

ChiPPS E-Journal

Children's Project on Palliative/Hospice Services

Released in collaboration with the National Hospice and Palliative Care Organization

National Hospice and Palliative Care Organization
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ChiPPS E-Journal
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Issue Topic: Caring for Diverse Populations

Welcome to the 52nd issue of the ChiPPS E-Journal. This issue of our E-Journal explores topics related to caring for diverse populations. Professionals and volunteers who work in pediatric palliative/hospice care often are presented with children and families whose religious, cultural, and ethnic backgrounds are different from their own. How can professionals and volunteers best respond to such situations? How can they best prepare themselves to be helpful in these encounters? How do things look from the point of view of the children and family members who find themselves in such situations? This issue seeks to provide at least a beginning in discussing these matters.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by ChiPPS's E-Journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Our tentative plan for the remainder of 2018 is to develop an issue on issues related to adolescents and young adults. We are currently discussing topics to address in this E-Journal in 2019. If you have any thoughts about these topics, contributors, or future issues, please contact Christy at christytork@gmail.com or Ann at ann@here4U.net.

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Issue #52: Caring for Diverse Populations

Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.

Stuck in a Tunnel: Nothing Else Matters

p. 5

Scott Newport

In this article, our resident poet, essayist, and father of a child who died at a young age, muses about the situation of families who have a child with a life-threatening illness. Such families, he reflects, often can only think about one thing: How can I protect my child and save his or her life? He suggests that perhaps we “should consider explaining to staff and faculty that these families are not bad people for how they act, but to understand they are stuck in a tunnel and are unable to see outside it.”

Embracing Cultural Diversity: Seizing the Opportunity to Make Treasured Memories

p. 6

Marisel Nasis-Matuza, MS, RN, CPNP, and Marianne Muzic, LCSW, ACHP-SW

Drawing on their work at St. Mary’s Hospital for Children in Bayside, Queens, which they describe as the “largest and most experienced provider of long-term care to children with medically complex conditions and New York City’s only post-acute care facility for children,” the authors argue that even though it is not possible to know in advance everything about every culture that might be encountered, still “cultural competence embraces discovery, respects differences, and delivers care with dignity to all patients and their families. Genuine cultural competence entails curiosity and humility. It requires a commitment to develop a deeper understanding of the family’s health care preferences and a respect for their wishes. This can be accomplished by simply expressing an interest in their cultural heritage.” A case example illustrates such care in practice and a table describes “General religious post-death practices of the most common religions” that the authors have served.

Just Ask: Inquiry in the Context of Pediatric Palliative Care

p. 9

Suzanne S. Toce, MD, FAAP

In this article, Dr. Toce employs a case study from which to create a list of some of the many aspects of diversity that can be encountered in pediatric palliative/hospice care. She goes on to create additional lists of communication strategies and sample inquiries. The article concludes in this way: “Accept that culture is fluid and that diversity is universal. Work towards a shared understanding with the family and child. Do not stereotype. Treat each child and family member as a unique person with her/his own ‘culture.’ Treat every conversation as ‘cross cultural.’ To do that, you must be open and trusting, and you must inquire.” An annotated list of Toolkits and Additional Resources completes this article.

Providing Culturally Competent Perinatal Palliative Care

p. 15

Ginny Silva, MS, FNP, CNS, RN

This article focuses on the special situations encountered in perinatal palliative care and the increasing diversity in the U.S. population. In such circumstances, “The concept of culturally competent care applies not only to patients and families but also to those providing care.” If so, “Western approaches to death are not always appropriate for many grieving families.” That is, care providers must “treat others the way THEY want to be treated.” Illustrative cases demonstrate that “cultural care considerations may all be best served by allowing all families experiencing perinatal loss the opportunity to express hope and miracles while planning for more realistic outcomes and to replace tenderness over technology.”

Creating Inclusion and Well-Being for Underserved Grieving Children

p. 20

Linda Goldman, MS, LCPC, NBCC, FT

This article begins on a hopeful tone: “Emerging paradigms are shifting focus to solutions for every child by inviting a forum for discussion, offering insights that lift dialogue to a higher level of awareness, and creating welcoming environments whereby underserved children can grieve and grow.” Nevertheless, there is value in coming to appreciate some common signs of grieving and traumatized children as set forth here. Pictures and drawings show how marginalized children can be given new avenues for expression so that home, school, community, and peer groups can work together to meet the needs of such children. In this way, “Together we can seek solutions that make the impossible possible ... the dream that every grieving child feels loved, comforted, understood, and respected in their homes,



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classrooms, community, and world.”

Global Partners’ Volunteer Preparation Toolkit: Promoting Culturally-Sensitive Care p. 28
Elizabeth Arnold, MPH, Lindsay Engh, MPH, CHES, and Heather Willis, MA

“This article explores a free online resource to promote principles of culturally-sensitive care among an interdisciplinary team. The *Volunteer Preparation Toolkit* was created by Gundersen Global Partners, a program of Gundersen Medical Foundation at Gundersen Health System in La Crosse, Wisconsin, to prepare staff members for volunteer service in several communities around the world.” The program “has enlisted more than 670 volunteers over the past nine years to further healthcare, education and community development initiatives.” Here the authors describe their work and recommend that “evidence-based resources such as Global Partners’ *Volunteer Preparation Toolkit* can be utilized to promote cultural learning among staff, spark initial discussions, initiate changes to organizational policies, and bring peace to children and families who desire to be understood during their times of greatest need.”

Improving Pediatric Palliative Care for Latino Children and Their Families p. 33
Sara Muñoz-Blanco, MD, and Renee D. Boss, MD, MHS

Taking note of the fact that Latinos are the largest ethnic minority group in the United States, the authors point out that Latino children have worse health outcomes than other members of the U.S. population, largely as a result of barriers in access to care and also access to pediatric palliative care services. Although Latinos who live in the U.S. come from different countries and backgrounds, they share language, experiences and cultural values, and they often face barriers of limited English proficiency, limited availability of medical interpreters, the complexities of the U.S. health care system, and misunderstandings or knowledge gaps about PPC. Beliefs in “fatalismo,” “familismo,” and “respecto” may also influence Latino attitudes toward care. To address these challenges, the authors suggest several clinical, research, and policy strategies.

Supporting Transgender and Gender Nonconforming Children Living with Life-Threatening Illness p. 36

Jessie Rose Cohen, LCSW, and Ilana Sherer, MD

“This article aims to support HPC [hospice/palliative care] providers in offering gender affirming care to pediatric patients.” The authors explain the concepts of “transgender” and “gender nonconforming” as applied to TG/GNC individuals and provide tables that describe principles of gender affirming care, recommendations for inclusive palliative care for TG/GNC individuals, standards of practice within a gender affirming care model, and medical and legal resources for transgender individuals. Discussion of two extended case examples and of parents who are TG/GNC enrich this text. The authors conclude that “TG/GNC children and youth living with life-threatening illness benefit from a combined approach of pediatric palliative or hospice best practices in addition to gender affirmative care.”

Treating Children of Divorce: Obtaining Custody Documents and Setting Clear Ground Rules are Key p. 44

Karen Burke-Haynes, MD

This article seeks “to address some of the administrative challenges that may arise in the [medical] office in high conflict scenarios” with children who are involved in divorce. A case study describes appropriate care but inadequate consent. The author then offers some practical guidance to physicians on protecting their practices and avoiding problems. Reprinted by permission from the North Carolina Medical Board.

Cultural Sensitivity

Coalition to Support Grieving Students

Recognizing that different cultures express grief in different ways, the first piece of advice in this single-page document is, “Often what works best is to simply be present, express your concern, and remain available to provide helpful assistance.” Next the document recommends that those who seek to provide care should be observant by asking questions, watching out for assumptions, and being present and authentic. Reprinted by permission from the National Center for School Crisis and Bereavement (www.SchoolCrisisCenter.org).



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ADDITIONAL NOTES

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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpc.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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STUCK IN A TUNNEL: NOTHING ELSE MATTERS

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I've been thinking lately about decision making for families in pediatric palliative care.

I recently reflected on what a mom said while her daughter was nearing death in the PICU. Occasionally, I am asked to visit families in these high stakes situations.

"There's nothing else that matters beyond these walls," is what she whispered to me.

She was correct.

I was also thinking about yesterday, when I was in a cramped, dark place just above an office I was renovating. The tight space was a dusty attic with a ceiling that was only five feet tall. I was on my knees trying to carefully connect live electrical wires with just the light from my iPhone. I needed to be totally focused, not thinking about anything else. If I connected the wrong wires, I could have shut down the whole operation at the complex.

When I got home that evening I started to wonder about how our minds are wired. The thought immediately reminded me of a day when my son, Evan, was alive. Our private duty nurse had called me at home because Evan was having trouble breathing. My mind was totally focused on saving my son's life, nothing else mattered.

After the nurse and I agreed on ventilator settings and added a little oxygen, we stabilized Evan's respiratory status. I took a deep breath and remembered I needed to go back to work. While backing out of my driveway in my van, I hit a parked car. I know that stuff happens, but that was the third time it had happened since the birth of Evan.

My question is this: When families have a child with an acute or chronic life-limiting illness, is their ability to make good decisions impeded because their minds are overloaded with just one thought? How can I save my child's life? How can I protect that child? Primal instincts, I think.

In the short term, these questions are necessary not only for the parents but also for the providers of care. But if their minds are wired in such a way they can only think of these questions, is it possible they may forget about their other kids or maybe to pay the gas bill at their home? They may be so focused they forget about other things that could have large impact on their lives later. Or they may forget to look in their rearview window for cars that may be parked right behind them.

These thoughts have made me wonder if we need to help families understand these types of human dynamics while they are asked to make life-altering decisions. Or if one should consider explaining to staff and faculty that these families are not bad people for how they act, but to understand they are stuck in a tunnel and are unable to see outside it.

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EMBRACING CULTURAL DIVERSITY: SEIZING THE OPPORTUNITY TO MAKE TREASURED MEMORIES

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According to *Ethnologue: Languages of the World* (www.ethnologue.com), there are more than 7,097 languages spoken in the world. While the count is not exact, the *New York Times* reports that our state of New York is home to over 800 of them, with 138 different tongues spoken in New York's most diverse borough of Queens (<https://www.nytimes.com/2010/04/29/nyregion/29lost.html>). One neighborhood in Queens, Jackson Heights, boasts 167 languages, all within a few blocks, making it the most linguistically diverse neighborhood in the world. In another smaller Queens' neighborhood of Bayside, residents and families of St. Mary's Hospital for Children (see Note) currently speak 11 different languages. They also identify with 13 different religions.

With such an array of the spoken language comes an equal variety of cultures, traditions, and spiritual backgrounds. As health care providers, our goal is to provide the best possible care for all patients and their families. Realizing that our patients and their families have different belief systems, life experiences, value systems, faith traditions, and healthcare philosophies, the challenge in our multilingual and multicultural society is learning how to provide services that are aware of and sensitive to these differences. This is particularly essential during pediatric end-of-life care, a time that can be anxiety-ridden, or a time to make treasured memories.

Before delivering "culturally sensitive" care to patients, providers must become cognizant of the cultural attitudes upon which they form their judgements. Many times, behaviors of others are interpreted as negative because the fundamental value system of their culture is not understood. As providers of care, our understanding and beliefs regarding health and illness may differ significantly from the population we serve. Once providers recognize this underlying difference between health care providers and their patients, then the elements of "cultural identity" can be explored. These include language, tone of voice, family structure and authority, cooking and dining traditions, concept of time, spirituality and religion, and non-verbal cues such as gestures, body language, and facial expressions.

The Initiative for Pediatric Palliative Care (IPPC) Quality Improvement Project of 2002 outlined recommendations for providing culturally sensitive end-of-life care. The framework included understanding the influence of religion in pediatric palliative care, as well as understanding how culture influences lifestyle and shapes experiences of illness, pain, and death across cultural barriers. This approach reflects a commitment to culturally respectful, family-centered care of children with life-threatening conditions. An awareness of cultural norms and customs is vital in successfully supporting the child and family, reducing suffering, and providing care and comfort.

Different cultures have unique viewpoints on illness and the medical treatment a child should receive. This cultural diversity also guides beliefs about death, end-of-life care, and customs at funerals. General religious post-death practices of the most common religions represented at St. Mary's Hospital for Children are broadly summarized in Table 1. Note that care must be taken not to generalize faith traditions across all families. Rather, traditions are dynamic, and identification of these religious variations is not an end, but only a beginning to further exploration of individual family practices and traditions.



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TABLE 1:

RELIGION	FLOWERS	FOOD	PHOTOGRAPHY/ RECORDING	CREMATION	EMBALMING
Islam	No	Yes	No	Forbidden	Only if required by local law
Judaism	No	Yes – bring to “Shiva”	Voice recorder only	No	Traditionally prohibited
Hinduism	Yes, but not to funeral	No	No	Yes	Permitted but not typical
Buddhism	Yes, but no red flowers	No	No	Traditional & preferred	Accepted
Catholicism	Yes	Yes	Only with permission	Yes, but scattering of ashes not permitted	Yes

In today’s multicultural society, pediatric palliative care providers are faced with unique challenges when delivering culturally sensitive care to children and their families. With growing numbers of diverse cultures served, it is not possible to know everything about every culture. Rather, cultural competence embraces discovery, respects differences, and delivers care with dignity to all patients and their families. Genuine cultural competence entails curiosity and humility. It requires a commitment to develop a deeper understanding of the family’s health care preferences and a respect for their wishes. This can be accomplished by simply expressing an interest in their cultural heritage. Being careful not to make blanket generalizations, the relationship with each family must be slowly initiated, carefully establishing trust by asking questions such as “What would you like us to know about your family’s spiritual and cultural practices?” and “What is important to you and your family?” The information is then shared with the members of the Palliative Care Team, clearly communicating specific cultural and religious preferences for each individual family.

St. Mary’s developed the first in-patient pediatric palliative care program in the United States in 1984. Since then, St. Mary’s no longer has a dedicated Palliative Care Unit consisting of 9 beds. Today, over half of our 103 residents receive palliative care and are integrated in all four units. With a Palliative Care Team consisting of medical providers, nurses, social workers, pharmacists, therapists, nutritionists, complimentary care providers and volunteers, much information is gathered about our patients and families. We glean significant understanding of their wishes, values, relationship dynamics, and spirituality. With sensitivity and empathy, cultural preferences regarding decision making and advance planning are elicited and incorporated into the culturally competent pediatric palliative care we provide for our diverse patient population. Emphasis is placed on quality of life as defined by the parents and/or family. It is important to remember that at the end of a child’s life, parents need to feel they are being supported and their decisions are being respected.

After living at St. Mary’s for the past four years, Sara (name has been changed) died this past spring. Her parents faced many challenges, including disparities between family members converging in Bayside from all over the nation and Canada, as they made decisions regarding Sara’s palliative care. In the end, the parents were presented with the information they needed to make the best possible choices for their daughter. We understood their cultural traditions, respected their religious beliefs, and appreciated the complex circumstances facing this family. We took the time to discover what was important to this family in particular, despite being familiar with generalities of the Hindu faith. We used empathy to engage the parents in their daughter’s end-of-life care plan, allowing them control and supporting their decisions. For these parents, it was very important to have staff surround the family at the bedside vigil during Sara’s final days. Although we couldn’t eliminate the pain of losing their daughter, we did share their loss. They allowed us to enter their sacred space, and we were humbled to join them. It was an honor to provide the family with multiple opportunities to create treasured memories through legacy building by recognizing



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and embracing cultural diversity.

"...Words cannot express our immense gratitude! We could not have made it through this difficult journey without all of your love, support, help & guidance along every step of the way... So much love & care... enabled us to be at peace when we weren't by her side because we knew she was in great hands.

Thank you for allowing us to perform all of the necessary cultural rituals throughout her stay. Thank you for respecting all of our requests!! It truly means so much to us all!

...All the wonderful memories... we will treasure forever!"

- A Thank-you from Sara's parents

NOTE: St. Mary's Hospital for Children in Bayside, Queens is New York's "largest and most experienced provider of long-term care to children with medically complex conditions and New York City's only post-acute care facility for children... providing unparalleled continuum of care for patients... and much needed support for the families who love them."

