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The Morality of Medical Miracles: Ethical Reflections on Pediatric Oncology

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INTRODUCTION

Pediatric oncology is characterized by challenging decision making. At the time of diagnosis, the family is new to the revealed cancer, strangers to the pediatric oncologist and team who will be providing care, and loathe to face a situation in which urgent action is required, even if the long-term prognosis is favorable. When pediatric cancer relapses, the family and clinicians are usually in an established, trusting relationship, but they must now confront the fact that the original treatment has failed and the possibility that the cancer may now be fatal. These individuals – clinicians, parents, and child – must choose from among the treatments available at each stage of the disease. As Dr. R. put it, "at this point in the journey toward wellness, there is no ethical consensus about how they should collaborate in the process, and this further complicates an already complicated matter."

In my experience, some of most challenging ethical issues arise in the context of medical miracles. When a patient is acutely ill or dying, and the family expects a miraculous recovery from cancer or another life-threatening illness, the situation is frequently very challenging for clinicians, particularly when there is certainty from the family that the miracle will occur through divine intervention. When I was paged early Monday morning for an ethics consultation, this is exactly what Dr. R. was facing. His patient, Jeremiah, a two year old with lateral ocular melanoma (cancer of both right and left eyes) was approximately one week away from losing his vision permanently. The family was refusing treatment – which included a chemotherapy regimen proven to be successful in nearly 90% of pediatric patients – voicing that "if God wants our child to see, God will cure him. No extra treatment is necessary." They believed that pursuing aggressive medical treatment for their son's ocular cancer contradicted their faith in an all-powerful God. If there was something "less invasive than chemotherapy," they "would gladly consent. But we cannot lose sight of our faith. We believe in miracles, and we are going to wait for one."

ETHICS AND THE MIRACULOUS

Dr. R. shared my fear: even if this case went to court, and the parents were removed as decision makers for this particular treatment, it might be too late to salvage Jeremiah's vision. We needed a practical approach – and fast. I set up a second family meeting two days later to explore once more the medically appropriate options with the family in a balanced, non-argumentative manner. I was able to identify the meaning and significance of a miracle to the family. Doing so, I knew, would not only enable me to have a full sense of what Dr. R. was dealing with, and thus to inform a response to the family, but it also would provide an effective, non-confrontational way to begin the discussion. Further, I suggested to Dr. R. that by listening to the family first, he would convey a necessary sincerity about ascertaining the family's perspectives as well as respecting their beliefs.

The information provided in the initial conversation with the family enabled me to frame the agenda for the second meeting. It was important for Dr. R. to understand from the start that

little would be gained from trying to directly challenge the family's beliefs. "I can't believe they are doing this. It's preposterous! These are foolish beliefs, and they should recognize that before they attempt to blind this child." Dr. R.'s frustration was understandable but ultimately unhelpful. I suggested that we only respond to the family's concerns, not their beliefs or emotions. This was the only reasonable and responsible path to take. Contrarily, in arguing the validity of the family's belief, Dr. R. would only alienate them. I reminded Dr. R. that we frequently celebrate the convictions of our military veterans to die for their beliefs, and that this family was no less moral simply because their beliefs were estranged from the norm. Underlying my claim, however, was a follow-up ethical qualification: while we each have the right to make martyrs of ourselves, we do not have the right to make martyrs of others.

MIRACLES IN BIOMEDICINE: A PRACTICAL APPROACH TO THE FAMILY

I framed the meeting according to a fourfold approach: (1) emphasize nonabandonment; (2) cite professional obligations; (3) reframe the meaning and manifestation of the miracle; and (4) suggest that if a miracle is to occur, clinicians' actions would not prevent it. Regarding the first point, I ensured from the outset that, regardless of their value system, we would not abandon the Mom, Dad, or Jeremiah. One of the things patients and their loved ones fear when illness approaches is isolation and abandonment. This family therefore needed to know that the care team would be attentive to the needs and comfort of Jeremiah, and that their well-being would not be ignored. Of secondary importance was citing our professional obligations to Jeremiah and the family. Just as it is important for the care team to hear the family's perspective, it is also necessary for the family to appreciate the motivations and professional obligations of the clinicians involved in Jeremiah's care. When deciding to initiate, withdraw, or forego a particular treatment, the family must understand that the clinical team is required to determine whether the treatment is medically appropriate or effective.

Of tertiary importance was reframing the meaning and manifestation of the miracle. With care about and sensitivity to the family's broader story, I suggested that the miracle may have already occurred, or may occur in some other way. I asked, "Is there anything that's already happened through all of this that has been amazing or wondrous, like a kind of miracle?" The family shared that bitterly estranged family members were brought together over Jeremiah's ocular cancer, and, to everyone's astonishment, were able to reconcile. I went on to suggest that the available, highly-effective, proportionate medical treatment for Jeremiah may be a miracle in its own right. Of final importance was my suggestion that, if a miracle would occur, nothing that the clinical team would do could prevent it. For Jeremiah's family, whose worldview included an all-powerful, sovereign God, it was convincing that if it was truly God's will that a miraculous healing occur, then there is nothing human beings could do to prevent it – even in pursuit of chemotherapy. Thus, as the clinical team did what was expected of them, the family could go forward with the assurance that God would not allow the divine will to be thwarted.

MORAL OF THE STORY

By the end of our meeting, the family was comforted and assured that, in pursuing medical treatment, they were cooperating with God rather than betraying their Creator. Soon thereafter, Jeremiah would begin his chemotherapy regimen. The family's initial fear – that

science might fly in the face of their faith – was tempered by a reasonable and compassionate approach to thinking about these major issues, piece by piece.

The implications of Jeremiah's case are significant. The successful application of an approach for redirecting a family expecting a miracle must occur against the backdrop of continuous clinical efforts at establishing, encouraging, and sustaining the trust of the family. Clinical teams should not assume trust, but rather demonstrate over time that they are worthy of trust. The indispensable education I received from Jeremiah and his family gets at the heart of bioethics: that trust can thrive only when the communication is goal-oriented, patient-centered, understandable, jargon-free, truthful, honest, timely, and consistent.