

# Cultural and religious considerations in pediatric palliative care

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## ABSTRACT

**Objective:** A growing multicultural society presents healthcare providers with a difficult task of providing appropriate care for individuals who have different life experiences, beliefs, value systems, religions, languages, and notions of healthcare. This is especially vital when end-of-life care is needed during childhood. There is a dearth of literature addressing cultural considerations in the pediatric palliative care field. As members of a specific culture often do not ascribe to the same religious traditions, the purpose of this article was to explore and review how culture and religion informs and shapes pediatric palliative care.

**Method:** Comprehensive literature searches were completed through an online search of nine databases for articles published between 1980 and 2011: PsychINFO, MEDLINE®, *Journal of Citation Reports-Science Edition*, Embase, Scopus, CINAHL®, Social Sciences Citation Index (SSCI), EBSCO, and Ovid. Key terms included: *culture, transcultural, spiritual, international, ethnic, customs or religion AND end-of-life, palliative care, death, dying, cancer, or hospice, and children, pediatrics, or pediatric oncology*. Reference lists in the retrieved articles were examined for additional studies that fit the inclusion criteria, and relevant articles were included for review. In addition, web-based searches of specific journals were conducted. These included, but were not limited to: *Qualitative Health Research, Psycho-Oncology, Journal of Psychosocial Oncology, Journal of Pediatric Psychology, Journal of Pediatric Health Care, Journal of Pediatric Oncology Nursing, Omega, Social Work in Health Care, and Journal of Palliative Medicine*.

**Results:** Thirty-seven articles met eligibility criteria. From these, seven distinct themes emerged that have implications for pediatric palliative care. These include the role of culture in decision-making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and suffering, the meaning of death and dying, and location of end-of-life care.

**Significance of results:** The review of the literature provides insight into the influence of religion and how culture informs lifestyle and shapes the experiences of illness, pain, and end-of-life care. Recommendations for providing culturally sensitive end-of-life care are offered through the framework outlined in the Initiative for Pediatric Palliative Care Quality Improvement Project of 2002. Cultural traditions are dynamic, never static, and cannot be generalized to all families. Guidelines to aid in approaches to palliative care are provided, and providers are encouraged to define these important differences for each family under their care.

**KEYWORDS:** Culture, Pediatric palliative care, Religion, Spirituality, Children, Ethnicity

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## INTRODUCTION

A growing multicultural society presents healthcare providers with a difficult task of providing appropriate care for individuals who have different life experiences, beliefs, value systems, religions, languages, and notions of healthcare. Cultural practices and spiritual beliefs are the foundations on which many lives are based, and quality care requires medical providers to be both culturally sensitive and culturally competent. This is especially vital during the vulnerable period of end-of-life during childhood (Levetown, 1998; Contro et al., 2010). Although research has been growing in the palliative care field, the majority of literature on pediatric palliative care focuses on epidemiology, parental decision-making factors, models of care, ethical and legal considerations, symptom management, and ways of providing total care for the family (Gilmer, 2002; Tomlinson et al., 2006; Moody et al., 2011). Children with life-limiting and life-threatening illnesses that lead to death deserve a cultural reappraisal of how we care for them when the aim of care has shifted from curative to simply offering the best possible “health” and “quality of life” (Benini et al., 2008).

Beginning with brief overviews of cultural competence and pediatric palliative care, this article reviews the relevant literature, describes the influence that culture and religion can have on end-of-life pediatric care, and highlights the importance of integrating culture with death and dying traditions. Recommendations for providing culturally sensitive end-of-life care are offered through the framework outlined in the Initiative for Pediatric Palliative Care Quality Improvement Project of 2002. These include the following areas of improving pediatric palliative care: maximize family involvement, involve children in decision making, minimize pain, provide emotional and spiritual support to families, facilitate access to needs, enhance continuity of care, and offer bereavement support (Solomon et al., 2002).

### Cultural Competence

The concept of cultural competence and its necessity in treatment of diverse patients and families has flourished within the last decade. Research shows that cultural competence is more than accumulated knowledge of cultural practices; it encompasses a need for medical practitioners to consider their own constructs of bias and belief (Surbone, 2008; Kumagai & Lypson, 2009). Cultural competence must be considered in context of the diverse personal, medical and practitioner cultures that abound in clinical settings (Taylor, 2003). Moreover, cultural practices cannot be taken out of patient context. It is easy to

oversimplify cultural or religious practices. Social factors, such as class and literacy, differentiate individuals within cultural norms (Taylor, 2003). Likewise, practitioners must be aware of the contrary effect of perpetuating rigid stereotypes about what members of a particular “culture” believe, do, or want, and how that translates to provision of care. The modern view of cultural competence emphasizes its fluidity: a process that bridges care and patient need as a vital link in communication with patients and families during tragic circumstances.

### Pediatric Palliative Care

Palliative care is aimed at improving the quality of life for patients and their families who are confronted with life-threatening illness by providing support and care for pain, physical symptoms, psychological and social stress, and spirituality. Pediatric palliative care encompasses the same goals as adult palliative care, but focuses specifically on serving the unique needs of the child and family (Anghelescu et al., 2006). During youth, life-threatening illness is shaped by the child’s developmental context, which includes not only physical transitions but also psychological, emotional, and spiritual changes. For example, pediatric palliative care in the neonatal unit is fundamentally different from the pediatric palliative care appropriate with an adolescent, whose complexity of thought allows greater reflection regarding his or her beliefs and wishes about death (Himmelstein et al., 2004). A particular challenge specific to pediatric palliative services is that end-of-life care for a child seems inherently unnatural in the mind of many parents and doctors, who often struggle to accept that nothing more can be done for a child. It is not unheard of for children with leukemia to receive “a third or fourth bone marrow transplantation in an attempt to induce a short-term remission or to maintain some quality of life, but with no hope of cure” (Himmelstein et al., 2004, p. 1758), something typically outside the standard of medical care for an adult patient. Discrepancies in treatment goals between staff and family and lack of understanding of the concept of palliative care can also delay the introduction of pediatric palliative care services, and may prolong physical pain in children, as well as emotional and psychological suffering in their parents and treatment team (Koenig & Davies, 2002; Anghelescu et al., 2006; Mack & Wolfe, 2006; Davies et al., 2008).

Dealing with the potential loss of one’s child is a catastrophic experience across cultures (De Trill & Kovalcik, 1997); however, the literature suggests that cultural influences may further complicate the appropriate integration of pediatric palliative care.

A study conducted by Davies et al. (2008) found that nearly 40% of healthcare providers identified cultural differences as a frequently occurring barrier to adequate pediatric palliative care. For example, Latino parents tend to have an overarching belief that every effort should be made to save the child, a notion found to make parents hesitate to institute palliative care, regardless of illness severity (Thibodeaux & Deatrick, 2007). Sandoval (2003) found that African-American individuals with strong ties to Christianity might be hesitant to discontinue life-prolonging treatments because of a belief in divine rescue (Sandoval, 2003). In such circumstances, by accepting palliative care, parents may feel that their child is not being provided with the best possible care. Moreover, such interpretation can lead to a preference for life-prolonging treatments over interventions designed to reduce suffering and to provide comfort and support.

