Advance Care Planning and End of Life

Maurice G. Sholas

The finality of death can be disruptive, destabilizing, and debilitating to the person told that they will prematurely succumb, but it also affects everyone in that individual's support network. This reality is especially prescient when the individual dying is a child. Pediatric advanced care planning is emotionally impactful, and a practice area very relevant to the ethics community practicing in pediatric care centers. It is also complex because the parents, the medical care team, and psychological development governs the child's ability to participate. The challenges around planning for the death of a child have caused barriers in communication between careproviders and families. It has led to moral distress in clinicians, dissatisfaction in the parents, and avoidance of that portion of the arc of care. Also, it is a driver of discord in the treatment care team. There is no way to make the loss of a child feel positive or pleasant. But there are methods to make that process focus on dignity, inclusivity, collaboration, and respect. This issue of the *Journal of Pediatric Ethics* reviews perspectives that encompass end-of-life planning and clinical scenarios, from birth to young adulthood. There are the perspectives of medical providers, clinical ethicists, and parents. Thus, this is an exploration of the arc of a painful process, which for some is unavoidable. It intends to serve as a starting point for continued research, commentary, and active reflection.

Historically, the will of the parents has been overrepresented in pediatric end-of-life scenarios when accommodating the family perspective. Through a sense of paternalism, some children were prevented from being a part of decisions that affect the end of their life because it was thought they were unable to adequately process the situation and constructively contribute. There is not a rigid boundary separating children who are capable of only assent from those who are capable of true consent. There is a range of ages and life experiences that make some minors at various ages mature enough to "act intentionally with understanding."[1] Other children have been excluded from the process through a sense of materialism that is driven by the desire of the parents and careproviders to protect children from distress and sadness. The worry is that there is nothing to be gained by informing children of the circumstances around the foreseen end of their life and the choices that have to be made in the wake of that reality. The adults involved feel this information may cause children to be less hopeful and to be left emotionally traumatized. That view is not supported by research, as the articles in this issue demonstrate. Thus, it is a challenge and often and ethical conundrum to modernize the role of the pediatric patient in end-of-life advanced care planning.

Maurice G. Sholas, MD, PhD, Guest Editor-In-Chief, is Principal, Sholas Medical Consulting, LLC, New Orleans, Louisiana. *SholasMedicalConsulting@gmail.com, www.DocMoSho.com*

As we look at the process of including children in advanced care planning, two natural poles emerge. On one end there are neonates. They are defined nearly exclusively through the lens of their family's narrative and the framework of expectations in the minds of their parents. Those children are the passive recipients of the processes chosen for them by their parents, who struggle to realize that death does not represent a "tragic flaw . . . like Icarus flying too close to the sun."[2] In those situations there is no way to divine children's wishes and incorporate them into planning. On the other end of the spectrum there are mature minors who develop the ability to process and participate in end-of-life planning. Research has found that there is a positive response by mature children included in end-of-life planning, with no evidence that "the discussion itself will take away the hope of parents and family members."[3] The sensitive but essential steps of advanced care planning for children must leave parents and families convinced there is a "sense of reverence [and]. . . . human respect."[4] And they must also be honest, gentle, and caring processes that include children in a manner that is consistent with their developmental capacity and autonomy.[5]

Advanced care planning and end-of-life discussions are the medical incarnation of the proverbial spirit that no one wishes to summon. But it is important that clinical ethicists and medical provider communities work proactively with families to dispel that trepidation. To make nearly unbearable circumstances humane, all must do the work that makes a "simultaneously heartbreaking and beautiful journey"[6] as empowering and inclusive as possible. Difficult work this is; but indispensable in a setting that requires it.

NOTES

1. J. Needle, M. Lyon, D. Brunqell, and C. Heith, "Mature Minors, Mature Decisions: Advance Care Planning for Adolescent Patients with Life-Limiting Illness," in this issue of the *Journal of Pediatric Ethics* 1, no. 3 (Spring 2020).

2. L. Freitag, "Parental 'Holding and Letting Go' in End-of-Life Decision Making in the Neonatal Intensive Care Unit," in this issue of the *Journal of Pediatric Ethics* 1, no. 3 (Spring 2020).

3. Needle, Lyon, Brunquell, and Heith, "Mature Minors, Mature Decisions," see note 1 above.

4. E. Beaudry, "Precious Life; Precious Loss ," in this issue of the *Journal of Pediatric Ethics* 1, no. 3 (Spring 2020).

5. A. Lanzel, "Children's Views on Death and Dying: An Overview and Ethical Focus on Advance Care Planning Communication with Children," in this issue of the *Journal of Pediatric Ethics* 1, no. 3 (Spring 2020).

6. K. Olavson, "The Most Difficult Decision We Ever Had to Make," in this issue of the *Journal of Pediatric Ethics* 1, no. 3 (Spring 2020).