

Special Article

Pediatric Palliative Care in the Multicultural Context: Findings From a Workshop Conference



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Abstract

Context. In our increasingly multicultural society, providing sensitive and respectful pediatric palliative care is vital.

Objectives. We held a one-day workshop conference with stakeholders and pediatric clinicians to identify suggestions for navigating conflict when cultural differences are present and for informing standard care delivery.

Methods. Participants explored cases in one of four workshops focused on differences based on race/ethnicity, economic disparity, religion/spirituality, or family values. Each workshop was facilitated by two authors; separate transcriptionists recorded workshop discussions in real time. We used content analyses to qualitatively evaluate the texts and generate recommendations.

Results. Participants included 142 individuals representing over six unique disciplines, 25 of the U.S., and three nations. Although the conference focused on pediatric palliative care, findings were broadly generalizable to most medical settings. Participants identified key reasons cultural differences may create tension and then provided frameworks for communication, training, and clinical care. Specifically, recommendations included phrases to navigate emotional conflict, broken trust, unfamiliar family values, and conflict. Suggested approaches to training and clinical care included the development of core competencies in communication, history taking, needs assessment, and emotional intelligence. Important opportunities for scholarship included qualitative studies exploring diverse patient and family experiences, quantitative studies examining health disparities, and randomized clinical trials testing interventions designed to improve community partnerships, communication, or child health outcomes.

Conclusion. Taken together, findings provide a foundation for collaboration between patients, families, and clinicians of all cultures. *J Pain Symptom Manage* 2019;57:846–855. © 2019 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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Accepted for publication: January 14, 2019.

Introduction

Nearly 20 years ago, the American Academy of Pediatrics (AAP) first advocated that pediatric palliative care (PPC) be integrated into the clinical care of children with serious or life-limiting illness.¹ PPC has since evolved into its own subspecialty and has increasingly recognized the importance of incorporating the needs and perspectives of diverse populations. Similarly, the concept of “cultural humility” (the process of building relationships through discovery of another’s culture)² has entered into our nomenclature, care delivery, and pediatric training priorities.³

Providing culturally sensitive care is particularly important in pediatric palliative care settings because the subspecialty is defined by a holistic approach to a child’s “mind, body, and spirit”.⁴ Specifically, PPC provides expert-level pain and symptom management, communication support, and attention to a child’s psychosocial and spiritual needs. “Culture” (which can be concisely thought of as the customary beliefs, values, attitudes, social forms, practices, and material traits of a racial, ethnic, religious, or other social group)⁵ necessarily impacts this work. For example, PPC clinicians must explore patient and family perspectives to provide concordant decision support regarding goals of care.

Despite the clear importance of culturally relevant PPC, numerous barriers and challenges thwart the consistent provision of this care. Forty percent of pediatric health care providers have suggested that cultural differences are a frequent barrier to adequate PPC.⁶ Relatively little research has focused on the intersection of culture and PPC.^{7,8} Nevertheless, disparities in end of life and disease-based care related to race, ethnicity, primary language, and financial resources are well established.^{9–26} Furthermore, many have recognized the need to recognize and integrate religious and spiritual support into pediatric family-centered care, especially because it impacts medical decision making.^{26–35}

With all this in mind, we held a one-day workshop conference to engage experts and stakeholders in a discussion regarding future directions and priorities for PPC clinicians and researchers. Our objectives were twofold. First, we hoped to identify specific factors contributing to tensions and conflict when cultural differences are present. By building awareness of these complexities, we aimed to inform and improve clinical practice. Second, we endeavored to generate suggestions for how to integrate cultural humility into the navigation of “difficult” encounters, what actions might be taken to prevent or minimize future conflict, and how we can inform PPC scholarship focused on cultural differences, care delivery, and intervention.

Methods

The one-day conference (“Pediatric Palliative in a Multicultural Context: a conversation to determine our priorities in research and clinical care for children with life-limiting illness within the context of our diverse culture”) was held in July 2018 in Seattle, WA, with financial support provided via a grant from the Arthur Vining Davis Foundations. We advertised through list-serves for the AAP and American Academy of Hospice and Palliative Medicine special interest groups, national meetings, including the 2017 American Academy of Hospice and Palliative Medicine Annual Assembly, postcard mailings for the annual Seattle Children’s bioethics conference, and informally, by networking within the pediatric palliative care community.