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JUST ASK: INQUIRY IN THE CONTEXT OF PEDIATRIC PALLIATIVE CARE

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The topic of this issue concerns providing pediatric palliative care (PPC) in the context of cultural diversity. Culture can be considered to be *"that **complex whole** which includes knowledge, beliefs, arts, morals, laws, customs, and **any other capabilities and habits** acquired by [a human] as a member of society."* (Tylor, 1986; my bold highlights). Based on that broad definition, **all** communications between the health care provider and the child/adolescent and their family are cross-cultural. The education, knowledge, experience, and worldviews of providers are very different and diverse from that of the child/adolescent and family. Once you accept that the person in front of you is from a different "culture" in the broadest sense, you can begin inquiry that will help to form a foundation for collaborative care and decision-making in the context of PPC.

Consider this potential situation:

Cheng, the 13-year-old, first-born male of a native-born Hmong woman, is admitted to the pediatric ICU with the diagnosis of an osteosarcoma of his right thigh with metastases to his lungs and other bones. Cheng was 4 years old when he moved to the U.S. and is eager to participate in all discussions. Both the mother's father, who is the community elder, and her partner by a traditional but not legal marriage are present at the bedside. After stabilization, there are urgent decisions to be made. How do you establish a common understanding of the issues and a framework for collaborative decision-making?

What are some of the aspects of diversity that we encounter in PPC?

- **Personal identity**
 - Gender identity (and, for older children, sexual orientation)
 - Race/ethnic group
 - Age/developmental stage. There may also be diversity in the perceptions of developmental and mental health norms.
 - Ability; disability
- **Family/community identity**
 - Race, tribe, ethnic group, extended family
 - "Family" composition, structure, and caregiving situation
 - The role of the child within the family and within the group
 - Socioeconomic status
 - Social class
 - Access to health care/insurance status
 - Community status
 - Adopted/foster child/naturally born
 - Immigration status – citizen, naturalized citizen, refugee, immigrant, undocumented immigrant, migrant
- **Communication**
 - Preferred language; style of communication
 - Communication to children about death and dying, including attitudes concerning disclosure, truth telling, and patient autonomy (Weiner et al., 2013)
 - Manner of expressing distress
 - Non-verbal communication



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- **Life experience**
 - Education
 - Literacy
 - Health literacy
 - Living situation
 - Past and present health care experiences and relationship between patient/family and the health care provider(s)
 - Degree of acculturation
 - Experience of racism, discrimination

- **Psychosocial/behavioral environment**
 - Illnesses
 - Adverse childhood events – family instability, violence, abuse
 - Other stressors
 - Support systems – extended family, community, faith community, school
 - Ways of coping

- **Beliefs and behaviors**
 - Values, behaviors, customs
 - Religious/spiritual beliefs, including the role of pain and suffering, and the role of faith providers
 - Fears about discrimination, deportation etc.
 - Health beliefs
 - Explanatory illness model, meaning of illness
 - Traditional health beliefs and practices; reliance on alternative medicine, and non-licensed healers. Ask about “traditional healers” and use of alternative treatments. While respecting patient/family beliefs, the provider should continue to support evidence-based treatment.
 - Meaning of pain and suffering
 - Idioms of distress – how pain and symptoms are physically, emotionally, and verbally expressed
 - Trust or distrust of the health care system and/or providers
 - Death and dying rituals, and expressions of grief including
 - Usual end-of-life care
 - Meaning of death and dying
 - Location of end-of-life care and death
 - Access to and control of the body
 - Religious beliefs including belief in miracles
 - How hope for recovery is perceived among family members and the providers
 - The balance between fatalism and desire to control future events
 - Memory making, mementoes, legacies
 - Decision-making including the voice of the child. The parents are the usual unit of decision making in many but not all cultures. In some cultures it is a spiritual advisor, community leader, or male family elder. The perceived role of women in some cultures may diminish the voice of mothers or female adolescent patients. The recommendations of a female physician may be considered less worthy than that of a male physician.

The list is never ending and cultural traditions are ever changing. And remember that there may be even more diversity within a group than between groups or cultures. The child/adolescent and the parents are likely from very different “cultures,” often influenced by degree of acculturation. So, it is important to not assume that your knowledge or experience transfers to all members of that group or culture. Do not “stereotype.” You should inquire!



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Communication strategies

- Express and project interest, respect, and openness to different cultures and viewpoints.
- Be willing to adapt if possible
 - Minimize conflicts. Try to “stand with” and align with the family. In cases of difference, reaffirm that you and the family both want what is best for their child but may have different thoughts about what is most beneficial. Be clear about some aspects that are non-negotiable such as refusing to lie or hasten death. Consider accepting an unusual treatment decision if the family’s preferences are within their cultural norms and legally, ethically, and medically acceptable even if it is not what you would choose. The case reviewed by Penn and colleagues (2013) is an example of this occurring during a family care conference. Trust is central to the provider–child/family relationship.
- Be mindful of verbal and nonverbal communications – facial expressions, gestures, eye contact, and touching. Be sensitive about cultural taboos and actions.
- Use clear unambiguous language free of “jargon”
 - Use developmentally appropriate language with the child.
- Be clear about the child/family’s concept of disclosure – does it support honesty and trustworthiness? Does it signal a “wish” for that outcome? Is it disrespectful/impolite?
- Confirm understanding by asking the child/family to restate what you just told them – the “teach-back” method.
- Ask about immigration status only as necessary. Ensure the parents that you only ask because you are concerned that they may have fears about impact of their status on their child and treatment. Reassure them that there will be no legal impact. (Smith et al., 2009)
- Be aware that decisional conflict between the family and providers is higher in racial and ethnic minorities (Knapp et al., 2014). This may be, in part, from a mistrust of health care providers. This feeling has some basis in fact. Immigration status may intensify this mistrust. Primary language other than English enhances uncertainty and lack of support in decision-making. An ongoing provider–child/family relationship enhances trust and facilitates decision-making.
- Develop a culturally diverse provider group representative of the populations being treated to support optimal communication. Train all staff in cultural sensitivity strategies.
- Optimize model of care – the use of a medical home supports coordinated family-centered care. While there may be distrust of the “medical system,” those from diverse cultures tend to trust their long-term providers.

Some sample inquiries (use plain, understandable, unambiguous language and an interpreter as indicated):

- Speaking with the child/adolescent – Be open and receptive. Be loving and respectful (Van Hal et al., 2008). Encourage verbal and non-verbal communication. Your Child Life staff should be very helpful. Be literal and specific. Allow the child to guide the conversation. Empower the child within the tenets of the culture.
 - Tell me about yourself, your family and friends, and your daily life at home and in the hospital.
 - What makes you happy? What is your favorite thing to do? Who are your favorite friends?
 - Who do you go to when you feel sad? Who do you talk with?
 - What do you fear or worry about the most?
 - What do you think is happening? What do you think caused your illness/condition? Why is this happening? Do you think that anything you did or said caused the illness?
 - What do you think will make you better?
 - How do you think that you are doing?
 - If conversations about death and dying are appropriate:
 - What do you still want to accomplish?
 - What is your understanding of what happens after you die?
 - What memories do you want to leave your friends and family?
 - How is your family handling your illness?
 - What do you fear or worry about the most?



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- Speaking with the family and support people:
 - Tell me what I need to know about your family/culture/community so I can provide your child the best possible care.
 - Were you born in the U.S.? (If not) At what age did you immigrate?
 - How do you prefer to be addressed and spoken with?
 - What language do you speak at home? What language does your child speak most frequently? Would an interpreter be helpful?
 - Tell me about your child and his/her illness/condition. What do you think caused your child's illness?
 - In your community/culture, how would this illness be treated? What are your expectations of the treatment/intervention?
 - How would the doctors talk about illness?
 - In your community/culture, how are pain and various symptoms expressed?
 - How do you and your family members cope?
 - In your community/culture, who makes decisions?
 - Are there religious, spiritual, or cultural beliefs that are important to you? Are there beliefs that help guide the decisions? Are there treatments that are encouraged or supported, or that are not allowable?
 - What/who are sources of support for you?
 - Who would you like to be present as we discuss your child's condition and treatment options?
 - What role do you wish to play in caring for your ill child?
 - What are your beliefs about dying, death, the afterlife, and grieving?
 - Are there rituals that are important to your child/you?
 - What do you fear or worry about the most?
 - What questions do you have? (NOT Do you have any questions?)

Who can assist as “translators”?

- Language: Trained medical interpreters are optimal to translate language and help providers understand potential cultural implications. They are superior to untrained staff. Do not utilize a sibling or family member as a language translator unless absolutely necessary. There are some excellent recommendations available for working with interpreters when communicating about end of life care (Smith et al., 2009).
- Culture: To gain insight about cultural issues consider:
 - Trained medical interpreters representing the culture of interest
 - Social workers
 - Faith providers or spiritual leaders representing that group
 - Elders or religious leaders of that community or group
 - Health care providers from that cultural/ethnic/religious group.

Follow up about Cheng: You have a brief discussion with the Hmong translator about typical Hmong cultural beliefs including health beliefs impacting treatment. Through the interpreter, you speak with the mother, father and grandfather. Per the family's request, Cheng is not initially included in this discussion. As anticipated, the grandfather is the spokesperson for Cheng and the family. Among other things, you inquire about their usual decision-making process, religious/cultural beliefs, and about health beliefs including their explanatory illness model. You reassure the family that you will do everything possible to honor their beliefs and at the same time to safeguard Cheng's life. You project positivity. You have been coached by the interpreter how to inform the family about likely negative outcomes such as loss of his leg and/or death. The interpreter suggests alluding to “other adolescents this sick” and their potential negative outcomes. The interpreter notes that speaking about a potential negative outcome for Cheng directly would be perceived as “wishing” the negative outcome for him. You talk to the family about truth telling and disclosure and how it will positively help Cheng. They agree to include Cheng in the discussions. You then ask Cheng about his beliefs and note where they differ from his family's beliefs. While you feel as though you are doing “shuttle diplomacy,” you are able to negotiate the minefields of treating an Americanized Hmong adolescent while honoring the Hmong beliefs and traditions of his



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family. During Cheng's stay, the entire extended family visits frequently and is very pleased with the entire staff and feel that they have been very well informed and that their beliefs have been respected and honored.

As Dr. Betty Davies and colleagues note, "Parents' experiences are optimized when they receive sufficient information plus implications plus attention to questions, concerns, emotions, and **cultural values**" (Davies et al., 2010; my bold highlights). Accept that culture is fluid and that diversity is universal. Work towards a shared understanding with the family and child. Do not stereotype. Treat each child and family member as a unique person with her/his own "culture." Treat every conversation as "cross cultural." To do that, you must be open and trusting, and you must inquire.

Toolkits

There are excellent expert toolkits that can assist the provider in providing culturally competent care to diverse populations:

The American Academy of Pediatrics has a **Culturally Effective Care Toolkit** revised in 2/2018. While not specifically related to PPC, it focuses on strategies to engage the patient and family from diverse backgrounds. **Lead Author:** Denice Cora-Bramble, MD, MBA, FAAP. **Lead Staff:** Regina M. Shaefer. <https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/effective-care.aspx> (Accessed 6-18)

Gandhi-Rhodes K, Rose-Odogwu C; Together for Short Lives. The Diversity Toolkit. 2018 <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Diversity-Toolkit.pdf> (Accessed 6-18). This is a very thorough document that will help guide organizations as they improve their cultural competence in PPC.

Georgetown University National Center for Cultural Competence. Self-Assessments. <https://nccc.georgetown.edu/assessments/> (Accessed 6-18)

AHRQ Health Literacy Universal Precautions Toolkit. This health literacy toolkit and others referenced in the AAP toolkit are primarily for adult English speakers. <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html> (Accessed 6-18)

Additional Resources

AAP Committee on Pediatric Workforce. Enhancing Pediatric Workforce Diversity and Providing Culturally Effective Pediatric Care: Implications for Practice, Education, and Policy Making. *Pediatrics*, 2013; 132:e1105-1116

Davies B, Contro N, Larson J, Widger K. Culturally-Sensitive Information-Sharing in Pediatric Palliative Care. *Pediatrics*, 2010, 125 (4) e859-e865 primarily concerning Mexican and Chinese parents' perception of communication.

Givler A, Maani-Fogelman PA. **Cultural Competence in Pain and Palliative Care** <https://www.ncbi.nlm.nih.gov/books/NBK493154/>. Primarily concerns adults. Brief review of cultural end-of-life issues concerning death, pain and palliative care for many ethnicities.

Hatano Y, Yamada M, Fukui K. Shades of Truth: Cultural and Psychological Factors Affecting Communication in Pediatric Palliative Care. *J Pain Symptom Manage* 2011; 41:491-495. Discussion of cultural influences on the value of truth telling to children.

Her C, Culhane-Pera KA. Culturally responsive care for Hmong patients: Collaboration is a key treatment component. *Postgrad Med* 2004; 116(6):39-46



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Knapp C, Sberna-Hinojosa M, Baron-Lee J, Curtis C, Huang I. Does Decisional Conflict Differ Across Race and Ethnicity Groups? A Study of Parents Whose Children Have a Life-Threatening Illness. *J Palliat Med* 2014; 17:559-567.

Linton JM, Feudtner C. What Accounts for Differences or Disparities in Pediatric Palliative and End-of-Life Care? A Systematic Review Focusing on Possible Multilevel Mechanisms. *Pediatrics* 2008; 122:574-582.

Penn AA, Paris JJ, Moore MP. Decision making for seriously compromised newborns: The importance of exploring cultural differences and unintended consequences. *J Perinatol* 2013; 33:505-508.

Smith AK, Sudore RL, Perez-Stable EJ. Palliative Care for Latino Patients and Their Families: Whenever We Prayed, She Wept. *JAMA* 2009; 301(10):1047-1057. While primarily geared to adults, this article contains a nice summary of optimizing use of interpreters, strategies for clear health communication, questions to improve cultural understanding of illness, strategies to promote trustworthiness of health professionals, and issues that may affect end of life care for Latinos.

Tylor, E. in Seymour-Smith, C. (1986) *Macmillan Dictionary of Anthropology*. The Macmillan Press LTD.

Van Hal M, Bennett D, Berzins S. Cultural Competency in Paediatric Palliative Care Research Report. August 2008. <http://fcrc.albertahealthservices.ca/publications/cultural/Cultural-Competency-in-Palliative-Paediatric-Care-Research-Report.pdf> (Accessed 6-18). Included are:

- 1) A family/parent interview guide including inquiries into view of death and dying, the hospital experience, support system, grief and bereavement experiences, and meaning of their child's death.
- 2) A health care professions interview guide including questions about culturally competent PPC and cultural competence in the hospital setting.

Wiener L, McConnell DG, Latella L, Ludi E. Cultural and religious considerations in pediatric palliative care. *Palliat Support Care*. 2013 Feb; 11(1):47-67. doi: 10.1017/S1478951511001027. This article includes a helpful table of cultural considerations at end of life for multiple ethnicities.

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PROVIDING CULTURALLY COMPETENT PERINATAL PALLIATIVE CARE

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Background

Perinatal loss (miscarriage, fetal, and neonatal death) occurs in more than one million women per year in the United States, with early losses occurring in up to 25% of pregnancies, and late losses (those >or equal to 20 weeks) occurring in 2-4% of pregnancies (MacDorman & Gregory, 2015).

Perinatal loss is also a unique type of loss. The mother and her partner feel like parents, but have no child to parent. An unborn or newborn lost at birth is not known to others; thus, there is typically a limited circle of acquaintances to share and understand. This type of loss is often a taboo or uncomfortable subject, thus many perinatal losses are hidden and/or not discussed. Parents are often caught in an unintended conspiracy of silence (Cote-Arsenault & Denney-Koelsch, 2016, Nordin & Clark, 2015).

Perinatal palliative care is founded on the premise that all pregnancies, no matter how brief, are of value, not only to the family, but also to society at large (Kobler & Limbo, 2010; Ryan, Bernhard, & Fahlberg, 2015). The sense of loss occurs from the beginning of the diagnosis, and continues through birth, death, and the grieving process. The process of palliative care for this patient population attempts to enhance the quality of life for the mother during the pregnancy, and for the infant and family throughout the period of birth until death, as well as alleviating symptoms produced by any medical condition such as a life-limiting anomaly or conditions associated with severe prematurity (Ryan et al, 2015).

Significance

Palliative care has undergone immense development as a specialty in the past decade. Perinatal palliative care (PPC) is a more circumspect view of palliative care, involving care for families facing a pregnancy that may not survive, or a newborn facing a life of low probability of survival. How providers assist families facing such a loss often reflects lack of education and skill in this aspect of care, but this lack of skills may be even more evident when one considers a family from a different cultural background, whether these differences are linguistic, religious, or encompass different health traditions, leading to cultural conflict.