The underutilization of palliative care services among ethnic minorities, specifically Latino, Indian, Native and African-Americans, has been well described and often attributed to factors such as lack of the family's familiarity with hospice and palliative care services, language barriers, religious differences, difficulties in accessing insurance, distrust of the healthcare services, discomfort with introducing additional healthcare with professionals not of one's ethnic or cultural background into the home, physicians' discomfort, or a combination of factors (Greiner et al., 2003; Lyke & Colon, 2004; Hardy et al., 2011). However, there is a clear dearth of literature addressing cultural considerations in the pediatric palliative care field. Moreover, members of a specific culture often do not ascribe to the same religious traditions. This article sought to explore and address the influence of religion in pediatric palliative care, with emphasis on how culture informs lifestyle and shapes the universal experiences of illness, pain, and death.

## SEARCH METHODS

Literature reviewed for this article was identified through an online search of nine databases (PsychINFO®, MEDLINE®, *Journal of Citation Reports-Science Edition*, Embase, Scopus, CINAHL®, Social Sciences Citation Index (SSCI), EBSCO, and Ovid) for articles published between 1980 and 2011. Key terms: *culture, transcultural, spiritual, international, ethnic, custom or religion and end-of-life, palliative care, death, dying, cancer, or hospice, and children, pediatrics, or pediatric oncology* were combined. Reference lists in the retrieved articles were examined for additional studies that fit the inclusion criteria, and those relevant articles were also inclu-

ded for review. In addition, web-based searches of specific journals were conducted. These included, but were not limited to: *Qualitative Health Research, Psycho-Oncology, Journal of Psychosocial Oncology, Journal of Pediatric Psychology, Journal of Pediatric Health Care, Journal of Pediatric Oncology Nursing, Omega, Social Work in Health Care, and Journal of Palliative Medicine*. Studies were excluded if they focused on adjustment of children with serious illness rather than on cultural issues, or were not published in English.

Considering the limited number of published reports in the area of culture and pediatric palliative care, both qualitative and quantitative studies were included. Reference lists from retrieved articles and review articles were also searched for relevant studies. Two psychology students, a master's level social worker, and a scientific librarian conducted the search. Two separate reviewers with pediatric psychosocial oncology experience examined the full-text articles against the predetermined inclusion/exclusion criteria. Many other studies and resources provided important insights into cultural and religious beliefs that have applicability in end-of-life care, and are included in the references. Tables were constructed using categories such as demographic and cultural characteristics, followed by the creation of codes in order to perform a thematic analysis of the findings of each article. Once codes were independently grouped together in broad themes, consensus was obtained between the author (L.W.) and reviewers.

## RESULTS

Out of 93 articles identified through the literature searches, 37 met inclusion criteria: Crom, 1995; De Trill & Kovalcik, 1997; Flores et al., 1998, 2000; Levettown, 1998; Cantro et al., 2002; Crawley et al., 2002; Koenig & Davies, 2002; Solomon et al., 2002; Field & Behrman, 2003; Mazanec & Tyler, 2003; Himmelstein et al., 2004; Kato et al., 2004; Munet-Vilaro, 2004; Owens & Randhawa, 2004; Kemp, 2005; Abbe et al., 2006; Anghelescu et al., 2006; Campbell, 2006; Lobar et al., 2006; Mack et al., 2006; Meyer et al., 2006; Tomlinson et al., 2006; Kobler et al., 2007; Thibodeaux et al., 2007; Benini et al., 2008; Davies et al., 2008; Jacob et al., 2008; Kongnetiman et al., 2008; Surbone, 2008; Dell, 2009; Cantro et al., 2010; Gupta et al., 2010; Hatano et al., 2011; Moody et al., 2011). From these, seven distinct themes emerged that have implications for pediatric palliative care. These include the role of culture in decision making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and

suffering, the meaning of death and dying, and location of end-of-life care.

### The Role of Culture in Decision Making

Appreciation of cultural norms and customs is critical as it pertains to family decision makers and those who learn about the diagnosis or prognosis. For many cultures, family can be defined as not only immediate family members but also extended family and community members. For example, Olsen et al. (2007) report that Native American individuals may want information shared with community leaders so that they can help in decision making for the child. Mazanec and Tyler (2003) found that many African-American families prefer that conversations be initiated with the eldest member of the family, typically the male. Similar traditions of respecting the opinions of elders exist in Russian culture (Lipson et al., 1997; Matthews et al., 2006). Other studies found that Latino and Asian families when assessing the spiritual care needs of Latino and Asian families, other studies found that the family may stipulate that information be conveyed without the child present (Mazanec & Tyler, 2003; Brolley et al., 2007; Cardenas et al., 2007).

Child-rearing practices in different cultures may also play a role in decision making. Some cultures emphasize autonomy and independence, whereas others encourage boundary melding. For example, Japanese child rearing practices seem to blur boundaries between mother and child (Seiko, 1989; De Trill & Kovalcik, 1997). Other cultures emphasize living in harmony with one's environment rather than attempting to control it, which may lead to a more passive approach to illness and decision making. Illness may also have a different meaning depending upon which member of the family is ill. This is more prevalent for some traditional cultures that seem to present a strong desire to have male children to sustain the family line (Namboze, 1983).

Gender often plays a role in decision making. In both Asian and Latino families, the mother is typically regarded as the primary caregiver; therefore, decisions will often be placed in her hands (Himelstein et al., 2004; Phan & Tran, 2007). However, when possible, Latino women will seek the permission of the child's father before deciding to seek, continue, or discontinue treatment. This is a reflection of *familismo*, a term used to describe the power and strength of the family in Latino culture. *Familismo* is characterized by interdependence, affiliation, and cooperation (Cardenas et al., 2007). However, these traditional role assumptions are challenged when language becomes a barrier. The normative hierarchical family structure is often waived based

on the individual who speaks the best English, which often leads to a child or adolescent becoming the family spokesperson (Campbell, 2006). When the ill child is placed in a role of authority as translator of medical information for parents, conflict can ensue when treatment decisions need to be made (DeTrill & Kovalcik, 1997).

### Faith and the Involvement of Clergy

Parents of children receiving palliative care have noted that faith is central to their efforts to provide guidance, make sense of their situation, grant permission around end-of-life decision making, and to better cope (Meyer et al., 2006). Table 1 provides an overview of major faith traditions, beliefs, and practices at the end of life. Most families who are religious have certain customs around end-of-life care that they would like to have respected. Catholic Latino families will likely want a priest at the child's bedside to complete death rituals (e.g., reading of last rites) (Lee et al., 2007). Buddhists may wish to have a monk chant. However, the intention of this Table is not to be an algorithm, but rather a guide families of diverse faiths.

Whereas a guide for families of diverse faiths and religious traditions are important across cultures, the involvement of pastoral workers in pediatric palliative care is not universal. For example, Vietnamese families visited by the hospital chaplain often interpret this as a symbol of the child's impending death (Phan & Tran, 2007). Latino families may not want mental health workers involved in the grief process because they believe it signifies their grief as pathological (Cardenas et al., 2007). Overall knowledge of cultural differences is important, but it is vital that healthcare practitioners understand that such practices differ among people from the same heritage. For example, whereas most Vietnamese are Buddhist, they may have other religious affiliations such as Catholic, Evangelical Protestant, and Chinese Confucianism, and each religion may have a different practice. Asking family members about their preferences and rituals will help providers understand their particular needs and desires and reduce the likelihood of stereotyping.