At the time of registration, all participants were asked to provide credentials and affiliations. We defined “discipline” based on participant-reported degrees and/or roles; we assumed participants identifying as “MD,” “RN,” or “chaplain” represented disciplines of medicine, nursing, and chaplaincy, respectively. We determined regional representation based on the location of participants’ primary institution; for example, when a participant identified Seattle Children’s as her affiliation, she was assumed to live in Washington State. We did not query other demographic factors such as age and sex, nor did we inquire about cultural determinants such as race, ethnicity, state or country of origin, rural or urban home community, or religion.

In preparation, conference organizers (A. R. R., C. F., J. W., and R. H.) met virtually and identified four key themes to be addressed during the meeting. These included two evidence-based factors associated with health disparities (race/ethnicity and financial resources), and two critical elements of pediatric patient-centered care (religion/spirituality and family). Conference co-chairs (A.R.R. and R.H.) then organized the meeting to include the following: a morning of invited speakers who would underscore the role of each theme in societal definitions of “culture” (Appendix S1) and an afternoon of facilitated concurrent workshops aimed at identifying guiding principles for navigating each theme in clinical pediatric palliative care. Specifically, each workshop began with a clinical case adapted by the conference organizers from common experience and related to a theme of interest (race/ethnicity, economic disparity, religion/spirituality, family; Appendix S2).

Conference participants were informed of our intention to evaluate the conference proceedings and publish the findings. Each chose which group to attend based on personal or professional interest; groups were not assigned. Participants were instructed

to stay within their group once the workshop started. Two authors facilitated each workshop. They used a common framework, asking participants to consider elements of “respect, understanding, power, and trust” as they pertained to the clinical scenario at hand (Appendix S2). Each workshop group was tasked with identifying key “take-away messages” related to clinical care, education, or research, as determined by their group. Otherwise, facilitators were invited to navigate the discussion as needed to encourage group participation. In some cases, this took the form of a brainstorm regarding key targets of intervention; in others, this involved round-table solicitations of individual experiences, perspectives, and recommendations. A dedicated scribe transcribed proceedings from each workshop group.

Immediately after the conference, the authors convened and identified three main themes that had emerged from all the discussions, where “we” refers to pediatric clinicians: “how we speak,” “how we think,” and “how we learn”.³⁶ We then merged the transcriptions from each workshop and used the themes to direct two content analyses.^{37,38} The first analysis aimed to identify terms associated with perceived challenges and reasons for tension in clinical encounters seemingly focused on cultural differences (conference Objective 1). The second aimed to identify recommendations for navigating these encounters (conference Objective 2). Here, four authors (A.R.R., C.F., J.W., and R.H.) identified eight additional subthemes (“emotions,” “trust,” “unfamiliarity,” “conflict,” “context,” “education,” and “clinical practice”).³⁶ Finally, all authors arrived at consensus regarding exemplary quotations, clinical implications, and recommendations.

Findings

Conference participants included 142 individuals representing over six unique disciplines, including medicine (41%), nursing (17%), social work (9%), research (8%), chaplaincy (4%), and patient navigation (4%, Table 1). Participants were from 25 states, plus the U.K. and Canada; most (75%) were from the Western U.S., including 54% from Washington State.

Why Cultural Differences Feel Hard to Navigate. Participants identified multiple reasons clinical scenarios may feel additionally challenging to navigate when cultural differences exist (Fig. 1). These frequently included potential implicit and explicit biases and corresponding assumptions about a given patient, family, or cultural group. For example, Case 1 included a description of an “African American” former preemie with medical complexity and his “single mother who had received limited prenatal care” (Appendix S2). Although some participants believed that this

Table 1
Participant Characteristics (N = 142)

Discipline	n (%)
Medicine	58 (41)
Nursing	24 (17)
Social work	13 (9)
Research (nonclinician)	12 (8)
Chaplaincy	5 (4)
Patient navigation	5 (4)
Other ^a	25 (18)
<hr/>	
Region ^b	
West	107 (75)
Southwest	4 (3)
Midwest	7 (5)
Northeast	6 (4)
Southeast	13 (9)
U.K.	2 (1)
Canada	2 (1)
Unknown	1 (<1)

^aOther participant-identified disciplines: Administration (n = 4), Law (n = 2), Child Life (n = 2), Mental Health/Counseling (n = 2), Ethics (n = 1), Writer (n = 1), noncategorized roles (e.g., “volunteer” and “other hospital staff”) (n = 13).