Each culture has its own approach to dealing with perinatal loss. Grieving and death rituals vary across cultures and are often heavily influenced by religion (Lobar, Youngblat, & Brooten, 2006). We as care providers must become adept at learning, respecting, and dealing with death and loss from the perspective of the other person's view. Nurses and other care providers for families anticipating delivery of a baby who may not survive, or who may face critical illness that is life limiting, are often witnesses to their suffering and grief and may lack the ability to understand and relieve the grief (Somerville, 2007; Romesberg, 2004) as well as possess the self-awareness needed to examine our own attitudes and beliefs that may hinder adequate care (McGee & Johnson, 2014). Integrating culturally competent care for families of different backgrounds is imperative yet our approach for varying cultures can be misguided due to our lack of understanding and skills. This lack of a comprehensive understanding by providers is well documented in the literature (Broom et al., 2013).

The concept of culturally competent care applies not only to patients and families but also to those providing care. Western approaches to death are not always appropriate for many grieving families. The western approach often includes talking about the loss, also known as "talk therapy." Our western



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approach also includes viewing grief that is not expressed or is delayed as abnormal. Viewing grieving in a different culture may be more elaborate and protracted in other societies (Parkes, Laungani, & Young, 2015). Often there is no expert to help us understand others in their grief. Perinatal literature supports that all parents benefit from extensive counseling, support, and education presented by a multidisciplinary team (Munson & Leuthner, 2007; Wool, 2013). Staff caring for these families also require educational, ethical, and moral support, as well as the ability to provide cultural care that is sensitive, culturally appropriate, and culturally competent (Mixer et al., 2015; Somerville, 2007; Twamley et al, 2013).

Demographics and Diversity, Multiculturalism

Emerging data suggest that increasing diversity in the U.S. is on the rise, which may in turn signal that White Americans may soon relinquish a majority status (Burrow et al., 2015). By 2050, no particular ethnic group is expected to be a majority in the United States (Esterhuizen & Kirkpatrick, 2015). More than sixty million individuals in the USA speak a language other than English at home (Census Bureau 2011 Language Mapping). This reflects 20% of the USA population and has increased by 158% in the past three decades. The Census Bureau includes data for over 300 detailed languages with Spanish and Chinese as the top non-English languages spoken. A 2011 report shows that the percent speaking a language other than English at home increased from 17.9% in 2000 to 20.8% in 2011. Experts believe that NYC alone is home to as many as 800 languages.

Multiculturalism is the co-existence of diverse cultures, where culture includes racial, religious, political, or different ethnic groups and is manifested in: (1) customary behaviors; (2) cultural assumptions and values; (3) patterns of thinking; and (4) communication styles (Defining Multiculturalism. International Federation of Library Associations and Institutions, 2016). While the U.S. is a multicultural society, understanding and appreciating the various cultures encountered is often overlooked or misunderstood. When meeting with families, care providers should consider the acculturation of the family. Often this may involve experiencing “culture shock,” viewing different patient expectations to services such as patient autonomy versus paternalistic medicine, worldwide practices of limited medical disclosure, or cultural beliefs regarding how one handles disease and treatment. Language barriers alone can make individuals feel vulnerable and misinformed. Often, families may rely on other children to translate and communicate for them. Navigating our complex health systems may mean a delay in treatment or minimal involvement in care by the individual or family.

The basic tenets of diversity are not complex. First, don't be blind to differences. Also, culture and heritage are properties that make a way of life for specific populations (Spector, 2017). Accept others' perceptions as “true” for them. Most importantly, keep in mind that we judge ourselves by our intent. Others judge us by our impact. Choose behaviors that elicit an impact that is congruent with your intentions. A thoughtful method of achieving this is by invoking the Platinum Rule (Bennett, 2013). i.e., treat others the way THEY want to be treated. This rule accommodates the feelings and thoughts of others and is widely considered to be a more sensitive version of the Golden Rule.

Illustrative Cases

A 32-year-old mother presented in the latter half of her pregnancy to our perinatal palliative care team for the fetal diagnosis of multiple congenital anomalies incompatible with life. The patient was a recent immigrant from Haiti where she escaped following the devastation of her country's earthquake. She had witnessed the death of close family members and was able to immigrate due to her husband being in the USA. The patient spoke no English and her husband spoke some. The family was counseled regarding options and outcomes and, after discussion, chose palliative care. When the baby was stillborn, the family was strongly encouraged by staff to hold and view the infant, who was a normally appearing, term infant. Both mother and father declined. Staff followed our protocol and took pictures and made memories for them in a keepsake box including footprints, handprints, and a hair sample. At discharge, both parents declined the memory box, including pictures. Our social workers had provided them with burial information, including programs that would cost nothing. The family was very kind and appreciative in conversation but actually abandoned the baby in the hospital. Follow up phone calls and letters were ignored. Staff was especially saddened and surprised by this response. Further investigation by our team,



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with input from our interpreter services, gave us insight into this. In many Haitian families, especially those from rural settings, fetal anomalies and death are viewed as punishment for having an unhealthy baby, or proof that the mother was a bad person. Some feel viewing the horrors of others dying as causing the anomaly, in this case watching her aunt and grandmother die. Furthermore, most Haitians may interpret death as a curse. Understanding that the family viewed this baby as a curse certainly clarified their reluctance to hold or view, let alone to take her home to bury.

Patient AM, a 32-year-old Somali woman with a healthy five-year-old at home, presented at 32 weeks to our high risk clinic. Her fetus was found to have a lethal brain anomaly, and after consultation with our multidisciplinary team, agreed to PPC. The baby was born at term, and after an initial period of life support and ventilation, the family decided to redirect care. Understanding the predominantly religious Somali culture was key to interacting and caring for this family. Death is considered an act of God and is not to be questioned. Terminating a pregnancy is not an option, and most view such a situation as sent from God, and therefore, something that must be endured. Furthermore, this woman had other children die while living in a refugee camp in Kenya, so death was not new to her. Somalia is a country that has one of the highest infant death rates in the world, and a baby dying is almost a universally-accepted occurrence. It is a clan-based society with a strong network of family and friends, with a dominant position by males. In this case, the father and mother showed little emotion when their infant died in their arms. Only after input from our Somali interpreter and a staff nurse familiar with the culture were they able to explain that, even though this was a sad, unwelcome, but not unexpected occurrence, it was “normal” for them. The staff displayed great distress that a mother and father would not cry and show emotion at such a time. Appreciating the cultural differences allowed staff to give the family the space and time to grieve as they would in Somalia. This included a rather large group of women from the clan being allowed to openly wail at the bedside, an activity known as keening, and for the inclusion of the Imam to bless the baby and for the father to bathe the infant for immediate burial, as their culture dictates.

Death and bereavement across cultures involves a core of understandings, spiritual beliefs, rituals, expectations, and etiquette. Different kinds of deaths are understood and dealt with differently, whether generational, from the perspective of cultural embeddedness, the level of acculturation, or from the overlap between culture and religion. Language and linguistic interpretation must be considered, along with an understanding that often there may be no culturally accepted terms to describe the state of bereaved parent(s). The death of a child is inevitable in poorly-developed countries, and may include abbreviated rites. Each culture provides its own explanation for responses to the death of an infant or loss of a pregnancy (Spector, 2017).

Developing Cultural Competence in PPC

There is clearly a gap in knowledge regarding culturally and linguistically diverse families and end-of-life care. Understanding and recognizing this gap must be addressed to improve care. One must also understand that cultural consideration often involves religion. Cultural heritage helps shape how people grieve. Care providers must recognize that all cultures have developed adaptive grieving mechanisms. Also, one cannot assume that every aspect of a particular culture may be applied by all individuals and families within a given culture (Spector, 2017).

Believing we can be culturally “competent” is unrealistic without immersing oneself in that culture—which is rarely possible or realistic.

Many of us avoid addressing issues of difference because we are afraid of getting it wrong or offending others. What is realistic, admirable, and more attainable is to be culturally humble, to safeguard the premise of the Platinum Rule while caring for diverse families, especially those experiencing perinatal loss. Providing opportunities for families to practice rituals congruent with their culture and/or religion can allow meaning and significance to their baby’s existence, no matter how brief (Kobler, Limbo, & Kavanaugh, 2007). Assessing family needs using a family-centered approach while demonstrating sensitivity to ethnic, cultural, and religious differences will empower parents in their role and foster feelings of control and competence regardless of cultural background.



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Perinatal loss is a profound experience, not to be underestimated, regardless of ethnicity, diversity, spirituality, or religion. Each nurse and care provider must examine his or her own responses when providing care, reviewing one's own past experiences as well as finding ways of dealing with difficult issues. We must all work to create an environment where staff supports each other, to educate ourselves regarding diverse cultures by methods such as working with community support groups and our own hospital-based spiritual care departments and interpreter services. Education services and application of additional skills may be attained by developing professional relationships with local universities and intercultural global programs. Introducing staff to the Resolve Through Sharing® Bereavement Training in Perinatal Death program will provide organizations and staff the system-wide framework needed to provide sensitive, compassionate, and inclusive care. Furthermore, cultural care considerations may all be best served by allowing all families experiencing perinatal loss the opportunity to express hope and miracles while planning for more realistic outcomes and to replace tenderness over technology (Maron-Corwin & Corwin, 2008). Honor the baby and you honor the family.

References

- Bennett (2013). *Basic Concepts of Intercultural Communication: Paradigms, Principles, & Practices*. Intercultural Press, USA).
- Broom, A., Good, P., Kirby E., & Lwin, Z. (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal*, 43 (20), 1043-46.
- Burrow, A., Stanley, M., Sumner, R., & Hill, P. (2015). Purpose in life as a resource for increasing comfort with ethnic diversity. *Personality and Social Psychology Bulletin*, 40 (11), 1507-16.
- Cote-Arsenault, D., & Denney-Koelsch, E. (2016). "Have no regrets": Parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis. *Social Science & Medicine*. 154,100-9.
- Esterhuizen, P., & Kirkpatrick, M., (2015). Intercultural-Global competencies for the 21st century and beyond. *Journal of Continuing Education in Nursing*, 46 (5), 209-214.
- Kobler, K., & Limbo, R. (2010). Making a case: Creating a perinatal palliative care service using a perinatal bereavement program model. *Journal of Perinatal and Neonatal Nursing*, 25 (1), 32-41.
- Kobler, K., & Limbo, R. (2010). Making a case: Creating a perinatal palliative care service using a perinatal bereavement program model. *Journal of Perinatal and Neonatal Nursing*, 25 (1), 32-41.
- Kobler, K., Limbo, R., & Kavanaugh, K. (2007). Moments: the use of ritual in perinatal and pediatric death. *Maternal Child Health*, 32 (5), 289-95.
- Lobar, S., Youngblut, J., & Brooten, D. (2006). Cross-cultural beliefs, ceremonies, and rituals surrounding death of a loved one. *Pediatric Nursing*, 32 (1), 44-50.
- MacDorman, M., & Gregory, E., (2015). *Fetal and Perinatal Mortality: United States 2013, National Vital Statistics Reports*, 64 (8).
- Maron-Corwin, M., & Corwin, A. (2008). When tenderness should replace technology: The role of perinatal hospice. *NeoReviews*, 9, e348-352.
- McGee, P., & Johnson, M. (2014). Developing cultural competency in palliative care. *British Journal of Community Nursing*, 19 (2), 93.
- Mixer, S.J., Lindley, L., Wallace, H., Fornehed, M.L., & Wool, C. (2015). The relationship between the nursing environment and delivering culturally sensitive perinatal hospice care. *International Journal of Palliative Nursing*. 21(9), 423-9.
- No author. (2016). Defining multiculturalism. *Language use: Census Bureau*. Accessed June 30, 2018 @ census.gov.
- Nordin, T., & Clark, E. (2015). A family's experience with perinatal palliative care. *American Family Physician*, 91 (7), 442.
- Parkes, C. M., Laungani, P., & Young, B. (Eds.). (2015). *Death and bereavement across cultures*. New York: Routledge.
- Romesberg, T. (2004). Understanding grief. *Journal of Hospice and Palliative Nursing*, 6 (3), 161-170.
- Ryan, A., Bernhard, H., & Fahlberg, B. (2015). Best practices for perinatal palliative care. *Nursing*, 45(10), 14-5.
- Somerville, J. (2007). The paradox of palliative care nursing across cultural boundaries. *International Journal Palliative Nursing*, 13(12), 580-587.
- Spector, R. (2017). *Cultural diversity in health and illness* (9th ed.). New York: Pearson, p. 2-6.



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- Twamley, K., Kelly, P., Moss, R., Mancini, A., Craig, F., Koh, M., Polonsky, R., & Bluebond-Langner, M. (2013). Palliative care education in neonatal units: Impact on knowledge and attitudes. *British Medical Journal*. 3(2), 213-20.
- Wool, C. (2013). State of the science on perinatal palliative care. *JOGNN - Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 42(3):372-82; quiz E54-5.

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CREATING INCLUSION AND WELL-BEING FOR UNDERSERVED GRIEVING CHILDREN

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Adapted from *Creating Inclusion and Well-being for Marginalized Students: Whole-School Approaches to Supporting Children's Grief, Loss, and Trauma*, Linda Goldman, Editor, 2017, Jessica Kingsley.

"A voice and a choice may be the key that unlocks the door to empowerment for our grieving children."

Introduction

As hospice workers, educators, parents, clinicians, and caring adults we often ponder what kind of a world we are creating for our future generations. We are charged with the creation of a global human family whereby every child is important and the conditions under which she or he learns, grows, and grieves are equally important. One goal is to vigilantly battle, inwardly and outwardly, the war on exclusion, polarization, and multi-separate thinking that creates endless obstacles for the many already marginalized youth experiencing grief, loss, and trauma in our homes, classrooms, and community. Social exclusion has painful consequences. Young people cast off by society tend to suffer unjustly in a culture that views many as insignificant, faceless, and voiceless.

Creating inclusion and well-being for marginalized grieving children necessitates addressing those truly *left behind*. Yet, there is hope. Emerging paradigms are shifting focus to solutions for every child by inviting a forum for discussion, offering insights that lift dialogue to a higher level of awareness, and creating welcoming environments whereby underserved children can grieve and grow.

The Norm is the Grieving Child

Adjusting one's lens of vision to incorporate the diversity of cultures, issues, and understandings existing for young people in present society leads us to the conclusion that our norm is the grieving and traumatized child. Often this norm is fraught with multiple life challenges of loss, grief, and trauma, without accountability, dialogue, or interventions to meet the overflowing needs of each child. The following are a few powerful statistics from *The State of America's Children* (Children's Defense Fund, 2014):

Child Poverty: One in five children – 16.1 million were poor in 2012. p. 4

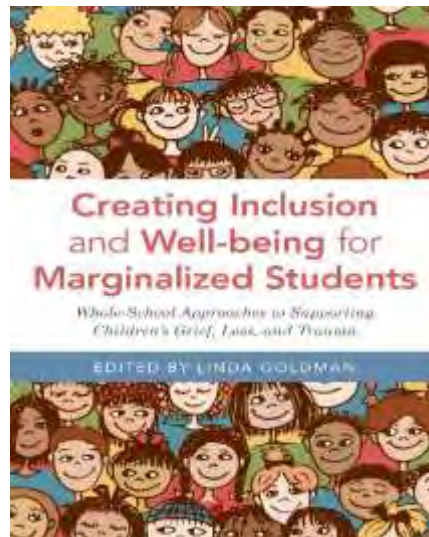
Homeless: Nearly 1.2 million public school children were homeless in 2011-2012. p. 4

Hunger: More than one in nine children lacked access to adequate food in 2012. p. 4

Child Welfare: A child is abused or neglected every 47 seconds. p. 43

Gun Violence: in 2010, guns killed 2694 children and teens. P. 6

Harassment: GLSEN'S National School Climate Survey 2014 reports schools nationwide are hostile environments for a distressing number of LGBT students. Seventy-four percent had been harassed for their sexual orientation and 55 percent for their gender expression (Goldman, 2017, p. 173).



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Common Signs of Grieving and Traumatized Children

Caring adults need to familiarize themselves with the following common signs of bereaved children in order to normalize these signs for parents and youth (Goldman, 2014, p. 45):

- Child retells events of the deceased's death and funeral.
- Child dreams of the deceased.
- Child imitates or idolizes behaviors of the deceased.
- Child feels the deceased is with him or her in some way.
- Child speaks of his or her loved one in the present.
- Child wants to "appear normal."
- Child enjoys wearing or holding something belonging to the loved one.
- Child rejects old friends and seeks new friends with a similar loss.
- Child bursts into tears in the middle of class.
- Child worries excessively about his or her own health or the health of loved ones.
- Child sometimes appears to be unfeeling about loss.
- Child becomes the bully or the "class clown."
- Child overly concerned with caretaking.

