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Communicating With Pediatric Families at End-of-Life Is Not a Fantasy

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The serious illness of a child is a stressful event for any parent. Further, a child's admission to a children's hospital, dedicated to pediatric care and research, can engender a host of parental emotions. Indeed, parents may experience anxiety, fear, sadness, regret, joy, hope, or other emotions at any perceived sign of their child's physiological recovery or downward spiral. Weiss and Fiester (2018) rightly note that children admitted to quaternary pediatric institutions, especially to the pediatric intensive care unit (PICU) or neonatal intensive care unit (NICU), tend to be those with complex disease and often include classic textbook pediatric illnesses. This might include hypoplastic left heart syndrome, respiratory syncytial virus, retinoblastoma, necrotizing enterocolitis, childhood leukemia, traumatic injury, or other pediatric anomalies (Ulrich 2017). "Longshot" treatments, or those that Weiss and Fiester (2018) define as interventions unlikely to benefit children but that conceivably could do so, provide a glimmer of hope for families when all other options fail. Weiss and Fiester further add that these "longshot" odds often transition through various stages until a "fantasy" stage is reached where the clinical team knows that there is no possible benefit to the child; further treatment only brings significant pain and suffering for not only the child and parent(s) but also the team members involved in implementing the designated intervention.

No parent wants to lose a child and endure the heartache and grief that comes with this loss; it is understandable that the first words nurses and physicians often hear parents utter in a crisis situation is to "do everything to save my child's life." Communication is absolutely essential at all stages of a child's trajectory of care. But as health care clinicians, we continue not to communicate well. Several studies point to communication problems that health care clinicians encounter with their patients and families, particularly at the end of life (Curtis et al. 2000). In fact, many barriers exist, as illustrated by the case exemplars outlined by Weiss and Fiester, and may include family misunderstanding about aggressive treatments, lack of clinician training and skills in end-of-life discussions, differences of opinion and

conflict regarding goals of care, and generalized discomfort with approaching families about end-of-life issues (Mack and Joffe 2014; Janvier, Barrington, and Farlow 2014).

Good communication, as Weiss and Fiester point out, needs to start well prior to reaching the “fantasy” stage where moral distress becomes an increasingly significant concern. Ideally, the clinicians who accept the patient transfer should have initiated conversations to explore parent hopes and goals, and to identify whether any previous discussions took place. Indeed, end-of-life scenarios continue to be cited as a root cause of moral distress, especially when discussions break down and there is a sense that unnecessary prolongation of suffering is an all too common and painful reality in the day-to-day care of seriously ill children. Moreover, palliative care is rarely introduced early enough in these settings, which may exacerbate communication gaps. As Nyborn and colleagues (2016) found among parents whose child died from cancer, “Frank disclosure fostered hope by relieving uncertainty and allowing them to make the best possible decisions for their children. Excessive optimism or a lack of information, in contrast, was sometimes experienced as a threat to hope and the parent–clinician relationship; and, a minority of parents were upset by clinician communication about prognosis” (626). Deficits in communication may stem from inadequate training, limited use of evidence-based standards, and reliance on “on-the-job-learning” (Feraco et al., 2016). Taken together, the absence of palliative care consultation and the known gaps in health care communication in life-threatening illness create an environment that can foster false hope and expectations in parents.

Weiss and Fiester’s steps for initiating discussions with families makes an important contribution to pediatric ethics and the overall goal of “collaborative communication” with families who are facing heart-wrenching decisions. In his essay on collaborative communication, Feudtner (2007) reports that this type of communication “emphasizes the relationships between people, viewing interpersonal communication and relationships as inexorably entwined” (584). He further outlines several goals of collaborative communication including but not limited to clarifying misunderstandings that might arise, collaboratively setting goals, and recognizing, respecting, and compassionately responding to differing perspectives.