^bRegions defined as: West = WA (n = 77), CA (n = 18), OR (n = 6), ID (n = 1), CO (n = 1), AK (n = 1), HI (n = 1); Southwest = TX (n = 2), AZ (n = 1), OK (n = 1); Midwest = IL (n = 2), MI (n = 2), OH (n = 1), MN (n = 1), WI (n = 1); Northeast = MA (n = 2), NJ (n = 2), PA (n = 1); Southeast = TN (n = 7), NC (n = 2), SC (n = 2), AL (n = 1), LA (n = 1).

demographic and background history provided important contextual information, others raised concerns about stigmatization. Describing one parent as “African American,” while not describing another as “white” unavoidably carries forward a history of discrimination and prejudices. More generally, using any label to identify another individual can limit rather than invite the openness and curiosity needed for individuals to bridge differences and work together with mutual understanding and respect.

Similarly, participants identified resource disparities as important and underappreciated challenges (Fig. 1), which can then perpetuate other disparities. These included preexisting inequities (perhaps the previously referenced mother did not have access to prenatal care because she lacked transportation, could not afford to leave work, or lived in a rural area) as well as inequities in real-time care delivery (perhaps the hospital lacked the necessary interpreter services, thereby impairing this mother’s health literacy). These inequities might position the mother to be perceived as less competent; clinical teams might assume she lacked either knowledge or resources to care for her child. Moreover, such biases might exacerbate already tense relationships. If this mother sensed her physicians’ distrust, then she might behave defensively. The clinical team, in turn, might label her as “difficult.” Through such interactions, over time, disparities can magnify into ever-wider differences in care delivery.

Other factors contributing to tension included differences in values, perspectives, and experiences (Fig. 1). Case 3 described the moral distress of a clinical team

Table 2
 “How to Speak”—Suggested Phrases That Work

Situation	Goal	Phrases to Try
Emotions are high	Respond to emotions and de-escalate them	<p>“You seem upset. Can you tell me about it?”</p> <p>“Any parent would be frustrated in this situation.”</p> <p>“Would you mind telling me what is on your mind?”</p>
Trust is broken	(Re)build bridges	<p>“I would like to try to make things better.”</p> <p>“I apologize.”</p> <p>“How have I let you down?”</p>
Family culture or beliefs feel unfamiliar	Elicit stories and values	<p>“Would you mind telling me about ... [your faith/your community/your life in [country]/your family/[patient]/what is important to you ...”</p> <p>“When you think about what is happening with your child, what worries you most?”</p>
	Build or strengthen relationship	<p>“What do I need to know about you/[patient]/your family to give you the best care possible?”</p> <p>“Who do you want to be part of your team?” [Consider probes regarding specific community members (e.g., clergy, cultural elders, etc.)]</p> <p>“Tell me about [how your family makes decisions/how your family likes to hear information]?”</p>
Patient/family and medical team disagree	Understand family perspective	<p>“When you get on the phone to tell [loved one] what is happening here, what will you say?”</p> <p>“I also hope for a miracle for your child. What do you think that would look like?”</p> <p>“I heard you say you want [insert preference]. Can you tell me more about your reasons?”</p>

“scripts.” For example, we need to acknowledge and manage the judgmental connotations attached to phrases like “no prenatal care,” which may simultaneously convey clinically important medical history while also potentially conveying disapproval. If biases contribute to defensiveness and subsequent impaired alignment between clinicians and families, then the medical team members need to recognize and redirect the process. Specifically, we must resist infectious negative judgment: if a trusted colleague describes a family as “difficult,” we must strive to separate and quarantine the judgments or feelings attached with this label. We must then seek to understand and remedy the causes giving rise to the perceived difficulties, such as cultural differences between the clinical team and family, or how individuals are reacting to the stress of illness.