A Step Further . . .

The word "traumatic" often describes extraordinary events such as the Sandy Hook Elementary School shooting 2012, and the school shooting at Marjory Stoneman Douglas High School (2018). Susan Craig Ph.D., a pioneer in child trauma, has done groundbreaking work in creating a paradigm for trauma sensitive environments. Craig suggests "Events are *not* traumatic in and of themselves; they *become* traumatic when they exceed a person's capacity to cope (Goldman, Chapter 5, 2017, p.76)." Trauma depends not only on the event, but also the resources available to help a child manage the situation and restore a sense of safety. Girls and boys depend on their caring adults to protect them from harm. In the absence of protective relationships with adults, children are especially vulnerable to developing symptoms of complex trauma.

Craig highlights (Goldman, Chapter 5, 2017, p.76) "The landmark study of Adverse Childhood Experiences (ACE; Felitti et al, 1998) documents the relationship between early trauma and anomalies in children's neurological development . . . left unattended, this affects the health, well-being, and capacity to learn (Karr-Morse & Wiley, 2012)." Often a deep-seated distrust of authority coupled with a hypersensitivity to perceptions of danger or threat, can seriously compromise children's ability to grieve and process a trauma. The greater the number of different types of trauma children are exposed to, the greater the potential for multiple symptoms.

Behavioral signs for grieving children include impulsivity, distractibility, hyperactivity, and inability to concentrate. These common signs of grief are often used in a behavioral checklist to diagnose and place kids in attention deficit and learning disabled tracks without recognition of the underlying grief and trauma present. Characteristics of traumatized youth often include aggression, startle reactions, hyper-vigilance,



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distance from an event, and other 'acting out' behaviors.

A new paradigm to consider is the concept of pain-based behavior—rather than the old notion of purposeful “trouble making.” Pain-based behavior can be an adaptive mechanism for an overwhelming life event, often met by adults with ineffective or harmful punitive measures for attention-seeking behavior driven by pain. Anglin (2014, p. 4) explains that, “Young people who have experienced trauma are literally living in a world of pain which shows in challenging behaviors.” Anglin defines pain-based behaviors “as behavior either of an ‘acting out’ or withdrawn nature . . . triggered by the re-experiencing of psycho-emotional pain (p. 54).”

Thomas was an eight-year-old child who displayed troubling behavior with outbursts, emotional explosions, and an overreaction to authority often noted with traumatized children. His father had been violently murdered and suspected of abusing Thomas prior to his death. Thomas had moved seven times before first grade because of Mom’s illness. He was labeled a “bad kid” in first grade. When asked to share something good about Thomas, his teacher, Mrs. Fine, responded, “There is nothing good about him!” Her vision of Thomas escalated into confrontations that resulted in continuous time outs, unsuccessful punishments, and school expulsions that attempted to modify destructive behavior.

When Thomas was asked to draw a picture about life before dad died, he shared the following depiction of life with Dad. “Help” is what he wrote. He drew a scribble picture, named it *A Tornado*, and said if that tornado could talk it would say, “Help Me.”



Figure 1 Help (Goldman, 2002, p. 123)

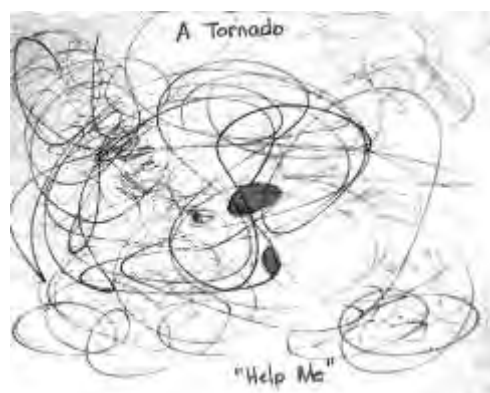


Figure 2 Help Me (Goldman, 2002, p. 124)

New Avenues for Expression

Marginalized young people often have little or no control over their life circumstances. These challenges include poverty, death, immigration, sexual exploitation, imprisonment, immigration, military deployment, and LGBT issues. The following are highlights from several chapters in *Creating Inclusion and Well-being of Marginalized Students* (Goldman, 2017) featuring innovative interventions that transform complex grief and trauma experiences into successful avenues for growth and healing.

Trauma-Informed Care: Caring adults can transform problems stemming from grief and trauma into opportunities for growth when professionals and parents shift to a mindset that incorporates love, understanding, and respect for the child. Jim Sporleder (Goldman, 2017, Chapter 15), past principal of Lincoln High School, presents the pitfalls of a system that only used punishment to shape behavior. He maintains there are vast benefits to establishing heartfelt connections and trauma informed care with young people that help modify unproductive ways of acting. Sporleder suggests “Kids can thrive over time with a trauma informed model that . . . still sets boundaries, hold students accountable, and teaches strategies to calm down (p. 282).”

Establishing a safe environment with an understanding that many behaviors and actions are pain-based



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rather than purposeful “oppositional” can enhance the healing process. Bath (2008) highlights (cf., Goldman, 2017, Chapter 2) three pillars of trauma-informed care for girls and boys that include safety, connections, and managing emotions. He explains, “Unfortunately the defining experience of any child who has experienced complex trauma is that of feeling unsafe. The first imperative is creating a safe place for them (p. 19).” Including children in decision making, giving them choices, maintaining consistency, and being honest and reliable are factors that help professionals and parents create and sustain that “oasis of safety.” Connections, the second pillar, are essential in developing trust that leads to safety. Adults who are available, honest, and able to become mentors and cheerleaders for young people provide an integral step for their healing, their growth, and their learning. The third pillar presented is impulse and emotion management. Reactivity is common for grieving and traumatized children. Supporting children in finding new ways to manage impulses and emotions, such as calming techniques and labeling feelings can enhance self-regulation.

Expressing Life Circumstances:

Kyle Schwartz offers a third grade teacher’s perspective that gives voice to her students to share life circumstances (2017). Kyle asked her students to respond to the phrase: “I wish my teacher knew . . .” Their answers were unexpected and telling, covering a range of topics from poverty, illness, deportation, and incarceration to bullying, loneliness, and peer rejection.

“I wish my teacher knew how much I miss my dad because he got deported to Mexico when I was 3 years old and I haven’t seen him in three years.”

“I wish my teacher knew sometimes my reading log is not signed because my Mom isn’t around a lot.”

“I wish my teacher knew I don’t have a friend to play with.”

“I wish my teacher knew I do not have pencils to homework.”

Figure 4 illustrates the hidden poverty disclosed by a child and the loss it creates. Ruby Payne Ph.D. suggests, “Two key strategies in combating poverty are developing relationships of mutual respect and building resources (Goldman, 2017, Chapter 5, p. 94).”

Maintaining Connection:

Incarceration represents a crucial childhood loss, the loss of the idealized family. The secondary losses of self-esteem, safety and protection, and daily routines follow. In addition, the child is likely going through phases of grief experienced from separation. Many kids have witnessed a parent being arrested and removed from the house by police. Cortina and Trutt (Goldman, 2017, Chapter 8) maintain, “Children of imprisoned parents suffer as well as their parents. They often lose contact with parents, or rarely visit them. Young people are more likely to drop out of school, engage in delinquency, and subsequently be incarcerated themselves (Dallaire, 2007). More mothers are being incarcerated, and evidence indicates this can be more damaging to children (p. 154).”

Get on the Bus is a visitation program that provides a family experience that bonds children with incarcerated parents. The primary purpose is to alleviate the suffering caused by a child’s separation from family. The program succeeds in strengthening the connection between the child and parent by establishing interventions that normalize child–parent interaction, build self-esteem, eliminate barriers to contact, and dispel negative impacts of parental incarceration.



Figure 3 I Wish (Goldman, 2017, p. 59)

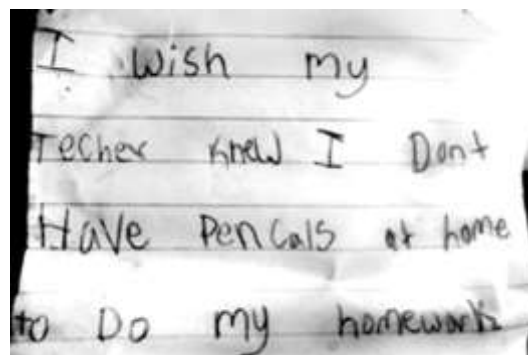


Figure 4 Pencils (Goldman, 2017, p. 94)



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Billy's letter to his incarcerated mom in Figure 5 illustrates a continuing family bond will exist after his visit. *Get on the Bus* serves as a model of what communities can do to join families during incarceration, decrease shame and stigma, and enhance a child's ability to learn and grow.

Unconditional love:

Marie Moreno, school principal of Las Americas, explains (Goldman, 2017, Chapter 6) her educational paradigm for underserved students, which seamlessly fits with the Truebridge resilience model (2014) that follows: "Teachers must show *unconditional love while still holding high expectations* (Goldman, 2017, p. 116)."



Figure 5 Letter (Goldman, 2017, p. 163)

Marie warns that, despite testing and state accountability, educators should take into account the prior experiences of students when they enter school. A majority of her school population did not speak English. In order to create practical and high *expectations* for young people challenged by a new life, a new culture, and a new language, students were grouped by language proficiency rather than grade level. Accommodations were implemented for all children to learn the alphabet together, and move through levels of learning English at their own pace. Marie's students were largely refugees, coming to America with trauma that led one boy to say, "I can't go on." This boy was *loved and cared for* enough to go on.

Las Americas provided social workers sensitive to students' past trauma, and funds for materials such as dictionaries and books that translate words from English into each of the 30 languages in this population. Student peer groups were created to help kids cope, and provide the support needed for success. As Moreno states, "They have experienced grief and loss at many levels ... They must feel that they are not alone (Goldman, 2017, p. 120)."

Resilience - The Protective Factors:

The theory of resilience recognizes that all individuals—children, youth, and adults—have basic human needs, which include, but are not limited to, the needs for safety, love, belonging, meaning, and accomplishment (Maslow, 1943).

Sara Truebridge, Ed.D., presents the following three major environmental protective factors (developmental supports and opportunities) can be identified that mitigate adversities and nourish the personal strengths associated with coping with grief and trauma leading to resilience (Goldman, 2017, Chapter 16).

- *Caring relationships*—provide a sense of connectedness and belonging; demonstrate "being there"; exude compassion and trust.
- *High expectations*—convey a focus on strengths; stabilize routines; offer positive messaging in the belief of others, as one is both challenged and supported at the same time.
- *Opportunities to participate and contribute*—contribute to personal power, inclusion, and self-efficacy; awaken the power and gifts of "service"; instill responsibility, voice, and choice (p. 303).

Resilience research consistently supports the paradigm that if these three inter-related protective factors exist together in any single environment—home, school, community, or peer group—they will play a role in whether a child's needs are met. Bonnie Benard's (2004) theory of resilience stresses that all three protective factors need to be present in just one of the environments to be able to maximize the tapping and fostering of a child's resilience. Furthermore, having all three protective factors in one environment,



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such as in hospice counseling, school, or home, will compensate for the fact that some of the protective factors are not present in other environments such as the family, community, or peer group. This is exemplified by classroom teacher Kyle Schwartz and high school principal Jim Sporleder, as they both share their use of these three protective factors in detail as a teacher and principal to meet the needs of many underserved students experiencing grief, loss, and trauma.

Truebridge (Goldman, 2017) maintains resilience is a process, not a trait, explaining that it is a dynamic process that involves how young people interact and negotiate with themselves, others, and the world, and how they engage and navigate through the resources available to thrive and move on a positive trajectory of success.

Emily was seven when the terrorist attack occurred. She was attending a school in New York when the Twin Towers was struck. She could see the burning building, smell the smoke, and hear the screams. She was terrified. A few weeks later she drew the following picture of people crying, a building burning, and angels in the background. Emily's resilience shines bright in what she wrote, as does her strength in her spiritual belief system.

"Once upon a time angels were watching and God knew *that everything was fine.*"

Strength-based Solutions:

These strength-based solutions inspire young people to trust, express, and move through grief and trauma to become all they can be in a nurturing environment of care and protection. They incorporate trauma-informed care with a resilience model that recognizes the common signs of grieving and traumatized children as pain based behaviors, capable of being transformed through safety, connection, and managing emotions.

This is a necessary tool for today's kids. No longer can we council, teach, or parent merely by following prescribed patterns and conventional approaches. In order to help bereaved girls and boys we must develop a deeper understanding of their underlying and sometimes hidden loss, grief, and trauma issues that impact their safety and well-being.



Figure 6 Angels (Goldman, 2006, p. 253)

A worthy goal is to transform children from being *the marginalized* and bring them to *the mainstream*, with equal opportunities. An initial step is the recognition of the diversity of today's population. Next we can establish a mandate to accommodate all children by providing the resources necessary to cope with loss and grief issues that may seem insurmountable. Then we can actualize successful outcomes by keeping open the minds and hearts of all of our grieving and traumatized children. This goal can be accomplished by comprehending the challenges they face, the issues that impact their lives, and the steps crucial in creating change. We must see what existing conditions there are, what can be done, and what is being done to catch our children before they fall.

In Conclusion

*"For all the children that feel invisible . . .
And for all the adults that have eyes to see them. "
Dedication, Goldman, 2017*

"Our underserved youth often live a life of marginalization in a pervasive culture of exclusion and accountability denial. It is required of all caring adults to become the voice of respect and adaptation for those young people unable to advocate for themselves and their life circumstances. Numerous girls and



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boys carry an enormous burden, many times disenfranchised from a system that too often neglects the needs of innocent children.

The magnitude of challenges they face is enormous, and the task before us can be overwhelming. Yet how can we *not* serve all children, real children, facing struggle and pain as they navigate grief and trauma? How can we *not* provide, ensure, and demonstrate effective interventions to relieve the array of complex difficulties they endure? How can we *not* seek to provide for the concerns of *all* children with courage, caring, and advocacy?

Together we can seek solutions that make the impossible possible ... the dream that every grieving child feels loved, comforted, understood, and respected in their homes, classrooms, community, and world (Goldman, 2017, p. 327-328)."

References:

Anglin, J.P. (2002). *Pain, Normality, and the Struggle for Congruence: Reinterpreting Residential Care for Children and Youth*. New York: Haworth Press.

Anglin, J.P. (2014). Pain-based behavior with children and adolescents in conflict. *Reclaiming Children and Youth* 22, 4, 53–55.

Bath, H. (2008). The three pillars of trauma-informed care. *Reclaiming Children and Youth* 17, 3, 17–21.

Benard, B. (2004). *Resiliency: What We Have Learned*. San Francisco, CA: WestEd.

Children's Defense Fund (2014). *The State of America's Children*. Washington, DC. Available at www.childrensdefense.org/library/each-day-in-america.html, accessed on 03/23/17.

Craig, S.E. (2016). *Trauma-Sensitive Schools: Learning Communities Transforming Children's Lives, K-5*. New York: Teachers College Press.

Dallaire, D.H. (2007). 'Incarcerated mothers and fathers: A comparison of risks for children and families. *Family Relations* 56, 5, 440–453.

Felitti, V.J., Anda, R.F., Nordenberg, D., Williamson, D.F. *et al.* (1998). Relationship of child abuse and household dysfunction to many of the leading causes of deaths in adults: The Adverse Childhood Experiences (ACE) study. *American Journal of Preventative Medicine* 14, 245–258.

GLSEN (2014). *National School Climate Survey*. Available at www.glsen.org/article/glsen-releases-national-school-climate-survey, accessed on 03/28/17.

Goldman, L. (2002). *Breaking the Silence: A Guide to Help Children with Complicated Grief, 2nd Edition*. New York: Taylor and Francis.

Goldman, L. (2006). *Raising Our Children to Be Resilient: A Guide to Help Children with Traumatic Grief*. New York: Taylor and Francis.

Goldman, L. (2009). *Great Answers to Difficult Questions about Death: What Children Need to Know*. London: Jessica Kingsley Publishers.

Goldman, L. (2014). *Life and Loss: A Guide to Help Grieving Children, 3rd Edition*. New York: Taylor and Francis.