In their structured approach to communication, Weiss and Fiester do not mention key elements of high-quality communication, such as language and tone. Parents with seriously ill children are filled with fear of the unknown, exhausted from the routines of a hospitalization, traumatized by images of ventilator support, drip lines, or other mechanical devices, and grieving the potential loss of their child. They are usually operating under extreme duress, physically (e.g., sleep deprivation; post-partum) and emotionally (grief, anger, etc.), all of which affect how they hear and absorb information. Communication with families not only should be tailored to the circumstances and stage, but should also take into account their baseline knowledge, expectations, health literacy, cultural circumstances, and capacity to receive and incorporate information, and should incorporate sensitivity and respect. More research on the aspects of communication that would be most helpful to parents, and research on the timing of sensitive and emotional discussions and how emotional stress influences informed understanding would be instructive. Tulsky and colleagues (2017) recently addressed the need for communication research with providers

and patients living with serious illness. Although pediatric communication was not their direct focus, communication issues are not unique to adult patients, and in fact, important nuances may exist in pediatric care, including the interactions between the child, parents, and the health care team.

Additionally, although the literature describes moral distress experienced by nurses, physicians, and other health care staff, we often fail to recognize, measure, and strategize about moral distress experienced by families. Weiss and Fiester do acknowledge that staff moral distress occurs. Parents, too, might recognize that there is nothing more that medicine can do to bring back their child, may also feel caught between what they perceive as provider recommendations and the suffering of their child, and they simply may not be able to bring themselves to ask for withdrawal of life-sustaining measures. Further, they might not know how to begin to ask questions related to end-of-life care services for their child, and any decisions they might be asked to make about limiting interventions or changing course may feel counter to their internal definition of “being a good parent” to their seriously ill child (Hinds et al. 2009). One important source of distress described by bereaved families is health care provider interactions with families around their decision making and their goals for their child (Mack et al., 2006). Attending to the stressful reality of these situations for both parents and health care providers requires a nuanced orientation that marries a relational, process-oriented approach and the functional assessment of when to initiate discussions. This is a hopeful path forward rooted in evidence already generated (Nyborn et al. 2016; Mack and Joffe 2014; Janvier, Barrington, and Farlow 2014).

Promoting an agenda to better understand the experience of moral distress in families, how they understand terminology in intensive situations, and what they find morally distressing in these situations is important. It may be that some of the root causes of family or parental moral distress are similar to those seen in clinicians—team communication issues, inconsistent messaging, inadequate pain management for the child, constraining institutional rules or policies, and disrespectful, demeaning, or dismissive physicians and nurses—leading to a breakdown in communication and further misunderstandings. Weiss and Fiester note that their structured approach to communication “helps to avoid not only inadvertent parental deception and false hope, but also the debilitating moral distress that the clinical team experiences when invasive care is continued without discussion of the changing clinical picture.” Better, more regularly structured and honest communication might also have an impact on the parent’s or family’s potential moral distress. While clinicians can experience moral distress from morally unfavorable circumstances while caring for patients and cumulative losses and suffering of their patients over time, parents with a child who is seriously ill or who dies find themselves in circumstances to which few others can relate. When a crisis occurs and a child is seriously ill, parents often suffer an existential crisis themselves, reliving those milestone moments in their child’s life and questioning their parenting skills or decisions that were made, wondering what they could have done differently or why God would allow for such pain and suffering.

Weiss and Fiester (2018) bring attention to the ethical challenges of pediatric care for seriously ill children, and broaden our thinking about ways to compassionately and respectfully incorporate parental preferences and goals into early and repeated discussions.

This is no easy feat for the physicians, nurses, and parents who want to see positive outcomes. But, incorporating meaningful engagement of and connection with parents (Feudtner 2007; Janvier, Barrington, and Farlow 2014) is an important step in improving end-of-life communication and potentially limiting the trauma families experience in the loss of a child. Weiss and Fiester (2018) offer tools to help make this a reality. ■

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