Similarly, participants suggested that medical education should target communication skills (including conflict resolution and eliciting family narratives), emotional intelligence (including the recognition and management of our own emotions), familiarity with social services and resources (to better meet patient needs), and implicit bias training that includes complex determinants of “culture” (Table 3). Finally, participants suggested that specific changes in clinical standard practices could minimize risk and narrow disparity gaps. These included standardized needs assessments, tools to discover and champion family strengths, and shifts in how clinicians communicate with one another.

Finally, participants in all groups agreed there were clear opportunities for scholarship (Fig. 2). Describing a translational research continuum for

Table 3
 “How to Think”—Suggested Approaches to Training and Clinical Care

Paradigm Shift	Targets to Minimize Conflict	Rationale	Action Items
Rethinking how we think	Recognize and intervene when you, other clinicians, or the family feels defensive	When people feel a need to defend themselves, they may not want to hear other opinions, negotiate, or even communicate. They may have negative physical and emotional reactions, in turn making collaboration even more difficult.	Become familiar with signs of defensiveness. When observed in a family, back up and explore their roots with curiosity and compassion. When observed in the medical team, intervene and diffuse them when away from the family. Be willing to reboot by responding to the emotion, or, if needed, taking a break and apologizing. Understand that defensiveness on the part of the medical team is part of the problem.
	Consider trauma-informed care	Many children and families have complex and traumatic histories before the child’s illness. These may be personal and/or longstanding race-based or culturally based historical narratives. These stories impact how patients and families perceive and navigate a child’s care.	Acknowledge prior trauma and the role it has played in a family’s life. Collaborate with interdisciplinary teams to recognize and respond to signs of trauma. Seek to establish safety, trust, transparency, and empowerment. Avoid situations in which the medical team may be responsible for “retraumatizing” families.
	Beware of “encoded” associations and stereotypes within medical terminology	Many descriptive phrases may contribute to explicit and implicit biases.	Avoid statements about families that are solely meant to paint a picture of a “difficult” family to the listener. Be cognizant of the power of word-framing when conveying medical information. For example, “a mother with limited access to prenatal care” paints a different picture than “a mother with no prenatal care” because the former allows for both system- and patient-level medical history. Give families a fresh start to tell you their stories.
	Consider how we talk to each other	Stereotypes, biases, negative labels, and misunderstandings may be perpetuated by medical teams. Divergent messages from medical team members contribute to conflict.	Routinely gather interdisciplinary teams to discuss a patient’s care plan.
	Be okay with messy	Understanding and conflict resolution can take time.	Give families time to process important information. Expect and tolerate negative emotion. It is normal. Keep coming back.
Reteaching what we teach	Communication	Conflict resolution demands communication skills.	Provide training on <ul style="list-style-type: none"> - how to respond to patient/family emotion or perceived defensiveness - how to elicit values - how to use patient-centric language and descriptions - how to listen actively
	Emotional intelligence	Our emotions impact how we approach clinical encounters.	Training regarding how to recognize and manage one’s own emotions
	Awareness of existing social services and resources	Screening for health-related social needs and familiarity with community-based and other available resources may facilitate quality care and better meet patient/family needs.	Provide training regarding <ul style="list-style-type: none"> - resource needs assessments and screening - available local resources/services - roles and expertise of interdisciplinary team members
	Conflict negotiation/resolution	When conflicts occur, medical teams must be prepared to remedy them.	Provide training regarding <ul style="list-style-type: none"> - motivational interviewing and conflict resolution skills - how to navigate different and equally valid options
	Biases	Awareness of implicit and explicit biases enable equitable care.	Provide training regarding self-awareness and personal biases, including their impact on clinical care

(Continued)