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- Goldman, L. (2017). *Creating Inclusion and Well-being for Marginalized Students: A Whole School Approach to Grief, Loss, and Trauma*. London: Jessica Kingsley.
- Karr-Morse, R. & Wiley, M.S. (2012). *Scared Sick: The Role of Childhood Trauma in Adult Disease*. Philadelphia, PA: Basic Books.
- Maslow, A.H. (1943). A theory of human motivation. *Psychological Review* 50, 4, 370–396.
- Payne, R.K. (2013). *A Framework for Understanding Poverty: A Cognitive Approach, 5th Edition*. Highlands, TX: aha! Process.
- Schwartz, K. (2016). *I Wish My Teacher Knew: How One Question Can Change Everything for Our Kids*. Boston, MA: Da Capo Press.
- Sporleder, J. & Forbes, H. (2016). *The Trauma Informed School: A Step-by-Step Implementation Guide for Administrators and School Personnel*. Boulder, CO: Beyond Consequences Institute.
- Truebridge, S. (2014). *Resilience Begins with Beliefs: Building on Student Strengths for Success in School*. New York: Teachers College Press.

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GLOBAL PARTNERS' VOLUNTEER PREPARATION TOOLKIT: PROMOTING CULTURALLY-SENSITIVE CARE

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For more than 20 years, medical professionals have been studying the role that culture plays in the beliefs and behaviors of patients (Pachter, 1994). Culture is, quite simply, “the customary beliefs, social forms, and material traits of a racial, religious, or social group” (Merriam-Webster, 2018). By this definition, it can be clearly understood that one’s culture permeates the growing, living, healing, and dying processes of every human being. Therefore, the need for health care professionals to provide culturally-sensitive care to patients with diverse values and beliefs is essential.

Nowhere is this more important, perhaps, than the field of pediatric palliative care, which addresses the holistic care of children with complex and chronic conditions: their physical, emotional or psychosocial, social, and spiritual domains (Liben, Papadatou, & Wolfe, 2007). It is well-documented in the literature that culture shapes a child’s and family’s decision-making, communication, faith, and spiritual activities, as well as their understanding of death and suffering (Wiener, McConnell, Latella, & Ludi, 2012). Healthcare organizations increasingly recognize this and incorporate topics like cultural humility into formal training programs on pediatric palliative care (Carter & Swan, 2012).

It can be challenging, however, to hold in-person training sessions to develop cultural competency among staff due to time and resource constraints. As an alternative, this article explores a free online resource to promote principles of culturally-sensitive care among an interdisciplinary team. The *Volunteer Preparation Toolkit* was created by Gundersen Global Partners, a program of Gundersen Medical Foundation at Gundersen Health System in La Crosse, Wisconsin, to prepare staff members for volunteer service in several communities around the world (See <http://www.gundersenhealth.org/foundation/programs-events/global-partners/volunteer-toolkit/>).

Gundersen’s Global Partners was created in 2008 to improve the health and well-being of global communities by inspiring volunteerism among Gundersen staff and community members (Gundersen Global Partners website, 2018). The program currently partners with communities located in Ethiopia, Nicaragua, South Dakota, and Wisconsin and has enlisted more than 670 volunteers over the past nine years to further healthcare, education and community development initiatives.

Through assessment and evaluation of the volunteer experience, one of the authors (Global Partners’ program director) along with other program leaders identified that gaining knowledge of the history and cultural aspects of the host community may help the volunteers to have a more successful experience, as well as provide a greater benefit to the host community through intentional, meaningful interactions. With



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the goal to improve interactions within cultures and better prepare the volunteer for these cultural exchanges, one of the authors – at the time a graduate student pursuing a Master’s in Public Health degree – developed, implemented, and evaluated the *Volunteer Preparation Toolkit* for Global Partners.

This toolkit was designed based on a literature review of best practices among similar mission-driven non-profits and previous Global Partners volunteer feedback. The toolkit has been placed on the Global Partners website and contains four modules: Cross-Cultural Sensitivity, Site-Specific Cultural Information (specific to the communities and cultures where Global Partners’ teams work), Sustainable Development, and Building Relationships.

The author chose to review three organizations that send volunteers to work with other cultures to analyze their pre-experience process in addition to reviewing previous volunteer experience survey data. The three organizations reviewed for this literature review were *Unite for Sight*, *RE-MEMBER*, and the *Peace Corps*. *Unite for Sight* is a non-profit global health delivery organization that empowers communities worldwide to improve eye health and eliminate preventable blindness (*Unite for Sight*, 2012). *RE-MEMBER* is an independent, non-profit organization on the Pine Ridge Reservation in South Dakota that engages in relationship building and outreach projects across Pine Ridge. The *Peace Corps* is an internationally recognized government organization established by President John F. Kennedy designed to promote world peace and friendship.

The three organizations reviewed all had one similar approach in common to the preparation process of volunteers: to provide information to the volunteers about cultural understanding and the history of the host community. The assumption was made that incorporating cultural understanding and information about the host community appeared to be a best practice within organizations that prepare volunteers for inter-cultural exchanges.

Through the responses from Global Partners Volunteer Experience Survey (2011), the following quotation from the Global Partners Volunteer Experience Survey (2011) gave insight into the volunteer experience: “I have learned from the Lakota [the Native American tribe that lives on the Pine Ridge Reservation] that the healing happens within the relationship.” This response is an example that demonstrates Jean Watson’s Human Caring Theory of the Caritas Processes, a nursing theory that Gundersen Health System has adopted. Jean Watson suggests that in nursing and other human encounters, we should realize that our interactions can be more humane, significant, and caring with purposeful use of Caritas principals (Summerell, 2015).

The cross pollination of Caritas and Global Partners could resonate with volunteers, causing a positive effect for both the volunteer and the host community. Caritas is “the science and art of caring, which helps create a culture of healing for all. Caritas helps us take care of our patients and families, ourselves, our colleagues, and our environment. A healing environment generates positive energy, compassion and enhances the ability to care. It speaks to the heart of who we are as human beings, not ONLY human doings. Caritas also adds value and meaning to our everyday work” (Caritas update PowerPoint, Liz Arnold, 3/30/2012).

While the *Volunteer Preparation Toolkit* was developed to prepare healthcare professionals for a global experience, much of the content (particularly Modules 1 & 4) can be applied directly at home to relationships with culturally-diverse patients.

Module 1 “Cross-Cultural Understanding” contains a wealth of information that can be applied to any cross-cultural setting, covering topics such as ethnocentrism and cultural views of time. The module outlines best practices for interacting with interpreters and patients who don’t speak English well or at all, and also shares the CRASH mnemonic as an easy-to-remember guide to practice cultural sensitivity. The module is intended to help the reader develop self-awareness, understanding, and practical skills to work effectively with someone from a different culture.

Similarly, Module 4 “Building Relationships” outlines the 10 Caritas processes based upon Jean Watson’s Human Caring Theory. Not only does practicing these processes create a healing environment through



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life and death, but it also fosters humility, which is at the heart of culturally-sensitive interactions.

The Peace Corps (2013) articulates the value of cultural learning by stating, “The goal is understanding. In cross-cultural training and living, the goal is learning about yourself and others.” It is less about knowing the exact beliefs that someone might hold, and more about recognizing they may be different from your own. It is about seeing beauty in the difference, and ultimately respecting and valuing what their process of growing, living, healing, and dying may be.

Those working in pediatric palliative care settings have a unique opportunity to apply these learnings. Liben, Papadatou, and Wolfe (2007) discuss core principles in the pediatric palliative field that may vary across cultures, including how to break bad news to parents, how to address topics with children, and how to discuss disease, diagnosis, and death.

Healthcare professionals who have greater awareness of their own beliefs in these areas may be better able to suspend their feelings and remain open to the desired approach of their patients and families. Similarly, those who engage in genuine teaching-learning experiences (Caritas process #7) will actively listen and learn from those they are seeking to care for.

A culturally-sensitive approach cannot be gained simply by reading a few modules online and memorizing a mnemonic. It is gained through practice, experience, and remaining in a continual state of learning rooted in humility (Tervalon & Muray-Garcia, 1998). Implementing and ingraining this shift towards culturally-sensitive care into pediatric palliative care or other departments require a commitment on the part on the part of the organization, clinical team and individuals (Schrank et al., 2017).

In line with other adult learning best-practices, providing didactic education and hands-on activities proves to be most effective for clinician education when combined with theory and highlighting direct consequences on a clinician’s practice (Raper, Gupta, Okusanya, & Morris, 2015). Trainings and educational sessions intended to increase cultural sensitivity have been most successful when approached in a direct way, explicitly targeting self-awareness and focusing on culture-general strategies rather than culture- or population-specific (Davis et al., 1999; Wachtler & Troein, 2003). It has been suggested that including cultural competencies and cultural awareness could be incorporated into clinician evaluation in a meaningful way to encourage participation in educational sessions and motivation for improvement (Brach & Fraserirector, 2000; Casillas et al., 2014).

Several self-assessment and peer-assessment tools exist to provide a baseline and improvement tracking for cultural-sensitivity development (Matsumoto & Hwang, 2013), although many of these tools have not been commonly used in health care settings. The studies that have measured the provider’s competence levels and improvements have been relatively small in scale and are often cited as a limitation to the study (Paez, Allen, Carson, & Cooper, 2007; Paez, Allen, Beach, Carson, & Cooper, 2009).

Experiential learning and cultural emersion continues to be an effective method to developing cultural-sensitivity when combined with a conscious learning plan and framework (Roberts, Conner, & Jones, 2013). Global Partners trips combine meaningful participation in a community-capacity building project for volunteers with long-term commitment and relationship with the communities served.

A focus group study illuminated several themes resulting in participation in a volunteer trip, including experiencing the context of the lives of others, can contribute to culturally-sensitivity development and a humbling experience leading to self-reflection and awareness (Cedergren et al., 2015). Further research with Global Partners’ 650+ volunteers shows an increase in workplace engagement overtime (Cedergren, Gullekson, & Arnold., 2016), perhaps providing a buffer to compassion fatigue that can happen in health care especially in palliative care (Harrison et al., 2017).

However, evidence-based resources such as Global Partners’ *Volunteer Preparation Toolkit* can be utilized to promote cultural learning among staff, spark initial discussions, initiate changes to organizational policies, and bring peace to children and families who desire to be understood during their



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times of greatest need.

References

- Arnold, E. (2011). Gundersen Lutheran Global Partners Volunteer Experience Survey. Global Partners.
- Arnold, E. (2012) Caritas update PowerPoint. Global Partners.
- Brach, C., & Fraserirector, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*. 57 (supplement: 1), 181-217.
- Carter, B. S., & Swan, R. (2012). Pediatric palliative care instruction for residents: An Introduction to IPPC. *American Journal of Hospice & Palliative Medicine*, 29(5), 375-378. DOI: 10.1177/1049909111425920
- Casillas, A., Paroz, S., Green, A., Wolff, H., Weber, O, Faucherre, F., & Bodenmann, P. (2014). Cultural competency of health-care providers in a Swiss university hospital: Self-assessed cross-cultural skillfulness in a cross-sectional study. *BMC Medical Education*. 14 (19), 1-8.
- Cedergren, A., Whitney, E., Ebert, K., Lube, L., & Arnold, L. (2015). Impact of Volunteerism on Personal Beliefs and Professional Practices Reflecting Organizational Mission among Employees of a Large Health System. Poster presented at: American Public Health Association. 2015 Oct 31-Nov 4; Chicago, IL.
- Cedergren, A., Gullekson, N., & Arnold, L. (2016). Employer Sponsored Volunteering and Organizational Engagement among Employees of a Large Health System. Poster presented at: Society for Public Health Education. 2016 Mar 30- Apr 1; Charlotte, North Carolina.
- Davis, D., O'Brien, M., Freemantle, F., Mazmanian, P., & Taylor-Vaisey, A. (1999). Impact of formal continuing medical education: Do conferences, workshops, rounds, and other traditional continuing education activities change physician behavior or health care outcomes? *Journal of the American Medical Association*. 282(9), 867-874
- Gundersen Global Partners. (2018). Global Partners website. Retrieved from <http://www.gundersenhealth.org/foundation/programs-events/global-partners/> on June 15, 2018.
- Harrison, K. L., Dzung, E., Ritchie, C. S., Shanafelt, T. D., Kamal, A. H., Bull, J. H., Tilburt, J. C., Swetz, K. M.. (2017). Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative. *Journal of Pain and Symptom Management*, 53(6), 1091-1096.
- Harrison, K. L., Dzung, E., Ritchie, C. S., Shanafelt, T. D., Kamal, A. H., Bull, J. H., Tilburt, J. C., Swetz, K. M.. (2017). Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative. *Journal of Pain and Symptom Management*, 53(6), 1091-1096.
- Liben, S., Papadatou, D., & Wolfe, J. (2007). Paediatric palliative care: Challenges and emerging ideas. *The Lancet*, 371(9615), 852-864. DOI: [https://doi.org/10.1016/S0140-6736\(07\)61203-3](https://doi.org/10.1016/S0140-6736(07)61203-3)
- Matsumoto, D., & Hwang, H. (2013). Assessing cultural competence: A review of available tests. *Journal of Cross-Cultural Psychology*. 44(6), 849-873.
- Merriam-Webster Dictionary. (2018). Definition of Culture. Retrieved from <https://www.merriam-webster.com/dictionary/culture> on June 15, 2018.
- Pachter, L. M. (1994). Culture and clinical care: Folk illness beliefs and behaviors and their implications for health care delivery. *JAMA*, 271(9), 690-694. DOI:10.1001/jama.1994.03510330068036



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- Paez, K., Allen, J., Carson, K., & Cooper, L. (2007). Provider and clinic cultural competence in a primary care setting. *Social Science and Medicine* 66, 1204-1216.
- Paez, K., Allen, J., Beach, M., Carson, K., & Cooper, L. (2009). Physician cultural competence and patient ratings of the patient-physician relationship. *Journal of General Internal Medicine*. 24(4), 495-498.
- Peace Corps. (2012). Peace Corps mission. Retrieved from <http://www.peacecorps.gov/about/mission/>
- Peace Corps. (2013). The Peace Corps welcomes you to Nicaragua: A Peace Corps publication for new volunteers. Retrieved from: <files.peacecorps.gov/manuals/welcomebooks/niwb524.pdf>
- Raper, S., Gupta, M. Okusanya, O., & Morris, J. (2015). Improving communication skills: A course for Academic Medical Center Surgery Residents and Faculty. *Association of Program Directors of Surgery, 2015 Annual Meeting Paper*. 1-10.
- Re-member. (2012) Re-member registration and informational packet. Retrieved from http://www.re-member.org/pre_trip_info.aspx
- Roberts, T. G., Conner, N. W., & Jones, B. L. (2013). An experiential learning framework for engaging learners during study abroad experiences. *NACTA Journal*, 57(3), 28-35. Retrieved from <http://login.ezproxy.lib.umn.edu/login?url=https://search-proquest-com.ezp2.lib.umn.edu/docview/1445180796?accountid=14586>
- Schrank, B., Rumpold, T., Amering, M., Masel, E., Watzke, H., & Schur, S. (2017). Pushing boundaries—culture-sensitive care in oncology and palliative care: A qualitative study. *Psycho-Oncology*, 26(6), 763-769.
- Summerell, P. (2015). Jean Watson's Caritas Processes: A model for transforming the nursing practice environment. *Critical Care Nurse*, 35(2), E66-E67.
- Tervalon, M., & Muray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physical training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*. 9(2), 117-125. [NOT CITED IN TEXT?]
- Unite for Sight. (2012). Unite for sight cultural competency online course. Retrieved from <http://www.uniteforsight.org/cultural-competency/>
- Unite for Sight. (2013). Unite for sight cultural competency module. Retrieved from <http://www.uniteforsight.org/cultural-competency/>
- Unite for Sight. (2013). Unite for Sight: ethics, quality, and equality: online global health course. Retrieved from <http://www.uniteforsight.org/global-health-course/>
- Wachtler, C., & Troein, M. (2003). A hidden curriculum: Mapping cultural competency in a medical programme. *Medical Education*. 37, 861-868.
- Wiener, L., McConnell, D., Latella, L., & Ludi, E. (2012). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67. <https://doi.org/10.1017/S1478951511001027>

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IMPROVING PEDIATRIC PALLIATIVE CARE FOR LATINO CHILDREN AND THEIR FAMILIES

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Demand for pediatric palliative care (PPC) is steadily growing. As medical technology continues to advance, the life expectancy of children with medical complexity is increasing. Latinos, the largest ethnic minority group in the United States (US), are a vulnerable and underserved population.¹ Compared to their White counterparts, Latino children have worse health outcomes, which in part is due to barriers in access to care.² The fact that Latino children incur lower hospice expenditures and higher ICU care at the end-of-life suggests barriers to access of PPC services as well.^{3,4} In our recent review of the literature, we found Latino children face significant barriers to quality PPC; however, reasons for these added barriers to PPC are understudied in this population.⁵ In this article, we present a summary of challenges specific to Latino children and their families that are believed to impact their experiences of PPC services.

