

Clinical Cases

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

Physicians need to understand the resources available to them to serve the sometimes conflicting needs of the pediatric patients' best interest and the religious beliefs of the patients' parents.

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

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 meningococemia 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 Soon afterward, the Lovells rescinded consent to surgical treatment and communicated that they wished to allow time to elapse so that God could heal Adam's dead and injured tissues.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 1

by Robert D. Orr, MD,CM

This case involves parental refusal/postponement of medically needed therapy based on a religious belief in miracles. The postponement resulted in increased patient suffering, prolonged hospital stay, and increased expense.

This case highlights potential tensions between 3 very important societal values: (a) parental responsibility and discretion; (b) professional and societal protection of vulnerable children; and (c) freedom of religion. Sometimes the outworking of such tensions leads to trade-offs, frustration, and the transition from a professional relationship that is collegial to one that is adversarial.

Parents are the natural guardians and stewards of their children. That stewardship entails a responsibility to seek the best interests of those children. Society allows parents rather wide latitude in raising and caring for their children, including societal nonintervention in situations which are potentially detrimental to those children (eg, matters of diet, lifestyle, activities, discipline). Our society is willing to step in and override parental authority, via child protective agencies, only when parental decisions involve abuse or neglect, including medical neglect.

Health care professionals shoulder a large part of the societal obligation to protect vulnerable children from medical neglect. When professionals identify a child who faces danger of death or disability because of parents' decisions, actions, or inactions, they are obligated by professional standards and mandated by state law to report the situation to the proper authorities. Those authorities will investigate and will often petition a court to determine whether the situation warrants removal of parental custody. In rare situations of imminent danger to the child, it is ethically justified for health care professionals to proceed with life-saving procedures over parental objections as the report is being made.

While making such reports is never pleasant, professionals are almost always willing to do so when a child is endangered because his or her parents demonstrate lack of understanding or lack of caring. It is distinctly more uncomfortable for them to report parents who clearly care for their children but hold personal, cultural or religious values that are at odds with those of the medical community [1,2]. There is a wide consensus in the medical profession and in the courts that even caring parents should not be allowed to refuse life- or limb-saving medications, transfusions, or procedures. Major difficulty often arises, however, in determining when the prognosis is sufficiently grave to warrant judicial intervention.

When parents hold a religious belief that leads them to refuse treatment for a child, at least 2 levels of understanding are needed in an effort to reach agreement. The parents need to understand the clinical situation as clearly as possible. This may sometimes be facilitated or augmented by obtaining a second (or third) opinion. It is ethically permissible to try to persuade the parents using honest facts and clear opinions, though it could be perceived as harassment if attempts at persuasion are frequent or authoritarian.

In addition, the health care professionals need to understand the religious belief as clearly as possible. These beliefs may sometimes be well understood and clearly articulated by the parents. It is often helpful, however, to involve a "religious translator" in the conversation, ie, a chaplain or perhaps another person from the parents' own faith tradition, and preferably a person with some depth of education and position of authority. One reason for utilizing such a resource person is that parents (or anyone) may sometimes focus on one religious tenet while ignoring a balancing tenet; eg, waiting for a miracle versus an obligation to preserve life and relieve suffering. A more objective look at the entire faith tradition may sometimes allow parents the freedom to consent to procedures without feeling they have abandoned the teachings of their faith.

In this case, the parents seem to have been influenced in their refusal of surgery by their minister. The medical professionals honored their request and negotiated an agreement that specific signs would trigger surgery. Over the next 2 1/2 weeks, while the child was stable, they attempted to persuade the parents. Clergy from the hospital and from the family were "regularly present to expand opportunities for mutual understanding of religious and medical issues." The narrative does not indicate the tone or content of these conversations. Neither does it mention the denominational affiliation of this family. Consultation could have been sought with other ministers from that tradition, or other persons of religious authority, to see if this family, and especially this minister, were following all the tenets of the faith or whether they held disproportionately to one tenet over another.

In the face of an insurmountable impasse and signs of clinical deterioration, the professionals correctly sought another clinical opinion. It was probably wise to seek that opinion from outside the institution because families sometimes feel "everybody here is against us" in these situations. When the urgency of the need for surgery was confirmed, they very appropriately involved the child protective agency. This threat convinced the parents to consent to life-saving surgery after involvement of yet another consultant.

From a purely medical perspective, this child's best interests could have been better served if the parents' original consent had not been withdrawn and the subsequent 2-3 week wait in the pediatric ICU and concomitant additional suffering had been avoided. From a purely religious perspective, the best interests of this family were better served by honoring parental beliefs and waiting for clarity about medical urgency. The professionals involved are to be commended for seeking compromise, and in ultimately doing their best to honor both of their obligations: to protect human life and to respect persons with differing beliefs.

Post-Script: It is easy to look back on this case critically and say "Miracles don't happen. Belief in miracles is irrational and should not be honored." Miraculous events in medicine are exceedingly rare, and are, by definition, unexplainable. However, we should not write off individuals merely because they profess belief in miracles. At the same time, medical professionals (and hospital public relations staff) should avoid using such terms as "miracle drug," miraculous outcomes, etc. Such incorrect usage trivializes an important element found in many faith traditions.

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Commentary 2

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

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.

*Adam Lovell is not the patient's real name and is used to protect the patient's privacy.

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