Table 3
Continued

Paradigm Shift	Targets to Minimize Conflict	Rationale	Action Items
Reconsidering standard clinical practices	Needs assessment	Disparities arise from multiple sources (e.g., income, education, neighborhood, housing, food security, violence/safety, transportation needs, family structure, language, health literacy, mental health, citizenship, insurance status, etc.).	Conduct systematic, longitudinal needs assessments/screens Create awareness regarding available community/hospital/government/other resources Foster community partnerships
	Approaches to needs	Sole focus on unmet needs fails to recognize family strengths.	Identify and champion strengths while also meeting unmet needs
	Communicating with each other	Conflicting messages from health care staff contribute to patient/family misunderstanding and dissatisfaction. Disparaging descriptions of families, even in private spaces, contribute to bias and stereotypes.	Maintain consistent messaging from health care teams Identify a primary team to guide decision making Identify families by their strengths rather than their limitations Recognize and correct critical or unkind descriptions
	Self-compassion and professional support	Pediatric clinical care can be stressful. Normalizing challenging scenarios and creating space to navigate residual stress or negative effect is necessary for personal and professional resilience.	Create standards for staff to express frustrations or emotions without judgment Create opportunities for facilitated debriefs (e.g., Schwartz Center Rounds)

this field, they agreed that qualitative methods are necessary to develop a better understanding of patients' and families' lived experiences. Quantitative methods are needed to rigorously measure resources, disparities, and factors contributing to patient outcomes. Finally, interventions are needed to improve these outcomes and inform clinical care.

Discussion

The overarching objective of the "Pediatric Palliative Care in a Multicultural Context" workshop conference was to bring stakeholders and experts together to learn from shared knowledge and experience. Specifically, we aimed to name the reasons that clinical encounters involving cultural differences sometimes feel challenging and then to provide preliminary guidance for clinicians, educators, and researchers to navigate these experiences. With input from 142 interdisciplinary participants, some from diverse geographical regions, we identified several factors that contribute to misunderstanding or conflict between clinicians and families. We then identified feasible opportunities for improvement, including how to navigate encounters in real time, minimize tension in future encounters, and inform both the art and science of pediatric communication and care delivery.

Although we designed and advertised this conference to focus on pediatric palliative care, our findings are not unique to this discipline. Rather, these findings may resonate with all clinicians (both pediatric and adult focused) whenever they manage symptoms, provide anticipatory guidance, participate in shared decision making, or explore family values. The provision of culturally sensitive, family-centered care is fundamental to good primary and subspecialty palliative care.

How to provide such care has not been well described. Indeed, while national organizations have called for "culturally and linguistically appropriate" medical care to establish trust and model respect for patients and families, integrating these recommendations into adult medical practice has been challenging.^{39–45} Few studies have been conducted in pediatric care settings.^{7,9} Existing empirical data underscore disparities in care based on several sociodemographic factors including race, ethnicity, language, and economic resources.^{12,24,26,46–50} Despite evidence from adult and pediatric studies that clinician support of religious or spiritual identity contributes to family trust and perceived support, relatively few pediatricians explore these factors during clinical encounters.^{31,35,51–59} Finally, while pediatrics is inherently "family centered" because the care of children relies on parent and caregiver input, how to navigate nuanced family-based culture and communication needs is less established.^{60,61}

Without doubt, culturally humble palliative care is important. Nor can there be doubt regarding the