Latinos that reside in the U.S. come from different countries and backgrounds. Yet they share language, experiences, and cultural values that influence their medical care and make them more similar than not. Limited English proficiency is an obvious barrier to care for Latino families. Despite the availability of and requirement to use medical interpreters, this service is underused.⁶ Miscommunication secondary to the language barrier can be a source of mistrust, confusion, and isolation for Latino families; this issue has meaningful implications in the setting of serious pediatric illness where communication is an essential PPC intervention.⁷ Notably, because the language barrier is easily identified, it can be mistaken as the only barrier, and thus, the only one addressed. This increases the vulnerability of Latino children with medical complexity or terminal illness and threatens the quality of PPC services they receive.

Latino cultural values are important to consider when offering PPC services to Latino families. Many Latino families hold fast to spirituality and religiosity, which can both be a source and a potential barrier to PPC.⁸ Some families may struggle to accept their child's terminal illness or the dying process because they are "waiting for a miracle." *Fatalismo*, which refers to Latinos' belief in fate, can lead families to view their child's illness as a test of faith; they may see PPC as giving up and defying their fate and faith in God. Latinos also often expect family-centered decision-making, often referred to as *familismo*.^{9,10} *Familismo* commonly involves nuclear as well as extended family; these relationships offer important supports for parents, nevertheless family-centered decision-making can be a complicated process. The desire to involve extended family can be logistically challenging for and unfamiliar to clinicians trained to prioritize patient autonomy. *Familismo* can also lead to fragmented understanding of illness, lack of consensus, and delays in care.⁸ Finally, *respeto* is a Latino cultural value that refers to the way Latinos interact with others according to age, socioeconomic status, and authority.¹¹ Deference to clinicians and a tendency to not question their recommendations can result in misunderstandings and apparent non-compliance with care, as when families do not question clinician recommendations yet do not follow them because they conflict with families' values and beliefs.¹¹

Awareness of available health services may also be challenging for some Latino families. Many struggle with the complexity of the U.S. healthcare system, in which PPC services are imbedded. In the Latin



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American medical system, one physician is usually in charge of care and communication with patients and families. However, care in the U.S. is often decentralized and multi-disciplinary. This perceived fragmented care, complicated by the language barrier, can undermine communication and trust between Latino families and clinicians.¹² Misconceptions and knowledge gaps about PPC are also common among Latino families. PPC services in Latin America are overall underdeveloped; few countries have well-integrated PPC services and the majority do not offer them at all.¹³ Thus, misconceptions may be more striking in Latino families whose prior knowledge and experience with PPC may be limited, or nonexistent, depending on their country of origin.

To address the barriers to PPC that Latino families may face, we suggest several clinical, research, and policy strategies.

Given that Latinos are the largest ethnic minority in the U.S., nearly all pediatric providers interact with Latino families. As language is usually the first barrier encountered, addressing this is a key step in providing quality care. Medical interpreters are widely available across a range of settings, but this service is underutilized.⁶ Its effects on workflow, technical issues, and using children who speak English as interpreters hinder providers from using medical interpreter services. More research is needed to explore additional system barriers and potential solutions to using medical interpreters, especially for PPC where nuanced and sensitive communication are essential. Advocating for universal communication skills for medical providers will also increase the likelihood that what is interpreted can build trust with Latino families and assess acculturation respectfully.

Cultural humility is essential to creating the space for Latino cultural values to shape the parent-provider relationship. This requires embedding Latino cultural values in education curricula of PPC trainees as well as experienced professionals. The goal is to integrate Latino cultural values in a culture-centered model of care. Assigning PPC continuity providers, for example, can help minimize miscommunications, misunderstandings, and mistrust with Latino families. Though this may be logistically challenging in inpatient settings, a continuity provider could attend family meetings, for example, and serve as a liaison between families and subspecialty on-service clinical teams.

We must also work to educate Latino families regarding the availability and value of PPC services for seriously-ill children. This should include evidenced-based outreach strategies, such as culturally-paired patient navigators, to bridge knowledge gaps and ameliorate anxiety and misconceptions regarding PPC, terminal illness, and death. Culturally-tailored communication tools, such as Question Prompt Lists, could give families permission to ask questions of clinicians in palliative and end-of-life conversations.¹⁴

Lastly, vulnerable Latino children depend on our advocacy efforts. As important as it is to implement the aforementioned strategies locally, affecting policy change through advocacy at the state and federal levels is equally important. Healthcare disparities for Latino children go beyond PPC. Advocating for immigration reform and increasing access to health insurance, for example, are key to expand access to PPC for medically vulnerable Latino children. With more research that explores barriers to PPC for Latino children and strategies to overcome them, state and federal policy can be changed, and ultimately, care for these children improved.

In summary, Latino children face additional barriers to comprehensive and quality PPC that go beyond language. Latino cultural values, limited knowledge and experience with PC, complexity of US healthcare system, and socioeconomic disparities make medically complex Latino children a vulnerable population. Advocacy efforts that effect policy change at the local, state, and federal levels are needed to deliver quality PPC for these children.

References

1. U.S. Census Bureau. *Table 10. Projections of the Population by Sex, Hispanic Origin, and Race for the United States: 2015 to 2060 (NP2014-T10)*. U.S. Census Bureau: Suitland, MD, USA, 2014.
2. Flores G, Tomany-Korman SC. The Language Spoken at Home and Disparities in Medical and Dental Health, Access to Care, and Use of Services in US Children. *Pediatrics*. 2008;121(6):e1703-e1714. doi:10.1542/peds.2007-2906.



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3. Knapp CA, Shenkman EA, Marcu MI, Madden VL, Terza J V. Pediatric Palliative Care: Describing Hospice Users and Identifying Factors that Affect Hospice Expenditures. *J Palliat Med*. 2009;12(3):223-229. doi:10.1089/jpm.2008.0248.
4. Johnston EE, Alvarez E, Saynina O, Sanders L, Bhatia S, Chamberlain LJ. Disparities in the Intensity of End-of-Life Care for Children With Cancer. *Pediatrics*. 2017;140(4):e20170671. doi:10.1542/peds.2017-0671.
5. Muñoz-Blanco, S; Raisanen, J; Donohue, PK; Boss, RD. Enhancing Pediatric Palliative Care for Latino Children and Their Families: A Review of the Literature and Recommendations for Research and Practice in the United States. *Children*. 2018;5(2):1-12. doi:10.3390/children5010002
6. Diamond LC, Wilson-stronks A, Jacobs EA, Diamond LC, Wilson-stronks MPHA, Jacobs EA. Do Hospitals Measure up to the National Culturally and Linguistically Appropriate Services. *Medical Care*. 2018;48(12):1080-1087.
7. Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med*. 2002;156(1):14-19. doi:10.1097/00004703-200206000-00030.
8. Cruz-Oliver DM, Sanchez-Reilly S. Barriers to Quality End-of-Life Care for Latinos. *J Hosp Palliat Nurs*. 2016;18(6):505-511. doi:10.1097/NJH.0000000000000277.
9. Smith AK, Sudore RL, Pérez-Stable EJ. Palliative care for Latino patients and their families: Whenever we prayed, she wept. *JAMA*. 2009;301(10):1047-1057, E1. doi:10.1001/jama.2009.308.
10. Campesino M, Schwartz GE. Spirituality among Latinas/os: Implications of culture in conceptualization and measurement. *Adv Nurs Sci*. 2006;29(1):69-81. doi:10.1016/j.biotechadv.2011.08.021.Secreted.
11. Adames HY, Chavez-Deñás NY, Fuentes M a, Salas SP, Perez-Chavez JG. Integration of Latino/a cultural values into palliative health care: A culture centered model. *Palliat Support Care*. 2014;12(2):149-157. doi:10.1017/S147895151300028X.
12. Contro N, Davies B, Larson J, Sourkes B. Away from home: Experiences of Mexican American families in pediatric palliative care. *J Soc Work End Life Palliat Care*. 2010;6(3-4):185-204. doi:10.1080/15524256.2010.529020.
13. Pastrana T, De Lima L, Wenk R, et al. *Atlas of Palliative Care in Latin America ALCP*. 1st ed. Houston: IAHPCC Press; 2012. [http://cuidadospaliativos.org/uploads/2013/12/Atlas of Palliative Care in Latin America.pdf](http://cuidadospaliativos.org/uploads/2013/12/Atlas_of_Palliative_Care_in_Latin_America.pdf).
14. Muñoz-Blanco, S; Boss, RD; DeCamp, L; Donohue PK. Hospital to Home Transition for Medically Vulnerable Latino Infants. *Under review*. 2018.

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SUPPORTING TRANSGENDER AND GENDER NONCONFORMING CHILDREN LIVING WITH LIFE-THREATENING ILLNESS

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Introduction

Individuals with transgender and gender nonconforming (TG/GNC) identities continue to become more visible, along with increased understanding of their unique needs. At least 0.6% of the population, or 1.7 million Americans,ⁱ TG/GNC people present across the spectrum of age, sexual orientation, race, geographic area, culture, socioeconomic status, and health status. Best practices for palliative care in this population exist but are focused on the needs of older adults.^{ii,iii} However, it is inevitable that TG/GNC children will be among those accessing hospice and palliative care (HPC) services. To that end, this article aims to support HPC providers in offering gender affirming care to pediatric patients. We present two cases of TG/GNC children experiencing life-threatening illness and demonstrate how tenets of the Gender Affirming Model of Care (see Table 1) align with Palliative Care Clinical Practice guidelines.^{iv, v, vi, vii}

Table 1: Principles of Gender Affirming Care

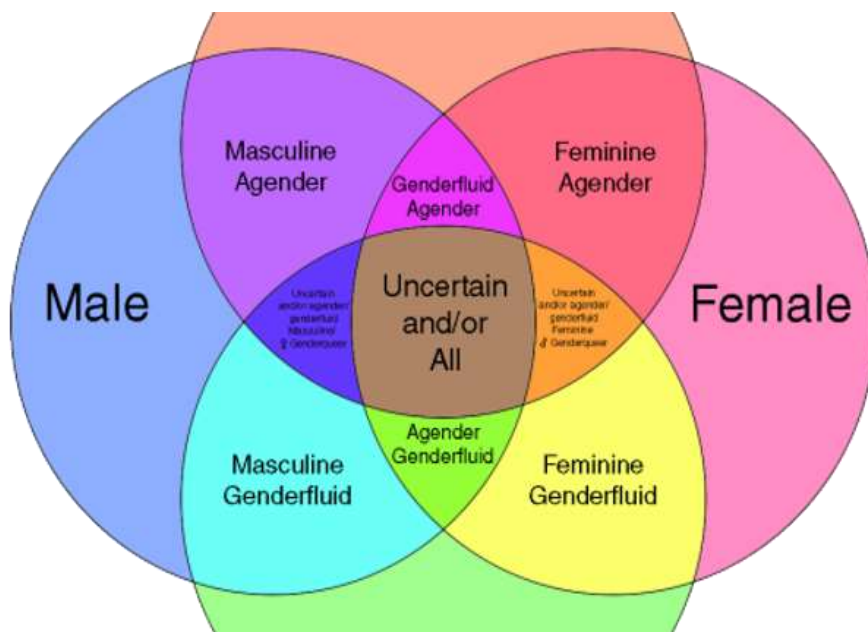
1. Gender variations are not disorders.
2. Gender variations are diverse across cultures and are not binary.
3. Gender is the complex interplay of biology, psychology, and culture/society.
4. Dysphoria is distress related to gender incongruence and varies across type and severity.
5. Acceptance by family/others significantly improves mental health outcomes
6. Standard of practice involves a multidisciplinary team approach (child/youth, family, gender specialist, mental health as indicated, medicine as indicated, legal, school, clergy, etc.)



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“Transgender” and “gender nonconforming” are umbrella terms that refer to someone whose gender identity (i.e., sense of male-ness or female-ness) does not align with their assigned birth sex based on genitals and chromosomes. TG/GNC individuals may identify specifically as “transgender” or simply as male or female, without the transgender label. In addition, some TG/GNC people are non-binary, meaning they do not identify with a male or female label. A comprehensive glossary of terms related to gender can be found at <https://www.hrc.org/resources/glossary-of-terms>.

“Transition” refers to the time and process that a person moves from one gender to others. It may involve social transition, which is changing name/pronoun/clothing to align with the gender identity; legal transition, involving change of name and gender documents; and medical transition, which can involve hormones or surgeries to physically change the body. It is important to note that transition looks different for every person, can take months or years, and is not a linear process. For children and youth, transition can also involve a “coming out” in spaces like school, youth groups or other activities. While some children may remain at a school and have a social transition (e.g., was known as female in 1st grade and transitioned to male in 2nd grade), other families choose to move children for a fresh start. The reasons are many for how to sort out which choices of transition are right for different people and beyond the scope of this article. Some people may move back and forth between genders or chose to change some aspects of their bodies or appearances but not others. In addition, financial and medical barriers make physical transition impossible for some people. For children and youth, transition often includes family work and ongoing support from a gender specialist to sort out gender wishes and needs. It is important to note that there is no such thing as a “complete transition,” and surgery and/or medical intervention are not necessary to legitimize a person’s identity as TG/GNC or fully male or female.

TG/GNC children experiencing the diagnosis of a serious or life-threatening illness should be approached with the same care and sensitivity as any child, with special attention paid to using their preferred name/pronoun and respect for their gender identity. It is not appropriate to ask a child to be their own advocate in the medical setting (although some may embrace this role). Therefore, it is especially important to have trainings and support in place to make sure that every person who interacts with this child knows the correct name and pronoun to use, and that the medical record reflects this information appropriately while also maintaining the child’s privacy. Recommendations for inclusive palliative care in LGBT adult populations can be extrapolated to the pediatric population and are noted in Table 2.^{viii} Specific to children and youth, visuals like posters, books, and play items should be made available for all without fear of judgement.



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Table 2: Recommendations for Inclusive Palliative Care for TG/GNC Individuals

1. Learn and practice LGBT-inclusive communication skills, including using the individual's preferred name and pronoun.
2. Create opportunity and space for patients to disclose their gender identity and protect privacy when preferred
3. Allow the patient to define who is family and the role of family in care
4. Extend bereavement and grief support services to chosen family/friends
5. Create and maintain a non-discriminatory and inclusive practice setting
6. Promote continuity of care

Case 1: Sienna

Sienna is a 4-year-old child who was Assigned Male at Birth (AMAB) yet identifies as a girl and uses female pronouns (she/her). She also is living with neuroblastoma and is likely to pass away within the year. Sienna's family got her cancer diagnosis when she was 1.5 and has been intensively involved in her care since that time. At age 2.5, Sienna told her family "I am a girl." At the time, their oncologist suggested they see a therapist, who ultimately told the family the gender assertion is "a fantasy so he can find a solution to the cancer. If he is a girl maybe he won't die."

Uncomfortable with the therapist's explanation, the family eventually sought counsel with an experienced *gender specialist*^{ix}, who encouraged the family to support Sienna in her identity by allowing her the freedom to explore clothing, toys, names, and pronouns. The grandparents, however, were not in support and would continue to call Sienna by the name given to her at birth "Samuel." One nurse and also the department of pediatrics receptionist also would call this child "Samuel" stating it was in the chart and they legally had to use that name. Another provider would use Sienna's chosen name with her, but then with the family and other providers return to the name and sex assigned at birth. The care team was unsure how to best navigate the conflict between the parents and grandparents, as they were all intimately involved in the care. Sienna would get so distraught she would start to refuse pain medication at times and was refusing to see her grandparents.

When the HPC became involved, they asked the parents for guidance in referring to Sienna. They were loving and compassionate and used female pronouns at all times to discuss her care. With the paternal grandparents, they referred to "your beloved grandchild" and acknowledged their grief in both acknowledging the gender transition and the terminal illness. In the processing of death, the team began to say "daughter" and this was a source of both grief and comfort for Sienna's parents. They discussed what Sienna might like to wear when it came time. Sienna's parents had big decisions to make about how they would navigate the death planning process related to Sienna's affirmed gender.

Discussion Sienna:

It is common for well-meaning adults to question the gender identity of a child like Sienna. However, gender identity emerges in children as early as age 2-3.^x When a child is cisgender (or identifies with the sex they were assigned at birth) and affirms they are a "boy" or "girl," no one questions this identification. It is when children affirm a gender other than their assigned birth sex that adults may comment that they are "too young to know." Gender identity is known to be an internal understanding of one's own self, and is a complex interplay between biology, genetics, and environment that is not yet fully understood. However, we do know that gender identity is intrinsic to the individual and cannot be changed or modified by external forces.

