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Issue Topic: Disparities and Inequities in Pediatric Palliative/Hospice Care

Welcome to the 64th issue of our Pediatric e-Journal. This issue offers a collection of articles that we hope will stimulate discussion on the interdependent and yet distinct topics of disparities and inequities in pediatric palliative and hospice care. We understand the two key terms in this discussion in the following ways:

*"**Disparity** implies a difference of some kind, whereas **inequity** implies unfairness and injustice. An overwhelming body of literature documents racial/ethnic **disparities** in health."*[1] So often when we think of disparities and inequities, we think of those associated with gender and race. In reality, there are many more. Consider the following factors that might result in disparities and inequities in pediatric palliative and hospice care:

- Race
- Ethnicity
- Culture
- Religion
- Language
- Gender
- Gender identity
- Socioeconomic status
- Financial status
- Age
- Education
- Physical and/or mental disability
- Physical appearance
- Chronic complex medical conditions
- Location: Rural vs. city vs. inner city vs. town
- Family composition
- Past history with the health care system

Any of these factors, alone or in combination, could result in inequity and/or disparity in availability of, access to, or acceptance of pediatric palliative care services.

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[1] Meghani SH, Gallagher RM. Disparity vs Inequity: Toward reconceptualization of pain treatment disparities. *Pain Medicine*, 2008;9(5):613-623 https://doi.org/10.1111/j.1526-4637.2007.00344.x

We hope the contents of this issue will provoke fruitful reflection about if or when disparities exist in pediatric palliative and hospice care; if or when those disparities become inequities; and what are the uncertainties in this disparity/inequity discussion.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing the topic of glimmers of hope for the fourth and final issue in 2021, and sustainability for our first issue in 2022.

We particularly invite contributions for articles on Sustainability. Let us explain.

The first issue of 2022 (#66) of the NHPCO Pediatric e-Journal will be on **Sustainability**. In three decades or so, the ChiPPS Newsletter, then the ChiPPS e-Journal, and now the NHPCO Pediatric e-Journal have never had an issue focusing on this topic. Why? We think that several factors have led to this. First, in the early days, there simply weren't enough pediatric palliative care (PPC) or pediatric hospice programs to make any generalizations. Second, there are still many very different ways that programs with varying foci sustain themselves. Thirdly, it isn't a very warm and fuzzy topic. Who likes to think of MONEY??? Yet supporting the very existence of our programs is crucial to providing palliative and hospice care to children/adolescents and their caregivers. Most of you reading this are part of a broader organization. **We are reaching out to you for contributions to Issue #66.**

What form might these written contributions take? Below are only some examples:
- A paragraph about how your program is supported
- An article about sources of support for your program
- Stories about how your program began and how the support has varied over time

What sources of support have you used and what are strategies that worked or were ineffective? Below are just some thoughts of possible topics:
- What models of care are most sustainable? Are you bundled with adult palliative care? With an adult hospice program? Does the parent organization support your pediatric services?
- What are the components supporting your bottom line? What are the income streams?
- Is your program supported by reimbursements for patient services? If so, what is your strategy?
- What are varying states doing to support pediatric palliative and/or hospice care?
- How you justify your costs to your top executives? How do you approach the leaders with the purse strings?

- How you engage the public in seeking support?
- How can families help in seeking support?
- What charitable events do you host?
- What reimbursement strategies are most effective?
- How do you sustain your staff?
- If your organization did not survive, what lessons can you pass on?
- Feel free to tell us your personal story or that of your organization!

We are eager to hear from you! There are many ways that you can address this topic in addition to the above. If you have an idea, we are happy to collaborate with you in sharing your story. Target deadline for submission of an article is November 1, 2021.

If you have any thoughts about Sustainability or any other topics, contributors, or future issues in 2022, please contact Christy Torkildson at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

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Issue #64: Disparities and Inequities in Pediatric Palliative/Hospice Care

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

Using a case example of a 14-year-old girl with cystic fibrosis, this article offers an extensive list of "simple steps to ensure that the child's voice is heard." The article ends with a valuable list of resources and the following comment: "We owe respect to all children regardless of their legal status. It is important to seek assent (or dissent) from all children. Their voices deserve to be heard and we need to know how to solicit and listen to those voices."

Do Racism and Social Injustice Impact Pediatric Symptom Management?   *p. 24*
Megan Perkins, PharmD, BCPS
This article begins by noting, "The medical community has a long history of inadequately treating black patients" and then adds that "pharmacists play an important role in reminding prescribers" that when it comes to medications, "the black community may have enhanced and/or reduced treatment response to certain medications." The author then advocates for the value of "trauma informed care" and concludes: "Whether you work as a pharmacist, physician, respiratory therapist, nurse, or any member of the healthcare team there is something you can do to reduce racism in the healthcare field, to be a part of providing justice for future generations of black children."

It's Different with Kids: A Conversation about Emotions & Implicit Bias   *p. 28*
Christy Torkildson, PhD, RN, PHN, FPCN
Using a case-based approach, "this article discusses how our emotions and actions can impact our ethical beings and our relationship with our patients, their families, and our colleagues." The author challenges readers to reflect on how their own emotional and implicit biases affect who they are when they first meet a patient and family. She concludes, "Simple things we can always do include being respectfully curious, listening deeply, and considering all aspects of the situation and all perspectives."

Inquisitiveness as a Foundational Tenet Towards Partnership and Limiting Disparities
in Pediatric EOL Care   *p. 35*
Kevin Gahagan, LCSW, CAPSW; Nicole McCann-Davis; and Yelena Zatulovsky, LCAT, LPMT, MA, MT-BC, CCLS, HPMT
In this article, cultural humility is defined as "as an experience of curiosity and inquisitiveness that can bridge the understanding between the pediatric patient and their family's experiences in the healthcare system, not just their spiritual and familial beliefs." The text is then organized around three general categories of questions: those related to pain and symptom management; those related to advance directives; and those concerned with family/care structure and dynamics. The authors then describe one care team's experiences with and reflection on the implementation of cultural humility and offer a case example of how this all works. The article concludes, "Supporting the unique needs of patients and their loved ones at the end of life requires a heightened sense of both understanding and curiosity, especially when serving our youngest patient population. Cultural humility is a concept and approach that, when practiced, benefits patients and all who are involved in their care." Such care "starts first by asking the right questions."

Gabrielle Karpinsky, MD, PhD, and Angela S. Czaja, MD, PhD
This article begins from the premise that "the hospital setting can be a unique opportunity for families to access PPC, as a point of healthcare contact and when circumstances surrounding hospitalizations necessitate consideration of quality of life and care directions." The text then explores two questions: "What barriers exist that prevent equitable and consistent involvement of PPC to aid communication, pain management, and emotional needs of patients and their families? And are there any potential solutions to mitigating these barriers?"

Ann Fitzsimons, BS, MBA
This article reports the results of a survey of Community Mental Health Directors in all the counties in the state of Michigan to determine "what their understanding was of the pediatric respite benefit, which and how children/families qualify for it, and who parents should contact to inquire about the benefit." The article describes the results of the survey, showing broadly an uneven distribution of the respite benefit across the state. The conclusion is, "The results of this study point to the need for much to be done to broaden access of this respite benefit to additional families who truly need and could be helped by it." Some next steps to ameliorate identified inequities are set forth.

Alida Yee, DNP CPNP-AC CHPPN, Catherine Stevens, DNP CPNP-PC, and Anne Marsh, MD
In this article, the authors seek to shape "for families the idea that grief is not the 'end of the road' but an essential beginning of a new journey commemorating their loss." To that end, the authors ask: "But what happens when a family is so impacted by social, economic, and environmental factors—the so-called social determinants of health—that they aren't afforded a physically or emotionally safe space to grieve?" The text then offers a list of key topics that can be used to assess and address grief in pediatric palliative care.

Arika Patneaude, LICSW, APHSW-C
Noting that with the COVID-19 pandemic virtual meetings have proliferated in great number, this author then asks if we ever think about how we present ourselves in such meetings? For example, she writes: "When I log into a virtual meeting, my screen is often filled with white faces staring back at me. I can see through facial expressions and body language what my colleagues and others *may* be feeling about what is being said in a way that I never have before." Can it be that racial trauma and personal microaggressions are sometimes directed, consciously or unconsciously, against Black, Indigenous, and people of color through the behaviors of others in such virtual meetings? She concludes, "My one ask of all of us is to take into consideration how our virtual presence may unintentionally impact those whose identities have been historically marginalized."

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Reflections – The Category of Us, Debbi Simmons Harris MA, GCAS-Creative Writing Narrative Medicine. Harris DS. Reflections: The Category of Us. *Complex Care Journal* 2021;ed 2, published online 2.28.2021. http://complexcarejournal.org/wp-content/uploads/2021/02/Harris-Commentary-final-2.28.pdf
(open access - **this is a MUST read!**)

Summary: This is a story of a family written by the mother of a now-adult with significant medical complexity. The family happens to be Black, but this fact impacts the care from the in-utero period onward. It is a story full of potentially preventable medical, spiritual, and emotional complications attributable to racism. It is a story of how a family copes with the significant challenges of caring for a child with considerable medical complexity with the additional barriers that result from racism. It is the story of a mother who struggles to overcome all the incidents that "chipped away at my dignity."

Who might find this information useful? Parents of children with medical complexity and all health care providers should read this article.

What is special about this article? While this is the story of the impact of bias on the part of the health care system for a single family, it pertains to all families and all health care systems. We can learn so much from this mother who worries that because of her time and energy expended overcoming barriers and providing care for her son, "there is no me any longer." The article is punctuated by wonderful pictures of the author's son, Joshua, and his family and stories of coping with a child with medical complexity. I particularly appreciated how Joshua had his voice heard by voting. Interestingly, there is a comment about the intersection of disability and ethics. Having established one pediatric bioethics committee in 1980 and been an ethics committee member for over 40 years, I appreciated the reminder. Practical information for families caring for children with medical complexity is offered as well as suggestion for those advocating for state funding. And the article wraps up with a heartfelt poem. That is indeed special!

Where and how can I apply this information? As a neonatologist, I cringed at the amount of suffering (experienced by the newborn, the family, and the health care providers) that might have been prevented by an attentive, bias-free system. The NICU shouldn't be an uneven "playing field." We health care providers can even it out. The author, who now describes herself an advocate, emphasizes, values, and expands on the art of listening. This is something

that we can all integrate into our day-to-day practice as we interact with co-workers, patients, and families. Ms. Harris reminds us poignantly how much words matter. We can review the lens through which we view those who come to us. Make sure that the lens is clear and not tinted (or tainted!) with biases. Providing the best care to all is our calling and our passion as health care providers. In addition to enhancing the lives of the child and caregivers, it minimizes health care costs associated with preventable conditions.

When should I start integrating this information into my practice and my everyday life? **NOW.**

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GENDER AND LANGUAGE: LET THERE BE LIGHT!

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The Hebrew scriptures, whatever your beliefs, offer astonishing existential, humanistic, and linguistic truths in their poetry and parables. In the story of creation, God speaks all things into being: "Let there be Light, and there was light." In this depiction of creation, nothing exists until it is named—and once it is named, it exists.

This is an ontological illustration of a cognitive phenomenon—something that happens for every person throughout their lives and in their everyday. Language is the mechanism by which we experience and, indeed, create our reality. Officially, this is known as the "Sapir–Whorf hypothesis," articulated by linguistic anthropologists Edward Sapir and Benjamin Whorf, which posits that "human thought is so rooted in language that language may actually control (or at least influence) what you can think about" (Ivy, 2016, p. 64). The pure form of this hypothesis puts untenable limits on human imagination and expression, but the fundamental point retains its truth.