### Communication: Spoken and Unspoken Language

Communication is a means by which people connect (Andrews, 2003), and verbal communication entails language, which can be a critical barrier in facilitating meaningful and deep communications that are foundational to pediatric palliative care (Kemp, 2005). Breakdowns in communication can lead to improper diagnosis, inadequate pain management,

**Table 1.** Major faith traditions, beliefs and practices regarding illness, dying and death<sup>a</sup>

	Buddhism <sup>b</sup>	Catholicism <sup>c</sup>	Hinduism <sup>d</sup>	Islam <sup>e</sup>	Jehovah's Witness <sup>f</sup>	Judaism <sup>g</sup>	Mormonism <sup>h</sup>	Protestantism <sup>i</sup>	7 <sup>th</sup> Day Adventists <sup>j</sup>
Illness/death rites or rituals	Family presence is important. May chant mantras as infant/child becomes seriously ill. The child's body should not be touched after death. Family may take the body home to prepare it for burial. The body should not be moved for 8 hours after death.	Sacrament of the sick with anointing of oil, communion, and final blessing by priest.	Ideal to be surrounded by family and friends who sing sacred hymns and say prayers or chant the dying person's mantra. When death is near, the family spiritual leader is asked to conduct final rites. The body should be as close to the ground as possible to help the soul absorb into the ground.	Body is washed 3 times. Muslim, burial performed within 24 hours. Cremation forbidden.	Prayer; reading Bible.	Prayers for the sick. No cremation. Living person always with body after death. Burial as soon after death as possible.	Laying on of hands, prayer, anointing with oil. Allow the ill to express sadness at life being cut short.	Variable; may include prayer, anointing body with oil, communion, laying on of hands, final blessing. Family presence may be important.	Prayer, anointing with oil
Autopsy	According to individual situation.	No restrictions.	If required by law.	Limited to medical and legal reasons.	If required by law.	If required by law.	No intrinsic objection.	No restrictions.	No restrictions.
Existence of Heaven	There are numerous heavens, hierarchically arranged and inhabited by joyous beings known as "gods" and "demi-gods".	"Heaven" is a condition rather than a place; provides eternal fullness of life. Supreme happiness flows from intimacy with God.	Heaven is a place similar to life on earth, but without sickness, old age, death. A soul enjoys the rewards of his or her good deeds.	Heaven is described as a "garden" having several layers with the highest being directly under God's throne. Souls are content.	Some people will go to heaven to rule with God and Jesus. The remainder of the righteous will enjoy paradise on earth.	Heaven is a place where anxiety and travail are ended. Quiet, peaceful, intellectual activity takes place and the mysteries of life are solved.	There are 3 "degrees of glory"; all are places of continuing growth and progress. Those who attain the highest level will live with God, Christ and their own families.	Varies. Some believe Heaven is a place with streets of gold, or a place to be in the presence of God, whereas others believe Heaven is a condition of eternal happiness and fulfillment.	Heaven is being in the presence of God. It is the dwelling place of God and will ultimately be located on the renewed earth.

Continued

Table 1. Continued

	Buddhism <sup>b</sup>	Catholicism <sup>c</sup>	Hinduism <sup>d</sup>	Islam <sup>e</sup>	Jehovah's Witness <sup>f</sup>	Judaism <sup>g</sup>	Mormonism <sup>h</sup>	Protestantism <sup>i</sup>	7 <sup>th</sup> Day Adventists <sup>j</sup>
Belief in reincarnation	Yes, all Buddhists believe in the notion of rebirth.	No, it contradicts basic Catholic teaching.	The notion of reincarnation and karma is a strong premise in Hindu thought.	No, there is only one life on earth.	No, Jehovah's Witnesses believe that at death life ceases to exist.	Recycling or transmigration of souls is an essential doctrine of traditional Jewish belief.	It is believed that every man and woman will be resurrected.	No, it is contrary to the Christian concept of salvation.	No, there is only one life on earth.

<sup>a</sup>These are general, historical beliefs and practices according to some world religions. Always inquire with your patient and family about their individual preferences.

<sup>b</sup>Kongnetiman et al., 2008.

<sup>c</sup>Johnson & McGee, 1998; Puchalski et al., 2004.

<sup>d</sup>Flood, 2003; Kongnetiman et al., 2008; Thrane, 2008.

<sup>e</sup>Johnson & McGee, 1998; Kongnetiman et al., 2008.

<sup>f</sup>Chambers, 2009; Watch Tower Bible and Tract Society of Pennsylvania, 2012.

<sup>g</sup>Lamm, 1967; Dubov, 1995; Johnson & McGee, 1998; Puchalski et al., 2004.

<sup>h</sup>Johnson & McGee, 1998.

<sup>i</sup>Johnson & McGee, 1998; Puchalski et al., 2004.

<sup>j</sup>General Conference of Seventh-Day Adventists, 1992.

underutilization of prescription medications, and difficulty in obtaining informed consent between Latino patients and their medical providers (Crom, 1995; Flores & Vega, 1998; Flores, et al., 1998, 2000) as well as in other cultures. Families can experience additional despair when language barriers result in an inability to acquire complete information about their child's health status or a physician's recommended interventions (Contro et al., 2002). This emphasizes the need for trained medical interpreters to be used to mediate communication between family and healthcare professionals (Field & Behrman, 2003; Randhawa et al., 2003). The choice of words, too, can create barriers to successful communication. For example, Native American, Filipino, Chinese, and Bosnian cultures emphasize that once words are spoken out loud, they may become a reality (Seairight & Gafford, 2005). Therefore, reluctance for parents to talk about end-of-life care may be based on the belief that acknowledgement of their child's impending mortality may be self fulfilling (Liu et al., 1999). In addition to the spoken word, other nonverbal cultural variations may impede accurate communication. Nodding the head in many Asian and Latino communities simply indicates listening, not agreement to what a healthcare professional is saying (Phan & Tran, 2007). Direct eye contact may be interpreted as aggressive or hostile in the Chinese and African American communities (Campbell, 2006). In Latino communities, direct eye contact can be viewed as a means of transferring illness via *mal ojo*, or evil eye (Lipson et al., 1997). A similar view is prevalent in both Native American and Vietnamese communities (Olsen et al., 2007; Phan & Tran, 2007).

In the United States, communicating difficult information is often accompanied by gestures such as touching the arm or hand, which are often used to convey warmth, empathy, or reassurance. However, gestures can be interpreted differently by other cultures and are imbued with great cultural significance and meaning. Some cultures are more tactile than others (Giger & Davidhizar, 2004). Touching a child's head, a common means of showing affection in European-American culture, can be viewed as disrespectful. For example, Native Americans have many traditions around the head and the hair, and prefer that no one touch their head unless absolutely necessary. Native Americans also prefer to have medical examinations conducted from the feet up rather than from the head down to demonstrate that the most important part of the body is attended to last (Olsen et al., 2007). More recent Vietnamese immigrants may have concerns about touching the patient's head (Phan & Tran, 2007). If this is an area of concern, head touching or patting as means of building rapport should not be used with the

child. Religious doctrine, too, must be respected. In the Orthodox Jewish traditions, touching a parent of the opposite sex, even if the intent is to show compassion, is prohibited. Similar views may be shared by individuals of Islamic faith (Campbell, 2006).