Gender affirmative care is often misunderstood as "promoting" a path to gender transition. In truth, a trained gender specialist is working with families to best understand issues of identity, expression, and in some cases dysphoria. Affirming practice involves "following a child's lead" thoughtfully and with

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appropriate caution. Children who are supported in their gender identity fare far better than their peers in unsupportive environments. Thus, while adults cannot influence the child's gender identity, they can influence the outcomes.^{xi} Social transition has been studied as a proxy for parental acceptance, and socially transitioned children like Sienna have similar mental health outcomes as their peers^{xii}.

Particularly in a case where a child and family have little control over the many variables of a life-threatening illness, they should expect a supportive care team to “meet them” with cultural humility and competence, just as the HPC team would with spiritual or ethnic identity. In Sienna's case, the HPC providers were able to recognize the needs of the parents to affirm their child's identity, even in her death by referring to her as “daughter.” The team recognized that this term “daughter” would both honor the child's assertion and likely bring feelings of grief, and in the grandparent's case, refusal to support. The experience of validation, love, and support can dramatically influence the child and family's perception of the dying process. This is not to say the gender is supported because the child is terminal. Conversely, in a similar child, without a life-threatening illness, the standard of care remains the same.

For a child who has affirmed a clear gender identity or expression other than the one assigned at birth, it can be a powerful act for the family to honor the child in death as they did in life. To that end, providers may help a family consider how to preserve the memory of their child in all ways, including the ways the child experienced themselves. Examples may include burial attire in line with child's affirmed gender expression or identity, naming the child in an obituary the way they identified, sharing stories and pictures of the child honoring the ways they were their authentic self, etc. This can be painful and confusing for some families for a variety of reasons. They may not yet know where the gender identity or exploration would land later in life, and the illness has shortened this timeline; they may hold specific spiritual beliefs or traditions that feel in conflict with the child's assertion; they may feel such deep grief that they cling to their sense of how they knew the child at birth before the illness. For example, a family with a *cisgender*^{xiii} boy who loved trains may be buried with a train, play train songs at his service, etc. A similar but unique example related to a TG/GNC child (AMAB) who loved butterfly wings may be remembered by passing out wings, having butterfly cookie, etc. HPC providers can help families find ways to attune and stay connected with their children as a deep form of love to preserve their memory. Best practices in HPC care for TG/GNC adults include openly discussing the wishes and preferences of the patient regarding burial rites. Clearly, these best practices may need to be adapted to meet the developmental stage of the pediatric patient, but many children are capable of expressing their wishes, and the goal of the HPC provider should be to facilitate the patient and family's involvement in these decisions as much as possible. It is equally important to honor the family's feelings, wishes, grief, and decisions. Optimal practice would include a plan that supports all members. When that is not possible, finding compromise and common ground to preserve the memory of the child is likely to lead to more authentic grief and healing for families. Examples of compromise may include language like “our beautiful child who loved dresses,” yet not say “daughter” for a child assigned male at birth; “we have dressed Sophie in her favorite suit and tie. She would love to be called Sophie and also Max today.” “You may not all know this, but Jordan told us he sometimes felt like a girl inside his heart. Please join us in saying goodbye to Jordan as the amazing gender fluid child he was.”

Case 2: Khalil

Khalil was a 17-year-old AFAB (Assigned Female at Birth) Transgender Male. He had only told his parents about his gender identity a few months prior to receiving a leukemia diagnosis. The family insisted on calling Khalil by his birth name, Kehlani. This was a source of distress for Khalil, who explained, “I always knew I felt something but I didn't know it was gender. Once I realized, I wanted everyone to use my chosen name.” At first Khalil thought he might be a lesbian. Then he learned about “gender identity versus gender expression” and that it is not the same as sexual orientation and felt “that fit better. I don't really feel like a girl who likes girls. I just feel like a boy.” Khalil was very distressed by the onset of his menses and by his fully developed chest of breast tissue. When Khalil started having physical symptoms likely related to the cancer, it created a focus on body he had been able to deny or avoid. He did not want to cause the family more stress, so he did not speak up to family about gender, yet told a few friends he wanted to be known as Khalil. Shortly after that he began to “bind” his chest, wearing a tight



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sports bra style garment to create a flatter chest appearance. After a month of being supported as Khalil by friends, he asked his parents to support the chosen name as well. Khalil's parents would not use the requested name. They said, "We love you Kehlani but we think you are just confused." The parents' responses were a significant source of distress for Khalil leading to the onset of suicidal ideation. Parents also felt that Khalil was causing damage to his body by using the chest binder. Khalil was physically uncomfortable in the chest binder, but the larger issue was the psychological distress of having his "female" body be obvious to others. "It made me want to die even more and everyone was trying to help me fight to live from cancer. It was so confusing and weird like I wanted to die and live at the same time."

Discussion Khalil:

Multiple studies show that the rate of suicidal ideation in TG/GNC individuals is around 40%, with rates of depression six times higher than the general population.^{xiv} In Khalil's case, his mental health disposition was further complicated by a cancer diagnosis.

In an otherwise healthy child, the family would have the time to get support and information needed. In a case where a family is already managing multiple appointments with high levels of worry about their child's health and illness, this type of intensive family support around gender may not be possible. To that end, providers being aware of best practices to support TG/GNC children and youth can prove a source of comfort and lead to increased quality of life and pain management. Unfortunately, many TG/GNC individuals delay/avoid medical care due to their fear of mistreatment by providers or may not disclose their identity to the provider when receiving care.^{xv} The Gender Affirmative Standards listed in Table 3 provide ways for the care team to support Khalil, while also respect the parents' lack of readiness to face Khalil's gender assertion.

Table 3: Standards of Practice within a Gender Affirming Care Model

1. Use the name the person prefers or requests to be called.
2. Use the pronoun the person asks you to use. It can be he, she, the singular they, or perhaps something unfamiliar to you such as zie/hir. If you do not know what pronoun to use, ask.
3. Unless it is medically relevant, do not ask the person about their genitals or surgical status.
4. Unless it is medically relevant, or you have been given express permission, do not share information about the person's gender identity with others.
5. Do not question the legitimacy of a gender assertion as a substitute for other issues "maybe you want to be a girl because the boy part of you got sick"
6. Have visuals (posters), books, and play materials that offer examples of all gender expressions and identities

Medical considerations:

Medical treatments for TG/GNC youth start in puberty and may include hormone blockers to delay endogenous puberty and block the development of secondary sex characteristics, as well as feminizing or masculinizing hormones to change the body's phenotype. The timing of surgery, if any, is variable, but generally waits until late adolescence or adulthood.

There is no clear established optimal age for these interventions, and the gender affirmative goal is to create a puberty timing that is congruent with the individual's peers. Sometimes interventions are delayed because parents do not feel ready to allow a step, despite a clear agreement on gender identity itself. Many families are worried about "getting it wrong" or regret. These concerns should be addressed and supported, yet not used as a definitive decision for care. Conversely, the Gender Affirmative Model offers a shift from "ages to stages" where gender consultation understands the interweaving of body, psyche, and environment and what steps make sense individually for each person. In addition, youth may choose non-medical options to masculinize or feminize their appearances, such as breast binding and masculine genital "tucking." For more information about the specific medical interventions, resources are listed in Table 4. Despite common concerns, transgender hormones and surgery pose far less medical risk than the social risks of an unsupportive family and environment. For example, hormones do not



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increase risk of cancers, but transgender people report that negative experiences with health care providers may cause them to delay needed care or experience inappropriate care, increasing the risk that a cancer goes undetected. High rates of un-insurance and poor provider education/comfort with TG/GNC individuals compound this problem and contribute to poorer health outcomes.⁹

During the several-year course of Khalil's cancer treatment, more questions may arise about his chest binding, or about taking testosterone or undergoing surgery to masculinize his appearance. While the parents and the care team may feel the need to prioritize cancer treatment, medical transition may also be an integral part of Khalil's experience as a young man. Although the decision may need to be carefully explored with the medical team to assure no contra-indications to therapy with his cancer treatment regimen, the psychosocial benefits of initiating medical transition may help Khalil relate to his body and his cancer treatment. According to the WPATH Standards of Care, the only absolute contra-indication for hormonal therapy are a thrombotic event or a hormone-mediated cancer, and so the benefits and risks of initiating or continuing hormone therapy must be carefully weighed by the patient, the family, and the multi-disciplinary medical team.^{xvi}

Legal Considerations:

Unfortunately, a final concern for TG/GNC individuals is around their legal rights. This may especially apply in the case of parents who themselves are TG/GNC. Many states and countries still do not allow people to change birth certificates or identity documents and may not recognize a person's marriage or parentage of their children. Lack of legal recognition could cause concerns about health insurance and benefits for surviving family members. More information to aid parents in addressing their legal questions and concerns can be found through the resources in Table 4.

Table 4: Medical and Legal Resources for Transgender Individuals	
Legal Organizations	<ul style="list-style-type: none"> • Transgender Law Center www.transgenderlawcenter.org • National Center for Lesbian Rights www.nclrights.org
Medical Information	<ul style="list-style-type: none"> • The Center of Excellence for Transgender Health www.transhealth.ucsf.edu • World Professional Association of Transgender Health (Standards of Care) www.wpath.org
Advance Care Planning	<ul style="list-style-type: none"> • Human Rights Campaign (Section on Health & Aging) http://www.hrc.org/issues/health-and-aging • National Resource Center On LGBT Aging http://www.lgbtagingcenter.org • Lambda Legal: Tax, Life, and Financial Planning https://www.lambdalegal.org/tax-season/protect-yourself

Parents who are TG/GNC

Pediatric palliative care teams may also encounter parents who themselves identify as TG/GNC. While comprehensive discussion of this group is beyond the scope of this article, the same principles of Gender Affirmative care can be applied to this population. Historically, given the frequent traumatic experiences TG/GNC people have had interfacing with healthcare systems, they may have deep hesitation or even have had trauma related to accessing care. To this end TG/GNC have lower rates of accessing care. When a child is ill, they often have to be more in mainstream spaces including healthcare, which can be a source of anxiety of how they will be treated in front of their child, particularly at a time already laden with stress.^{xvii} One important concept to highlight is that of "chosen family," wherein TG/GNC individuals may have familial ties that replace or augment kinship ties with biological relatives, often due to rejection by their own family of origin. In addition, due to limitation of legal rights for TG/GNC people, spouses and children may lack a protective legal relationship. Gender Affirmative Care recognizes that each individual has the right to define who counts as their family, what family means to them, and who will be involved in their care planning and process, and may mean that hospital/institutional policies may need to be changed or supplanted to allow chosen family members the same access as legal/biological family members, as noted in Table 1.



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In addition, the pediatric palliative care team may encounter TG/GNC parents in the context of reproductive care and should recognize that masculine-identified people can choose to give birth and may encounter reproductive difficulties and loss in the same manner as cisgender parents. Similarly, those Assigned Male at Birth may deeply grieve their inability to carry a pregnancy as their cisgender female counterparts are often able to do. The palliative care provider should pay special attention to language surrounding this parent's relationship, i.e., using terms like "expectant parent/father" in lieu of "pregnant woman," or "gestational parent" instead of "birth mother." Always suggested is simply to ask the person what terms they use.^{xviii}

Conclusion

TG/GNC children and youth living with life-threatening illness benefit from a combined approach of pediatric palliative or hospice best practices in addition to gender affirmative care. Pediatric Palliative and Hospice Care guidelines and recommendations include ensuring that all large health care organizations serving children with life-threatening conditions have dedicated interdisciplinary teams that act as a cornerstone of patient safety and quality for patients with life-threatening conditions; that teams should facilitate clear, compassionate, and forthright discussions about medical issues and the goals of care; and support families, siblings, and health care staff.^{xix} Similarly, Gender Affirmative Care offers an interdisciplinary approach that takes into account all members of a caregiving and provider system with a focus on care that increases positive mental health outcomes, thereby reducing distress (mental health/gender dysphoria). Levels of dysphoria that need to be addressed by care teams are akin to pain management standards.

As literature in pediatric palliative care suggests, palliative care principles of "compassion, warmth, flexibility, presence" are not only crucial but make a significant positive impact on a family's experience of their child's care and in some cases the dying process. It is known LGBT children and youth that are supported in their identity have significantly better outcomes^{xx}. Both models understand that all members of a caregiving system need compassion, information and support.

The danger of prioritizing a medical illness over gender expression/identity is that the distress caused by the need to be "seen" or affirmed may interrupt or distract from the organic process of being with a child in treatment, illness, and death. When a child is affirmed and supported they are most available in cognitive and emotional ways including during times of illness. Attunement to expressed identity creates emotional safety, which in turn may allow a patient to more easily accept comfort, cooperate with treatment protocols, tolerate difficult conversations, and to know that they can truly turn to their families and the care team without hesitation. Here, the pediatric palliative care provider encountering TG/GNC children and youth can lean into these shared care principles and affirm their patient's gender identities and expressions. It is here at this intersection the provider offers patients and families improved quality of life and/or death.

For providers and families (information, books, support groups, resources, and research) see:

<https://www.genderspectrum.org/>

References

- ⁱ Gates, G. In US, More Adults Identifying as LGBT. Gallup Daily Tracking: Social and Policy Issues. 2017 Jan 11. <http://news.gallup.com/poll/201731/lgbt-identification-rises.aspx>
- ⁱⁱ Acquaviva K. (2017). *LGBT-inclusive hospice and palliative care*. New York: Harrington Park Press.
- ⁱⁱⁱ Maingi, S., A. Bagabag, & S. O'Mahony. (2017). Current Best Practices for Sexual and Gender Minorities in Hospice and Palliative Care Settings. *Journal of Pain and Symptom Management*, 55(5), 1420–1427.
- ^{iv} National Consensus Project for Quality Palliative Care (2009). *Clinical practice guidelines for quality palliative care*, 2nd ed.



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- ^v Cacciatore, et al. (2017). The Long Road to Farewell: The Needs of Families with Dying Children.” *Omega, Journal of Death and Dying*. First published online.
- ^{vi} Coolhart D., Shipman D.L. (2017). Working Toward Family Attunement: Family Therapy with Transgender and Gender-Nonconforming Children and Adolescents. *Psychiatric Clinics of North America*, 40(1), pp. 113-125.
- ^{vii} Keo-Meier, C. & Ehrensaft, D. (Ed.) (2018). *The Gender Affirmative Model: An Interdisciplinary Approach to Supporting Transgender and Gender Expansive Children*. APA Publications.
- ^{viii} Cloyes, K. G., W. Hull, & A. Davis. (2018). Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers. *Seminars in Oncology Nursing*, 34(1), 60-71.
- ^{ix*} Gender Specialist refers to a mental health trained person (often a psychologist or clinically trained therapist) who works to assist the child and family in understanding the nuances within gender identity and gender expression, and is specifically trained to not pathologize gender or conflate it with mental health concerns, but rather work to understand types of dysphoria or distress present and how that relates to care plan suggestions.
- ^x Gender Identity in Children. [Healthychildren.org](https://www.healthychildren.org/English/ages-stages/gradeschool/Pages/Gender-Identity-and-Gender-Confusion-In-Children.aspx). American Academy of Pediatrics: 2015.
- ^{xi} Ehrensaft, D., et al. (2018). Prepubertal social gender transitions: What we know; what we can learn—A view from a gender affirmative lens. *International Journal of Transgenderism*, 1-18. Published online.
- ^{xii} Olson, K. R., et al. (2016). Mental health of transgender children who are supported in their identities. *Pediatrics*, 137(3), e20153223.
- ^{xiii*} Cisgender refers to a person whose gender identity corresponds with the sex the person had or was identified as having at birth (<https://www.merriam-webster.com/dictionary/cisgender>).
- ^{xiv} Haas, A. P., Rodgers, P. L., & Herman, J. (2014). Suicide attempts among transgender and gender non-conforming adults: Findings of the national transgender discrimination survey. American Foundation for Suicide Prevention.
- ^{xv} James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). Executive Summary of the Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.
- ^{xvi} Coleman, Eli, et al. (2012). Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *International Journal of Transgenderism*, 13(4), 165-232.
- ^{xvii} Singh, A. A., & Dickey, L. M. (Eds.), *Affirmative Counseling and Psychological Practice with Transgender and Gender Nonconforming Clients*. (APA, 2017)
- ^{xviii} For more information on TG/GNC parents, see: <https://www.lambdalegal.org/know-your-rights/article/trans-parenting-faq>
- ^{xix} American Academy of Pediatrics. (2013 Nov.). Policy Statement: Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations. *Pediatrics*, 132(5).
- ^{xx} <https://familyproject.sfsu.edu/>
The **Family Acceptance Project**® is a research, intervention, education and policy initiative that works to prevent health and mental health risks for LGBT youth.