You've probably heard the old saw that "'Eskimos have a million words for snow." (It's actually somewhere between 50 and 200; academics disagree.) Each one encapsulates "snow" in a particular form with a particular quality, such as powder snow, snow that is crusted on the surface, drifting snow, still snow, remembered snow, forgotten snow, snow that falls in large wet flakes, snow that falls in small flakes, snow that has melted and refrozen, snow that has been marked by wolves, snow that has been marked by people, blowing snow, snow that has been packed down, snow in beards, snow mixed with mud, snow mixed with Husky dung, snow mixed with the lead Husky dung . . . and so on (James, n.d.).

Because snow and its infinitely varied qualities are omnipresent in the arctic experience, Inuit and Yupik languages evolved many different words to capture these nuances, not as a matter of aesthetics but of survival. An experience that is rich, varied, and important will likely produce a rich, varied, and semantically important vocabulary.

An example familiar to anyone working with small children is a principal task of childhood development—to learn to "name and tame" emotions (Shonkoff & Phillips, 2000). Through common conversation and deliberate teaching, children learn that *this* feeling means "I'm mad," and *that* feeling means, "I'm sad," and from there, "When I'm mad, I can pound my pillow but not my baby brother." Emotional self-regulation, emotional intelligence, and

empathy all rely on our ability to comprehend and shape our experience through language (Mayer & Salovey, 1997; Brackett et al., 2011).

This phenomenon of naming = existence also profoundly impacts identity. Negative labels attached to children in their formative years can distort and damage self-perception to the point, Becker's "labeling theory" (1963) maintains, of creating a glide path to delinquency or lifelong social disability. Positive labels can bolster self-esteem and contribute to personal efficacy and success, but they, too, can have downsides: The girl who is labeled the "nice one" can develop a habit of subjugating her own needs to those of others to an unhealthy degree, or the boy who is labeled "a math genius" might reject an innate interest in music (Kim, 2019).

The LGBTQIA+ community is all too familiar with these kinds of distorting and damaging labels. The list of dehumanizing slurs used against them is long. Some terms, such as "queer," historically used to ridicule, have been reclaimed and infused with a new positive power; whereas others, such as "gay" as in "that's so gay," were made derogatory all over again (Postic & Prough, 2014). But there's another dimension of labeling/naming in gender that is perhaps not as much commented on: the importance of broadening our vocabulary beyond the binary "male/female," "boy/girl," "man/woman" to identify a veritable kaleidoscope of experience and identity, and thereby give each one reality and respect.

In 2014, Facebook famously expanded their member profile gender options to 50+ different options (see one list here), including an option to create a "custom" term (Goldman, 2014). At the time, many of these options were new to the vernacular, but in the years since, many have mainstreamed (e.g., "cis," "nonbinary," "gender fluid," etc.). At the time, these terms were so new to general discourse that a number of publications took the opportunity to provide glossaries and explanations, such as this effort by the stodgy *Washington Post*: "Confused by Facebook's gender options? Here's what they mean . . ." (Dewey, 2014; for a more authoritative version, see GLAAD's list). Facebook didn't make up these terms out of the air; they'd been circulating *soto voce* in society, of course, for years, but by incorporating them into a social media platform used, at the time, by 800 million daily (Smith, 2015), they did dramatically boost awareness and adoption.

This vocabulary expansion was greeted by equal amounts of puzzlement, ridicule, and celebration, but the recognition that there are *at least more than two* genders has become more widely institutionalized in the U.S. in the years since. (Indigenous and non-western cultures had this figured out long ago [Independent Lens, 2015; Picq & Tikuna, 2019].) For instance, 20 states and the District of Columbia now allow a person to select "X" instead of "M" or "F" as their gender designation on drivers' licenses (MAP, 2021). The U.S. State Department announced on June 30, 2021, that it will begin the process of making such an option available on U.S. passports, without requiring physician proof of transition (Karanth, 2021). The common college application still presents only two options for sex (male or female), but it offers a free-text field for students who wish to "share more about your gender identity" (The Common Application, 2021).

Also in 2014, 151 organizations supported a letter submitted by the Fenway Institute and the Center for American Progress to the U.S. Office of the National Coordinator for Health Information Technology. The letter strongly recommended that electronic health records collect data on sex, sexual orientation, and gender identity as three separate items instead of simply asking for "sex" and offering only "Male," "Female," or "Unknown" as options (Leventhal, 2018). The following year, the Office issued new regulations: "Any outpatient clinic receiving federal incentive payments for using a government-certified electronic health care record—as 78 percent of them do—would have to *use software* that collects sexual orientation and gender identity information by 2018" (Landman, 2017, emphasis added). Except for Federally Qualified Health Centers, the *collection of the data,* however, was made optional.

As a writer and editor, I am especially attuned to the rules governing scholarly, clinical, and popular writing. I'm old enough to remember when moving away from "mailman" to "mail carrier," from "waitress" to "server," from "chairman" to "chair" sparked impassioned social debate. At my very first professional job, as an editorial assistant for the health sciences division of Addison-Wesley Publishing Company, I spent many hours editing manuscripts coming in from authors who'd learned their grammar in the 1930s, changing "man" to "person" and "him" to "him or her" and re-gendering physicians, at least occasionally, as female and nurses as male.

In 1983, McGraw-Hill published the first "Guidelines for Bias-Free Publishing." In 2010, the section in the American Psychological Association's *Publication Manual* addressing bias-free language comprised seven short sections with one each on gender and sexual orientation (APA, 2010). In the 2020 edition, "Bias-Free Language Guidelines" now constitutes an entire chapter, the sections on gender and sexual orientation spanning five pages in 9-point type (APA, 2020).

Two innovations between the 2010 and 2020 APA manuals are particularly telling: the sanction of using "they/their" as a nongendered singular pronoun (as in "the physician's appointment with their patient is . . .") and the emphasis on establishing a linguistic and behavioral safety zone in which the person can identify as they choose to, how they choose to, and to whom they care to. Writers are cautioned to only include descriptive information about race, disability, age, sex, or gender if it is directly germane to the discussion. In other words, a case study should introduce Patient G as a 75-year-old, African American, transgender man only if those features—all or any of them—are relevant to the facts of the clinical case. (Of note, the American Medical Association's *Manual of Style,* 2020 edition, is not as expansive in its consideration of bias-free language, but reflects similar principles and has also sanctioned the singular "they" [AMA, 2020].)

Beyond rainy-day reading for grammar nerds, these style manuals set the tone for all writing by clinicians, faculty, researchers, and students in the health professions and for all editing by journals, textbook, and trade publishers of any repute. Such editorial interventions are not just a matter of imposing "proper form" but a genuine project to change not only what we say but *how we think*.

Going back to "chairman," the argument was that if a young mind reads and hears only "chairman," then it is impossible—or at least much more difficult—for that mind to conceive of a woman in that role. If that young mind belongs to a girl, she might unconsciously exclude from the list of possibilities for herself someday occupying the seat of authority over a committee or board.

If another impressionable young mind has no word to describe "a person whose gender identity differs from the social expectations for the physical sex they were born with," how will they make sense of their lived experience of "being a boy" but "feeling like a girl"? How, without a culturally agreed-upon term to describe this identity, can that person present themselves to a world in a way that invites understanding? How can another mind—young and impressionable or older and more ossified—comprehend some part of the experience of the person before them if there is no term to describe it?

An experience that is rich, varied, and important requires a rich, varied, semantically, *and socially* important vocabulary.

In this process, the earlier point about the dangers of labeling should not get lost. As the *APA Manual* cautions us, such terms are for the *person to adopt and use for themselves,* not for teachers, bosses, editors, or clinicians to impose upon them. Adopting a stance akin to cultural humility, we can create an openness to hearing how the person might wish to *describe or identify themselves.* But having the names, learning and using the appropriate terminology as guided by the person, we can now bring these identities and the rich and varied experiences they represent into common discourse, common understanding, and acceptance. Let there be light!

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ADVANCE CARE PLANNING FOR TRANSGENDER AND NON-BINARY YOUTH

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Youth receiving palliative care services face unique challenges with advance care planning (ACP). This is particularly true of transgender and non-binary youth, a population that faces significant health disparities and barriers to care. Palliative professionals regularly engage with patients and families about ACP, which include the discussions about health care preferences and goals and the completion of documents to capture those preferences. Those who are under 18 years of age do not have the legal ability to designate an *agent* (i.e., the person chosen to make decisions on their behalf, should they be unable to do so), so their parents or guardians are legally their decision makers. Despite being unable to formalize their wishes, many individuals of this age are able to express preferences and make decisions about their care, which may or may not be congruent with what their parents or guardians choose. While some parents and guardians may incorporate their child's preferences into care decisions, this is not universal, nor is it mandatory.

Youth 18 and older are legally able to designate an agent, though many do not, whether due to patient's lack of understanding about the importance of ACP discussions and completion of related documents, reluctance of providers to engage in these discussions with their patients, or provider's lack of time, training, and knowledge about the importance of ACP. In situations where the youth is unable to make decisions and these documents have not been completed, decision-making power regularly defaults back to the parents or guardians, based on state law. For transgender and non-binary youth, who are statistically less likely to have supportive, affirming parents or guardians, these dynamics become increasingly complex. This article demonstrates the importance of ACP for transgender and non-binary youth and highlights areas of focus when engaging in ACP discussions with this vulnerable population.

Affirming Language

To understand this population and avoid disparities and inequities in care, terminology related to gender minority individuals must be understood. We live, at this point in time, within a society that largely subscribes to the *gender binary*, a societally reinforced concept that there are only two genders—male and female—and everyone in society must subscribe to one of those two genders, congruent only with their sex assigned at birth. *Sex assigned at birth* is the label given to an individual prior to or upon being born, usually based upon their external genitalia. Those who adhere to this binary believe that men and women are distinct from one another and thus should subscribe to specific societal roles determined by their sex assigned at birth.

Moving beyond the gender binary requires a deeper understanding of the language that has evolved to define gender. *Gender identity* defines an individual's internal understanding of their gender and how they perceive themselves. Complementary, *gender expression* is the outward expression of one's gender identity, usually conveyed through name, pronouns, clothing, hair, voice, body, and behaviors. It is important to recognize that one's gender expression may or may not be congruent with their gender identity in the ways projected by society through the gender binary. A transgender man, for example, may wear a skirt, deemed by society currently to be a feminine clothing item, despite clothing possessing no inherent gender, evidenced by male-identifying individuals throughout history having worn skirts and dresses.

Those who identify their gender as congruent with their sex assigned at birth are defined as *cisgender*, whereas those for whom their gender identity does not match their sex assigned at birth are defined as *transgender*. The term *non-binary* defines those whose gender identity and/or expression exists outside of the gender binary, such as identifying as a blend of masculine and feminine, neither masculine nor feminine, fluid across the spectrum of masculine and feminine, or somewhere in-between. Individuals who self-identify as non-binary may or may not also define themselves as transgender or existing under the transgender umbrella. Other terms considered to fall under the non-binary umbrella include *genderqueer*, *genderfluid*, *agender*, and *bigender*. Some American Indian and Alaska Native communities use the term *two-spirit* to describe a similar concept of someone who identifies as possessing both male and female essence or spirit; this term, however, is specific to these communities and should not be used by individuals outside of them.

The terminology defined here is meant to provide context for this article. However, it is recognized and honored that terminology is a product of its time and thus will evolve and change. Within this article, *transgender and non-binary* is utilized to define those who feel and self-identify as incongruent with or different than their sex assigned at birth, personally identifying as transgender, non-binary, or any other related term. *Transgender and non-binary* is used with recognition that a broad umbrella term does not exist to capture the lived experiences of all individuals with these identities and that this terminology may change with time and outdate itself as our society continues to evolve.

