparities in child health outcomes associated with linguistic minoritization, such that linguistically minoritized families experience health disparities independent of social determinants of health such as race, ethnicity, socioeconomic status, perceived discrimination (Eneriz-Wiemer et al., 2014), this study extends those findings by suggesting that disparities in health care among those who are linguistically minoritized may also be attributed to interlocking systems of oppression resulting from the legacy of colonialism and imperialism in Latin America (Quijano, 2000).

Finally, interpreters also described contextual cues about why families might be distressed during IME, including the child's hospitalization or medical condition, which is consistent with how clinicians have described indicators of distress (Needle et al., 2009; Rothschild et al., 2020; Söllner et al., 2001); past medical experiences, and factors external to the medical environment (e.g., economic insecurity). Notably, interpreters described instances of clinicians eliciting distress from families (e.g., when a clinician mentioned surgery, a clinician's attitude towards the family), which could result in iatrogenic events, defined as the causation of a disease, a harmful complication, or other ill effect by any medical activity. Although iatrogenic events have historically been used to describe medical phenomena (e.g., infection, treatment complications), this term may be applied to emotional or psychosocial distress (Forgey & Bursch, 2013). Therefore, the medical care team inclusive of medical clinicians and medical interpreters may benefit from adopting a trauma informed care approach to families in distress. Medical care teams should also continue to recognize and consider how medical, personal, and situational factors, in addition to the family's experience with the medical system, can heighten stress during IME especially for families who are already undergoing stressful medical encounters.

Cultural concepts of distress

When asked about cultural nuances in distress expression, interpreters varied in their broader cultural conceptualization of distress. By and large and as outlined above, all interpreters alluded to the diversity in how families expressed distress and what factors influenced distress expression during IME by describing different distress cues and medical, situational, or culture systemic factors. A small number of interpreters emphasized the importance of balancing the individuality and cultural similarities between Spanish speaking families, which may contrast with how the US medical system might be grouping Spanish-speaking families together as one entity due to shared language or perceived similarities based on language use. Interpreters' ability to integrate cultural knowledge during IME may be associated with the concept of cultural intelligence, defined as the ability of the individual to interact effectively with people who are culturally diverse with the cultural context of the individual (Ang et al., 2006; Earley & Ang, 2003), and may be the reason why interpreters are better able to identify and conceptualize cultural concepts of distress among families in IME. Interpreters' cultural intelligence may be an important resource for medical team members who are unfamiliar with or unaware of the vast cultural differences within broader communities who use a shared language (e.g., Spanish speaking Mexicans, Puerto Ricans, Peruvians, etc.).

Some interpreters noted that *distress is obvious* since everyone in the IME should be able to identify when patients or families are distressed. Specifically, interpreters attributed more "obvious" expressions of distress to overt and outward-facing behaviors such as body language, including pacing and finger tapping, verbal cues such as escalating vocal tones, and emotions such as anger, sadness, and fear. However, an "obvious" indicator to one interpreter may not be obvious to another interpreter or medical clinician, which may be suggestive of the individual's subjectivity in the identification of distress expression. Distress could be obvious to certain interpreters due to shared cultural norms that are obvious to individuals with shared cultural experiences (e.g., obvious to interpreters who have lived in the Caribbean, but not obvious to interpreters who have only lived in Mexico), professional experience with distressing encounters, interpreters' professional experience more broadly, emotional intelligence, cultural intelligence, and lived experience, among other factors. Collectively, these results continue to highlight individual differences among Spanish-English interpreters in pediatric medical settings in their identification of distress communication and positionality.

Interpreters who described *distress as universal* typically associated it with emotional expression, such that sadness, anger, and fear are identified and expressed by all peoples, which is likely why clinicians and interpreters, regardless of cultural upbringing are identifying similar distress cues. Indeed, universality in expression and identification of emotional states have been documented among multiple global communities (Ekman, 1992; Kannampallil et al., 2020). However, emotional expressions are also influenced by cultural norms and expectations because when, whether, and how emotions are expressed likely vary by cultural groups [i.e., universality and context-specific theoretical perspective; (Lerner, 2018)]. When applied to distressing IME, families likely experience similar emotions of anger, fear, or sadness. While some families may express emotions outwardly and in public, other families may express emotions in private or more subtly. Thus, distress expression, especially emotional expressions of distress, during IME is likely simultaneously universal and culture-specific. Medical care teams may benefit from checking in with all families, regardless of presence of distress cues, especially during intense, high acuity, or historically stressful medical encounters.

Additionally, it is also important to consider culture-specific and culture-bound concepts of distress that may arise during stressful IME. Currently, DSM-V cultural concepts of distress among individuals with Latin American inclusive of North, Central and South America and the Caribbean backgrounds include *ataque de nervios* (commonly reported symptoms include uncontrollable shouting, attacks of crying, trembling, heat in the chest rising into the head, and verbal or physical aggression), *nervios* (common symptoms include headaches and "brain aches," irritability, stomach disturbances, sleep difficulties, nervousness, tearfulness, inability to concentrate, trembling, tingling sensations, and mareos), and *susto*, a concept of distress attributed to a frightening event that causes the soul to leave the body and results in unhappiness and sickness; (American Psychiatric Association, 2013; Kaiser & Jo Weaver, 2019; Kohrt et al., 2014; Lewis-Fernández & Kirmayer, 2019). These concepts of distress minimally recognize symptoms related to emotional internalization such as withdrawal or disengagement, which interpreters from the current study reported as indicative of distress. Thus, continued exploration of emotional suppression or avoidance is warranted in order to have a more comprehensive and nuanced understanding of cultural concepts of distress.

Relatedly, interpreters described specific intersectional considerations related to cultural nuances in distress expression. Interpreters described culture-bound expressions of distress related to the family's perceived intersecting social identity such as country of origin, education, and geographic location, and highlighted the dichotomy of expressing and withholding emotions. Since more public expressions of distress are more noticeable and were associated with families with more socioeconomic and political privilege (e.g., class, education, geographic location) in the current study, it is important to also notice families who appear withdrawn or quiet and ensure that their emotional needs are addressed. Medical care teams can support families by asking how they are feeling, providing them time to process the information, and perhaps connecting them with community who can help support them throughout this stressful time. It would also be beneficial for medical care teams to continue cultivating cultural and emotional intelligence and approach families respectfully, especially because the care team or the US medical system might contribute to families in IME’s distress (i.e., iatrogenic events), in addition to other external stressors that might be impacting their overall wellbeing.

