



EVERYDAY ETHICS IN THE PICU: LIVING AND DYING IN THE “GRAY AREA”

Kristin Meade, MD

Haslinger Pediatric Palliative Care Division
kmeade@chmca.org

Sarah Friebert, MD

Director, A Palette of Care
Haslinger Pediatric Palliative Care Division
Akron Children's Hospital
sfriebert@chmca.org

Jacob is a 14 year-old boy with cerebral palsy and intellectual disability due to a history of extreme prematurity and intraventricular hemorrhage. He suffers from recurrent seizures requiring multiple medications. He is wheelchair-bound and requires full assistance with all activities of daily living. He has a VP shunt for hydrocephalus, a baclofen pump for treatment of spasticity, and a G-tube and Nissen due to severe dysphagia and reflux. Because of worsening obstructive apnea and restrictive lung disease from scoliosis, he has required BiPAP at night for the last year. He is unable to speak, but can vocalize, smile, and recognize people. Four years ago Jacob was placed in an institution because the family was unable to take care of his multiple needs at home; however, his family remains actively involved in his care. Over the last 3 years, he has required 5 intensive care unit (ICU) admissions for respiratory distress attributed to aspiration pneumonia, each requiring prolonged intubation. After each illness, his baseline status deteriorated slightly, but he was ultimately able to return to his facility. During his most recent hospitalization, multiple staff members voiced their distress related to Jacob's repeated admissions and the sense that the family was prolonging his suffering by choosing intubation and ICU-level care. On the other hand, the parents felt that his quality of life was still good enough between episodes to justify his admissions, and continued to pursue an aggressive plan of care. After a 4-week admission, Jacob was discharged back to his facility.

Cases like this one are ubiquitous in pediatric ICUs across the country. Each story has a different “flavor,” but the fundamental issues are the same; that is, what are the ethical principles related to the repeated use of aggressive, life-sustaining therapies in children with chronic, severe medical and/or developmental disabilities with a debatable baseline quality of life? While the extreme ethics cases capture the headlines and spur numerous contentious debates, cases like Jacob occur on such a regular basis as to feel almost routine. However, the ethical issues invoked can be some of the most difficult and distressing issues that medical providers face.

One of the unanticipated outcomes of the advancement of modern medicine is the dramatic increase in the prevalence of children with complex medical diseases and/or developmental disabilities over the last few decades, thanks in large part to the use of medical technology, complex multi-disciplinary care, and high-quality home nursing care.¹ A subset of these children is considered medically fragile, meaning that they have complex chronic, multi-system diseases that require medical technology and intermittent-to-continual care to assure their safety and manage their complex needs.² This population is often



characterized by their underlying medical instability and frequent utilization of acute medical care, ranging from clinic visits to inpatient admissions including ICU-level care.³ These patients often acquire the unfortunate label of “frequent fliers,” and their care is frequently a source of conflict within the ICU setting; disagreements are common, either between families and providers in relation to goals of care, or within the care team, in relation to the appropriateness of continuing or discontinuing aggressive care.⁴

Best Interest Standard

Unlike adult medicine, where the principles of autonomy and substituted judgment guide decision making, pediatrics relies almost solely on the principle of the best interest standard, which stipulates that all medical decisions made by surrogate decision makers reflect the best interest of that child. In almost all situations, this is a notoriously subjective decision. Decisions for patients like Jacob with severe, chronic medical and developmental disability, however, magnify this subjectivity. These are patients that often fill the “gray area” of decision making; two different, devoted, and loving caregivers could appropriately make opposite decisions in the same situation, as these decisions are based on a values judgment, taking into account quality of life, suffering, and moral obligations. Based on an inherent selection bias, patients in this “gray area” whose families choose to continue aggressive medical interventions are becoming an increasing presence in pediatric ICUs and inpatient units.⁵

Ambivalence and Moral Distress

With the continued improvement in available medical technologies, ambivalence related to the use of these treatments is a common dilemma faced by medical providers.⁶ While they may see the potential benefit of sustaining life through aggressive therapies and the use of medical technology, providers may also see the potential harm and suffering that comes from the use of these same treatments.⁷ Ambivalence, itself, does not lead to distress, but there is often significant overlap with moral distress, which has been defined as the distress felt when one has the impression that he or she is required to act against a core personal or ethical obligation based on an external force.⁸

Many studies of moral distress have documented that providers often feel tremendous anguish when providing care to children or adults in situations where they may feel that the treatment is overly aggressive, is merely prolonging suffering, and/or survival would lead to such a poor quality of life that death might be preferable.^{9,10} Few, if any, studies specifically address moral distress related to the repeated utilization of acute care for this specific population. Nevertheless, anecdotal evidence suggests that many medical providers feel significant distress when they feel obligated to provide aggressive care to children like Jacob repeatedly, even though the decision maker feels that this care is ethically and morally appropriate.