Advance Care Planning

Holistic advance care planning (ACP) should address medical, physical, emotional, and spiritual needs. For youth living with serious and/or life-limiting illness, ACP should be discussed in detail, regardless of whether or not the individual can legally designate these preferences. While a framework for having these discussions with transgender and non-binary youth does not yet exist, existing ACP documents can be adapted to formalize this information. For example, Voicing My CHOiCES™ can be used as a framework for navigating holistic ACP discussions. This document is designed for adolescents and young adults with serious illness and, while not a legal document, can be used to facilitate care discussions and complete legal ACP documents for those 18 years of age or older. The recommendations below can be applied

when completing this or other documents and when engaging in ACP discussions with transgender and non-binary youth. It is recommended that completion of formal, legal documents takes place following these discussions for all youth age 18 or older. Regardless of the manner in which preferences are expressed, providers should advocate for their patients and their wishes.

To create an affirming environment and prevent inequity, providers should begin all care discussions by asking about name and pronouns and preferences for when to use both. For some transgender and non-binary youth, they may want these used universally; however, for many others, parents or guardians may be unaware of their gender identity and thus their affirming name and pronouns will be reserved for use only in private settings. With electronic medical records (EMR) now releasing most notes directly to patients, it is also important that providers engage in informed consent discussions about implications of updating demographics in the EMR with the youth's affirming name and pronouns, and of using them while documenting. For those youth whose parents are not aware or supportive, updating the EMR without this discussion has the potential to cause harm. The desire to provide affirming care must always include awareness of potential safety concerns and strategies for harm reduction.

Transgender and non-binary youth should have the opportunity to designate who they would like at bedside and care discussions, such as family meetings. For transgender and non-binary youth, however, family may be defined differently. For some, family is defined as *family of origin*, meaning the individuals who are related through biology or adoption, typically those with which or by whom someone has been raised. For others, family is defined as *chosen family*, meaning the individuals identified for their kinship bonds, mutual support, and love, regardless of biological or legal connection. The concept of chosen family is particularly embraced by the LGBTQ+ (lesbian, gay, bisexual, transgender, and queer) community. Transgender and non-binary youth may have complex, limited, or no relationships with their family of origin, including their parents or guardians, which further necessitates completion of ACP documents for these individuals as soon as they turn 18 years old. For those transgender and non-binary youth under 18, ACP discussions allow for providers to advocate for their patients' needs within the context of complex family dynamics.

Discussions should also take place regarding preferences for physical care needs, such as using the bathroom, changing clothes, getting dressed, maintaining hair, and bathing. Transgender and non-binary youth may have specific clothing and hair style preferences that are gender affirming. They may also report desire for physical assistance and care by individuals whose gender identity is congruent with theirs (i.e., a transgender female may desire receiving care, such as bathing assistance, by a female-identifying person) or report other preferences related to personal history, such as sexual trauma or abuse, as this is more prevalent in the transgender community (i.e., a transgender man or non-binary person may feel more comfortable receiving physical support from a female-identifying person if there is historical trauma from cisgender men). Providers are encouraged to advocate for transgender and non-binary youth to receive physical care affirming to their gender, regardless of care setting.

Finally, for those transgender and non-binary youth with life-limiting illness, discussions should take place about how they wish to be honored and remembered after death. For transgender and non-binary youth who do not or are unable to designate preferences, there is risk that unsupportive loved ones may not honor their true identity after their death, such as not using affirming name, pronouns, and photographs in their obituary or at their remembrance service. On the other hand, the opportunity to vocalize these preferences creates the opportunity for validation of their gender identity, such as expressing what clothing they would like to wear for their service, cremation, or burial and picking the photographs they would like used at their service. Additionally, as religion may carry specific trauma for some transgender and non-binary youth, they can express their desire for spiritual and/or religious elements, or a lack thereof at their service that are affirming to their identity and honor their experiences. Engagement in end-of-life care planning also provides the opportunity for chosen family, including partners, to play a significant role in activities, such as planning for and speaking at the service.

ACP discussions are a challenging yet critical aspect of patient-centered care. This population, who faces unique challenges and disparities, requires special attention when addressing ACP to mitigate harm and improve outcomes. By creating opportunities for open dialogue about and documentation of preferences, providers can create a more affirming life and death for transgender and non-binary youth with serious and/or life-limiting illnesses.

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AGE INEQUITY IN PEDIATRIC PALLIATIVE CARE:
HOW CAN CHILDREN'S VOICES BE HEARD?

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I suppose that the simple answer to the above question is: Adults just don't know how to listen! There are indeed barriers. Even clinicians may have limited knowledge as to the mechanisms of child assent and dissent, as well as the recommendations of professional organizations. There are few tools to assess the capacity of a child who is still a minor and not emancipated. Even pediatricians may not have the skills to appropriately communicate with children and their parents at the end of the child's life. Without such conversations, disclosure of poor prognosis and engaging the child in shared decision-making is challenging.

There are multiple factors involved in hearing the child's voice. The child's age and stage of development, experience with chronic conditions or illness, view of the options, and desire to protect the parents may all impact on their preferences.

There are currently standard conditions under which the parent's consent is usually waived: Emergency care, child abuse, and mature or emancipated minor status. Most states favor the adolescent's voice in matters of sexual and reproductive health, substance abuse, mental health, and reportable infectious disease.

How can we amplify the child's voice? For minor children, how do we assess their capacity or "functional competence" so that we can seek their assent and dissent? There are multiple facets of decision-making capacity including cognitive, emotional, reasoning, social, and communicative aspects. Unfortunately, there are no standardized tools to assess the decisional capacity of a minor child. (Parenthetically, decision-making capacity is not equivalent to agreeing with the health care team!)

In addition to developmental stage, experience with chronic illness contributes to skills necessary to make an informed decision. Culture, race/ethnicity, family dynamics, pain, medications, neurologic impairment, and psychiatric conditions can influence decision-making. As the risk increases, greater certainty of their capacity is required. Dissent is obvious. The child can simply refuse to comply, or they can express their dissatisfaction with the plan (children are very good at displaying dissatisfaction…). The clarity of the communication is influenced by their maturity, understanding of their condition and prognosis, treatments offered, and family coherence. Clearly disclosure of the diagnosis, prognosis, and treatment options is frequently necessary prior to including the child in treatment decisions and amplifying their voice. The

trigger for these conversations is frequently a new diagnosis or change in trajectory of the disease or condition and/or prognosis.

Consider the following possible situation: Elena is a 14-year-old female with advanced cystic fibrosis. Her pulmonary team has recommended a lung transplantation, but she does not want to pursue that treatment course. How can Elena's voice be heard and her participation in decision-making be ensured? What if her parents disagree?

What are some simple steps to ensure that the child's voice is heard?
- Verify what the parents/caregivers have reviewed with their child and what their preferences are about communication and treatment options.
  - "What have you told _____ about the change in his/her condition?"
  - If the family has not shared the prognosis with the child: "Tell me why you have chosen not to tell _____ about her/his diagnosis (or prognosis) with her/him?"
  - Review your policy about honesty with respect to communications with their child. Reiterate that you will not lie if the child asks you a direct question about their condition.
  - Some parents don't accept that their child knows that death is imminent (The child usually knows…). How isolated this child must feel!
- Using simple, age and culturally appropriate language, determine what the child/adolescent knows about their diagnosis, prognosis, and treatment options.
  - Consider using books, movies, fairy tales, play, drawings etc. Child life specialists may be very helpful with this.
  - Some simple questions may be helpful
    - "What has it been like living with _____?"
    - "What do you understand about the medicine you are taking?"
    - "How do you think that your treatment has been going?"
    - "What do you enjoy doing?"
    - "Has your disease/condition kept you from doing the things that you like to do?"
  - Ask how much additional information the child/adolescent would like and how they would like to be involved in decision-making. While most children wish to be involved, some children wish to avoid it.
    - "How do you want to be involved in deciding what to do next?"
  - Provide resources to determine and document goals and preferences, such as:
    - Five Wishes, My Wishes (Pediatric version of 5 Wishes), Voicing My CHOiCES
    - Respecting Choices
    - FAmily-CEntered (FACE) Pediatric Advanced Care Planning
    - POLST (varies by state)
    - If 18 or over, or emancipated minor: Durable power of attorney for health care
- Disclose accurate information and frame realistic hopes.

- o Acknowledge uncertainties. This quote from Betty Davies remains pertinent today: "An uncertain prognosis should serve as a signal to initiate palliative care rather than to avoid it, even when it is not yet appropriate to begin end of life care."
  - o Reiterate that disclosure actually supports hopes. When the family members, including the child, have accurate information, they are less anxious, worried, and depressed. They feel more in control and less isolated. The child/adolescent has the opportunity to participate and make their remaining time more meaningful.
- Support shared decision-making, inclusive of the voice of the child/adolescent.
  - o Conversations should begin early in the course of the disease or condition and occur periodically.
  - o Clarify goals and expectations for physical health, site of care, psychosocial and spiritual support, and social support.
  - o Inquire about religious, ethnic, and cultural values that might impact on decision-making.
  - o While most parents prefer a shared decision-making model and participation along with the health care team, inquire as to their preference.
  - o Participation of the child depends on age and cognitive and emotional capacity. Even a 6-year-old or a cognitively impaired but communicative older child can participate:
    - ▪ "Where do you want your IV? Left or right hand?"
    - ▪ "How do you think that the treatment is working?"
    - ▪ "Where do you like to have your treatments?"
    - ▪ "What do you want to do this week?"
  - o **Only offer options that are medically and ethically appropriate**. Describe likely responses to each option, including uncertainties. Let the child know that they may not have veto power.
  - o **Include the child's preferences and encourage participation.**
    - ▪ "What are your biggest worries about the treatment choices?"
    - ▪ "Can you tell me how you made this decision?"
    - ▪ "How is the treatment affecting you?"
    - ▪ "Do you think that the treatment is helping you?"
    - ▪ "What is important to you for the next few weeks?"
  - o Inquire about the hopes of the child and the family.
    - ▪ "What are you hoping for?"
    - ▪ "What are you worried about the most?"
    - ▪ "Who do you turn to for support?"
    - ▪ If hopes for a cure or a miracle are expressed, one might say something like: "I hope for that as well, but I fear that it is not likely" or "I hope that as well, but I also think that we should be prepared in case he/she doesn't get better. Could we discuss some additional goals?"
    - ▪ Try to align the child's and the family's hopes.

- Help the child and family clarify potential new (smaller, possibly achievable) hopes and goals.
  - Allow time. Listen.
  - After all this, what if the minor child and parents disagree? What if the parents want more aggressive treatment that the minor child? What if the minor child wants more aggressive treatment than the parents? A joint meeting between the child/adolescent and the parents might help clarify perspectives. Lots of listening and "shuttle diplomacy" are involved! Offer an ethics consultation in cases of unresolved conflicts.
- At the end of each conversation, summarize your understanding of the current plan and your follow up plan. Document the plan in the medical record and communicate with all health care providers.

  Elena's case: The team meets to discuss all aspects of Elena's capacity to assent/dissent and agrees that she seems well informed and capable of participating in decision-making. They discuss with Elena her experience of living with CF, how she arrived at her decision, and who she turns to for support. They elicit her hopes and fears. A joint meeting with the team, Elena, and her parents helps the parents see her perspective. Together, Elena and her parents complete the My Wishes document.

We owe respect to all children regardless of their legal status. It is important to seek assent (or dissent) from all children. Their voices deserve to be heard and we need to know how to solicit and listen to those voices.

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DO RACISM AND SOCIAL INJUSTICE IMPACT PEDIATRIC SYMPTOM MANAGEMENT?