Finally, interpreter roles might also be a factor in how interpreters conceptualize distress as universal and/or culture specific. On the visible end, interpreters may intervene in IME to, among other objectives, clarify meaning; advocate for patients; explain contextual, cultural or technical concepts; and soften inflammatory language (Hsieh, 2007). In the message clarifier role, interpreters monitor for possible words or concepts that might lead to misunderstanding and clarify possible sources of confusion for the patient, clinician, or interpreter. The cultural clarifier role goes beyond message clarification and involves facilitating communication (e.g., communicating cultural beliefs about health and illness that may vary from the biomedical perspective) between individuals who do not share a common culture. When applied to distress expressions, interpreter roles related to being a message clarifier might be more associated with communicating universal distress expressions, while being a cultural clarifier might be more associated with communicating culture-specific distress expression.

Medical care teams would likely benefit from increased and more nuanced knowledge of interpreter roles during IME. Specifically, all clinicians should understand that interpreters relay and clarify information, including cultural messages, and may engage in advocacy during the encounter. It might also be helpful to reconceptualize how interpreters are scheduled to make time for discussions related to families’ distress during IME. Since building trust is integral to integrating interpreters to the medical care team, the medical system would benefit from hiring more interpreters, providing all medical interpreters with adequate psychosocial supports and resources especially if they are tasked with engaging in distressing encounters, and building extra time at the beginning and end of the encounter to provide adequate time for interpreters to discuss concerns with the medical clinician.

Ultimately, the results from the study highlight the heterogeneity in interpreters that facilitate communication in IME and encourages movement away from the current conceptualization of interpreters as conduits of language and as solely responsible for linguistic transfer (Dysart-Gale, 2005, 2007; Fatahi et al., 2008; E. Rosenberg et al., 2007). Rather, results from the study delineate how interpreters shift between the roles of message converter, message clarifier, cultural broker, and advocate, especially when distress cues are culture-bound (Hsieh & Kramer, 2012). Therefore, it may be beneficial for medical care teams to reconceptualize medical interpreters' roles of being just invisible "conduits of language" to visible cultural clarifiers since results of this study indicate that interpreters go beyond "just speaking language" during distressing IME. This reconceptualization of interpreter roles speaks to their immense contribution to the medical care team as cultural brokers and as experts in communication.

Summary: Indicators and cultural concepts of distress

Individuals who primarily speak Spanish and require interpretation services in pediatric medical encounters present distress similarly and uniquely during stressful IME. Interpreters highlighted how there is immense variability among Spanish speakers across geographical locations, within a specific country, within each region, and even within each county. Interpreters and medical clinicians can continue to consider cultural concepts of distress by cultivating cultural and emotional intelligence in the context of distressing IME. Special attention could be given to the family's intersecting social identities, particularly education, geographic location, country of origin, and cultural communication patterns, and their experience in the US medical system. It might also be beneficial to leverage the presence of interpreters in

IME since interpreters might provide additional insight to cultural concepts of distress and how the medical care team could take culture-bound expressions of distress into consideration when conceptualizing the family's presenting concern and planning for treatment.

Lived experience and positionality

Collectively, results from the study highlight how culture is present in all aspects of the IME, from intrapersonal (i.e., within the interpreter; reflexivity), interpersonal (i.e., identifying families' distress, emotions, positionality), and systemically (i.e., understanding cultural concepts of distress, culture systemic considerations), which emphasize culture's role throughout the ecological systems (Trinidad, 2000; Vélez-Agosto et al., 2017). On an intrapersonal and interpersonal level, results suggested that interpreters' own background and personal stories, personal and professional experiences, and intersecting social identities, influenced their approach to interpreting, including how they identify distress expression and cultural concepts of distress expression of families in IME. Lived experience likely explains why medical interpreters have unique perspectives, both between the interpreters themselves and vis-à-vis medical clinicians, about distress expression and cultural concepts of distress. Continued integration of cross-cultural understanding across all bio-socioecological systems (e.g., microsystem, mesosystems, etc.) may be beneficial since it may broaden and provide more nuanced understanding about family experience during distressing encounters.

Interpreters often described themselves as *bicultural* given their nuanced understanding of both their own culture, other Latin American cultures, and the United States culture. Biculturalism has historically been described as "comfort and proficiency with both one's heritage culture and the culture of the country or region in which one has settled," or "behaving in ways consistent with the two cultural contexts, [and] also holding values from one's heritage and receiving cultural streams, as well as identify with both cultures" (Mistry & Wu, 2010; Schwartz & Unger, 2010). This study extends these findings by documenting how interpreters not only described themselves as being bicultural through the lens of intersecting social identities, including ethnic identification as Latina/o or related to their heritage country (e.g., Mexican, or Mexican-American), immigration status, acculturation, spoken languages, but also through their professional identity as an interpreter and their interactions with others in professional and personal capacities. In other words, interpreters in this study are likely to describe biculturalism through the lens of intersecting social identities (e.g., immigration status, nationality) and interpersonal relationships, on the one hand, and through their professional occupation as an interpreter within the American medical system.

Interpreter's identification as bicultural could also indicate that medical interprets are likely to have skills that transcend being bilingual, since they also possess linguistic and cultural expertise (Gile, 2009) and are capable of mediating emotional transfer (Aranda et al., 2021; Gutierrez et al., 2019), which may include highly distressing emotional content among IME participants. While some interpreters identify as bicultural, it may be worthwhile to consider if and whether interpreters identify as multicultural given their immersion in the US American culture, their own cultural origins, Latin American culture more broadly, and the US medical system.

Interpreters described culture inherently intersectional since their descriptions of families' cultural concepts of distress expression included elements of country of origin, religion, education, geographic location, economics, linguistics, and race (Broom et al., 2020). These descriptions about cultural considerations were likely a reflection of their own cultural understanding, including their intersecting social identities, their personal stories and backgrounds, and experience in interpreted medical encounters (Dodgson, 2019; McHugh et al., 2020) and how these experiences might have influenced their interactions with families and the medical team during IME (i.e., positionality). Distress was reportedly easier to identify and understand if the family they are interpreting for is from a similar geographic location (e.g., "easier to understand families who also come from the Caribbean"), which suggests that interpreter's perceptions about the family's intersecting social identities and how these identities relate to their own intersecting social identities impacted the interpreter's perceptions about and identification of distress expression.

Although the process of reflexivity and positionality has only been historically encouraged in research and academia (Berger, 2015; Creswell, 2014; Dodgson, 2019), many interpreters in this study were aware of their own positionalities and how it influenced their work during IME, and demonstrated cultural intelligence when navigating distressing encounters (Ang et al., 2006; Earley & Ang, 2003). Continued encouragement in more systemic ways for interpreters to engage in the process of introspection regarding their own social identities, worldviews, and beliefs and how it may interact with families *and* clinicians in IME, especially during distressing encounters, could result in heightened awareness, and improved cross-cultural and cross-linguistic communication, and ultimately, improved health outcomes for families from minoritized backgrounds.