Added to the complexity of the decisions is the realization that, typically, ICU-level care is not fundamentally futile; that is, aggressive care will likely return that child to or close to his/her previous baseline. Conflicts, therefore, arise from a more nuanced ethical perspective: providers (or decision makers) may feel that the perceived suffering from an acute care admission is excessive given the patient's baseline quality of life and overall prognosis, or the acknowledgment that even if this child survives this hospitalization, he or she will likely return for the same or similar acute illness in the future.¹¹ The difficulty with this argument is that it places all of the weight on a subjective assessment of suffering and quality of life, risk and benefit. Who, then, defines quality of life? What degree of “quality” is worth



saving through aggressive therapies, and which is not? This issue is at the heart of most conflicts over goals of care related to this population.

Defining Suffering; Defining Quality of Life.

It goes without saying that there is no mutually agreed-upon definition of quality of life or suffering within the medical profession. Such subjective assessments are as varied as the staff themselves, having been shaped by moral beliefs and personal and professional experiences. Even within a person, assessments shift over time, altered by new experiences, both positive and negative. Variability in the subjective assessment of quality of life and suffering is expected and, in itself, is not a problem. However, an increasing body of literature suggests that these assessments do have a dramatic impact on the decisions surrogates will ultimately make.¹² As most deaths in the ICU (both pediatric and adult) now involve the active forgoing or discontinuation of aggressive medical interventions,¹³ physicians need to be acutely aware that their assessments and recommendations carry great weight.

Added to this inherent variability, medical providers often underestimate the quality of life of patients or their baseline functioning.¹⁴ An understanding of both of these dimensions is of utmost importance when setting goals, assisting in decision making, and determining appropriateness of forgoing or discontinuing aggressive life-sustaining therapies. Like Jacob, children in the ICU, by the mere fact that they are critically ill in the ICU, will not be at or near their baseline. This leads to the concern that providers may have a biased perspective on the appropriateness of medical interventions based on inaccurate information about a patient's baseline quality of life.

While the recommendations of the physicians and other staff may carry great weight, the final decision ultimately lies in the hands of the designated medical decision maker. There are extreme and rare situations where treatment (or non-treatment) is deemed to be either ethically obligatory or forbidden and a specific decision can legally be forced upon the decision maker. In reality, though, most medical decisions related to children with complex, chronic medical and developmental disabilities lie in the ethical "gray area." As long as medical decision makers can argue that a decision is ethically appropriate and is in the child's best interest, and there is no clear conflict of interest, medical providers are generally obligated to follow those wishes, even if they may disagree. Situations such as these often lead to conflict: in some, providers may feel strongly that suffering clearly outweighs any benefits and discontinuing aggressive treatment would be humane and selfless; in other situations, providers may feel that a decision maker is "giving up" on a child prematurely. In such unique and challenging situations, ethically appropriate decisions can still lead to great amounts of moral distress and conflict.

Coping with the Conflicts

Knowing that children like Jacob will likely become an even greater presence in acute care medical settings, it is of utmost importance that the medical community takes thoughtful and deliberate steps to address the ethical issues that have and will continue to surface. Systems need to be set up to allow providers to cope with their ethical distress in a positive and proactive way, in order to be able to respect and honor the rights of medical decision makers. This would include methods to insure effective communication amongst providers, so that the subtleties of goals of care discussions are shared with those who may not be privy to these discussions (particularly bedside nurses). Providers must be aware



of their own biases and be as objective as possible when guiding families through complex decision making.

Lastly, we need to create support networks for patients and decision makers, so that they can work through these complex decisions in sensitive, non-judgmental ways over time, appreciating that their decisions may shift based on the circumstances. Ideally, these discussions should occur prior to an acute illness, providing families with anticipatory guidance and educating them about the decisions they may ultimately face. Goal-directed advance care planning should be included in these discussions between families and their primary medical team(s) to clarify the patient's and family's wishes, as a proactive approach will not only be more beneficial to patients, but may also help to minimize moral distress among staff. Despite the best-laid plans, however, circumstances may dictate that such discussions take place in the ICU. When this occurs, interdisciplinary team conversations with patients and families, including the primary care provider(s), involved subspecialists, palliative care team, and ICU staff can result in improved adherence to goal-directed interventions and reduced suffering for all, including the care team(s).

Caring for this unique population carries with it both great challenges and great rewards. By being aware of the complex ethical underpinnings of the care provided to this population and finding ways to cope with the inevitable conflicts, we can maximize the rewards and minimize the challenges, in order to create a work culture that is both sustainable and meaningful.

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