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"When do I stop being cute?"
"Am I next?"
"At what age do I go from being cute to dangerous?"

Images of protesters holding signs flooded social media during the Black Lives Matter protests in the summer of 2020, shining a spotlight on the disproportionate frequency of police brutality against the Black community.[1] The signs held by Black children told the story of a sobering reality. Early on, Black children must learn how to navigate social and racial injustice in all areas of their life. There is substantial evidence of racial disparities among Black adults in healthcare, but there has been less recognition of how this endemic impacts Black children.[2] The murder of George Floyd sparked conversations and change around the country regarding police brutality, but it also opened the door for conversations regarding racial and social injustice in several sectors, including healthcare.[3] The Black Lives Matter protests may have been the catalyst for change that will provide justice for future generations.

In 2020, the American Pediatric Society (APS) selected racism and social injustice as the theme for their issue of the year.[4] Racism and social injustice contribute to higher rates of disease-related deaths, discrepancies in maternal and child health care, reduced availability of healthcare services and insurance coverage, and higher rates of mental health issues and substance abuse that adversely impact Black children into adulthood.

Social determinants of health are impacted by economic, political, and social factors that are linked to health inequities. Racism has been identified as a social determinant of health and has been linked to birth disparities and mental health issues in children and adolescents.[5] Chronic stress can predispose children to chronic health disease due to prolonged stress hormone exposure. Health inequities are also secondary to economic, social, and political conditions. As a result, poverty, housing, education, and insurance also have negative effects on the health outcomes of Black children.

The medical community has a long history of inadequately treating Black patients. From believing Black patients were immune to yellow fever in the 1792 outbreak, to the Tuskegee Syphilis Study, and most recently to the disproportionate impact of COVID on the Black community. These historical instances of abuse have led the Black community to approach healthcare with mistrust and skepticism. In a 2016 study, half of the medical students and

residents surveyed believed several myths about Black patients: a Black patient's skin is thicker than a white patient's; Black patients don't feel pain; and a Black patient's blood coagulates quicker than a white patient's.[6] Compared to other ethnicities, Black patients have lower life expectancies, higher blood pressure, lower rates of influenza vaccination, and higher incidence of mental health issues.[7] Myths aside, ethnicity may play a role in risk factors pertaining to diseases or medications. Sickle cell disease is frequently seen within the Black community, with an estimated prevalence of 1 of out every 365 Black births and 1 in 13 Black babies being born with the sickle cell trait.[8] A Black patient in a sickle cell crisis will likely have uncontrolled pain and inferior care due to the myth that Black patients do not feel pain.

Regarding medications, the Black community may have enhanced and/or reduced treatment response to certain medications. Pharmacists play an important role in reminding prescribers of these clinical pearls. In general, Black patients have less efficacy with angiotensin converting enzyme (ACE) inhibitors, angiotensin receptor blockers (ARBs), and most beta-blockers when used as monotherapy due to low activity of the renin-angiotensin system.[9] Isosorbide/hydralazine (BiDil®) was the first medication approved by the FDA for a particular racial-ethnic group, but it is not approved for use in children.[10] Black children may respond less to albuterol, which can impact disease control and long-term complications.[11]

Trauma-informed care is a newer conversation occurring within the healthcare community. The Centers for Disease Control and Prevention have recognized that toxic childhood stress is a risk factor for health issues (cognitive, behavioral, psychological). Trauma-informed care is the foundation on which the APS recommends a new approach to pediatric care to prevent, recognize, and treat trauma-related health effects.[12-14]

As healthcare providers, we have taken an oath to first do no harm and each professional has the capability to be an ally, to be an advocate, and to be a part of change. As healthcare professionals, how can we do our part in mitigating the impact of racial inequalities and social injustice on the children we help take care of? While our training focuses on medications, we can do more to be an ally and advocate. We can actively work on learning how to be anti-racist, recognizing our own unconscious bias, and improving patient relationships through perspective talking and empathy.[15,16] Clinicians can incorporate culture diversity, anti-racism, and inclusivity training into the workplace.[17] Fostering a safe and inclusive culture so that patients feel seen and heard is an important building block. Given the newness of trauma-informed care, healthcare professionals should seek out training to become more educated and prepared to shift their practice. Advocating for enhanced cross-cultural education in health programs and mandating continuing education requirements focused on reducing racism in healthcare are other ways that healthcare professionals can work to reduce racial bias in their field.

Failure to increase awareness and to address and reduce racism will continue to undercut health equity for Black children. In the words of the Dalai Lama, "just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far-reaching effects." Whether you work as a pharmacist, physician, respiratory therapist, nurse, or any

member of the healthcare team, there is something you can do to reduce racism in the healthcare field, to be a part of providing justice for future generations of Black children.

Resources

- The Impact of Racism on Child and Adolescent Health from The American Academy of Pediatrics. Available at:
  https://pediatrics.aappublications.org/content/144/2/e20191765#sec-6
- Key Resources for Promoting Equity and Reducing Disparities by Substance Abuse and Mental Health Service Administration. Available at:
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- A Kids Book About (https://akidsbookabout.com) – a series of books that help parents and caregivers facilitate conversations about racism, white privilege, anxiety, LGBTQ+ and more. Books are separated into children ages 0-4 and 5-9.

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IT'S DIFFERENT WITH KIDS: A CONVERSATION ABOUT EMOTIONS & IMPLICIT BIAS

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Using a case-based approach, this article discusses the intersection of ethics, palliative care, and implicit bias. The case presented in this article is a compilation of years of experience and in no way represents a particular patient, family, care provider, or institution. Any such likeness is strictly coincidental. We know that the "plan of care" presented in this article is not the standard of care, but we are using this scenario as an illustration of how emotion and implicit bias can be a factor. The focus of this article is on implicit bias in relation to our emotions and actions. Additionally, this article discusses how our emotions and actions can impact our ethical beings and our relationship with our patients, their families, and our colleagues. This article is based on a previous presentation and hence is deliberately written as if we are having a conversation.

Definitions:

In order to make sure we are using a common language, we provide some simple definitions of terms that may trigger some thoughts and feelings. As you read this article, please keep in mind what pops into your mind as we explore this case study and what are the challenges you may have been faced with. We will be discussing our own implicit bias, i.e., thoughts and feelings outside of conscious awareness and control (Project Implicit, 1998). Moral distress occurs when you believe you know the ethically correct thing to do but something or someone restricts your ability to pursue the right course of action (Wocial & Weaver, 2013).

Please note that the word "physician" is used here to refer to all healthcare provider members of our interdisciplinary teams.

The box to the right is a very brief listing of ethical principles. Keep these principles in mind as we go through our case. Also consider some of the issues we commonly face in pediatric palliative care such as capacity, consent, assent, and confidentiality, as well as the emotions these issues may bring to the surface.

> **BASIC ETHICAL PRINCIPLES:**
> **Autonomy** – make their own decisions/self-determination
> **Beneficence** – to do good, to be of benefit
> **Non-Maleficence** – to do no harm
> **Justice** – being just, fair distribution of good/services – equal treatment
> **Veracity** – truth
> **Fidelity** – loyalty, support, non-abandonment
> **Confidentiality** – trust compassion & respect

Carla's Story

Carla was a previously healthy 11-year-old, an eager student, active in school and after-school sports. She was a proud older sister to her 6-year-old sibling, both being raised by a single, Spanish speaking only, mom in an urban area. Late one evening Carla was brought to the emergency room (ER) of the local children's hospital with headaches, talking, walking, and complaining of fatigue. She started seizing in the ER and became unresponsive. She was quickly intubated due to respiratory failure.

Over the next 12 hours Carla developed a rash over her trunk and legs, her heart rate rose to 155 beats per minute, her pupils dilated and became non-reactive, and she started posturing. There was rapid deterioration of Carla's condition and still the etiology was unknown, cultures were still pending. A brain MRI was done with concern for herniation; unfortunately, the MRI confirmed herniation-significant edema, subdural effusion, and significant infarctions.

Following this, the first care conference with the primary team was held with Carla's mom, the ICU attending, the Palliative Care Team social worker and nurse coordinator, an interpreter, ICU social worker, ICU resident, ICU fellow, and hospital chaplain. Carla's mom was alone, her significant other had stayed home to make sure her youngest daughter returned home from school safely but he was on speaker by phone. Carla's biological father was unknown. The meeting was prescheduled and coordinated with the staff but not with mom since "she was always at the bedside." At this time the ICU Attending informed Carla's mother that a brain death exam would be done and that following this process Carla would be disconnected from the machines since "we expect that her brain is dead, and she cannot get better." As they leave the room, the attending is overheard saying, "we are in for a fight."

However, nothing is black and white, many issues and challenges are represented in this scenario. Can you think of some? What is the role of the palliative care team here?

On the fourth day following admission, parents and friends from Carla's softball team visited bringing food and cards. Following their visit, a second care conference was held. The same hospital staff attended with the addition of a neurologist and pulmonologist. At this conference Carla's mom attended with her brother and boyfriend (the only father figure Carla knew). The family was informed by the ICU attending that the first formal brain death exam had been completed and that following the second exam in two days the machines would be withdrawn. Both the uncle and stepfather stated, "she'll wake up," and they requested a second opinion. Both reiterated that they believed their God would see Carla through this journey if medicine could not. They were clear that they did not support withdrawal of any interventions. Carla's mom simply sat and cried…

What jumps out for you?

Who Are We When We Walk Into the Room?

There is much that contributes to who we are personally and professionally. Our family and personal histories, our racial/ethnic/religious/spiritual/age/gender/socio-economic backgrounds, our current beliefs, our professional experiences, our conscious and unconscious biases, our assumptions, and factors that may not be listed here.

Conscious/Unconscious bias – Bias is a strong inclination of the mind. It is preconceived notions or opinions about someone or something and can include social stereotypes. Ross states, "Categorizing people without realizing it is as natural as breathing and allows us to navigate the world" (2020, 1). Conscious biases are explicit whereas unconscious biases are implicit—not uncommon manifestations of our tendency to try to organize how we think and understand people who may be different than ourselves in one way or another.

What biases might be in play in this case study? Are we describing families as "good" vs "difficult"? Are we at risk of broad stroke generalizations that might interrupt or divert our own inquiries, and stop us from pursuing communication that would teach us more about individuals or individual families or communities? We should, theoretically, be leaving this all at the door; enter the room without bias or preconceived notions or expectations—but we are not always successful in doing so.

Our feelings can include some or all of the feelings listed in the box to the right.

We know that moral distress can be a potential indicator of emotion—what else can it indicate? Reviewing the list of feelings in the box. Are we also grieving?

• Angry	• Exhausted & Overwhelmed
• Confused	• Bitter
• Frustrated	• Burned Out
• Responsible	• Traumatized
• Annoyed	• Emotionally or Ethically Dissonant
• Morally Distressed	• Sad
• Grieving (cumulative)	• Conflict of Conscience
	• Other?

For example, what if the hospital where Carla is a patient is a busy children's hospital and trauma center, sees 12 deaths within 60 hours or 2.5 days; three deaths in the ICU happened in less than an hour—none expected, one death of a child who was well known to all staff having been treated at the hospital over several years for a complex medical condition, a child who sustained horrendous child abuse, a pair of siblings who died from a motor vehicle accident, two children who died from complications from chemotherapy, two others who were withdrawn from support following non-accidental trauma and death by neurological criteria and one from overwhelming sepsis of unknown origin. nine of these children died in the ICU, three were pronounced in the ER. Families see all, so do all staff, from all departments.

If Carla's situation is happening during one of those weeks, when we meet with Carla's family, are we 100% present? What other feelings come to mind?