### **Communication with Children about Death: Truth Telling**

Communication with patients and families in palliative care is influenced by many factors beyond the child's age, especially regarding the cultural dimensions of truth telling (Hatano et al., 2011). If a parent opposes disclosure of a terminal illness (especially when the child is an adolescent), conflict between the healthcare team and family can occur, even when cultural norms are followed. Western psychosocial care recommends that parents should be committed to truthfulness beginning at the child's initial diagnosis and encourages open, age-appropriate communication with children (Matthews et al., 2006). Reluctance to discuss death can represent parents' own pain and inability to accept the certainty of their child's end of life. Families may decide not to discuss death even if their child may anticipate not surviving the illness, and nondisclosure can interfere with preparation for dying (Davies et al., 2008).

There are many cultures where nondisclosure of life-threatening diagnoses to a child is acceptable (Elwyn et al., 1998). Chinese, Korean, and Russian-American families often choose not to convey a death diagnosis to the child for fear that this will damage his or her hope, causing a poorer prognosis (Brolley et al., 2007; University of Washington Medical Center, 2007; Song & Ahn, 2007). Parental decisions about whether to inform a child about impending death may also depend upon whether they believe the emotional burden associated with this knowledge may be harmful to their child or may expedite the child's death (Woo, 1999; Payne & Chapman, 2005; Gupta et al., 2010).

Lack of communication can lead to emotional distance at a time when closeness is most needed. If the family is comfortable with their child participating in his or her end-of-life care, documents that address advance care planning may be useful to initiate such conversations (Wiener et al., 2008). Most hospice programs require an advance directive (AD) prior to services being provided. However, research shows that non-white adults, particularly Asians, Hispanics, African-Americans, and Mexican-Americans, have lower rates of completing written ADs than other ethnic groups. Factors that elucidate this claim include distrust of the healthcare system, varying cultural perspectives on death and suffering, the role of family dynamics (Baker, 2002;

Perkins et al., 2002; Searight & Gafford, 2005), an aversion to signing legally binding documents (Kitzes & Berger, 2004), or a view that discussions about advance directives is disrespectful and can bring bad luck (Orona et al., 1994). No research was found that examined cross-cultural similarities and differences pertaining to parental attitudes toward advance care planning for one's child. Parents, however, often have strong wishes about their child's end-of-life care but may express them at different times to different people — or not at all. Diligently learning about the child's and family's wishes, some of which may be rooted in ethnic culture, is paramount to avoiding communication pitfalls (Perkins, et al., 2002). For example, appointing a specific family member to be in charge of end-of-life decision making may lead to extended family conflict for many Latinos, who find a consensually oriented decision-making approach more acceptable (Morrison et al., 1998). Alternatively, presenting issues in hypothetical terms to determine level of comfort (Srivastava, 2007) may be less threatening to those who find direct conversations about death disrespectful or unacceptable.

### **Meaning of Pain and Suffering**

Regardless of whether a family chooses to discuss impending death with their child, the management of their child's pain and suffering is a critical issue for all parents. In a landmark study designed to gain greater understanding and insight into the symptoms experienced by children at the end of life, Wolfe et al. (2000) found that 89% of parents believed their children suffered "a lot" or "a great deal" from at least one symptom in the last month of life. In other studies, inadequate assessment of pain was found to be a barrier to effective pain treatment in children from diverse ethnic backgrounds (Flores & Vega, 1998; Abbe et al., 2006; Ljungman et al., 2006; Jacob et al., 2008). Specifically, language and cultural barriers make pain assessment and treatment particularly challenging for clinicians. Anderson and colleagues (2000) discovered minorities in the United States to be at greater risk for unmanaged pain because of a lack of medical insurance, poor access to appropriate preventive care, delay in reporting symptoms, cultural beliefs, distrust of medicine, and other factors associated with physician judgment. It is possible that these barriers exist for families considering pediatric palliative care and pain management.

The perception and experience of physical pain and the meaning pain has to one's existence varies by culture (Davidhizar & Bartlett, 2000). In the Chinese culture, pain has been understood as a result of blocked Qi. To resolve the pain, the blockage must be

removed and the patient must return to a state of harmony with the universe (Chen et al., 2008). Latino individuals have been noted to interpret pain and suffering as a form of punishment from a spiritual power — with the sick individual needing to endure pain to be granted entrance to heaven (Davidhizar & Giger, 2004) and as a test of their personal fortitude (Munet-Vilaro, 2004). Other countries such as India, Bangladesh, Nepal, Pakistan, and others in South Asia were found to share similar views of reincarnation pain (Matthews et al., 2006). For the reasons mentioned, individuals from these cultures may be more likely to under report pain or feel they have to endure it. Whether these findings hold true for children as well as adults is not known.

Culture can also influence the request for medications or treatments to assist in ameliorating pain (Post et al., 1996). Chinese, Korean, Vietnamese, and Native Americans have been reported to view asking for assistance with pain as a sign of disrespect (Burhansstipanov & Hollow, 2001; Gunnarsdottir et al., 2002). Campbell (2006) found that Vietnamese individuals often find it rude to say no to a doctor, therefore increasing the likelihood that they will not contradict doctor's orders if the amount of pain medication is insufficient. Within this cultural frame of mind, medical professionals are viewed as experts in their respective areas and are not to be corrected. If the patient explained that more medication might be necessary, the pain could be more adequately controlled (Dell, 2009). Alternatively, cultures that value self-control and stoicism in the face of pain further decrease the likelihood of voicing complaints of unmanaged pain (Brolley et al., 2007). Research conducted on pain perception in Native Americans found that this population will often not report pain, or will do so through metaphors or storytelling, making pain management challenging. For example, one Native American patient told a long, detailed story about the pain of one of his tribesman, when the pain was actually his own (Olsen et al., 2007). Children raised within these cultural norms may adopt similar styles to describe or attribute their pain or the need for pain management.

Choice of treatment at the end of life may also reflect cultural differences that are incongruous or supplemental with the medical treatment provided in the hospital or as recommended by hospice providers. Latino individuals with indigenous roots may engage in healing rituals that seek to remove evil spirits from the body of the sick individual (Mazanec & Tyler, 2003). Some practices commonly described in the literature include the use of amulets, herbs, or natural remedies. Chinese Americans may incorporate special cloths or amulets into treatment and may

give the sick individual special foods in an attempt to restore balance in metaphysical energies (Mazanec & Tyler, 2003). Asian, Native American, and Latino individuals may choose to augment Western medical treatments with specific herbs deemed beneficial for their child, such as ginseng, an herb often used by Korean families (Brolley et al., 2007; Song & Ahn, 2007). Vietnamese families may use a practice known as *cao gio* (coin rubbing) or *bat gio* (skin pinching) as a means of removing noxious elements from the body (Campbell, 2006). Native Americans might seek treatment in a sweat lodge prior to and in conjunction with hospital-based treatment as a means of purifying the body of toxins introduced by European-Americans. This act is thought to repair physical and spiritual damage to an individual. Alternative medicine, such as massage, acupuncture, or moxibuxtion<sup>1</sup> might also be viewed as front-line treatments across cultures (Campbell, 2006). Moreover, many ethnic minorities in the United States will often seek medical help from traditional healers before using standard medical hospitals or outpatient settings (Cardenas et al., 2007). Different customs and traditions related to cause of illness and proper treatment can significantly impact the degree to which families will seek out and follow through with treatment. Research is lacking but it has been suggested that less acculturated families may also have less access to health insurance (Flores & Vega, 1998). Consequently, it is possible that minority children might initially present with greater severity of disease than individuals who are more acculturated to United States society.