Perceptions about the family's cultural identities and cultural concepts of distress may also be influenced by implicit bias, defined as unconscious (or implicit) associations that influence judgement, attitudes and behaviors (Amodio & Mendoza, 2010), which could be due to interlocking systems of oppression that are embedded within medical, educational, and cultural system. Implicit bias among health care professionals have been documented in a systematic review, with evidence indicating that biases are likely to influence diagnosis and treatment decisions and levels of care (Fitzgerald & Hurst, 2017). In the context of distressing IME, it may also be worthwhile to explore the role of implicit bias, and more specifically, how social cognitions about the interpreter's self and their relation to others could influence identification and communication of family distress, and the likelihood of referral to appropriate services (e.g., psychology, social work) to help manage distressing encounters. Fortunately, there is evidence to suggest that implicit intergroup biases can be successfully reduced in adults (Lai et al., 2014), especially through increased personal contact with outgroup members. Since interpreters frequently interact with families and clinicians who are outside of their cultural group or community (e.g., families from other Latin American countries), they are likely amenable to interventions that decrease implicit bias in the health care system.

Limitations

Although we invited interpreters of all language pairs to participate in this study, the interpreters who were interviewed for this study were all Spanish-English interpreters. External agency interpreters (distinct from in-house contractors, who were included), who are called to interpret when hospital employees and in-house contractors are not available, and virtual/phone-based interpreters, were also not included in the participant pool. These factors may limit the degree to which this study's findings generalize to non-Spanish-English interpreters, or to interpreters from different environment, such as external agencies or phone/virtual interpreters. These factors warrant further exploration. Cultural concepts of distress may be unique in different cultures and may be expressed differently especially since cultural concepts of distress exist in other cultures.

It is also plausible that interpreting in pediatrics may pose unique stressors to families and could be very different from distress experiences in other populations (e.g., adult, victim services, legal), since pediatric interpreting may be tetradic (i.e., involving four parties: the health care clinician, interpreter, parent/caregiver, and child who may be bilingual). It would be beneficial to determine which expressions of distress could be generalizable for all families, and which are more applicable in pediatric medical settings.

Future Directions

Results of the study suggested that pediatric medical interpreters and medical clinicians are likely attending and responding to similar distress cues during IME (Balistreri et al., 2021; Rothschild et al., 2020; Yagiela et al., 2019). However, families in IME continue to experience inequities in their health care (Arthur et al., 2015; Obregon et al., 2019; Zurca et al., 2017). It would be beneficial to explore whether and why families who use interpretation services receive poorer quality healthcare compared to English-speaking families despite similarities in distress cues across all families, with special attention to how intersectional systemic oppression, implicit bias, difficulty understanding cultural concepts, and/or relying on interpreters to manage distress could be factors that influence distress identification and management for families in IME.

Additionally, given the heterogeneity of distress cues reported in the study, future studies would benefit from continued exploration of distress sensitivity and threshold by exploring how medical care teams, inclusive of medical interpreters, react to the number of distress cues presented by the family, the frequency and/or intensity of the distress cue, and what emotions these cues evoke within the medical care team. It might be beneficial to consider distress sensitivity and threshold within the context of emotional intelligence and cultural intelligence since these attributes likely play a role in the appraisal and response to distress during IME.

Additionally, thinking about distress sensitivity within the context of interpreter's ethical guidelines (relating to neutrality and impartiality), roles, positionality and implicit bias would also be important, since these factors also impact interpreter's appraisal and response to distress during IME.

Finally, continued exploration of positionality among all members of the care team would also be important to consider in future studies. Other experiences that might warrant research include exploring the influence of secondary traumatic stress among interpreters (Meadors et al., 2010; Mehus & Becher, 2016), and how that influence interpreters' experience of identifying, communication, and addressing distress during IME.

Conclusion

Interpreters from the current study collectively reported that families in IME expressed distress in various ways through a combination of visual cues, auditory cues, interpersonal cues, and contextual cues. Interpreters also perceived that distress expression among Spanish-speaking families in IME is diverse and simultaneously culture-specific and universal, some of which are influenced by cultural norms specific to the families' intersecting social identities. Therefore, cultural concepts of distress and more covert expressions of distress (e.g., withdrawal) should be considered when identifying family distress. Additionally, interpreters in IME present with unique beliefs and lived experiences, which bidirectionally influence their cultural and emotional intelligence, and ultimately, their ability to identify distress and cultural concepts of distress. Medical care teams inclusive of clinicians and medical interpreters should continue to cultivate their own cultural and emotional intelligence to better understand cultural concepts of distress of families from multiply minoritized backgrounds in the health care system.

Finally, clinicians and medical interpreters may benefit from collaboratively working together to better identify when families are distressed. Although some interpreters may take on the role of cultural broker, it is crucial that the responsibility of identifying, understanding, and addressing cultural concepts of distress is shared between the interpreter and the medical clinician. One way to improve communication is to invite interpreters in discussions about the care of the family. Doing so likely increases the likelihood of cross-linguistic and cross-cultural conversations, which may ultimately improve health outcomes and combat health care inequities stemming from intersectional oppression.

References

Abbe, M., Simon, C., Angiolillo, A., Ruccione, K., & Kodish, E. D. (2006). A survey of language barriers from the perspective of pediatric oncologists, interpreters, and parents. In *Pediatric Blood and Cancer*. https://doi.org/10.1002/pbc.20841

Abela, K. M., Wardell, D., Rozmus, C., & LoBiondo-Wood, G. (2020). Impact of paediatric critical illness and injury on families: An updated systematic review. *Journal of Pediatric Nursing*, *51*, 21–31. https://doi.org/10.1016/j.pedn.2019.10.013

American Psychiatric Association. (2013). *Cultural concepts in DSM-5*. 1. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&cad=rja&uact=8&ved=0CCoQFjAC&url=http://www.dsm5.org/Research/Documents/RLF et al_Culture and Anxiety DOs.pdf&ei=QRQDVbDrCY_yoASVoYKACA&usg=AFQjCNEi2qkYmKCVsRvecB70aNYKIZ9jAg&sig2=T

Amodio, D. M., & Mendoza, S. A. (2010). Implicit intergroup bias: Cognitive, affective, and motivational underpinnings. *Handbook of Implicit Social Cognition: Measurement, Theory, and Applications.*, *212*.

Ang, S., Van Dyne, L., & Koh, C. (2006). Personality correlates of the four-factor model of cultural intelligence. In *Group and Organization Management* (Vol. 31, Issue 1). https://doi.org/10.1177/1059601105275267

Angelelli, C. (2004a). *Revisiting the interpreter's role: A study of conference, court, and medical interpreters in Canada, Mexico, and the United States*.