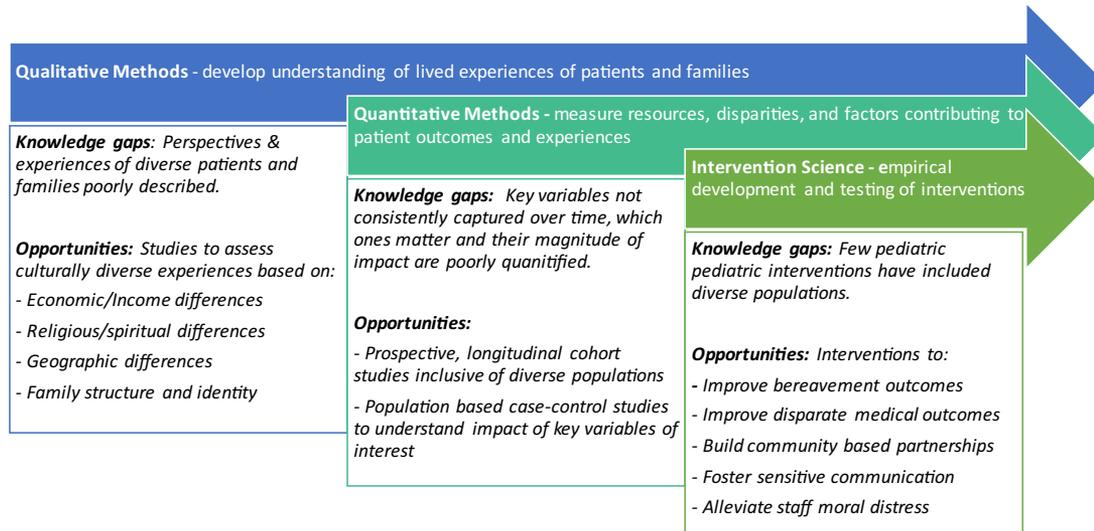


Fig. 2. "How to learn." Suggested directions for translational research designed to inform and improve clinical care in the context of cultural diversity.

existence of room for improvement. Well-intentioned clinicians with strong egalitarian values often harbor implicit biases.^{62,63} Recognizing those biases is a key step toward ensuring equitable care. From there, spending sufficient time on individual patient-level narratives (including values, prior experiences with trauma, faith, and cultural identity) can reduce the influence of implicit and explicit biases.⁶⁴

While our findings provide early and additional guidance for providing culturally sensitive care, our report should be interpreted with two main limitations kept in mind. First, this conference included diverse stakeholders, but no formal patient or family representatives, and as such, findings may not represent patient and family preferences. While we had some degree of diverse geographic representation, most of our participants were from the Pacific Northwest, and we did not collect information regarding participants' race, ethnic, religious, or other cultural determinants to assess representativeness in these regards. Taken together, our findings may not be generalizable. Second, we did not conduct a qualitative study; rather, we endeavored to generate ideas for future clinical and research applications. Our workshop format was deliberately flexible to promote group engagement and discussion. While this flexibility enabled a breadth of perspectives and recommendations, our approach was too variable to confirm consistency (or "saturation") of qualitative findings.

Conclusion

Emphasizing the importance of providing culturally sensitive and appropriate care is not to deny

the very real challenges of doing so. This project identified key variables perceived to contribute to tension and conflict in clinical encounters, as well as several ideas for clinicians and researchers to navigate these experiences. In general, these include tools to use in real time (such as phrases to try when a family's culture feels foreign), suggestions for how to minimize future conflict (for instance, educational programs targeting emotional intelligence, implicit bias, and conflict resolution), and proposed directions for future investigation (such as community-based participatory research to improve disparities). Together, findings from this conference will facilitate a necessary and overdue conversation in clinical pediatric palliative care, aspiring ultimately to provide a foundation for building trust and collaboration between patients, families, and clinicians of all cultures.

Disclosures and Acknowledgments

The authors are grateful to the Arthur Vining Davis Foundations for supporting this conference and this publication. The authors are grateful to their speakers, Ann Fadiman, Jann Murray-Garcia, Myra Bluebond-Langner, Aasim Padela, and Ronit Elk for their thoughtful presentations and support of this work. The authors thank all the participants for their energy and contribution.

The authors have no conflicts of interest relevant to this article to disclose. This study was funded by Arthur Vining Davis Foundations. The information presented here represents the opinions of the authors and not necessarily the funders.

