

Clinical Challenges in Parental Expression of Hope and Miracles

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The concepts of hope and the medical miracle are ubiquitous in modern medical practice and can often become central aspects of a critically ill patient's or his family's hospital experience.¹⁻³ Cases where these beliefs are especially strong even make their way into mainstream media, as in the 2013 case of the California teen who became brain dead after a complication from a tonsillectomy. In this case, her family fought a widely publicized court battle to be able to keep her on mechanical support and move her out of state to another facility. They believed that, despite what was explained to them regarding the diagnosis of brain death, their daughter would one day recover.⁴ A high prevalence of spirituality within the American population serves as a foundation for expectations in miracles⁵ and pediatricians may frequently encounter similar ideas in conversations with families.

Despite all of the limitations in contemporary practice, physicians are acutely aware of the popular confidence in medical technology and the tendency for families to hope for outcomes that are medically unattainable. The unprecedented explosion of rapid medical advancement through the 20th century has helped to perpetuate the belief that technology has the ability to repair any affliction. With the advent of the mechanical ventilator and proliferation in its use from the 1960s to 1970s, it was suddenly possible to even prevent death. The new technology mandated the medical community to outline technical definitions of cardiac death and brain death, which is a debate that continues today.⁶ To the layperson, this and other examples of modern medical sophistication illustrate our ability to achieve seemingly impossible outcomes. To a more religiously prescribed individual, these achievements may be attributed to the divine.

Although attestations of hope for a miracle and the healing power of prayer are common themes in the narrative of many families, many young clinicians admit that current medical school education does not leave one adequately prepared to deal with the unique challenges that accompany these notions.⁷ These include, but are not limited to, how to effectively communicate with a family who expresses hope for an outcome that seems improbable, how to successfully integrate care for the child with caring for her family, how to proceed when a family insists on prolonging care in hopes of a miraculous recovery, what families mean by the word

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“miracle,” and how to come to terms with broad social misperceptions of what medicine can realistically achieve. Failure to effectively manage these issues can often lead to strife and subsequent ethical dilemmas and consultations.

Pediatricians may experience reluctance in conveying what they regard as “brutal honesty” in fear that by doing so they may extinguish the hopes of, and consequently lose rapport with, families of the children they are treating. This situation may lead to a certain degree of silence regarding the true prognosis for fear that the family will view them as “giving up” on the child or even as medically incompetent if they are overly pessimistic. But before attempting to successfully navigate the realm of preserving hope within prognostic discussions, an understanding of the complexity of hope is needed. Hope is not a homogenous notion but takes many forms and is unique to individuals. It is also not static but evolves as circumstances change. William Ruddick describes one of the most basic types of hope as being “vital” by defining a person and shaping his life.⁸ This “vital hope,” if lost, plummets the person into crisis and forces him to subsequently seek out new hopes, “survival hopes,” to be able to continue a meaningful life. An example of a “vital hope” is a person’s child. When a child is nearing death, one possible response of a parent facing this loss is to begin to seek out and express strong survival hopes, such as for a “miracle.” Physicians often hear illustrations of this in the PICUs and NICUs: “God will heal my child”; “We’re praying for a miracle”; “My child is a fighter. Your prognosis is wrong. He will walk out of here.”

Although experience and practice make these interactions easier, even clinicians without much previous involvement in similar cases can affirm hopes for recovery or cure while still conveying medical

information that does not gloss over the gravity of a given situation. In medicine, practitioners often base their hopes on probabilities. When the probability of a good outcome becomes exceedingly low, any hope they had for their patient is often lost. It is then natural to feel that in relaying a poor prognosis, they will also take away whatever hopes the family had remaining. Ruddick also points out, however, that unlike medical professionals, families often base their hopes in possibilities rather than probabilities. In this sense, no matter how terrible the prediction of outcome, hope can abide. This belief does not conflict with natural science, but rather acknowledges the vast limitations of our own scientific knowledge.

In caring for critical patients, physicians may experience instances of trepidation over continuing aggressive treatment of a child who is near death because the family insists on it. They often feel as if they are prolonging suffering because of a continuing hope for a “miracle.” Practitioners sense that the child becomes devalued as his own moral agent for the sake of the family, with the definition of “the patient” often becoming increasingly ambiguous. It can become difficult, then, to continue to build a relationship that promotes shared decision-making and parental autonomy. This situation is especially true when our own ideas of spirituality and those of the family are dissimilar. We can feel obliged to accommodate to a family’s unrealistic demands and become unfulfilled professionally and personally.

As pediatricians, we must be cognizant that we are often, if not always, treating a family unit as opposed to only the child.⁹ Consequently, we must navigate the complex relationship between the pediatric patient, his family, and ourselves. If the doctor-family relationship is viewed in this light, our obligation can gain clarity. When

a family states they are hoping for a miracle, we can redirect focus toward smaller, more realistically attainable goals without overtly dismissing their hope for outcomes we likely cannot effectuate. Families invariably have specific wishes and goals for improving their child’s condition, such as better pain control, lightening of sedation for improved meaningful interaction, or relief of discomfort from symptoms such as excessive secretions or nausea. In these instances, the involvement of a palliative care team may be useful, even if the family does not wish to de-escalate care. By focusing on what we can improve, we can reconcile our role in the treatment of the child and the family while maintaining the balance of beneficence in medical practice and parental autonomy.

In working through these complex challenges thoughtfully and maintaining the notion that we are not always correct in our prognostications, we can gain insight to and become comfortable in interactions with families who hope for miraculous outcomes. Facing the death of a child not only overtakes a family at that moment but also becomes a part of their lifelong identities. By striving to gain a deeper understanding of where each family is coming from, we can more successfully coexist with their hopes and beliefs while working productively to attain smaller goals to satisfy the patient, his family, and, importantly, ourselves.

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