Angelelli, C. V. (2004b). *Medical interpreting and cross-cultural communication*. Cambridge, U.K; New York : Cambridge University Press.

Aranda, C. Á., Gutiérrez, R. L., & Li, S. (2021). Towards a collaborative structure of interpreter-mediated medical consultations: Complementing functions between healthcare interpreters and providers. *Social Science and Medicine, 269*. https://doi.org/10.1016/j.socscimed.2020.113529

Arthur, K. C., Mangione-Smith, R., Meischke, H., Zhou, C., Strelitz, B., Acosta Garcia, M., & Brown, J. C. (2015). Impact of English proficiency on care experiences in a pediatric emergency department. *Academic Pediatrics, 15*(2), 218–224. https://doi.org/10.1016/j.acap.2014.06.019

Balistreri, K. A., Lim, P. S., Linneman, N. G., Tager, J., Davies, W. H., Scanlon, M. c., Murkowski, K., Lee, K. J., Karst, J. S., Magner, K. K., Lander, J., Johaningsmeir, S., & Rothschild, C. B. (2021). *Critical care fellows' perceptions of parent distress in the Pediatric Intensive Care Unit*. https://doi.org/10.1542/peds.147.3_meetingabstract.523

Bancroft, M. A., Allen, K., Green, C. E., & Feuerle, L. M. (2018). *Breaking silence: Interpreting for victim services*. Ayuda.

Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. In *Public Opinion Quarterly*. https://doi.org/10.1093/poq/nfm006

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2). https://doi.org/10.1177/1468794112468475

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research, 26*(13), 1802–1811. https://doi.org/10.1177/1049732316654870

Blumberg, S. J., O'Connor, K. S., & Kenney, G. (2005). Unworried parents of well children: A look at uninsured children who reportedly do not need health insurance. *Pediatrics*.

https://doi.org/10.1542/peds.2004-2085

Bot, H. (2005). Dialogue interpreting in mental health. In *Utrecht Series in Language and Communication*.

Broom, A., Kirby, E., Kokanović, R., Woodland, L., Wyld, D., de Souza, P., Koh, E. S., & Lwin, Z. (2020). Individualising difference, negotiating culture: Intersections of culture and care. *Health (United Kingdom)*, *24*(5), 552–571. https://doi.org/10.1177/1363459319829192

Bryant-Davis, T. (2005). Thriving in the wake of trauma. In *International Contributions in Psychology*.

Bryant-Davis, T. (2019). The cultural context of trauma recovery: Considering the posttraumatic stress disorder practice guideline and intersectionality. *Psychotherapy*, *56*(3), 400–408. https://doi.org/10.1037/pst0000241

Cohen, A., Rivara, F., Marcuse, E., Mcphillips, H., & Davis, R. (2005). Are language barriers associated with serious medical events in hospitalized pediatric patients? *Pediatrics*, *116*(3), 575–579. https://doi.org/10.1542/peds.2005-0521

Coker, T. R., Rodriguez, M. A., & Flores, G. (2010). Family-centered care for US children with special health care needs: Who gets it and why? *Pediatrics*. https://doi.org/10.1542/peds.2009-1994

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*(6). https://doi.org/10.2307/1229039

Creswell, J. W. (2014). Research design: Qualitative, quantitative, and mixed methods approaches. *Research Design Qualitative Quantitative and Mixed Methods Approaches*.

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. *Journal of Child and Adolescent Psychopharmacology*. https://doi.org/10.1089/cap.2013.0066

Dimberg, U., & Öhman, A. (1996). Behold the wrath: Psychophysiological responses to facial stimuli. *Motivation and Emotion*, *20*(2). https://doi.org/10.1007/BF02253869

Dodgson, J. E. (2019). Reflexivity in qualitative research. *Journal of Human Lactation*, *35*(2). https://doi.org/10.1177/0890334419830990

Doherty, S., Macintyre, A., & Wyne, T. (2010). How does it feel for you? The emotional impact and specific challenges of mental health interpreting. In *Mental Health Review Journal*. https://doi.org/10.5042/mhrj.2010.0657

Doyle, S. (2007). Member checking with older women: A framework for negotiating meaning. *Health Care for Women International*, *28*(10), 888–908. https://doi.org/10.1080/07399330701615325

Dunlap, J. L., Jaramillo, J. D., Koppolu, R., Wright, R., Mendoza, F., & Bruzoni, M. (2015). The effects of language concordant care on patient satisfaction and clinical understanding for Hispanic pediatric surgery patients. *Journal of Pediatric Surgery*, *50*(9), 1586–1589. https://doi.org/10.1016/j.jpedsurg.2014.12.020

Dysart-Gale, D. (2005). Communication models, professionalization, and the work of medical interpreters. In *Health Communication* (Vol. 17, Issue 1). https://doi.org/10.1207/s15327027hc1701_6

Dysart-Gale, D. (2007). Clinicians and medical interpreters: Negotiating culturally appropriate care for patients with limited English ability. *Family and Community Health*. https://doi.org/10.1097/01.FCH.0000277766.62408.96

Earley, P. C., & Ang, S. (2003). Cultural intelligence: Individual interactions across cultures. In

Stanford University Press. https://doi.org/10.5860/choice.41-4760

Ekman, P. (1992). Are there basic emotions? *Psychological Review*, *99*(3). https://doi.org/10.1037/0033-295X.99.3.550

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, *4*(1). https://doi.org/10.1177/2158244014522633

Eneriz-Wiemer, M., Sanders, L. M., Barr, D. A., & Mendoza, F. S. (2014). Parental Limited English Proficiency and Health Outcomes for Children With Special Health Care Needs: A Systematic Review. *Academic Pediatrics*, *14*(2), 128–136. https://doi.org/10.1016/j.acap.2013.10.003

Fatahi, N., Hellström, M., Skott, C., & Mattsson, B. (2008). General practitioners' views on consultations with interpreters: A triad situation with complex issues. *Scandinavian Journal of Primary Health Care*, *26*(1), 40–45. https://doi.org/10.1080/02813430701877633

Firew, T., Sano, E. D., Lee, J. W., Flores, S., Lang, K., Salman, K., Greene, M. C., & Chang, B. P. (2020). Protecting the front line: A cross-sectional survey analysis of the occupational factors contributing to healthcare workers' infection and psychological distress during the COVID-19 pandemic in the USA. *BMJ Open*, *10*(10), e042752. https://doi.org/10.1136/bmjopen-2020-042752

Fitzgerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: A systematic review. *BMC Medical Ethics*. https://doi.org/10.1186/s12910-017-0179-8

Flores, G., Abreu, M., & Tomany-Korman, S. C. (2005). Limited English proficiency, primary language at home, and disparities in children's health care: How language barriers are measured matters. *Public Health Reports*, *120*(4), 418–430.

https://doi.org/10.1177/003335490512000409

Fogel, A., Nazir, S., & Ray, S. (2019). Cultural assessment and treatment of psychiatric patients. In *StatPearls*.