We really need to dig deep sometimes to identify how we are feeling and, more specifically, how we are feeling towards another—and why. What factors are in play (who are we when we walk in the room?). This influences how we feel. We need to consider how our feelings inform what we think about someone, their manner, their presence, their actions, their choices. When, for example, we feel dissonance or ambivalence, how does that inform our actions? We need emotional intelligence, which includes how we manage and understand our emotions, how we use our emotions and knowing how our emotions may be perceived (Goleman, 2021).

Carla's Story Continued, Day 4

The healthcare providers ask the family to accept the medical decision and recommend engaging in memory making activities. The family is overheard saying, "We're going to stand our ground." One of the attendings states, "I knew we were going to have a fight…"

How do you think the team is feeling? How can this impact their actions, language, posture in relation to the family? The language of battle is embedded in medicine and has over time become an acceptable paradigm. Has this become a battle because of emotions? Is this ethical? Is it ever ethical?

There is also the added layer to all of this—these are kids, emotionally and medically different situations than with adult patients.

How do we appear to families?

How do feelings impact our relationships with patients and families? Can our feelings become factors that ethically influence our own actions? How might we gain insight? How do we identify and acknowledge our own beliefs vs our emotions? What can we do in response and, perhaps where necessary, make some changes?

Carla's Story Continued, Day 6

On day six, the second brain death exam is completed, and death is pronounced. The third case conference is held with the family stating, "We must witness God doing his work to heal his daughter." They request more time with Carla and do not agree with the plan for withdrawal of life-sustaining technology. The family is

- How might we gain insight to our biases?
- How might we be accountable?
- How do we identify and acknowledge our beliefs, our own narratives in relation to others?
- Are we acting and/or reacting in subtle or not-so-subtle ways?
- Are we exhibiting micro-aggressions or not-so-micro aggressions?
- What about our manner, our posture?
- Are we being fair, or are our feelings about families or about the situation the driving force rather than a sense of neutrality?
- Do our feelings essentially seep in and do our actions then become an ethical issue?
- Are we, in any way, assuming a paternalistic posture or have the appearance of doing so – perhaps imposing our views in a manner that challenges the parental role and authority?
- Do we provide or expect different timelines for different families based on conscious or unconscious biases?
- Are we being fair, or are our feelings about families and about the situation the driving force rather than a sense of neutrality?

informed of the second exam and told that the machines will be removed the next day. No one addresses their request for more time or their disagreement with the stated plan.

We have not specifically addressed the religious/spiritual component, the belief in miracles, the family's repeated perspective – for them this is not just a medical journey. The timeline. What is the role of pediatric palliative care? Could the palliative care team have intervened in a helpful way? If so, how? What about the role of the Ethics Committee?

As mentioned earlier, nothing is black and white, many issues and challenges are represented in this case. What are some of the issues we have not discussed? What resonates with you or strikes you with regards to the team's relationship with Carla's family?

Carl Schneider stated, "Even patients/parents sufficiently well-educated and reflective…frequently describe no decisional process at all. Instead, they invoke intuition, instinct, and impulse" (1998). This is the reality we see every day, a parent's instinct to "save" their child.

How do we come to an agreed-upon plan of care when a provider is readying for a fight and intent on the medical plan of care and the family is asking for time not included in that plan of care?

Conclusion

Working with children who have complex medical conditions is challenging. There are times when a certain child or family will hit a chord deep within us, where we feel an intense connection. There are others that we simply cannot understand or relate to. There are others who may be in a similar situation that was traumatic or challenging and invokes many different feelings. We should ask ourselves, have our feelings become factors that influence our own actions? How might we be accountable?

Would a different paradigm or style of conversation be effective? Given who we are when we walk into the room and given what we know and understand about the patient/family, can we provide an environment that promotes safe, honest, and beneficial discourse? Do we need to excuse ourselves from a particular patient situation? Consider palliative care and/or ethics consults—separate the conversations from the existing medical model of engagement. How do we weave in the ethical principles of autonomy, beneficence, non-maleficence, and justice/fairness?

Simple things we can always do include being respectfully curious, listening deeply, and considering all aspects of the situation and all perspectives. We need to work to gain insight to our biases, identify and acknowledge our beliefs, and understand our own narratives in relation to others. We cannot possibly know all there is to know simply by observing a family in a moment of time or reading the medical record. The experts in this are, of course, the patients and families themselves. We must be respectfully curious, inquire, ask questions, do not

assume. And after taking in what we have heard, we can integrate that information, reflect, do our internal analysis of who we are, how we are responding (internally and externally), how we might appear to others, and, important to this "conversation," how we feel. I am a great believer in "the pause:" pause before you enter the room, take the time to check-in with yourself.

One of my favorite books is *Pooh and the Philosophers* by John Tyerman Williams (1996). In "Lessons from Winnie the Pooh," Williams writes,

> We also see how great his anguish was when we go on to read "his arms were so stiff from holding on to the string of the balloon all that time that they stayed up straight in the air for more than a week."

What a brilliant picture of the way in which habit and emotion may cling to a belief that evidence and reason have rejected.

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General Resources

The following website has online resources including a self-assessment of implicit bias. https://implicit.harvard.edu/implicit/takeatest.html

Institute for Healthcare Improvement has many resources on their website including learning modules at http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Anurag-Gupta-How-Does-Implicit-Bias-Affect-Health-Care.aspx

Joint Commission offers a Quick Safety Issue 23 on Implicit Bias, which can be accessed at https://www.jointcommission.org/resources/news-and-multimedia/newsletters/newsletters/quick-safety/quick-safety-issue-23-implicit-bias-in-health-care/implicit-bias-in-health-care/

Ohio State University - Kirwan Institute for the Study of Race and Ethnicity; Implicit Bias Module
Series. https://kirwaninstitute.osu.edu/implicit-bias-training

More Resources

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INQUISITIVENESS AS A FOUNDATIONAL TENET
TOWARDS PARTNERSHIP AND LIMITING DISPARITIES IN PEDIATRIC EOL CARE

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Partnering with the families of pediatric patients, and the patients themselves, can be challenging due to many factors. We often consider terminality of a child or adolescent as against the natural order of life, which can breed the imposition of our biases, both positive and negative, to the care that we provide as clinicians. This can create a new meaning in the disparities in healthcare experienced by this vulnerable population, their parents/guardians, their siblings, their grandparents, and their communities. In NHPCO's 2018 Facts & Figures, the general hospice population demonstrated several inequities in care. Sadly, even when looking at the classifications by age group, the pediatric population was excluded. There may exist limited data points for pediatric healthcare providers, but our review of literature made these difficult to identify. The lack of an equivalent set of statistical figures for these patients may further predict a wider divide between the expectations of these families and our impositions of care and support. Defining a good end-of-life experience for a pediatric patient is challenging enough.

Our Why & Process

In acknowledgement of our own responsibility towards decreasing this gap in care, we decided to dive headfirst into the concepts of cultural humility. We defined humility as an experience of curiosity and inquisitiveness that can bridge the understanding between the pediatric patient and their family's experiences in the healthcare system, not just their spiritual and familial beliefs. We took the opportunity to establish a set of questions that could be utilized by any member of our team that touches patients and families, including the nurses in our 24/7 call center and our consultants who help patients elect the hospice benefit to access EOL care. The questions themselves focused on six primary areas of care: communication norms, tradition and health beliefs (which included any historical narratives and healthcare disparities that may impact care), considerations for pain and symptom management, considerations for advance directives, considerations for imminent dying and death, and family structure and dynamics. We then highlighted the three subgroups that frequently influence our pediatric patients and implemented these directly into the nursing and social work assessments and routine re-evaluations:

1. Considerations for Pain & Symptom Management
    a. [If patient is verbal, please ask both patient and primary caregiver(s)]. How do you view the experience of pain? Are you comfortable identifying/rating it? Are you comfortable verbalizing it?
        i. Are there any differences between your views and those of your family-of-choice/community?
    b. [If patient is verbal, please ask both patient and primary caregiver(s)]. How do you view medication? Are there medications that you are concerned about?
        i. Are there any differences between your views and those of your family-of-choice/community?
2. Considerations for Advance Directives
    a. How are conversations related to final wishes, DNR, etc., best initiated with you (and your family-of-choice)?
    b. (Threshold Question) Is there something that is key to your quality of life (e.g., like when someone must perform personal care for you or when you aren't able to attend school anymore), that when no longer possible would indicate a time to focus on discussing your final wishes?
    c. How do you define "suffering"?
3. Family/Care Structure and Dynamics
    a. In your family-of-choice, who makes decisions about important plans, needs, etc.?
    b. Who would you like to be involved in discussions and decision-making?
    c. Are there any members of your community (like clergy) that should be involved in meetings to support you and your family-of-choice's needs?

The assessments created several additional constructs that could influence historical healthcare experiences and expectations. For example, we ask where the family has spent most of their

life, in recognition that many pediatric patients come to the United States for treatment that may then turn into end-of-life care when the patient's prognosis has shifted their goals/needs. We further seek to recognize the social support system. Though not unique to this population, we specifically ask about the patient's siblings, grandparents, friends, the larger family unit, and even the healthcare providers that initially made the hospice referral. With the implementation of concurrent care for children, this reinforces the greater responsibility of the broader team in coordinating care that honors the patient's and family's autonomy. Recognizing another disparity existing in this population related to a pediatric patient's ability to assent to care, we include in the goals of care section the utilization of elements of *My Wishes* and *Voicing My Choices*, if the patient is verbal to participate in the process, as a catalyst towards improving communications between families.

A Team's Experiences & Reflection on the Implementation of Cultural Humility

Our Wisconsin *Sweet Pea* team has been providing care to the pediatric population for over a decade. They are one of the few local programs that will provide EOL care to pediatric patients at home, and as such have become a beacon of expertise to the greater community. Their participation in the revisions of these assessments was paramount; it promoted their compliance and acceptance immediately, and their willingness to provide honest feedback to the burdens and/or benefits of the cultural humility questions embedded. They reported the following:

"Allowing the clinician to practice from a framework of cultural humility has allowed for authentic dialogue to emerge from the RN and social work assessments. The hospice team reports feeling confident in asking open-ended questions to best understand more clearly how recently relocating to the United States and interfacing with a healthcare system that is unfamiliar, all influence their end-of-life decision making and overall experience.

"Since the utilization of the newly created assessments, the nurses and social workers have reported an increase in visits being made by clinicians (Physicians, Nurse Practitioners, Registered Nurses, and Social Workers) from the referring Children's Hospital system, in partnership with hospice staff seeing the pediatric patient in their home environment. These assessment questions provided the hospice team more clearly-defined language related to the palliative goals being shaped by the patient and family's experiences since their admission to hospice services. Being able to more accurately use the patient/family's own words has led the referring healthcare workers to more readily see the significance and benefit of their ongoing involvement to the patient and family plan of care.

"The depth of the answers to these questions, and the ability of the hospice team to share these responses with the referring healthcare workers, has allowed a more cohesive and genuinely receptive response from the hospice team and referring healthcare system alike. Being able to provide choices and options that sincerely reflect what, through assessment of that individual patient and family, is believed to be potentially preferable care plan options, has allowed for a patient-provider symbiosis that is imperative, especially when embracing the

reality that no matter how well supported or comfortable the death of the terminally ill child, it will likely never end with what the then bereaved will categorized as a preferable outcome."

