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CASE AND COMMENTARY

Faith-Based Decisions: Parents Who Refuse Appropriate Care for Their Children, Commentary 2

Commentary by William E. Novotny, MD and Ronald M. Perkin, MD, MA

Case

Adam Lovell, an active 2 ½ -year-old boy, was healthy until the day his parents took him to the local emergency department for vomiting and a suspected case of acute gastroenteritis. To the physicians, Adam appeared lethargic and was responsive only to painful stimulus. A blood culture was obtained, and other laboratory tests were performed. The blood culture later grew a meningococcus. Within hours "purple splotches" appeared on his face, legs, and trunk. Adam was diagnosed with meningococcemia and was started on appropriate antibiotics and steroids administered intravenously. Adam was intubated to stabilize his airway and transported to the County Memorial Hospital. On arrival, his perfusion was poor and blood pressure low. The tips of all his digits were dark blue; purpura (purple splotches) were present over most of his trunk, feet, and hands in a "stocking-glove" distribution. Intravenous fluid boluses and vasoactive drug infusions were administered. Adam's parents consented to multiple blood component therapy to treat a coagulopathy. Adam was also treated for respiratory failure related to meningococcal sepsis with both conventional and high frequency mechanical ventilation for the first 11 days of hospitalization.

At 10 days, Adam had well demarcated patches of dry, devitalized tissue (dry gangrene) on both of his feet, his left hand, and the fingers of his right hand. An eschar was present on the posterior surface of his right thigh. Ulcerated areas of skin were present in the perineal region. Consulting surgeons talked to his parents about the risks, benefits, and alternatives of amputation and debridement of portions of both of Adam's feet, his left hand, and the fingers of his right hand. The Lovells consented to the debridement and surgical treatment and signed the consent form. Shortly thereafter the family's minister came to the hospital and prayed with Adam's parents for God to restore life to the devitalized tissues. Soon afterward, the Lovells rescinded consent to surgical treatment and communicated that they wished to allow time to elapse so that God could heal Adam's dead and injured tissues. When the physician and the surgeon told Adam's parents that infection and sepsis would be inevitable without treatment, they agreed verbally that, in the event of sepsis, amputation should be performed.

Over the ensuing 2 ½ weeks, physicians met with the Lovells and vigorously attempted to persuade them to proceed with Adam's amputation and debridement of

dead tissues. Mr. and Mrs. Lovell remained adamant that an expectant approach be maintained. During this time neither sepsis nor wet gangrene, which would have offered absolute indication for surgical intervention, occurred. Despite the best efforts of the family and staff, many hours elapsed where Adam remained quiet and alone in his bed. He would cry and appeared to be sad. At times he cried out "hand" while gazing at his outstretched and mummified hands. During visits, the Lovells read the Bible to Adam and assured him that God would direct his hands and feet to re-grow. The Lovells asserted to the staff that Jesus had arisen from the dead and shown himself to believers, and that God would revitalize Adam's dead tissues. Both family-associated and hospital-based clergy were regularly present to expand opportunities for mutual understanding of religious and medical issues. Adam's parents were repeatedly confronted with the ever-present and increasingly imminent reality that Adam needed amputations to prevent new onset of sepsis and to avoid possible death from sepsis.

After almost a month in the pediatric intensive care unit, Adam began to experience fevers and his white blood cell counts increased; both signs were indicative of developing infection. Therapy with topical and systemic antibiotics was continued and modified. His parents were informed of the changes and of the increasing need to consent to surgical therapy. In an effort to reinforce the inescapable need for surgical therapy, the physicians consulted with a burn surgeon at a neighboring institution by telemedicine. The surgeon confirmed that amputation was unavoidable. These communications were shared with the Lovells, who nevertheless, were not dissuaded from insisting upon further observation. Despite considerable effort to understand and support the parents by their own family members, by the medical staff, by social service, by psychology and by clergy (hospital and family), a clear impasse had been reached. The Division of Social Services (DSS) was engaged to evaluate the case for a possible claim of medical neglect against Adam's parents. With the possibility of the child's custody being assumed by DSS, the parents signed consent for amputation and debridement. The mother signed consent because "only death would take my baby from me." The family requested that a "hands-on" surgical evaluation be performed at another medical facility. This request was granted. Expedited transfer was made, surgical intervention was deemed necessary by the receiving surgeon and amputation and debridement followed within 2 days.