Forgey, M., & Bursch, B. (2013). Assessment and management of pediatric iatrogenic medical trauma. *Current Psychiatry Reports*, *15*(2). https://doi.org/10.1007/s11920-012-0340-5

Freeman, W. J., Weiss, A. J., & Heslin, K. C. (2006). Overview of U.S. hospital stays in 2016: Variation by Geographic region: Statistical brief #246. *Healthcare Cost and Utilization Project (HCUP) Statistical Briefs*, 1–15. http://www.ncbi.nlm.nih.gov/pubmed/30720972

Gile, D. (2009). Basic concepts and models for interpreter and translator trainingNo Title. *Amsterdam/Philadelphia: John Benjamins*.

Gross, J. J., & Muñoz, R. F. (1995). Emotion regulation and mental health. *Clinical Psychology: Science and Practice*, *2*(2). https://doi.org/10.1111/j.1468-2850.1995.tb00036.x

Gutierrez, A. M., Statham, E. E., Robinson, J. O., Slashinski, M. J., Scollon, S., Bergstrom, K. L., Street, R. L., Parsons, D. W., Plon, S. E., & McGuire, A. L. (2019). Agents of empathy: How medical interpreters bridge sociocultural gaps in genomic sequencing disclosures with Spanish-speaking families. *Patient Education and Counseling*, *102*(5). https://doi.org/10.1016/j.pec.2018.12.012

Hsieh, E. (2007). Interpreters as co-diagnosticians: Overlapping roles and services between providers and interpreters. *Social Science & Medicine*, *64*(4), 924–937. https://doi.org/10.1016/j.socscimed.2006.10.015

Hsieh, E., & Hong, S. J. (2010). Not all are desired: Providers’ views on interpreters’ emotional support for patients. *Patient Education and Counseling*, *81*(2), 192–197. https://doi.org/10.1016/j.pec.2010.04.004

Hsieh, E., & Kramer, E. M. (2012). Medical interpreters as tools: Dangers and challenges in the utilitarian approach to interpreters' roles and functions. *Patient Education and Counseling*, *89*(1). https://doi.org/10.1016/j.pec.2012.07.001

Hsieh, E., & Nicodemus, B. (2015). Conceptualizing emotion in healthcare interpreting: A normative approach to interpreters' emotion work. *Patient Education and Counseling*, *98*(12), 1474–1481. https://doi.org/10.1016/j.pec.2015.06.012

Inkelas, M., Raghavan, R., Larson, K., Kuo, A. A., & Ortega, A. N. (2007). Unmet mental health need and access to services for children with special health care needs and their families. *Ambulatory Pediatrics*. https://doi.org/10.1016/j.ambp.2007.08.001

Jimenez, N., Fuentes, M., Frias-Garcia, M., Crawley, D., Moore, M., & Rivara, F. (2020). Transitions to outpatient care after traumatic brain injury for Hispanic children. *Hospital Pediatrics*, *10*(6), 509–515. https://doi.org/10.1542/hpeds.2019-0304

Jimenez, N., Jackson, D. L., Zhou, C., Ayala, N. C., & Ebel, B. E. (2014). Postoperative pain management in children, parental English proficiency, and access to interpretation. *Hospital Pediatrics*, *4*(1), 23–30. https://doi.org/10.1542/hpeds.2013-0031

Juckett, G., & Unger, K. (2014). Appropriate use of medical interpreters. *American Family Physician*, *90*(7), 476–480.

Jungner, J. G. (2018). *Communication over language barriers in paediatric oncology care : a prerequisite for equity in care*.

Kaiser, B. N., & Jo Weaver, L. (2019). Culture-bound syndromes, idioms of distress, and cultural concepts of distress: New directions for an old concept in psychological anthropology. *Transcultural Psychiatry*, *56*(4), 589–598. https://doi.org/10.1177/1363461519862708

Kannampallil, T. G., Goss, C. W., Evanoff, B. A., Strickland, J. R., McAlister, R. P., & Duncan, J. (2020). Exposure to COVID-19 patients increases physician trainee stress and burnout. *PLoS ONE*, *15*(8 August), 1–12. https://doi.org/10.1371/journal.pone.0237301

Karliner, L. S., Jacobs, E. A., Chen, A. H., & Mutha, S. (2007). Do professional interpreters improve clinical care for patients with limited english proficiency? A systematic review of the literature. *Health Services Research*, *42*(2), 727–754. https://doi.org/10.1111/j.1475-6773.2006.00629.x

Keltner, D., & Kring, A. M. (1998). Emotion, social function, and psychopathology. *Review of General Psychology*, *2*(3). https://doi.org/10.1037/1089-2680.2.3.320

Kenney, M. K., Denboba, D., Strickland, B., & Newacheck, P. W. (2011). Assessing family-provider partnerships and satisfaction with care among us children with special health care needs. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2010.08.001

Kohrt, B. A., Rasmussen, A., Kaiser, B. N., Haroz, E. E., Maharjan, S. M., Mutamba, B. B., De Jong, J. T. V. M., & Hinton, D. E. (2014). Cultural concepts of distress and psychiatric disorders: Literature review and research recommendations for global mental health epidemiology. *International Journal of Epidemiology*, *43*(2), 365–406. https://doi.org/10.1093/ije/dyt227

Lai, C. K., Marini, M., Lehr, S. A., Cerruti, C., Shin, J. E. L., Joy-Gaba, J. A., Ho, A. K., Teachman, B. A., Wojcik, S. P., Koleva, S. P., Frazier, R. S., Heiphetz, L., Chen, E. E., Turner, R. N., Haidt, J., Kesebir, S., Hawkins, C. B., Schaefer, H. S., Rubichi, S., … Nosek, B. A. (2014). Reducing implicit racial preferences: A comparative investigation of 17 interventions. *Journal of Experimental Psychology: General*, *143*(4). https://doi.org/10.1037/a0036260

Lerner, R. M. (2018). Concepts and theories of human development: Fourth edition. In *Concepts and Theories of Human Development*. https://doi.org/10.4324/9780203581629

Levetown, M. (2008). Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics*, *121*(5), E1441–E1460. https://doi.org/10.1542/peds.2008-0565

Levin, A. B., Fisher, K. R., Cato, K. D., Zurca, A. D., & October, T. W. (2015). An evaluation of family-centered rounds in the PICU: Room for improvement suggested by families and providers. *Pediatric Critical Care Medicine*, *16*(9), 801–807. https://doi.org/10.1097/PCC.0000000000000486

Lewis-Fernández, R., & Kirmayer, L. J. (2019). Cultural concepts of distress and psychiatric disorders: Understanding symptom experience and expression in context. *Transcultural Psychiatry*, *56*(4), 786–803. https://doi.org/10.1177/1363461519861795

Lion, K. C., Mangione-Smith, R., Martyn, M., Hencz, P., Fernandez, J., & Tamura, G. (2013). Comprehension on family-centered rounds for limited English proficient families. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2012.12.002

Llewellyn-Jones, P., & Lee, R. G. (2013). Getting to the core of role: Defining Interpreters' role-space. *International Journal of Interpreter Education*, *5*(2), 54–72.