### Meaning of Illness, Dying and Death

A common existential or spiritual issue often grappled with by children and young adults living with a life-threatening illness is the search for the meaning of pain, illness, suffering, and death. This meaning is not static across cultures. Native American children and families, for example, typically have a holistic view of both health and sickness (Olsen et al., 2007). Believing in a delicate balance between nature, spirituality, people, and the greater community, any balance disruption can lead to illness and/or death (Olsen et al., 2007). In Chinese, Korean, and Vietnamese cultures, illness and death are viewed as a natural part of life (Brolley et al., 2007; Phan & Tran, 2007; Song & Ahn, 2007), and

<sup>1</sup>Moxibuxtion is a traditional Chinese medical technique that involves the burning of mugwort, a small spongy herb. This is thought to accelerate healing in the sick individual (Mazanec & Tyler, 2003).



illness may occur when there is an imbalance in competing energies within the body (Matthews et al., 2006). These energies include, but are not limited to, hot and cold and light and dark (Brolley et al., 2007).

Vietnamese families describe illness as a conflict between the body and nature (Phan & Tran, 2007). Many Asian individuals of Buddhist, Confucian, or Hindu faiths may attribute illness and suffering to bad karma (Brolley et al., 2007) and view suffering as a mechanism for atoning for sins committed in a former life. Avoidance of suffering will only transfer pain to the next life (Mazanec & Tyler, 2003). South Asian communities also often attribute illness and suffering to sins committed in a previous life (Matthews et al., 2006). For this reason, individuals within these communities who are critically ill may be stigmatized rather than treated empathetically; they are seen as deserving the affliction from which they are suffering (Chaturvedi, 2008). Muslims believe that illness can result from bad actions, in this or past lives, and that illness washes away a person's sins (Minarik, 1996). Korean and Russian individuals sometimes view illness as arising from interfamilial or peer conflict (Brolley et al., 2007; Song & Ahn, 2007). Latino families will often interpret death as something both natural and uncontrollable, and believe that one's fate is often left in the hands of God (Cardenas et al., 2007). Actions taken at the end of life may be associated with later bereavement reactions. For example, people in the Chinese culture who believe a "bad death" is a curse may be overwhelmed with guilt if they have been unable to facilitate what they believe to be a "good death" for their child (Xu, 2007).

Himmelstein et al. (2004) recommends conducting spiritual assessments with the child and family as an essential element of pediatric palliative care. This includes assessing the child's hopes, dreams, and values as reported by the child, beliefs about the meaning of life and death, and opinion on the role of prayer and ritual in times of illness. In addition, conversations around past experiences with death or other traumatic events are often useful in determining the child's view of what occurs to someone following both physical and metaphysical death (Himmelstein et al., 2004). Gently probing spiritual values surrounding pain and suffering can also facilitate appropriate spiritual care for a child and family. If, for example, one learns that the child is experiencing spiritual distress because his or her pain cannot be overcome with meditation, then counseling from a spiritual advisor might improve quality of care and communication (Whitman, 2007; Thrane, 2010). Family members may benefit from being asked if there are times that they would like a minister or

other spiritual leader present as such support can reduce distress and suffering throughout the trajectory of the child's illness and death (Braun & Nichols, 1997).

### Location of End-of-Life Care

The meaning and purpose sought in both life and death, including rituals and customs, might be linked to a specific desired setting for end-of-life care. Religious practices post-death are broadly addressed in Table 1. Limited literature is available on cultural differences pertaining to whether one's final days are best spent at home or in a medical facility. Some Chinese individuals believe that death in the home is a sign of bad luck, whereas other Chinese individuals fear that if an individual dies while in the hospital, his or her soul will be lost (Mazanec & Tyler, 2003). Both Latino and Filipino families may prefer that the child die at home. Many Filipino families prefer that every family member possible say a personal goodbye to the child, which calls for sensitivity by hospice or hospital workers and may impact on home-based or hospital-based palliative care (Mazanec & Tyler, 2003). Moreover, if any stigma exists around the child's illness, families might ask that hospice workers be discreet in arrival and departure from the home so as not to draw attention to the family (Chaturvedi, 2008).

Indian families may prefer that end-of-life care focus on symptom management and control of the child's pain. They may not see a need to involve the palliative care team in addressing the spiritual or holistic needs of the child (Owens & Randhawa, 2004). Many Indian families will also designate certain rooms in their home for specific activities, which may impact home care. Healthcare professionals will be expected to spend their time not in the child's sick room but rather in a room designated for greeting and hosting guests.

When death occurs, cultural differences in expressions of grief may be observed. In Latino culture, the grief process may be displayed very publicly. Family members often wail at the bedside of the sick individual, both before and after death (Cardenas et al., 2007). Such conduct is not permitted in Islam, which holds that believers are to face bereavement like all the other trials of life, with patience, and wailing could indicate discontent with Islam (al-Jawziyyah, 1997). Beliefs and traditions may also mandate how the body should be cleaned, prepared, and cared for following a child's death. Such traditions may also include who touches the body last, whether someone needs to stay with the body until burial, and rituals of giving forgiveness for any harm or discomfort caused during

his/her lifetime. Families may have strong feelings about issues such as autopsy and organ donation. It is critically important that each family be asked about their own traditions and beliefs so that whenever possible, arrangements can be made to respectfully accommodate families (Kobler et al., 2007).

## CLINICAL IMPLICATIONS AND FUTURE DIRECTIONS

Models of pediatric palliative care call for a family-centered approach and early integration of palliative care to enhance the quality of life for the child and family members (Wolfe et al., 2000). A family-centered approach is also appropriate cross-culturally, as it aligns with collectivist traditions and is sensitive to structural differences in family roles and values. As the patient population in the United States becomes increasingly multicultural, a nascent body of evidence supports cross-cultural training, the use of cross-cultural principles, and the appreciation of the needs of immigrant patients and families. The Institute of Medicine has published two reports underlining the necessity for cross-cultural training (Institute of Medicine, 2001, 2011). In 2002, the Initiative for Pediatric Palliative Care (IPPC) undertook a quality improvement project designed to help improve both access to and utilization of pediatric palliative care. The IPPC group specifically highlighted the exigency of providing care that is culturally sensitive, but specific directives on *how* to accomplish this were not provided. Table 2 provides information on how to provide culturally sensitive care within the pediatric palliative setting by synthesizing IPPC's framework. Considerations for tailoring these suggestions to align with best practices for cultural competency and sensitivity within different ethnic populations are reviewed in Table 3.

There are now a plethora of online resources to assist in implementing cultural competence (see University of Washington Medical Center's Culture Clues<sup>®</sup>; Ethnomed; Health Resources Service Administration (HRSA) Cultural Competence Resources for Health Care Providers). The trouble now is not availability of resources, but creating a balance of cultural education with individual conversations. Concepts of culture should not be used to predict individual behavior, as this can lead to stereotyping (Crawley et al., 2002). Future research regarding culturally based preferences in pediatric palliative care will help physicians improve working models of palliative care to ensure the best quality of life and end-of-life care for the child and family faced with a life-threatening illness.