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TREATING CHILDREN OF DIVORCE: OBTAINING CUSTODY DOCUMENTS AND SETTING CLEAR GROUND RULES ARE KEY

Karen Burke-Haynes, MD

Newsletter: [Forum, Summer 2015](#)

Aug 27, 2015

Currently over 1 million children experience divorce each year and up to 61% of children in this country will experience their childhood in single-parent homes. The process of separation and divorce strains relationships and erodes communication. The negative emotions associated with this can impact professional relationships within the healthcare setting. The licensee who cares for minor children will likely have to manage some aspect of the controversies attendant to divorce and separation. Licensee entanglement in the legal battles that erupt is not unusual. Review of complaints against licensees presented to the NCMB confirms this.

In this article, I've attempted to address some of the administrative challenges that may arise in the office in high conflict scenarios. Intensified relational dynamics typically characterize the first two or three years after separation/divorce. Much of this resolves after this time. There is, however, a group of parents (eight to 15%) for whom conflict continues for years after divorce. Licensees caring for minor children in the primary care setting as well as other areas of specialization would benefit from formulating strategies to manage the fallout of these bitter interactions. It is important to note that these dynamics not only negatively impact the physician-patient care relationship but also the administrative staff who are most often the front-line negotiators of parental hostilities.

The American Academy of Pediatrics position statements provide insight and guidelines for addressing the emotional, developmental and physical needs that arise in divorce and separation. However, there is little mention of strategies for assisting practices and institutions in mitigating risks that stem from high conflict scenarios.

Careful consideration and development of a systematic response is warranted and can be extremely important to licensees. Consider the following malpractice case reviewed recently by the Board:

Case Study: Appropriate care, inadequate consent

The Board received a malpractice payment report regarding a payment made on behalf of a board certified pediatric specialist with no prior history of actions against his license. The licensee was successfully sued by a parent in spite of having provided medically relevant and appropriate care to the minor child. The patient was brought in for care by the father, who had physical custody and shared legal custody. The setting was one of ongoing conflict after an extremely contentious divorce. The clinician was consulted by a major academic center to assist in supporting the psychological needs of the patient. Care was arranged by the father and assumed by the clinician to have been confirmed with the mother. Care was delivered over a two-year period. Records documented that the child did well under the physician's care. Review of records confirmed competent and appropriate care of the patient. However, the licensee was accused by the mother of being a biased advocate. The physician's clinic notes were used to support the mother's case. The Board determined that there was no violation of the Medical Practice Act involved in the case and no board action was taken. However, because a payment that met criteria established by state law was made on the physician's behalf, the payment is public information. As a result, there is now a public malpractice payment reported on the licensee's information page on the NCMB's website.

Practical guidance on protecting your practice and avoiding problems

Conversations with local attorneys familiar with high conflict divorce dynamics and a review of complaints presented by custodial and noncustodial parents to the Board suggest the need to support licensees with practical advice on managing these cases to mitigate potential risks.

One of the first steps for a medical office is to ensure that the practice has access to all relevant legal documents that state the terms of custody and care of the minor(s) involved. Parental and custodial



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relationship disclosure should be standard for all pediatric patients. In shared custody arrangements, documents should be requested from both parents. If parents are unwilling or unable to provide copies, these documents can also be obtained from the Clerk of Court office that has jurisdiction over the case. These are public documents and are available if the case number is provided. To ensure consistent access to custody documents, there may be benefit to using the Clerk of Court as the standard source of custody information. Front office staff should be informed of the importance of obtaining custody documents and trained to request and maintain them.

I offer the following advice, based on more than 25 years of pediatric practice in academic and private practice settings:

Establish terms of custody: Custody may refer to both physical and legal rights. The decision to treat a minor child based on input of one parent in the setting of joint legal custody should be based on medical necessity and be clearly documented in the record.

Set office policies: Develop standard office policies for obtaining information on custody arrangements for all new patients prior to establishing care. Clarify marital status and gather all addresses.

Use a healthcare contract: Develop a written, signed informal contract that states the parents' commitments regarding healthcare decision making for the patient and communication with the office. This may be used as a reference point when conflict arises. It is not intended to be a legal document, but rather to serve as a behavior contract.

Be proactive: Once conflict is identified, declare a timeout. Attempt to meet with parents separately or together to present the practice's position and outline policies regarding authorization for treatment and other matters.

Set clear boundaries: Avoid playing the role of peacekeeper. Your focus should be on your patient and avoiding barriers to quality patient care.

Remain neutral: Avoid being pulled into the dynamic of acting as a character witness - no taking sides. If there is clear evidence of abuse or neglect, document, follow the law and report or refer to appropriate community agencies.

Set clear goals: For example providing quality care with minimal disruption of normal office workflows and mitigation the risk of litigation or other unfavorable action on the part of a disgruntled parent.

Establish consequences: Clearly inform parents of the possibility of patient dismissal from the practice early in communication if there is evidence of unwillingness to accept boundaries. The priority of rendering good care cannot be achieved if there is no agreement on the process by which this is to be done. The responsibility for this rests with the parents.

Understand the legal process: Clinicians may be called to testify as a fact witness or an expert witness in custody or other legal proceedings. A fact witness is generally used to establish matters such as a parent's level of concern regarding the child, and general observations of the pediatrician of parental dynamics, while expert witnesses typically provide information solely on medical facts and aspects of medical care. Fact witnesses may not receive compensation for their time unless there is a contract specifying that time will be compensated. It may be prudent to include a standard statement in your policies that the parent agrees to compensate for services should a subpoena be issued, regardless of the licensee's designation as a fact or expert witness.

These points should serve as general guidelines for developing individualized protocols depending on the



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unique needs of the practice. The sooner a practice develops clear policies, documents and procedures for handling cases involving shared custody, the better protected and prepared its providers will be.

The suggestions I've presented above are certainly not exhaustive, however, they highlight major areas that should be addressed as individual offices and programs develop protocols.

I welcome feedback and suggestions that might be helpful to share with colleagues regarding this challenging subject.

Send comments to forum@ncmedboard.org

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Cultural Sensitivity

Take-Home Message

Families from different cultures may follow specific traditions, rituals, and practices after a death. Although there are real differences between cultures, the fundamental experience of grief is universal. Rather than attempting to gain knowledge about every culture, teachers can aspire to achieve a general sensitivity to the unique needs of children and families coping with loss.

Different Cultures Express Grief in Different Ways

Individuals from different cultures may follow specific traditions and practices after the death of a loved one. These practices are informed by the different cultural beliefs, norms, and expectations that guide the bereaved person's behaviors.

One culture may expect its members not to speak the name of the person who died. Another may encourage families to name the next child born after the deceased. People of one culture may believe that each tear shed creates another hardship for the deceased, so remain quiet and reserved at funerals. Those of another may believe the extent of love for the person who died is demonstrated by the degree of emotions expressed at the funeral.

It is understandable that school personnel may not be familiar with the rituals and expectations of every culture represented among their students. Sometimes, rather than reaching out to a family after the death of a loved one, school staff will minimize their interactions with the family to avoid doing something inappropriate or offending the family somehow.

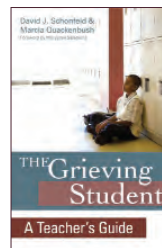
Although these are real differences, the fundamental experience of grief is universal. If someone is able to be empathetic, thoughtful, sensitive, and supportive to grieving children of one culture, chances are quite good that this person will be able to help children of another culture as well. Being observant, genuinely curious, respectful, and responsive to your students will enable you to learn about their families and cultures and be guided by their responses. Often what works best is to simply be present, express your concern, and remain available to provide helpful assistance.

Be Observant

We are all enriched when we learn about different cultural beliefs, expectations, and traditions. When we recognize that there is a range of acceptable ways to experience and express grief, we can watch for approaches that may vary from our own and explore ways to bridge cultural differences in order to truly help our students and their families.

1. Ask questions. Ask openly when you are unsure what would be most helpful for a family or individual. For example:
 - “Can you tell me how your family and your culture recognize and cope with the death of a family member? How does this fit with your own preferences at this time?”
 - “Can you help me understand how I can best be of help to you and your family?”
2. Watch out for assumptions. Even if you know about the common practices of a culture, this may not accurately predict how a family or individual from that culture will behave. Many people have been exposed to multiple cultures. Parents sometimes have different beliefs or practices from their children. Some families or individuals choose to follow practices of a different culture when these align better with their current beliefs or preferences.

Assumptions may result in stereotypes that cloud our perceptions and make us miss opportunities to be helpful.
3. Be present and authentic. Even if you don't know about a particular culture's practices concerning death and grief, you can approach the family with an open mind and heart. Be guided by their responses. This works well across many different cultures.



For more information on supporting grieving students, refer to *The Grieving Student: A Teacher's Guide* by David Schonfeld and Marcia Quackenbush.

LEAD FOUNDING MEMBERS



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ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **NHPCO Palliative Care Online Resources:**

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community –Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

2. **Pediatric Hospice and Palliative Care Resources:**

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
 - *When Your Child is in Pain*
 - *Talking With Your Child About His or Her Illness*
 - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
 - *When a Child Dies: A Guide for Family and Friends*
 - *Helping Children Cope with the Loss of a Loved One*
- **NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
 - *Nonpharmacological Pain Management for Children*
 - *Sibling Grief*
 - *Pediatric Pain Management Strategies*
 - *Communicating with a Child Experiencing The Death of a Loved One: Developmental Considerations*
- **Center to Advance Palliative Care:** Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
 - [Three Palliative Care Leadership Centers™ \(PCLC\) locations now offer training for pediatric programs:](#) Recognizing the unique needs of pediatric patients and their families, three Palliative Care Leadership Centers™ (PCLC) locations are also offering training geared specifically to pediatric palliative care programs.
 - [The Pediatric Palliative Care Field Guide:](#) A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.



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- [The CAPC Pediatric Palliative Care Toolkit](#): A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.
- Take a look at the new Creative Therapies Toolkit developed by PA Pediatric Palliative Care Coalition. This resource is for caregivers and families. <http://www.ppcc-pa.org/creative-therapies/>
- Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched [the Chronic Pain Assessment Toolbox for Children with Disabilities](#). The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:
 1. Chronic pain in children with cerebral palsy and the development of the Toolbox
 2. The sections of the Toolbox and how to start with based on your needs
 3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

Check them out here: <http://hollandbloorview.ca/Toolbox>

3. Pediatric Hospice and Palliative Care Training:

- **NHPCO's Interdisciplinary Conference**
 Preconference Dates: November 3-4, 2018; **Expert Interdisciplinary Care for the Developing Pediatric Team**
 Main Conference Dates: November 5-7, 2018
 Hyatt Regency New Orleans, New Orleans, LA
<https://www.nhpc.org/IDC2018>
- **4th Annual Pediatric Palliative Care Coalition Conference**
Celebrating the Past and Strengthening the Future of Pediatric Palliative and Hospice Care
 Friday, October 5, 2018
 8:00 a.m. – 4:00 p.m.
 Sheraton Harrisburg-Hershey, Harrisburg, PA
 For more information or to register:
[PPCC conference](#)
- **Upcoming [2018 Webinars](#) provided by the Pediatric Care Coalition:**
 - September 25th
Transitioning Adolescents into Adult Care
 With Parag Shah, MD and Rebecca Boudos - Lurie Children's Hospital
 - October 18th
Medical Marijuana
 With Elissa Miller, MD Nemours/Alfred I. DuPont Hospital for Children and Billie Winegard, MD Children's Hospital of Illinois
 - November 13th
Understanding the Parent Perspective: Pediatric end of life and bereavement
 With Blyth Lord, Ed.M and Nancy Frumer-Styron, J.D., PhD.
- **Pediatric Hospice and Palliative Care: Advances and Innovations (Pedi-Innovate):**



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This summer pediatrics course will be a forum for interdisciplinary healthcare professionals and others with an interest in pediatric palliative care to deepen their knowledge and understanding of this nascent and rapidly-evolving field.

Through this course, we aim to advance pediatrics in hospice and palliative care for children with serious illness, thereby optimizing their quality of life, regardless of treatment course or illness trajectory. Learners will improve their knowledge, competence, and change their performance, leading over time to enhanced patient outcomes.

August 9-11, 2018

Minneapolis, MN

<http://aahpm.org/meetings/pediatrics-course>

4. Journal/News Articles

- **Let Me See My Baby:** Most doulas help families welcome the arrival of their newborn and support them as their journey into parenthood begins, but bereavement doula Amy Banson, holds their hands and helps heal their hearts as they say goodbye. Read more [here](#).
- **Supporting the Patient Journey—The Role of Palliative Care in Pediatrics:** Slightly fewer than 250 palliative care providers are focused on serving children in the United States. Read more [here](#)

5. **Trends in Ped Pall Care Citation List** The document, Trends in Pediatric Palliative Care Citation List and Commentary, 2018; #6, is generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. This issue contains a commentary by Dr. Meaghann Shaw Weaver, MD, MPH, on the feature article: Randall, D. C. (2017). Two Futures: Financial and Practical Realities for Parents of Living With a Life Limited Child, published in Comprehensive Child and Adolescent Nursing, 40(4), 257–267, together with a 2½-page list of recent publications. To see this and past citation lists and expert commentaries, visit <http://pediatricpalliative.com/research-blog/>

6. **The American Academy of Pediatrics published a Policy Statement in November, 2016**, on Helping Children and Families Deal with Divorce and Separation. This statement was written by George J. Cohen, Carol C. Weitzman, and the Committee on Psychosocial Aspects of Child and Family Health, Section on Developmental and Behavioral Pediatrics. The Statement can be accessed at <http://pediatrics.aappublications.org/content/early/2016/11/24/peds.2016-3020>

The Policy Statement states that there are over 800,000 divorces and parent separations per year in the U.S., affecting over 1 million children. Both children and their parents often endure emotional trauma throughout and after this divorce/separation process. The Statement urges physicians to be aware of family dysfunction as a result of this, which may indicate that some form of intervention is needed such as age-appropriate explanations or counseling for the child and advice/guidance for the parent(s). Referrals to professionals specializing in the social, emotional and legal aspects of separation/divorce is also suggested as a helpful intervention for some families.

The Statement outlines a range of children's and parents' reactions to the divorce. It also devotes significant space to educating on the legal aspects of divorce and how it can impact care for these children by health care professionals. Lastly, it writes about the pediatrician's role in caring for children who are from divorced/separated households from anticipatory guidance to follow-through after the divorce/separation. The Statement also provides a list of suggestions for assisting these children and their families.

This may also be a valuable resource for healthcare professionals working with families separated due to immigration reforms in the U.S. where these separations are/can cause these children and their families great emotional and psychological trauma. Hopefully, these



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psychosocial needs will be attended to by medical and/or mental health professionals in contact with these children and their families during the separations and after they are reunited.

7. Cultural Competency in Paediatric Palliative Care Research Report (August, 2008)

This 87-page Report from Alberta Health Services in Canada, though somewhat dated, provides a comprehensive overview of Cultural Competency, and especially as it relates to pediatric palliative care. It recognizes that with the significant influx of immigrants from Middle-Eastern, Eastern European, African, and South American countries, among others, healthcare professionals in Canada are not prepared to address the diverse differences in cultural and religious values, beliefs, and traditions that are encountering with their pediatric patients. This is especially important as those in pediatric palliative/hospice care try to offer culturally-sensitive end-of-life services for these children and their families.

The purpose of the Report was to explore the challenges and needs families and health care professionals experience when receiving or providing palliative care and grief/bereavement support. Two of the reasons for compilation of the Report were to educate on the ethno-cultural values/beliefs of different populations as a child is dying and after the child has died and to help identify what the learning needs of health care professionals who provide pediatric palliative care are so that they can better provide more competent culturally-sensitive care to their pediatric patients.

A full copy of this Report is available at

<file:///C:/Users/anne/Downloads/Alberta%20art%20on%20cultural%20competency%20in%20PC.pdf>

- 8. Subjects and Contributors for Future Issues of This E-Journal.** For upcoming E-Journal issues, we plan to address issues related to adolescents and young adults. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at ctorkildson@mail.cho.org or christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

- 9. Reader's Corner.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

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Children's Project on Palliative/Hospice Services

ChiPPS serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization.

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