Lotstein, D. S., Ghandour, R., Cash, A., McGuire, E., Strickland, B., & Newacheck, P. (2009). Planning for health care transitions: Results from the 2005-2006 national survey of children with special health care needs. *Pediatrics*. https://doi.org/10.1542/peds.2008-1298

Mattson, G., & Kuo, D. Z. (2019). Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics*. https://doi.org/10.1542/peds.2018-3171

Mayer, J. D., & Salovey, P. (1993). The intelligence of emotional intelligence. In *Intelligence*

(Vol. 17, Issue 4). https://doi.org/10.1016/0160-2896(93)90010-3

Mayer, J. D., Salovey, P., & Caruso, D. R. (2004). Emotional intelligence: Theory, findings, and implications. In *Psychological Inquiry* (Vol. 15, Issue 3). https://doi.org/10.1207/s15327965pli1503_02

McHugh, S. K., Lawton, R., O'Hara, J. K., & Sheard, L. (2020). Does team reflexivity impact teamwork and communication in interprofessional hospital-based healthcare teams? A systematic review and narrative synthesis. In *BMJ Quality and Safety* (Vol. 29, Issue 8). https://doi.org/10.1136/bmjqs-2019-009921

Meadors, P., Lamson, A., Swanson, M., White, M., & Sira, N. (2010). Secondary traumatization in pediatric healthcare providers: Compassion fatigue, burnout, and secondary traumatic stress. *Omega: Journal of Death and Dying*, *60*(2), 103–128. https://doi.org/10.2190/OM.60.2.a

Mehus, C. J., & Becher, E. H. (2016). Secondary traumatic stress, burnout, and compassion satisfaction in a sample of spoken-language interpreters. *Traumatology*, *22*(4), 249–254. https://doi.org/10.1037/trm0000023

Mistry, J., & Wu, J. (2010). Navigating cultural worlds and negotiating identities: A conceptual model. In *Human Development* (Vol. 53, Issue 1). https://doi.org/10.1159/000268136

Needle, J. S., O'Riordan, M., & Smith, P. G. (2009). Parental anxiety and medical comprehension within 24 hrs of a child's admission to the pediatric intensive care unit. *Pediatric Critical Care Medicine*. https://doi.org/10.1097/PCC.0b013e3181a706c9

Nelson, L. P., & Gold, J. I. (2012). Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: A review. *Pediatric Critical Care Medicine*, *13*(3), 338–347. https://doi.org/10.1097/PCC.0b013e3182196a8f

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1). https://doi.org/10.1177/1609406917733847

Obregon, E., Martin, C. R., Frantz, I. D., Patel, P., & Smith, V. C. (2019). Neonatal Intensive Care Unit discharge preparedness among families with limited english proficiency. *Journal of Perinatology*, *39*(1), 135–142. https://doi.org/10.1038/s41372-018-0255-z

Oropeza, M. V., Varghese, M. M., & Kanno, Y. (2010). Linguistic minority students in higher education: Using, resisting, and negotiating multiple labels. *Equity and Excellence in Education*, *43*(2), 216–231. https://doi.org/10.1080/10665681003666304

Pediatrics, A. A. of. (2002, July 1). *The medical home*. Pediatrics. https://doi.org/10.1542/peds.110.1.184

Persons, J. B. (2008). What Is the case formulation approach to cognitive-behavior therapy? In *The Case Formulation Approach to Cognitive-Behavior Therapy*.

Persons, J. B., & Hong, J. J. (2015). Case formulation and the outcome of cognitive behaviour therapy. In *Case Formulation in Cognitive Behaviour Therapy: The Treatment of Challenging and Complex Cases*. https://doi.org/10.4324/9781315694191-8

Quijano, A. (2000). Coloniality of power and Eurocentrism in Latin America. *International Sociology*, *15*(2). https://doi.org/10.1177/0268580900015002005

Ranjan, P., Kumari, A., & Chakrawarty, A. (2015). How can doctors improve their communication skills? *Journal of Clinical and Diagnostic Research*, *9*(3). https://doi.org/10.7860/JCDR/2015/12072.5712

Rea, K. E., Rao, P., Hill, E., Saylor, K. M., & Cousino, M. K. (2018). Families' experiences with pediatric family-centered rounds: A systematic review. *Pediatrics, 141*(3).

https://doi.org/10.1542/peds.2017-1883

Resera, E., Tribe, R., & Lane, P. (2015). Interpreting in mental health, roles and dynamics in practice. *International Journal of Culture and Mental Health*. https://doi.org/10.1080/17542863.2014.921207

Riera, A., Ocasio, A., Tiyyagura, G., Krumeich, L., Ragins, K., Thomas, A., Trevino, S., & Vaca, F. E. (2015). Latino caregiver experiences with asthma health communication. *Qualitative Health Research*, *25*(1), 16–26. https://doi.org/10.1177/1049732314549474

Rosenberg, A. R., Dussel, V., Kang, T., Geyer, J. R., Gerhardt, C. A., Feudtner, C., & Wolfe, J. (2013). Psychological distress in parents of children with advanced cancer. *JAMA Pediatrics*. https://doi.org/10.1001/jamapediatrics.2013.628

Rosenberg, E., Leanza, Y., & Seller, R. (2007). Doctor–patient communication in primary care with an interpreter: Physician perceptions of professional and family interpreters. *Patient Education and Counselling*, *67*(3), 286–292. https://doi.org/10.1016/j.pec.2007.03.011

Rothschild, C. B., Rychlik, K. L., Goodman, D. M., Charleston, E., Brown, M. L., Michelson, K. N., Ali, F. N., Alvarado, V., Duerst, R. E., Goldberg, M., Goldberger, A. R., Johnston, A., Kathman, A. G., Lange, L., Leander, K., Persell, S. D., Redd, L., Reichek, J. L., Rojas, E., … Victor-Son, D. E. (2020). Association between resilience and psychological morbidity in parents of critically ill children. *Pediatric Critical Care Medicine*. https://doi.org/10.1097/PCC.0000000000002237

Saldaña, J. (2016). The coding manual for qualitative researchers. *Sage*.