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Appendix S1

Conference Topics and Invited Speakers

Title	Speaker	Affiliation
Lessons from <i>The Spirit Catches You and You Fall Down</i> : a Hmong Child, her American Doctors, and the Collision of Two Cultures	Anne Fadiman	Yale University
Cultural Humility and Transforming Scripts of Inequity	Jann Murray Garcia, MD, MPH	University of California, Davis
Truth-Telling, Disclosure Practices, and Good Parent Beliefs	Myra Bluebond-Langner, PhD	University College, London, UK
End of Life Preferences Based on Religion and Faith	Aasim Padelá, MD, MSc	University of Chicago
Developing a Culturally-Based Palliative Care Program to Reflect the Needs of Specific Groups	Ronit Elk, PhD	University of Alabama, Birmingham

Appendix S2. Workshop Introduction Text and Clinical Cases

Introduction Text (Provided in Writing With Conference Agenda to All Participants)

We would like to examine the broad concept of decision making in the multicultural context. The purpose of this session is to bring together our shared understanding from knowledge of the evidence and our experience. It may be helpful in this discussion to consider the following values:

- Respect: foster respect/rules, limits, barriers, and shortcuts
- Understanding: understanding/appreciating different cultural view
- Power: recognizing the power dynamics in relationships
- Trust: developing trust between patient, family, clinicians

Cases (One of the Following Provided in Writing to Participants in Each Workshop or “Breakout” Room)

Case #1

Matthew is a six-month-old African American boy with multiple medical diagnoses. He was born at 27 weeks of gestation to his single mother who had received limited prenatal care. His neonatal course was complicated by respiratory failure and severe intracranial hemorrhage, resulting in profound developmental disability, tracheostomy, and G-tube dependence. Now, his team is considering discharge and has raised concerns about medical foster care, citing concerns about the family’s ability to meet his complex medical needs. There is no history of abuse or neglect and no history of child protection team involvement, and Matthew’s mother has been present at the bedside and is eager to care for him at home. During a care conference, she says, “you wouldn’t be asking about this if we were rich and white.”

Case #2

Brian is a 16-year-old young man with Duchenne muscular dystrophy who is seen in clinic twice per year. He presented to clinic after an 18-month absence with a new complaint of dyspnea when supine. On evaluation, his physician notes that Brian is not using his BiPap machine and does not know its whereabouts. He has lost nearly 40 pounds and has a grade 2 decubitus ulcer over his left ischial tuberosity. His scoliosis has progressed from 13° to 35°, and his ejection fraction has declined from 42% to 21%. Brian’s mother explains that she experienced domestic violence at home and has been living in transitional housing for over a year. They missed their clinic visits because they had no address to receive the clinic appointment notices and no phone for contact. Their options were extremely limited because few shelters could accommodate a family with a child in a power wheelchair who required care for all activities of daily living. In the post-clinic meeting the attending remarks, “I doubt

that we will be successful providing the assisted ventilation, a complex heart failure regimen, and nursing care that Brian will need in this setting, palliative care and hospice may make more sense.

Case #3

Chloe was healthy 8-month-old until she accidentally fell out of her mother's arms onto a concrete sidewalk 20 feet below. She was resuscitated at the scene but suffered a neurologically devastating traumatic brain injury that required right-sided hemicraniectomy and splenectomy. Her course was further complicated by craniectomy site skin necrosis, wound breakdown, and significant local infection. She never regained consciousness and remained ventilator dependent. Her wound care was complicated and her infection responded to treatment only intermittently. The ICU team has now concluded, after multiple consultations, that death is inevitable and that the intensive intervention is only prolonging the dying process. When this information is presented to the family, they seek counsel from their pastor. The pastor has encouraged them not to give up because "God is about to perform a miracle." The family has persisted in opposing any suggestion to limit intervention for Chloe. Moral distress among the ICU staff continues to mount as the family becomes more entrenched. In many conversations, the staff expresses their opinion that they cannot distinguish between the family's religious conviction and their personal guilt. The staff are increasingly concerned that they were being compelled to provide inappropriate care.

Case #4

Marc is a 14-year-old boy with progressive metastatic Ewing sarcoma. He and his family live 5 hours from the nearest hospital and have stayed in local housing when he receives cancer treatment. His parents are divorced and have been amicable throughout his treatment. They disagree, however, on what to do now that his disease is worse. His mother, Martha, wants to remain at the hospital to receive experimental therapy; her goal is to help other children and, she hopes, slow down the progression of disease. His father, Tom, wants to return to their home and local community so that Marc can be near their extended family, friends, and church community. When asked, Marc says he wants his parents to make decisions on his behalf and says they will pick "whatever is best."