Commonly, the pediatric hospice team would report situations where they felt that the patient's plan of care was being created by adult decision makers without representation of the end-of-life wishes that were being voiced by the patient themselves. In one such scenario, the team was able to utilize the assessment questions to open a dialog where parents of a 7-year-old were able to listen and hear for the first time that she wanted to die in their family home, and not at the hospital as they had been planning. A 17-year-old patient found the courage to explain to her divorced parents with whom she lived at each house 50 percent of the time, that she had been feeling like she was letting them both down because she didn't agree in totality with either one of what were their two very different preferred approaches to her end-of-life care. The hospice team was able to support this family in having a discussion that until then had not occurred using the concepts enmeshed in the new assessment tool. The result ended up being less trips to the hospital, more time spent with friends/family, better symptom management with a more robust medication regiment, and the change in code status to a DNR. The patient and her parents found value in understanding that everyone contributed to the development of the care plan and that importantly it encapsulated their collective voice.

From a preliminary review, the *Sweet Pea* team utilizes their expertise in a more comprehensive way following the implementation of the questions related to cultural humility. Furthermore, the experiences with patients and their families-of-choice have become more honest, more impartial, and more collaborative, even in acknowledging the participation of the pediatric patients themselves. Our team has verbalized a growing proficiency that bridges the principles of honoring diversity, equity, and inclusion.

The Story of J.R., Her Mother, and Her Grandparents

J.R. was born at 35 weeks gestation after her mother came to the hospital due to thinking she was withdrawing from heroin only to discover she was in preterm labor. J.R.'s mother had been using heroin, cocaine, and alcohol during the pregnancy. J.R. was having difficulty latching due to the premature birth. Per consultation with the hospital care team, the family decided on G-tube placement. During the G-tube surgery the patient's bowel suffered an injury and J.R. became septic. Seizures and brain damage were sustained due to the infection. It was at this time that J.R. was referred and then admitted to hospice services with a diagnosis of respiratory failure with hypoxia and hypercapnia.

The nurse and social work assessments that were completed for J.R. allowed for the clinicians to understand key factors in supporting the development of J.R.'s care planning starting from admission. J.R.'s mother was able to explain that her parents, J.R.'s grandparents, would become the primary caregivers. Without feeling stigmatized, J.R.'s mother could define her role in being involved in decision-making and care, but also define the role for the grandparents that would best meet their family's needs. J.R.'s mother and grandparents were able to jointly

define what members of their community/social system were important to their process, and in what capacity.

By asking the assessment questions, J.R.'s mother and grandparents were able to confidently express their thoughts and beliefs about the use of medications in promoting pain and symptom management. J.R.'s mother and grandparents were able to define not only what medications they were initially comfortable with using for symptom management, but also how those medications would be stored and who would have access to them. J.R.'s mother was supported in understanding the potential use of opioids for palliation, while also navigating her own methadone treatment. Through these open conversations, a rapport was built where the family was able to accept the expertise and support of the hospice team, unencumbered by a fear of stigmatization.

Considerations related to J.R.'s advance directives and end-of-life decision-making were another part of the initial assessments that was positively influenced by the refocused evaluations. From the start of care, J.R.'s family felt empowered to define the altered code status plan that best represented their wishes. By honoring and embracing these choices, the hospice team incorporated language in subsequent visits that demonstrated understanding and in support of their decisions. The family, who had historically demonstrated confidence with their ongoing relationship with the Children's Hospital system, increasingly started seeking the guidance of the hospice team when facing pivotal choices for J.R.'s care…both teams were able to wrap their arms around the end-of-life experience that J.R., her mother, and her grandparents would have. J.R.'s relationship with hospice has been enhanced by the humility and inquisitiveness being imbedded within assessments and its influence on the overall delivery of care.

J.R. has now been on hospice services for eight months. Over the past several months J.R.'s family has expressed in detail how having many family members in Mexico, being bilingual, and their customs/traditions all help to shape how they raise and care for J.R. While the grandparents have remained instrumental in J.R.'s care, the hospice team has embraced the evolving communication surrounding decision-making that now is more inclusive of the mother's thoughts and feelings. J.R.'s mother has been able to increase her role as a direct caregiver and now attends most of her appointments. J.R.'s primary physician and team from the Children's Hospital have also experienced the benefits of a family who continue to feel more comfortable sharing their individualized preferences for J.R.'s care.

Cultural Humility and the Patient Experience

As an organization, the cultural humility assessment questions are consistently used with our pediatric patients. After experiencing firsthand the benefits of asking these questions when serving pediatric patients, our next step involves the inclusion of these questions for every Seasons Hospice & Palliative Care patient. In preparation, the team must prioritize questions from all six areas of care to best support the cultural needs of our patients while also respecting the time and space of both patients and caregivers. By asking the cultural assessment questions

referenced, the hospice care team was able to learn J.R.'s family's traditions and experiences being bilingual in the United States. These details can have great influence on the plan of care developed by the hospice team with a deeper consideration of what is most important to the patient and their family-of-choice.

Supporting the unique needs of patients and their loved ones at the end of life requires a heightened sense of both understanding and curiosity, especially when serving our youngest patient population. Cultural humility is a concept and approach that, when practiced, benefits patients and all who are involved in their care—those who are related and those who are part of the patient's general care team. Pediatric hospice care provides an opportunity to guide families who are often experiencing very complex emotions through a time that no parent or guardian hopes for. Providing inclusive care that addresses the needs of the "whole" patient starts first by asking the right questions. By knowing the answers, we are provided information that will improve the quality of care provided and strengthened alignment amongst the entire support system.

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OPPORTUNITIES FOR PEDIATRIC PALLIATIVE CARE INVOLVEMENT IN ACUTE HOSPITALIZATIONS: WHY DO DISPARITIES PERSIST?

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The number of children living with life-limiting conditions has continued to rise, given the advancements in medical care and technology.[1] These children often require frequent hospitalizations for routine as well as unexpected urgent or emergent care including intensive care unit admission. Additionally, previously healthy children can be admitted for newly acquired conditions such as traumatic brain injury or severe illness that result in significant morbidity and mortality. Families of these children often face challenging decisions, including those at the end-of-life, or during an acute hospitalization which require thoughtful and family-centered support. Pediatric palliative care (PPC) has emerged as a specialized resource to provide such support for children with existing or newly identified life-limiting conditions and their family.

The hospital setting can be a unique opportunity for families to access PPC, as a point of healthcare contact and when circumstances surrounding hospitalizations necessitate consideration of quality of life and care directions.[2,3] Yet, available data suggests these resources may not be as accessible to all pediatric populations, with potential disparities based on race, socio-economic status, and geography.[4-6] Furthermore, even with apparent access, the effectiveness of PPC may be still be disparate. Thus, the question remains, what barriers exist that prevent equitable and consistent involvement of PPC to aid communication, pain management, and emotional needs of patients and their families? And are there any potential solutions to mitigating these barriers?

Determining the etiology behind observed disparities is complex and likely multifactorial. Numerous conceptual frameworks attempt to describe contributing factors to health and healthcare disparities in general, and by extension, identify potential solutions.[7] However, the factors most commonly associated can be organized as: individual (and family) characteristics, the environment or community, and the healthcare system (including provider). Individual factors include not only race, ethnicity, and socio-economic status, but also the specific life-limiting condition, the level of health literacy and culturally-based knowledge, and beliefs and attitudes towards palliative care and death. Environmental factors such as air quality may not be as relevant for hospital-based PPC, but community resources or support can certainly impact access or acceptance. Finally, in addition to the simple availability of PPC services within a particular hospital system, the approach to palliative care (consultative vs integrative, primary vs secondary), the inherent biases of team members, and the presence or absence of other services that support the unique needs of patients and families from differing backgrounds can influence the use and effectiveness of PPC. During the acute hospitalization, particularly in a time of crisis—which may or may not signify the end of life—the inhibiting factors for certain populations may be further exacerbated.

Even as they enter the hospitalization, families may have differing understandings and perceptions of palliative care. Many parents caring for children with chronic illness have a strong negative connotation of palliative care, i.e., "the p word," as they associate it with death and dying rather than a holistic and longitudinal approach.[8,9] Parents from ethnic and racial minority backgrounds may have difficulties in understanding prognostic discussions due to cultural or language differences, or historical experiences that influence reactions and expectations around death and dying—including a preference for dying in-hospital and avoiding of life-limiting care directions.[10-13] Experiences from prior healthcare encounters or personal non-health experiences may also raise concern for misunderstanding or suspicion about healthcare in general.

Adding to these individual factors, the hospital setting can further exacerbate disparities between families of different backgrounds. The system itself is often complex and challenging to navigate, with layers of team members that can change throughout a hospital course. For families with limited health literacy or language barriers, the ability to understand their child's illness or illness course can be limited. Even when translators are available, it is unusual to have them constantly at the bedside, leaving it to family members to interpret clinical care with potential for misunderstanding. The limitations on visitors, particularly in high acuity locations such as the intensive care unit, may leave the parents without usual community support when they need to communicate about the child's status and healthcare needs and decision, which can be challenging for those whose lives and support systems rely heavily upon a cultural or religious community.

Team member biases may also influence the decision to engage palliative care services. Some healthcare professionals may still equate palliative care with end-of-life care only and may be reluctant to involve palliative care for families who are perceived as "in denial" or overwhelmed by hospitalization, perceptions easily exacerbated by the individual factors described above and

assumptions made based on known or presumed backgrounds. Furthermore, tensions can arise when values about quality of life and death and dying appear to differ between families and care teams, and, given the discrepancies between minority representation in healthcare and the general population, these conflicts may be more apparent when these differences are present. Finally, team members may choose to avoid the topic of palliative care, in general, because of their own discomfort with the concept of palliative care and even more likely when there may be conflict between family desires and team perception of prognosis.

As with the potential factors contributing to disparities, potential solutions to ensure equity in pediatric palliative care are likely multifold. Because palliative care should ideally be a longitudinal relationship, early connection with the help of primary care teams and community resources is essential for trust building and strong bidirectional understanding of a family's experience and perspective based on their background. But what can be done to advance the goal of consistent and equal access to, and benefit from, palliative care in the acute hospitalization?

Many options would fall under the umbrella of good family-centered care—i.e., based on the child and family's specific situation, take the necessarily steps to ensure clear communication and understanding of their perceptions and values towards shared decision-making from day 1 of hospitalization. Identify health literacy or language barriers and provide supportive services, understand cultural and community expectations through conversation or engaging outside resources, and ensure access to insurance coverage to reduce financial concerns. Each of these efforts helps build trust between families and the medical team, who are often new faces, improve understanding of the child's illness, illness course, and prognosis, and reduce barriers that result from personal experiences in and outside the hospital and fears of discriminatory treatment. Thus, when palliative care is explored early during the hospitalization, receptivity and effectiveness may be improved.

From a health systems perspective, there are several options to improve access to all children and families in need of palliative care involvement. Currently, palliative care as a distinct service is limited to a number of pediatric centers and even those in existence, may be small with few PC practitioners. There may be limited financial incentive on the hospital's side due to poor reimbursement, although some data exists of the financial benefit associated with palliative care involvement.[14] With PC considered a limited resource, any biases or challenges that exist may influence a team's decision to engage PC for a particular family. If services were expanded and more available across the country, more systematic approaches to palliative care consultation or integration could be applied with more consistent involvement.

Screening tools or trigger criteria have been suggested for critically ill populations and, when applied, have demonstrated an increase in number of PC consultations.[15] While the true impact beyond increased access has not been clearly demonstrated and there are concerns about removing the primary team's judgement in individual situations,[16] such tools could be solutions to remove any inherent biases limiting teams from referring certain patients for PC. Finally, ongoing education of healthcare team members is essential to reduce barriers for all

populations. Interprofessional education about the role of PC and recognition of the potential for disparities based on cultural, racial, or other different backgrounds, including their own biases, is important.[17] Additionally, improving team member comfort with addressing palliative care needs for all children may open the conversations early in a hospital course.[18] This is particularly important for centers that have limited PC resources, as the hospital team will need to have knowledge, skills, and attitude to support their patients and families across all populations for whom they care.