## Study Limitations and Future Research Directions

Several limitations to this review of cultural considerations in pediatric palliative care are important to note. The influx of immigrants into the United States makes it impossible to document all cross-cultural differences, especially as ethnic communities represent many different national origins, cultures, languages, and traditions. Therefore, research lags behind real time. Most current literature addresses cultural differences from an informative angle, providing a survey of practices and beliefs unique to ethnic groups. Group and individual viewpoints within cultural differences are not well explored. Some areas of needed study include practitioner bias, results of cross-cultural training, and healthcare system handling of cultural practices that may bump into Western ways of medical services delivery. Also, future studies should address a systems perspective in cultural differences, training, practitioner accommodation, and patient and family responses pertaining to a child's death in particular. Additionally, few empirically based studies concerning cultural variances within pediatric palliative care have been published, and most of these concern adult cohorts. The pediatric data available are primarily descriptive or based on parent report. Finally, the studies identified through this search were limited by great variability in terms of sample size, study setting, patient demographics, and measurements used. These weaknesses in the literature limit conclusions and extrapolation. It is hoped that the current review will inspire both new and seasoned researchers to investigate best practices in diverse nations to promote excellent care for children at the end of life. The authors hoped to learn about the appropriateness for members of a healthcare team to attend funerals in different faith and cultural communities. Such information was not found in this search. This would be another important area of exploration in future studies.

## CONCLUSIONS

A number of potential barriers to Western ideas of appropriate pediatric palliative care emerged from the literature. These cultural barriers may not be manifested overtly by patients or their families, but can result in the misinterpretation of medical information (De Trill & Kovalcik, 1997) and care options at the end of life. Palliative care commands knowledge and respect of individual value systems, beliefs, family structure, religion, ethnic roots, and cultural norms, as well as group cultural practices. Understanding ethnic variations is only a start, not an end, to the needed exploration (Perkins et al.,

**Table 2.** Synthesizing IPPC's framework to provide culturally sensitive pediatric palliative care

Content areas	Recommendations	Cultural examples
Maximize family involvement in decision making and care planning, allowing comfort for individual family members.	Family structure and roles differ cross-culturally. Family beliefs differ within a cultural/spiritual community. Avoid stereotypes. It is important to initially assess families' religious beliefs, rituals, and dietary practices to avoid future conflict. Talk with parents or designated decision makers about their perceived and desired role in caring for the ill child. Ask about their perceptions and fears regarding the disease and outcome (De Trill & Kovalcik, 1997).	Native Americans may want information shared with community leaders to help in the decision-making process (Olsen et al., 2007). Asian and Latino families often place decisions in the mother's hands, as she is typically the primary caregiver (Himelstein et al., 2004). When possible, women from Latino cultures will seek permission of the child's father; relates to <i>familismo</i> – concept of the strength of family (Cardenas et al., 2007). Traditionally, the eldest male in Vietnamese families makes decisions (Lee et al., 2007). In Russian culture, the entire family makes decisions – the patient and the person closest to the patient have the most influence (Milshteyn & Petrov, 2007).
Inform and involve children with life-threatening illnesses in decisions about their care as fully as possible, given their developmental abilities and desires.	To avoid conflict between the healthcare providers and the family, honest and open communication to children should occur with caregiver consent. The child's age, awareness of his/her fate and lack of communication can interfere with end-of-life care (Davies et al., 2008).	Chinese, Korean, and Russian-Americans normally decide not to convey the diagnosis to the child (Brolley et al., 2007; Song & Ahn, 2007 University of Washington Medical Center, 2007). Latino families prefer to hear the diagnosis first so they can relay the information to the child (Lipson et al., 1997; Sandoval, 2003).
Reduce pain and distressful symptoms for children with life-threatening illnesses.	Many cultures have different interpretations of enduring pain and relief of pain. Assess family attitudes and beliefs in order to reduce pain and distress. Ask how pain and suffering have been managed in the past and whether strong beliefs exist pertaining to treatment. Great care should be taken in discussing any medical condition to assure understanding. May receive a more accurate picture of suffering by asking about changes in functioning rather than a description of pain.	Chinese families may incorporate special cloths into treatment (Mazanec & Tyler, 2003). Asian-Americans may request or stop using pain medications because of fear of side effects, a belief that pain will be a burden to family members, and "deeply-rooted values and beliefs of stoicism and fatalism which inhibit pain expression" (Dhingra, 2008, p. 29). Asian, Native American, and Latino families may augment Western medicine with specific herbs (Mazanec & Tyler, 2003; Brolley et al., 2007) whereas other ethnic minorities may seek medical attention from traditional healers (Cardenas et al., 2007; Olsen et al., 2007; Phan & Tran, 2007). Nodding the head indicates the person is listening; it does not signify agreement (such as pain is under control). Vietnamese families may take part in " <i>cao gio</i> " (coin rubbing) or " <i>bat gio</i> " (skin pinching) to remove noxious elements from the child's

Continued

**Table 2.** *Continued*

Content areas	Recommendations	Cultural examples
Provide emotional and spiritual support to children and families as they cope with the multiple losses associated with life-threatening conditions.	<p>In some cultures, emotional well-being may be considered a family issue and incorporation of mental health services can be misinterpreted as an implication of mental illness. Mental health workers should be careful when discussing their role and services – limit psychological terminology when possible. Because of some cultural differences, documented religion might not address spiritual beliefs or traditions. Spiritual assessments are essential in pediatric palliative care. The term “palliative” can be perceived in many cultures as giving up hope; time and consideration are needed when introducing the concept.</p>	<p>body (Campbell, 2006; Phan &amp; Tran, 2007). Latino and Filipino individuals may wail at the patient’s bedside to indicate their respect (Mazanec &amp; Tyler, 2003). Morphine may be feared and seen as a sign of hopelessness in Russian and Indian cultures (Milshteyn &amp; Petrov, 2007). Korean families believe that mental illness is shameful and stigmatizing (Brolley et al., 2007). Latino families see mental illness as a sign of weakness (Cardenas et al., 2007). It is always helpful to ask whether there is anything that the family would like to share about their faith, their child’s emotional well-being, or beliefs about illness that can help provide the best care possible. Psychological problems can be presented as vague physical complaints. Symptoms of depression may be expressed as a cultural metaphor such as having “heart problems,” “being out of harmony,” or having problems with social or physical universe.</p>
Facilitate continuity of care across settings, both within and outside the hospital. Offer bereavement support to the child and the family before and after a child’s death.	<p>Ethnic minorities under-utilize hospice services (Mazanec &amp; Tyler, 2003; Sandoval, 2003). Hospice workers should be sensitive to cultural practices when taking care of children within a family home. Inquire about personal family traditions. Family practices may conflict with healthcare policies. Ask before incorporating spiritual care prior to death. Such visits can be viewed negatively by some cultures. Both spiritual and psychosocial providers should adequately explain their role and purpose for visiting. Appropriate communication methods are vital for home-based and hospital based healthcare professionals. Ask if and how the family would like to be contacted.</p>	<p>Nearly all Japanese children with cancer will die in a hospital (Kato et al., 2004). Some Chinese-Americans believe that death at home is bad luck, whereas others fear that death in a hospital means they may lose their soul (Mazanec &amp; Tyler, 2003). Filipino families want every family member to say a personal goodbye to the dying person (Mazanec &amp; Tyler, 2003). Latino families may want to stay with the body until burial (Kobler et al., 2007). Some Latino families believe that the child’s spirit is lost if the child dies in the hospital. They may also want to light candles for 24 hours or display pictures of saints to honor the child (Cardenas et al., 2007). Vietnamese families who are seen by a chaplain believe that the chaplain’s presence is a sign of finality (Campbell, 2006). Catholic Latino families may want a priest to be present at the bedside to complete death rituals (Cardenas et al., 2007; Phan &amp; Tran, 2007).</p>

IPPC, Initiative for Pediatric Palliative Care.