Schwartz, S. J., & Unger, J. B. (2010). Biculturalism and context: What is biculturalism, and when is it adaptive? Commentary on Mistry and Wu. *Human Development*, *53*(1), 26–32. https://doi.org/10.1159/000268137

Schwei, R. J., Guerrero, N., Small, A. L., & Jacobs, E. A. (2019). *Physician perceptions of the types of roles interpreters play in limited English proficient pediatric encounters and how they evaluate the quality of interpretation*. *20*. https://doi.org/10.1017/S1463423618000890

Seltz, L. B., Zimmer, L., Ochoa-Nunez, L., Rustici, M., Bryant, L., & Fox, D. (2011). Latino families' experiences with family-centered rounds at an academic children's hospital. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2011.06.002

Sheldon, L. K., Ellington, L., Barrett, R., Dudley, W. N., Clayton, M. F., & Rinaldi, K. (2009). Nurse responsiveness to cancer patient expressions of emotion. *Patient Education and Counseling*, *76*(1), 63–70. https://doi.org/10.1016/j.pec.2008.11.010

Singh, G. K., Strickland, B. B., Ghandour, R. M., & Van Dyck, P. C. (2009). Geographic disparities in access to the medical home among US CSHCN. *Pediatrics*. https://doi.org/10.1542/peds.2009-1255E

Sinow, C. S., Corso, I., Lorenzo, J., Lawrence, K. A., Magnus, D. C., & Van Cleave, A. C. (2017). Alterations in Spanish language interpretation during pediatric critical care family meetings. *Critical Care Medicine*. https://doi.org/10.1097/CCM.0000000000002650

Söllner, W., DeVries, A., Steixner, E., Lukas, P., Sprinzl, G., Rumpold, G., & Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer*. https://doi.org/10.1054/bjoc.2000.1545

Stephen, J. M., & Zoucha, R. (2020). Spanish speaking, limited English proficient parents whose children are hospitalized: An integrative review. *Journal of Pediatric Nursing*, *52*, 30–40. https://doi.org/10.1016/j.pedn.2020.02.033

Stevenson, R. S., Rosales, A., Fortier, M. A., Campos, B., Golianu, B., Zuk, J., Gold, J., & Kain,

Z. N. (2017). The Role of ethnicity and acculturation in preoperative distress in parents of children undergoing surgery. *Journal of Immigrant and Minority Health*. https://doi.org/10.1007/s10903-016-0357-7

Stremler, R., Haddad, S., Pullenayegum, E., & Parshuram, C. (2017). Psychological outcomes in parents of critically ill hospitalized children. *Journal of Pediatric Nursing*, *34*, 36–43. https://doi.org/10.1016/j.pedn.2017.01.012

Studdert, D. M., Burns, J. P., Mello, M. M., Puopolo, A. L., Truog, R. D., & Brennan, T. A. (2003). Nature of conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics*, *112*(3), 553–558. https://doi.org/10.1542/peds.112.3.553

Subramony, A., Schwartz, T., & Hametz, P. (2012). Family-centered rounds and communication about discharge between families and inpatient medical teams. *Clinical Pediatrics*. https://doi.org/10.1177/0009922812446012

Tam, I., Huang, M., Patel, A., Rhee, K., & Fisher, E. (2019). Spanish interpreter services for the hospitalized pediatric patient: Provider and interpreter perceptions. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2019.08.012

Thornton, J. D., Pham, K., Engelberg, R. A., Jackson, J. C., & Curtis, J. R. (2009). Families with limited English proficiency receive less information and support in interpreted intensive care unit family conferences. *Critical Care Medicine*. https://doi.org/10.1097/CCM.0b013e3181926430

Trinidad, C. R. (2000). *A cultural-psychological analysis of emotions*.

Van Cleave, A. C., Roosen-Runge, M. U., Miller, A. B., Milner, L. C., Karkazis, K. A., & Magnus, D. C. (2014). Quality of communication in interpreted versus noninterpreted PICU family meetings. *Critical Care Medicine*. https://doi.org/10.1097/CCM.0000000000000177

Vélez-Agosto, N. M., Soto-Crespo, J. G., Vizcarrondo-Oppenheimer, M., Vega-Molina, S., & García Coll, C. (2017). Bronfenbrenner’s bioecological theory revision: Moving culture from the macro into the micro. *Perspectives on Psychological Science*, *12*(5). https://doi.org/10.1177/1745691617704397

Vernon, M., & Miller, K. (2001). Interpreting in mental health settings: Issues and concerns. *American Annals of the Deaf*. https://doi.org/10.1353/aad.2012.0200

Wagner, E. H. (1998). What will it take to improve care for chronic illness? *Effective Clinical Practice*.

Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. In *Palliative and Supportive Care*. https://doi.org/10.1017/S1478951511001027

Williams, A., Oulton, K., Sell, D., & Wray, J. (2018). Healthcare professional and interpreter perspectives on working with and caring for non-English speaking families in a tertiary paediatric healthcare setting. *Ethnicity & Health*, *23*(7), 767–780. https://doi.org/10.1080/13557858.2017.1294662

Willis, G. D. (2005). Cognitive interviewing in practice. *Cognitive Interviewing: A Tool Used for Improving Questionnaire Design*.

Yagiela, L. M., Carlton, E. F., Meert, K. L., Odetola, F. O., & Cousino, M. K. (2019). Parent medical traumatic stress and associated family outcomes after pediatric critical illness: A systematic review. *Pediatric Critical Care Medicine*, *20*(8), 759–768. https://doi.org/10.1097/PCC.0000000000001985

Yu, S. M., Nyman, R. M., Kogan, M. D., Huang, Z. J., & Schwalberg, R. H. (2004). Parent’s language of interview and access to care for children with special health care needs.