Ultimately, with an issue as complex as disparities in pediatric palliative care within an acute hospitalization setting, additional research needs to be performed to develop a better understanding of specific contributing factors and, importantly, define meaningful outcomes in addition to identify effective interventions. Many outcomes considered as "good" with respect to palliative care may not be perceived as good outcomes by families from all backgrounds. Available hospital data sources can be limited on a large scale, with respect to accurately identifying individual characteristics, the involvement of palliative care, and outcomes that aren't routinely collected as part of administrative data. Furthermore, there can be reluctance to ask families to participate in palliative care or end-of-life research, further exacerbated by exclusion of families whose primary language is not English.[19] Despite these challenges, however, it is crucial to continue advancing this work at all levels to ensure we, as a healthcare community, are providing for the unique needs of all children and families who would benefit from pediatric palliative care.

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RESPITE: (ONE OF) THE GREAT DIVIDES IN PEDIATRIC PALLIATIVE CARE

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In 2016, a Respite Work Group was formed coming out of a statewide Michigan Pediatric Palliative/Hospice Care Conference held in 2015. This work group was comprised of pediatric palliative care physicians/nurses/social workers, child life specialists, parents of children with medically complex conditions, community organizations supporting these families, and others. Some of this Respite Work Group's objectives included:

- Assessing the benefits of respite for children and their caregivers;
- Identifying the adequacy of current benefits or reimbursement by commercial and state payers; and
- Defining the criteria for eligibility for the respite benefit in Michigan.

As the work group evolved further under the Children's Palliative Care Coalition of Michigan, it created its own respite definition as follows: *"Relief from the pressures of caregiving, regardless of where the caregiving takes place. This could include, but not be limited to, home, hospital, school, camps, etc."* This was broader, and somewhat in contrast to, other respite benefit definitions being offered up by the state, including:

- *"Respite services provide limited and temporary relief for families caring for beneficiaries with complex health care needs when the care needs require nursing services in lieu of the trained caregivers. Services are provided in the home by hourly skilled and licensed nursing services as appropriate.*" (Source: State of Michigan's Department of Health and Human Services Children's Special Health Care Services)
- *"Respite is a type of support available to families of children with developmental disabilities or serious emotional disturbances. It is provided on an intermittent or short-term basis to provide the parent with a break from caring for their child with a disability."* (A Family Guide to Respite for Children in Michigan as published by the State of Michigan)

So what the respite benefit was, what the qualifications were to even apply for it, where it could be offered, and by whom, was (and continues to be) somewhat confusing in Michigan. So, in 2017, a survey was launched by here4U, Inc. under the umbrella of the Children's Palliative Care Coalition of Michigan, with the Executive Directors of the Michigan Community Mental Health Boards for all the counties in Michigan. These individuals had been identified as being responsible for distributing the respite benefit to pediatric families in Michigan. The purpose of this survey was to query these Community Mental Health Directors on what their

understanding was of the pediatric respite benefit, which and how children/families qualify for it, and who parents should contact to inquire about the benefit, among other questions. With much persistence, the survey resulted in a response rate representative of 93% of the total county coverage in the state of Michigan.

Going into the survey, the Respite Work Group had as a hypothesis that this respite benefit was not distributed equally across the state. We had heard over and over again from families with medically complex children that some families "got everything" and some "got nothing." And while the families who "got nothing" (in terms of respite and other benefits for their medically complex child) did not wish other families to have benefits taken away from them, they did express a desire for broader access of benefits like pediatric respite to more families. The Respite Work Group wanted to see if this uneven (some would say unequitable) distribution of the respite benefit was supported in the data.

Results from this survey with Community Mental Health Directors would, in fact, prove that even those in charge of the "purse strings" for this pediatric respite benefit in Michigan agree that the benefit is not provided equally across families with medically complex children in the state. Specifically, the data show that:

- In terms of where this respite benefit is delivered, nearly all of these directors consider respite care at home a benefit for the pediatric clients in their county; three-fourths agree respite can also be provided at a camp/special summer camp.
  - Care delivered in a group home in the community or at school is only considered a respite benefit by less than one-third of these directors.
- And while nearly all these directors feel children requiring significant behavioral supports at home do qualify for the respite benefit in their county, only slightly more than half feel children with severe chronic or complex medical conditions or requiring significant medical supports at home (e.g., ventilators, tracheostomies, oxygen, etc.) qualify for pediatric respite.
  - Relatedly, nine of ten of these Community Mental Health Directors say that a child has to have an intellectual disability, as defined in Michigan state law, to be eligible for the state's respite benefit.
- There is a significant range in the average number of hours respite care is given per month to a pediatric client in their county from 30% claiming a low of 1-10 hours to eight percent citing a high of 31-40 hours.
  - In-between these extremes, 19% of directors report an average of 11-20 hours of respite care/month to a pediatric client in their county, with an additional eight percent citing an average of 21-30 hours/month.
- There is also large variation (presumably driven by county size/population) in terms of the number of pediatric clients under 18 who currently receive respite benefits in their county from nearly one-third citing 1-25 clients to six percent citing over 500 pediatric clients, with close to one-quarter of directors "not knowing" how many pediatric clients receive respite benefits in their county.

- These directors' "best estimate" of the % of pediatric clients who need respite who actually qualify for it and/or receive it in their county is perhaps the most staggering statistic that truly shows this "great divide."
  - One-fourth of these directors feel less than 50% of pediatric clients who need respite actually qualify for it and/or receive it.
  - One-half cite that 60%-100% of their pediatric clients in their county need and qualify and/or receive the respite benefit.
  - An additional one-fourth don't know how many need it and qualify for it and/or receive the benefit.

There are several reasons for why pediatric clients who need the respite benefit in Michigan do not qualify and/or receive it, with the biggest being, according to these directors, a lack of qualified respite workers to fill this need for these families. Specifically, eight of ten of these Community Mental Health Directors cite there not being enough respite workers available to provide this type of care to the child in their area, in addition to nearly two-thirds claiming the family is unable to identify respite workers to fill this need. It is a well-known fact that this country faces a severe nursing shortage in our health systems and in community care, which also is very much present for families needing trained professionals and people to provide respite care in their homes as well.

However, the survey sheds some surprising insights into other barriers as to why more families who need respite do not qualify and/or receive it, including:

- The family does not qualify for the benefit per eligibility requirements (24%)
- There is not enough respite funding available (16%)
- Parents/families don't know how to navigate the system (16%)

Limited funding has always been a strongly hypothesized reason as to why families couldn't receive the respite benefit—that there simply wasn't enough money to go around to pay for all the families who needed it. At least in Michigan, these results would suggest that is not the case, which certainly warrants further investigation. Sadly, families not knowing how to work the system is a commonplace occurrence, yet this seems severely underreported here. And yes, while there are "SuperMoms" who have figured all/a lot of this red tape out of how to apply for benefits they/their child needs (respite and otherwise), there are many families left without adequate help to know what to do, who to go to, what to say, etc., to get what they need. These results seem somewhat questionable given their low percentages and will be cause for further work in the future in Michigan.

In the end, what we can discern from this Community Mental Health Directors survey in Michigan on the topic of the respite benefit for children/families who need it is:

- The understanding of where respite can be provided is too narrow; while home is the primary place this relief is needed by families, it is not/should not be the ONLY place;

- The law in Michigan (or these Community Health Directors' interpretation of the law) seems very/too limited to just children requiring behavioral supports due to having intellectual disabilities; this appears to leave a significant number of pediatric families of children with complex medical conditions who may *not* necessarily have intellectual disabilities at a disadvantage of not receiving this respite benefit;
- The distribution in hours of respite provided seems quite varied and while some of this presumably is based on whether the child has medical interventions, and which ones which could require overnight relief, this distribution and how it's decided needs to be understood better to ensure it is fair/equitable; and
- The significant % of families who need respite who simply don't qualify for it or receive it is high and presumably is not all due to a trained respite worker shortage—funding and education/support to navigate the system also contribute to this gap in provision of this benefit.

The results of this study point to the need for much to be done to broaden access of this respite benefit to additional families who truly need and could be helped by it. The respite benefit definition seems narrow, the hours offered are too varied, and even those who distribute the benefit don't think all the families who need it qualify for it and/or receive it. Again, none of the families who don't receive respite, or who only have very limited respite hours, desire to have this benefit reduced for those who are being provided with significant hours and respite worker help. They just want to receive some share of this benefit to also realize "relief from the burdens of caregiving" of a medically complex child. We have much work to do to reduce this disparity between the pediatric clients who qualify and/ or receive this respite benefit—to help close this one (of many) great divides in the benefits provided (or not provided) to our pediatric palliative care/hospice families.

As some next steps to address the inequities we have identified in the provision of this respite benefit to more families in Michigan, we are considering and/or working on the following:

- Further analyzing the data to understand it from a deeper perspective with respect to regions of the state (urban vs. suburban), these directors' advice to families seeking the benefit, by profile of the directors (e.g., duration of being in a decision-making role to disburse this benefit), etc.;
- Conducting a similar survey with parents/families of children with medically complex conditions so as to look at their results in the absolute, as well as comparatively vs. the directors, on the key questions to identify gaps in perceptions;
- Creating a Family Advisory Council to provide a parent perspective on needed services like respite, as well as to inform, review, and provide input into our surveys and subsequent respite/other benefits resource development;
- Collaborating with the Advocacy and Education Work Groups of the Children's Palliative Care Coalition of Michigan to develop plans to:
  - Demonstrate the need for pediatric respite benefits for more Michigan families;

- o Lobby/advocate with the Coalition for improved access to respite (and over time, other) benefits for our children with medically complex families;
- o Determine if education/training of the Community Mental Health Directors is needed on the respite benefit, who qualifies, etc., and what format this education/training should take; and
- o Begin to explore models of care for respite and assess what's needed and could be workable for Michigan.

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SOCIAL DETERMINANTS OF GRIEF AND PEDIATRIC PALLIATIVE CARE

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"When will I have to pay for her funeral?"

As I sat beside a mother as her child took her last breaths, this question was clearly weighing heavily on her mind and heart. The expense of a funeral and burial or cremation for a child is rarely something considered in a family's budget, and so the question itself was not unexpected. However, having developed a rapport with this family over the several weeks prior to this moment, I suspected there was more to the question. I took a deeper dive into what she was asking. The response I received was unfortunately all too familiar.

"I don't think I can pay for both the funeral and my rent this month."

We talk at length about grief in pediatric palliative care. Grief not only encompasses bereavement with the death of a child, but also occurs with other losses: the loss of the anticipated newborn period when a child is born critically ill, the loss of dreams for the future when a child is diagnosed with a chronic or life-limiting disease, or the loss or disruption of familiar family routines when a child is admitted to the hospital with an injury or illness. We explain to families that this grief is "normal," something that can be expected with any loss. This normalization of grief is not intended to minimize the intense physical, emotional, and

spiritual suffering in the experience of loss. Rather, it is intended to help shape for families the idea that grief is not the "end of the road" but an essential beginning of a new journey commemorating their loss (Schuelke et al., 2021; Kochen et al., 2020). But what happens when a family is so impacted by social, economic, and environmental factors—the so-called social determinants of health—that they aren't afforded a physically or emotionally safe space to grieve?