**Table 3.** *Ethnicity and cultural considerations at end of life*

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/end of life care
Chinese (Lipson et al., 1996; Mazanec & Tyler, 2003; Payne & Chapman, 2005; Campbell, 2006; Brolley et al., 2007)	Loyalty to family and devotion to traditions emphasized. When possible, engage the whole family in discussions that involve decisions and education about care.	May be reluctant to say “no” to a doctor or healthcare provider because it may be considered disrespectful or cause disharmony. Direct eye contact may be interpreted as hostile or rude, specifically with women. A slight bow demonstrates respect for authority figures. Patient and family may nod, say “yes” or offer other affirmative vocalizations, but this often conveys that they heard what the staff member is saying, not necessarily agreement, approval or understanding.	Illness and death often viewed as a natural part of life. Health is the result of balancing competing energies: hot and cold, light and dark.	May incorporate special cloths or amulets. May consume special foods and herbs that restore yin/yang balance. Patients may seek traditional Chinese therapies such as massage, acupuncture, and moxibuxtion (traditional Chinese medicine technique that involves the burning of mugwort, a small, spongy herb, to facilitate healing).	There is no one monolithic Chinese culture. Rituals will depend upon religion (Buddhism, Confucianism, Taoism, Christianity). Some believe that death in the home is a sign of bad luck. Some believe that if a person were to die in the hospital, his/her soul would get lost. Typically will not want organ donation or autopsy to be performed.
Japanese (Long, 2004; Pierce, 2007; Kongnetiman et al., 2008)	Family members collectively make the decision regarding medical treatment	Patient and family may use nonverbal, subtle, and indirect communication. Families prefer to be told the diagnosis directly first to decide whether or not to tell the patient.	Death is viewed as natural, inevitable and not the final aspect of life. Beliefs of reincarnation may be present. Families may not acknowledge that death is caused by cancer because cancer is stigmatized in Japanese culture.	May perform Reiki – a Japanese method of reducing stress and promoting relaxation as a healing mechanism. Other healing methods may include acupuncture and moxibuxtion. The prayer of “pillow sutra” may be recited before moving the body. May refer to die at home rather than in a hospital. Family members may gather around the bedside and have a minister perform special chants.	May prefer cremation instead of burial. Belief that the body should be whole to be properly reincarnated. May not want organ donation.
Korean	Mothers are exclusive caregivers, but the oldest	It is respectful to give a slight bow when you greet	If Buddhist or Confucian, illness and death are seen	May seek help from a hanui, or traditional	The patient will often trust family to make medical

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**Table 3.** *Continued*

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/end of life care
(Murphy, 1995; Song & Ahn, 2007)	male is typically the spokesperson	someone. Sustained eye contact is uncommon. Men and men may shake hands, but women and men and women and women do not. Self-control is often of high priority; patient may not express pain verbally.	as a natural part of life. Symptoms may be result of bad karma Illness can result from conflict in family and peer relationships. Health is the result of balancing competing energies: hot and cold, light and dark.	healer, who often uses herbs. Ginseng is especially common.	decisions for him/her, and see no need for an advanced directive. May view Western medicine as too strong, and as a result may alter how much medicine is taken (only taking half, stopping medication before told).
Vietnamese (Lee et al., 2007; Phan & Tran, 2007)	The women in the family are the primary providers.	The family spokesperson may be the person with the best English. Family and patient may nod or say yes to demonstrate that they hear you, not as a sign of assent or understanding. Often seen as disrespectful to say no to a doctor as they are the expert. May avoid eye contact as sign of respect. May not request medicine for pain, even when needed.	Illness may be explained as imbalance between the body and nature, the result of germs, or the result of a behavioral cause.	May utilize coin rubbing ( <i>ao gio</i> ) or skin pinching ( <i>bat gio</i> ) to aid in removal of unwanted elements in the body.	Visit from a hospital chaplain may be viewed as signifying impending death. These visits should be explained thoroughly before occurring.
Filipino (Mazanec & Tyler, 2003; Kemp & Rasbridge, 2004; Lobar et al., 2006; Diversicare, 2009)	In the Philippines, family may be an extended multi-generational household. Philippine community persons should be contacted when family is not available.	Communication should be directed toward the head of the family, and should not take place while patient is present. On first encounter, use Mr. Mrs., Miss or professional title.	Sometimes discussing end-of-life preferences is avoided as it is thought it may hasten death	Most (90%) are Catholic; will often utilize “sacrament of the sick.” Use of rosary beads and frequent use of rosary beads and prayer at bedside.	Individuals will likely prefer to die at home. Family may prefer to clean body after death. Each family member may wish to personally say goodbye. Typically do not want organ donation, autopsy or cremation. Loud demonstrations involving crying and wailing show respect, importance, and love for the deceased.

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**Table 3.** *Continued*

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/end of life care
<p>South Asian: India, Bangladesh, Nepal, Pakistan, Maldives, Sri Lanka (Laungani, 1996; Minarik, 1996; Moazam, 2000; Periyakoil et al., 2011)</p>	<p>While the decision maker is typically the family patriarch, the family is actively involved and death is viewed as a family and communal process. Rituals are very important.</p>	<p>Communication is enhanced when providers ask specific questions such as How do you think your child's sickness should be treated? What alternative therapies are you using currently? How do you want us to help you? Who do you turn to for help? Who should be involved in decision making? Close knit family is common structure. Family members and physicians may share decision-making duties.</p>	<p>Cancer (and other chronic or terminal illnesses) is often attributed to sins committed in a past life. Because of this, there is often stigma associated with serious illness, and sometimes even social isolation of the family. May feel that the illness is washing away her/his sins and would resolve once the sins are washed away or by doing certain religious rituals. Illness should not be capitalized.</p>	<p>Many South Asians are Hindu, and may request such rituals as: Putting patient on the ground instead of in a bed Pouring holy water into the mouth or onto the bed of patient</p>	<p>Health professionals within the home should be cognizant of the spatial culture. Certain rooms are often delegated for specific activities, such as greeting or caring for the sick. Moslem death rituals may include ceremonial washing of the body with holy waters, directional positioning of the body toward the Holy Land of Mecca, and recitation of the Holy Koran by loved ones. May be different preferences for care of the remains of their child. Ask about preferred rites and rituals in a sensitive and gentle manner.</p>
<p>Latino (Mazanec &amp; Tyler, 2003; Sandoval, 2003; Davidhizar &amp; Giger, 2004; Cardenas et al., 2007; Tellez-Giron, 2007)</p>	<p>Mother determines when a person needs care, but the permission to seek/ continue/ discontinue care comes from the father. Usually spokesperson is typically the father or oldest male. Although a male often speaks for the household, decisions are typically made as a family. <i>Familismo</i> is a term used to describe the power and strength of the family in Latino culture, and is characterized by interdependence, affiliation, and cooperation. The family is a source of emotional support and there is a high degree of intimacy between all family members. Patients will likely want to be near to and be able to see their family as much as possible.</p>	<p>Nodding often used to signify respect, and should not be taken as a sign of assent. Eye contact may be avoided by some Latino groups as a sign of respect, or because of the belief in evil eye. <i>Personalismo</i>: Having informal conversations with all family members, and not just addressing the patient and his or her parent can build trust. Mutual respect must be demonstrated. <i>Respeto</i> is highly valued in terms of familial hierarchy. Should address older individuals using Señor or Señora.</p>	<p>Pain often viewed as a form of punishment. The suffering of pain must be endured if the individual is to enter heaven. Illness may be seen as the result of an imbalance (between external and internal causes, hot and cold, natural and supernatural). May believe that the patient was specially selected for suffering. Belief in <i>espiritismo</i>: good and evil spirits affect health and well-being. Some believe that illness can be explained by <i>mal ojo</i>, or evil eye. For example, if people admire a child without touching them, child can become ill. Death viewed as a natural end to the life process, and something that is completely out of one's control (in hands of God).</p>	<p>Wailing at bedside of sick individual is common and seen as sign of respect. May seek care from <i>curanderos</i> (folk healers). Often use amulets or rosaries when praying for sick individual, and may display pictures of saints in hospital room. May ask to have candles lit at all times while the individual is in the hospital. May have concern that the spirit will get lost in the hospital room. After death, often offer daily masses and light candles in honor of the deceased.</p>	<p>Many Latinos will not want to stop life prolonging treatments, regardless of the severity of the illness of the child/individual. <i>Jerarquismo</i> may influence the family's belief that there is a medical cure for the patient. Do not typically utilize hospice services, perhaps due to unfamiliarity with system, language barriers, or distrust of healthcare system. Would greatly benefit from increased education regarding hospice. Prefer for individual to die at home (death in hospital could indicate loss of soul). Those who are Catholic (90%) will often want to have a priest or clergy member say the last rites when death is near. Often prefer to cleanse the body by themselves after death, as a sign of respect for life and death.</p>