Commentary 2

The validity of parental consent for children has been taken for granted even though the presumption that parents invariably choose in their child's best interest may at times be inaccurate. Rights are virtually never absolute and parents are not at liberty to destroy, maim, or neglect their children. Similarly, by societal convention, health care choices available to parents are not unlimited. Parents are restricted to choices that conform to societal norms. It has been suggested that parents might refuse a medical recommendation for at least 3 categories of reasons: neglect, disagreement based upon religious or other values, or inability to comply.[1] By this categorization the parents of the child discussed in the case report were neither neglectful nor

unable to comply. Clearly there was disagreement based upon religious beliefs. In 1977 Ruth Macklin wrote "Freedom of religion does not include the right to act in a manner that will result in harm or death to another."[2]

Another view, voiced by Peter Rosen, is that "whether…(the guardians)…are sincere, sane, and in every other capacity model parents, their insistence upon treatment that is scientifically inferior to conventionally accepted treatment is abusive, even if their intent is not."[3] The *American Academy of Pediatrics* recognizes the "important role of religion in the personal, spiritual, and social lives of many individuals and cautions physicians and other health care professionals to avoid unnecessary polarization when conflict over religious practices arise. Nevertheless, physicians who believe that parental religious convictions interfere with appropriate medical care that is likely to prevent substantial harm or suffering or death should request court authorization to override parental authority or, under circumstances involving an imminent threat or a child's life, intervene over parental objections."[4] In the case at hand, the health care team had unanimity of opinion regarding the fact that delaying surgical intervention was scientifically inferior and inadequate. The question that ultimately proved most challenging to answer was the point in time when the parental choice became unacceptable.

Surgical recommendation to perform amputation was initially made at 10 days into the hospitalization. The parents were repeatedly and vigorously apprised that delay in surgery might result in the need for more extensive amputations, other organ system morbidity, or even death secondary to sepsis. Surgical therapy was provisionally refused, and this refusal was accepted by the health care team. This refusal of surgical intervention was followed by efforts to further discuss and understand religious issues, provide parents with surgical opinion from another health care center, and continue to meet the daily health care needs of the child. In the absence of "hard-data" in the literature that addressed the medical/surgical/ rehabilitative outcomes of children with gangrenous extremities treated in an expectant manner, "common-sense health care assessment" by the health care team did weigh progressively toward limiting further procrastination for the performance of surgical therapy. The hope that further discussion might persuade the parents of the need for surgical intervention faded with time. The increasing threat of sepsis mandated that child protective services be involved to evaluate for "medical neglect" or that the court be directly petitioned to hold a hearing to evaluate the need for surgery. The US Supreme Court in *Prince vs Commonwealth of Massachusetts* has determined that parents do not have the right to expose children to ill health or death in the course of their own expression of religion.[5]

The proposition that it is inappropriate for strangers (nonfamily) to be part of the agonizing treat-or-let-be decisions ignores the reality that a diligent and skillful health care team is initially more objective and later more intimately acquainted with the health care needs of the child. Particularly in the critical care environment, though the health care team begins as only a team of objective strangers, its members evolve into loving and informed allies who act from a sense of both duty

and beneficence. The perspective of the health care team is unique, intimate and important. The voice of its members needs to be heard in a court of law after concerted effort over time to understand and educate both the parents and the health care team has failed to resolve fundamental issues regarding care.

References

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William E. Novotny, MD is an associate professor of pediatrics in the Pediatric Critical Care Department at the Brody School of Medicine at East Carolina University.

Ronald M. Perkin, MD, MA is a professor in and chairman of the Department of Pediatrics at the Brody School of Medicine at East Carolina University as well as the medical director of the University Health Systems of Eastern Carolina Children's Hospital.

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