To begin to address this question, we must first take a quick trip back to Human Psychology 101. Arthur Maslow's "Hierarchy of Needs," first introduced in 1943, is a well-known psychosocial development theory and, for those of us more psychology-averse, is one of the easier theories to apply into practice (Kenrick et al., 2010). Maslow proposes that higher level thinking, processing, and emoting cannot take place until more basic individual needs such as food, shelter, and love from others is present. While certain responses such as crying, fatigue, and even vomiting are physical symptoms of grief, the emotional and mental work of processing loss requires a certain availability of the mind to access thinking beyond day-to-day survival. The work of processing and finding meaning from grief, we would argue, could be considered a higher-level emotional task.

Which brings us back to the question "How can a family properly grieve when basic physical needs for survival are at risk?" The short answer is many cannot. Caregivers and families who experience inequity in daily life are thought to have a higher incidence of mental health concerns such as depression and anxiety, financial and employment difficulties, and an overall higher level and longer duration of significant grief after the loss of a loved one (Bindley et al., 2019). This data does not specifically address child loss, but it would be relatively safe to anticipate similar and perhaps even more significant ramifications for the parents and caregivers we encounter in pediatric palliative care (Schuelke et al., 2021).

The grief process and the idea of healthy grieving is complex. The process of healthy grieving for one family may look very different from the process of healthy grieving for another family. At the same time, there are some factors that have been widely noted to contribute to healthy grief versus unhealthy or "complicated" grief. In one study of bereaved parents after a child's death from cancer, parents and/or caregivers who reported higher levels of "family cohesion" and "social resources" were more likely to have improved coping in the years following their child's death (Vegsund et al., 2019). Poverty, on the other hand, has been associated with higher rates of impaired coping in the bereavement period (Newsome et al., 2019). When we compare these potential determinants of coping with the social determinants of health, we find similarities. The social determinants of health as noted in Healthy People 2030 are the following: economic stability, education access and quality, healthcare access and quality, neighborhood and built environment (i.e. access to safe housing, adequate utilities, and recreational areas), and social and community context (US Department of Health and Human Services, 2021). Looking at these variables, a case could be made that the social determinants of health are also the social determinants of grief.

As human beings, we also each hold expectations or assumptions of how a grieving parent will behave that can impact our reaction to families as we care for them in their grief. Care team members may expect families to express themselves through tears or through a desire to hold their child. We may assume that a family is not "coping appropriately" if they do not meet the expectations of dominant cultural norms. The tangible and intangible ways that our biases shift our caregiving interactions with families may be an important root cause of disparities in grief and bereavement care. Palliative care teams cultivate opportunities for therapeutic silence and empathic listening that can allow safe spaces for families to grieve the loss of their child in whatever way they are experiencing it (Halifax, 2008).

The interdisciplinary framework of the pediatric palliative care team is uniquely suited to assess and assist with overcoming some of the inequities and disparities that may interfere with the grieving process. Addressing these concerns may help families create a safer space to harness the healing power of the grief.

The ABC's of assessing and addressing grief in pediatric palliative care:
- **Acute physical symptom management:** A caregiver who is sitting at the bedside watching their child writhe in pain or struggle to breathe is unlikely to focus on their own needs until the child's comfort is achieved.
- **Basic physical needs of the family:** A comprehensive initial social work assessment is an essential part of family-centered care. Like physical symptom management, a caregiver will be hard-pressed to delve into their own psychosocial and spiritual suffering and grief if concerns about food, shelter, and childcare have not been addressed.
- **Child life support:** Assess the emotional needs of the child and any siblings. Children grieve too! Child life specialists are uniquely prepared to provide developmentally appropriate play to assist children in processing the world around them.
- **Dig deeper:** One of the beautiful and privileged aspects of the specialized pediatric palliative care team is having a group of individuals who can pull up a chair and have a conversation in situations where the primary medical team may not be able to do so. Ask that time-honored palliative care question "What else?": What else are you hoping for? What else are you worried about?
- **Existential and Spiritual Care Support:** Engage the spiritual care team. Spiritual and existential suffering can hinder the grief process. Some families also find comfort in religious and spiritual practices when experiencing grief and loss.
- **Follow-up regularly:** Especially when there is a death of a child, the family's experience of loss often extends beyond the loss of the child to include the loss of the care team. Families are forced to transition from a space in which they are surrounded and supported by robust interdisciplinary care teams, back to their homes. This can often feel very isolating to families and adds to the sense to the experience of loss. Routine post-discharge and post-mortem follow-up is an important part of bereavement care.
- **Give space for therapeutic silence:** Caregivers often share the most amazing stories after sitting in silence for five or ten minutes. While there is sometimes discomfort in

sitting in silence, so much of palliative care is about finding comfort in the uncomfortable. Especially in the acute care setting, families are used to care teams coming in and talking at them, and so it is understandable that having an individual sit down and ask them to share their journey may take some time to process.

Similar to adequate nutrition, shelter, and love, it is time to recognize the experience of grief as a fundamental right of humankind and address the inequities that our families face which hinder the ability to walk through grief when encountering loss in the pediatric setting. Specialty pediatric palliative care teams are offered a distinct opportunity to assess and care for our grieving families and should be leveraged to guide these imperative conversations.

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ZOOM—AN ADDITION TO RACIAL TRAUMA

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I sit here in the Pacific Northwest (PNW), where Black people are literally a minority among minorities. According to the NIH National Library of Medicine, Black people make up 0.93% of the population in the PNW region that includes five states: Alaska, Idaho, Montana, Oregon, and Washington. Having grown up in the PNW, and having made my life here as an adult, it is truly a homogenous region and I see it in my daily interactions where I am one of a couple, or a few, if I am lucky, Black people in my professional world.

Since it is not obvious, I am a Black woman. I am also a Manager in Palliative Care and Clinical Bioethics. During the pandemic, a few of us on my team have had the privilege of working from home while many of us continue to provide the clinical support that patients, families, and the institutions we work in need us to show up for. As a Black person, it truly is a privilege to not have to go out into a world that is dangerous in the ways that we know, can see, and feel but also with a literal invisible attacker lurking and waiting to infect us.

Racial trauma is real, and it exists despite people who want to say that it does not because their one Black friend told them that they have never experienced racism. Racial trauma shows up in the way that BIPOC (Black, Indigenous, People of Color) are treated, the personal microaggressions that are directed at us, the unjust organizations in which we work, and the racist policies in banking, real estate, the legal system, healthcare, government, and other institutions of power.

One place that I never had on my radar as being a place to experience racial trauma showing up in my life was in virtual meetings. Until the pandemic, like many people, virtual meetings were not a thing for me. Meetings happened in person, in large (and sometimes not so large) conference rooms, in auditoriums, in spaces where I did not have to look directly in the faces of other participants for any sustained length of time. Sometimes, if I was lucky, I got to travel to exotic places like Boston or San Diego for these meetings. Now traveling for meetings is a public health risk so we remain in our home offices and log in virtually.

When I log into a virtual meeting, my screen is often filled with white faces staring back at me. I can see through facial expressions and body language what my colleagues and others *may be* feeling about what is being said in a way that I never have before. Once, I was in a virtual meeting with a group of very smart people—including four Black women and ten or so participants who were white. We were talking about justice and how to further build equity into the foundation of our work. As one of the Black women was speaking, I saw a white

colleague cross their arms and roll their eyes. They were not looking off somewhere, their eyes were not wandering in the way that in these virtual meetings our eyes tend to wander, taking in all the information; they appeared obviously agitated by what our colleague was saying about equity and responded with directed eye rolls and a shaking of their head. This is by no means an isolated event.

After that meeting, I started paying more attention to how white colleagues responded, *specifically* when BIPOC colleagues were speaking. I have noticed white colleagues obviously checking out and looking at another screen, maybe reading email, maybe working on another project, maybe even scrolling social media. I have noticed white colleagues, in particular, turning off their cameras, obviously checking their phones or another screen. I have seen a number of white colleagues openly express disinterest, disgust, and roll their eyes in the manner that my colleague in the earlier example did specifically when a BIPOC person is speaking. I wonder, is this another way that microaggressions and implicit biases are now showing up? Are colleagues tuning out as we all have done when the topic is uninteresting? Or, is it because colleagues are in the comfort of their home and may not have the same attention to professionalism that they do in a meeting where there is not a screen and miles of internet cable between them and a colleague?

As the months have gone by, we have remained in a virtual environment for a lot longer than anticipated. I have noticed how much noticing these behaviors has added to the racialized trauma that I already experience by being in the world in the skin I am in. Not only am I barraged by what is happening in our nation—literal white supremacists storming the Capital, Black and Brown lives being plainly snuffed out in plain sight, recorded and played over and over again, among many other traumas, but I am now barraged by white colleagues who either are not aware (or do not care?) that what they reveal in a virtual setting through facial expressions and body language when these atrocities are named or when we are discussing policy change to bring more equity into the work that we do is plainly seen. Ten months ago, when many of us transitioned to a virtual workplace, I never anticipated the additional racialized trauma that witnessing these behaviors from white colleagues would add to my soul. As experts in communication, those of us in palliative care need to be *extra* aware of what our non-verbal cues are projecting. Not just for the patients and families we so expertly serve, but also in this new virtual world for our colleagues who historically and currently experience racial trauma. My one ask of all of us is to take into consideration how our virtual presence may unintentionally impact those whose identities have been historically marginalized; BIPOC, women, LGBTQIA, and so forth.

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ITEMS OF INTEREST

In each issue of our Pediatric E-journal, we offer additional items of interest.

1. **Launch of PPC NOW E-Newsletter**
   The National Pediatric Palliative Care Task Force, an initiative of the National Coalition of Hospice and Palliative Care, has launched an e-newsletter, PPC NOW. The quarterly publication will keep stakeholders informed about Task Force activities and initiatives and feature news about state and national PPC policy and legislative actions, educational opportunities, and firsthand stories and insights from families and providers. Read the inaugural edition of PPC NOW and sign up to receive the newsletter.

2. **NHPCO Palliative Care Online Resources:**
   NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpco.org/pediatrics. Also, more palliative care resources are available at www.nhpco.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

3. **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

   - **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources like:
     - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
     - *Consideration for Complex Pediatric Palliative Care Discharges*
     - *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*

4. **Trends in Pediatric Palliative Care Research**
Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit their blog, browse in their library, or join the Zotero group. View the New Citation List in their library.

5. **Pediatric Hospice and Palliative Care Training:**
- Upcoming Webinars provided by the Pediatric Care Coalition:
  - September 23: Beyond Words: Using Expressive and Integrative Therapies ats Communication Tools
  - October 19: Bereaved Parents View on End-of-Life Care
  - November 16: Alternative Payment Strategies to Enhance Access to Pediatric Palliative Care
- Registration is open for the 2021 Next-Level Perinatal Palliative Care Virtual Training Course - Sept. 22, 2021 - Friday, Sept. 24, 2021
- University of Iowa Stead Family Children's Hospital Pediatric Pain & Palliative Care Annual Conference - November 11: Being their Voice: The Complexities Surrounding the Care of Children with Significant Health Care Needs

6. **Telemedicine Resources from Family Voices**
Family Voices offered a Telehealth Academy in the Fall of 2020 as part of a CARES-Act-Telehealth for Family Engagement Grant. Available resources include:
  - Telehealth Academy
  - Telehealth Curriculum
  - Family-Centered Telehealth
  - Planning for a Successful Telehealth Visit
  - Preparing for a Successful Telehealth Visit worksheet

7. **Promoting Telehealth**
The American Academy of Pediatrics website on telehealth features videos, graphics, and articles that can be used for promoting telehealth offerings in a user-friendly way for children, adolescents, and families.

8. **Pediatric Resource on Medication Coverage:**
In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled Determination of Hospice Medication Coverage in CHILDREN.

9. **Subjects and Contributors for Future Issues of This E-Journal**
We are currently discussing the topic of glimmers of hope for the fourth and final issue

in 2021 and sustainability for our first issue in 2022. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

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