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**Table 3.** *Continued*

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/ end of life care
Native American (Campbell, 2006; Olsen et al., 2007)	Family unit includes not just immediate and extended family, but also community leaders.	Direct eye contact may be interpreted as hostile, rude or dangerous to the soul. Pain will either not be expressed or may be expressed through storytelling rituals. Storytelling is also used as a way to build trust and relationships with people. Silence is highly valued.	Often view health and illness as holistic in nature. People, community, nature and spirituality are all connected, as are physical, spiritual, emotional and mental health. People become sick when there is a disruption in the balance of these forces.	May want to seek traditional healers for help in restoring harmony of sources of life. Herbal remedies may be used in conjunction with healing ceremonies. May use sweat lodges	Typically do not want organ donation or autopsy to be performed. Grieving is considered normal and natural, and wailing is common. May be hesitant to involve mental health as this connotes grieving is a sign of mental illness. May be hesitant to sign advance directives or other end of life documents because of general mistrust of signed documents (history of misuse of written treaties and documents with Native Americans by the U.S. government and other majority entities).
African- American (Mazanec & Tyler, 2003; Sandoval, 2003; Campbell, 2006; Mitchem, 2007)	Place large importance on family.	Conversation should be initiated with the eldest member of the family. Likely to see public displays of emotion from the family. Direct eye contact may be interpreted as hostile or rude.	In African-American folk healing, human life is understood relationally. Illness is derived from germs and from situations that break connections with others. Death is not a formal break with life because the spirit/soul continues and may be able to interact from the next plane of existence.	Story and action are intertwined in healing. The healer or “rootworker” is important as this person can orchestrate the natural, spiritual, and relational aspects of life.	Rely on healthcare team for help with cleaning and preparation of body. May refuse to stop life prolonging treatments because of a belief in <i>divine rescue</i> . This signifies that an all-powerful God can bring about miraculous interventions and is derived from the Old Testament. Do not typically complete advance directives, in part because of belief that this limits access to appropriate medical care. Often will prefer a life-prolonging treatment to a pain-reducing one. May see palliative care as an effort on the part of medical providers to deny them the best treatment possible.
Caribbean-American (Lipson et al., 1997; Fernandez Olmos &	Men hold a position of authority whereas women are seen as the nurturers and tend to the	Families may be more expressive or	Healing practices often originated in spiritual practices.	Those who require balance due to illness may seek out the help of a priest of	Close relatives will likely want to be present at the time of the patient’s death

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**Table 3.** *Continued*

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/end of life care
Paravisini-Gebert, 2003)	family. Children are to be respectful of elders.	demonstrative than the average family.	Sickness and death are not always attributable to natural causes – a curse can cut lives short. Afro-Cuban therapies are often plant based and herbs are used for spiritual cleansing.	Ocha. Prayer and hymn-singing at the patient's bedside may occur. Some Caribbean-Americans may use voodoo practices in addition to following Catholic traditions. Those who practice Voodoo will have rituals that evolve around spirits that represent a fusion of African and Creole gods, the spirits of deified ancestors, and Catholic saints.	and efforts to bring the family together are important. Patient and family may desire that, if the patient is of age, he or she have holy communion before his or her death. Older generations may believe that the body needs to be intact for it to pass into the afterlife, thus may object to either autopsy or organ donation. Burial is most common, and funerals are very important. Home is usually kept open for a week to welcome mourners.
Russian- American (Milshteyn & Petrov, 2007; University of Washington Medical Center, 2007).	The parent or the eldest child typically makes decisions.	The patient is often not told of prognosis as there is a belief that this will only worsen his or her condition. Often prefer that the doctor, rather than a nurse or other staff member, communicate diagnosis and treatment considerations. Family members often want to have long conversations with the doctor regarding the patient, and prefer these conversations be held in a private room. Family members may appear cheerful with patient to avoid causing further distress to patient.	Illness may be attributed to environmental causes, including familial stress and conflict. For many Russians, and specifically Russian Jews, nutrition is extremely important to health. If a patient can eat it is seen as a very positive sign.	Family is very important, and usually at least one family member will always be at the bedside of the patient. Laying of the hands often used. Religious icons may be brought to the hospital room. The earth is considered sacred, and therefore soil might be brought into the room in jars or pots.	Often will not grieve in front of the dying individual; however it is acceptable for the patient to express their pain and grief openly. Providing a patient with morphine may be interpreted to mean that the patient's case is hopeless/terminal. Autopsy is acceptable, but organ donation often is not. Typically will not want to sign an advance directive or durable power of attorney document. All relatives and friends are expected to visit the patient if death is judged to be close. Often prefer a priest, rabbi, or other religious figure to be present at the death. Family may either close the eyes and mouth of patient after death or place coins on their eyes. If the child dies in the hospital, may request the body to be brought by the

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Table 3. Continued

Ethnicity	Family structure/ Role of family	Communication considerations	Meaning of illness, suffering, and death	Healing practices and rituals	Considerations for palliative/ end of life care
					<p>home for a final visit.            Wailing and other public expressions of mourning common in the home, not in public.            Often have specific rituals for washing the deceased's body.</p>

2002). Beliefs and practices vary along the spectrum of education and Western acculturation. Moreover, families may not be able to perform traditional rituals or customs within Western cultures, and feel they must conform to practices that differ greatly from their own fundamental beliefs, values, and practices (Laungani, 1996). At the end of a child's life, the focus needs to be on quality as defined by the family, not the provider. Supporting parents so that they can fulfill their traditional role as caregivers, protectors, decision makers, providers of love and physical tenderness, and instillers of faith (Meyer et al., 2006) requires an individualized approach to end-of-life care. Respecting beliefs, customs, and traditions with a focus on preserving the integrity and sanctity of the parent–child relationship is of utmost importance in pediatric palliative care.

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