Ambulatory Pediatrics. https://doi.org/10.1367/A03-094R.1

Yu, S. M., & Singh, G. K. (2009). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics*. https://doi.org/10.1542/peds.2009-1255M

Zendedel, R., Schouten, B. C., van Weert, J. C. M., & van den Putte, B. (2016). Informal interpreting in general practice: Comparing the perspectives of general practitioners, migrant patients and family interpreters. *Patient Education and Counseling*, *99*(6), 981–987. https://doi.org/10.1016/j.pec.2015.12.021

Zurca, A. D., Fisher, K. R., Flor, R. J., Gonzalez-Marques, C. D., Wang, J., Cheng, Y. I., & October, T. W. (2017). Communication with limited English-proficient families in the PICU. *Hospital Pediatrics*, *7*(1), 9–15. https://doi.org/10.1542/hpeds.2016-0071

Appendix A. Demographics Questionnaire

1. Please enter your participant ID number, provided by the interviewer.
2. What is your gender identity?
3. What race(s) and ethnicit(y/ies) do you consider yourself to be? Choose all that apply
    a. Black or African-American
    b. Asian (including South Asian and Southeast Asian)
    c. Latino/Latina/Latinx
    d. Middle Eastern
    e. American Indian or Native Alaskan
    f. Pacific Islander
    g. White
    h. Other (please specify)
4. How do you identify in terms of your ancestry or ethnic origin? (e.g., Cambodian, Puerto Rican; specify if you identify as a hyphenated ethnic origin, such as Mexican-American)
5. What is your interpreting language pair? Choose all that apply.
    a. Spanish- English
    b. Hmong- English
    c. Burmese- English
    d. Mandarin- English
    e. Arabic- English
    f. Somali- English
    g. Other (please specify)
6. How many years have you been interpreting?
    a. Total years interpreting
    b. Total years at Children's Wisconsin
7. Which of the following levels do you work at Children's Wisconsin? (choose all that apply) Please include total years you have interpreted in the following departments:
    a. Level 1 (i.e., Audiology/Speech, Dental)
    b. Level 2 (i.e., Asthma/ Allergy, Pulmonology)
    c. Level 3 (i.e., Special Needs, Inpatient)
8. What is your level of training specifically in interpreting? Choose all that apply.
    a. No training
    b. 40-hour course
    c. On the job training
    d. Technical school program
    e. Undergraduate Major or Minor in Interpreting
    f. Graduate Degree in Translation and Interpreting Studies
9. Have you taken a national medical interpreter certification exam?
    a. Yes
    b. No
10. How many years of experience interpreting did you have before taking the national medical interpreter certification exam?
11. What other areas have you interpreted in other than medical?
    a. Legal
    b. Social Services
    c. Educational
    d. Conference Interpreting
    e. Other
12. Which departments do you like to interpret?
13. As an interpreter, have you ever received information or education on working with patient trauma and stress?
    a. Yes
    b. No

14. As an interpreter, have you received information or education on coping strategies for managing your own stress and emotions?
    a. Yes
    b. No

Appendix B. Interview Guide

Background and motivation

1. Why did you become medical interpreter?
    a. Follow up: What in your life inspired you to do this work?
2. What training did you get to become an interpreter?
3. What do you think is most important in your work as an interpreter? Why?

Identifying distress and disclosure of family distress to the provider

4. What indicates to you that a family is distressed?
    a. Great, we are interested in the full spectrum of distressed families. Families may present distress in many ways, including the ways you've mentioned, withdrawing, being difficult, or being tearful.
    b. Do you notice cultural differences when families express distress? If so, what have you noticed?
5. If a patient is distressed, should it be brought up in the interpreted medical encounter?
    a. If not, why?
    b. If yes, who should bring it up in the encounter? What makes you choose that person?
    c. If they say interpreter, ask:
        i. What do you consider when deciding whether or not to bring up that a patient is feeling distressed?
        ii. Describe how you would communicate that a patient is distressed to the provider?
        iii. When is it the appropriate time to communicate that to the provider?
6. How would you handle an encounter in which the patient expressed distressed, and the provider doesn't notice?
    a. What if the provider doesn't address the patient's distress?
7. How would you handle an encounter in which you believe the patient is distressed and the provider doesn't notice?
    a. What if the provider doesn't address the patient's distress?
8. We're going to ask you about things that make interpreting for distressed families easier or more difficult:
    a. Is there anything that makes it easier or harder to interpret family distress to a provider?
    b. Are there specific things that providers do or expect that make it easier or harder to communicate?
9. Have you talked to provider about a family's distress after an encounter or stopped interpreting during an encounter to talk to a provider about a family's distress?
    a. If so, can you talk about that and why you discussed the family's distress?
    b. If not, have you ever felt like you wanted to talk to a provider about a family's distress? What stopped you?

Appendix C. Cognitive Interview

1. How easy were the interview questions to listen to and understand?

Very Easy	Somewhat Easy	Neutral	Somewhat Difficult	Very Difficult
1	2	3	4	5

2. Were there any interview questions that could be clearer?

3. Was anything unclear on this background questionnaire?

4. How often do you think about or notice these topics on a day to day basis as an interpreter working in pediatric hospitals?

	Never	Occasionally	Often	Constantly
The training I received to become an interpreter	1	2	3	4
The role(s) I play as an interpreter during medical encounters	1	2	3	4
How I communicate emotion	1	2	3	4
Identifying patient and family distress	1	2	3	4
Addressing patient and family distress	1	2	3	4
Interpreter-provider collaboration	1	2	3	4
Impact of distress disclosure	1	2	3	4
Resources and supports for me and other interpreters	1	2	3	4

5. Are there any topics that were left out and should be included that are relevant for interpreters working at a pediatric hospital?

6. Is there anything that you would change about the interview or questionnaire?

7. What was your comfort level when addressing the topics covered in the interview?

8. Do you have any other overall thoughts or opinions of the interview or questionnaire?

9. Were there any topics covered in the interview you would prefer to address in written form as opposed to verbally with the interviewer?

Appendix D. Member Check

Section 2

When we asked about interpreting in situations where families are feeling distressed, there were a couple of things we heard. First, it sounds like interpreters notice cultural features or features of the families' identity like education that impact how families show or express their distress. It also sounds like interpreters see a lot of diversity in how families from different cultures show their emotions and distress.

We also heard that when a family is distressed, some interpreters think that it's the provider's job to notice and address it, and it isn't the interpreter's job to call attention to it. Or if the family doesn't bring it up, it's not the interpreter's job to draw attention to it. Other interpreters thought that if they noticed the family is distressed, they might bring it up to the provider either during or after the interpreting encounter. Other interpreters said they wouldn't bring up that they think a family is distressed unless they had a feeling that it would impact the patient's health or the families in some negative way.

1. We're interested in hearing your thoughts about those statements, if you think our interpretation sounds about right to you or if you think we're missing something here.
2. We're curious to hear how much of your own personal story or background might help you understand the families' cultural ways of expressing distress. How might your life experience help you understand how folks from different cultures express their distress?
3. Do you think that your background or personal story plays a role in the actions you might take to address the family's distress?
4. Is there anything else you want to add or think we should know about how families from different background express their distress?
5. Is there anything else you want to add or think we should know about how distress of families from different background should be communicated through an interpreter?

Wrap up

1. Is there anything you think is important for us to know while we prepare to share this information with the interpreting team?
2. If you could share this information with people who work at CW, who would you want to share this with and what would you want them to know?