

ETHICS

ETHICS IN ACTION

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A 19-year-old mother presents with her 12-day-old daughter. According to the mother, the child “doesn’t act right.” The delivery was at a different hospital, and the mother does not know if she had Group B strep. The child is fussy and has a rectal temp of 39.1 C. You explain your concern about possible sepsis to the mother and tell her that her daughter will need to have blood drawn, be catheterized for urine, and have a lumbar puncture for cerebrospinal fluid analysis, and that she will need to be admitted and started on antibiotics. The mother tells you she doesn’t think the child is that ill and refuses all care, and states her intent to take the child home. Several people, including the resident physician, attending physician, nurse, social worker, and inpatient pediatric attending all try to explain to her the very serious risk of infection in the child, and the risk of death or permanent disability should they leave. The mother is adamantly refusing all intervention, including options such as treating and admitting the child but deferring the lumbar puncture. She is bundling the child up and preparing to leave. What should you do?

It is generally accepted, on both legal and ethical principles, that parents have a right to make decisions regarding the medical care of their minor children. However, this right must be closely balanced with the need for beneficence, to ensure that the child’s best interests and health are being protected, given that children, due to their inability to make decisions for themselves, are considered a vulnerable population. In order to permit parents as much freedom as possible to fill their parental role as they see fit, society allows great latitude in decision-making, even in instances where the decisions may be detrimental to the child’s health (including in areas of diet, obesity, discipline, and vaccination), requiring intervention only in cases of clear neglect or imminent harm to the child. This situation naturally sets up occasional tensions between parental discretion and society’s obligation to protect the well-being of children.

Health care professionals comprise one of the social institutions specifically charged with serving as advocates for a child’s well being. Every state has mandatory reporting laws for suspected cases of abuse or neglect. While most providers are more than willing to deal with the inevitable confrontation with parents that reporting causes in the context of clear abuse or neglect, it becomes much less appealing when the parent(s) are jeopardizing the child’s health not through callous indifference but due to either a lack of understanding of the seriousness of the medical issues or religious beliefs concerning medical care.

The largest number of legal cases have revolved around religious beliefs that conflict with medical care, and the courts have generally held that parents cannot withhold life- or limb-saving treatment for their child. In less serious matters, the courts have generally allowed much more latitude.

From an ethical perspective, while respect for autonomy (in this case, of the parent(s)) is always a primary goal, our duty here is not to the parent, but to the child. While the majority of these febrile neonates do not have serious bacterial infections, the incidence is high enough that treatment of the child for an SBI is the most appropriate course of action, clinically and ethically. Many parents are concerned about the pain and suffering of their child resulting from medical interventions, and reassurance and steps to minimize discomfort, such as use of local anesthesia, can be offered. While not clinically ideal, even forgoing a certain portion of the diagnostic process (such as a lumbar puncture) but still admitting and treating the child may be a reasonable compromise with a concerned but objecting parent. Refusal of any care in this case amounts to endangering the child, and the principle of beneficence applies: the parents should not be allowed to refuse life- or limb-saving care for their child.

In this case specifically, it appears that the parent did not appreciate the potential seriousness of the issue. This makes an argument about truly informed refusal difficult. When the parent(s) seem to lack understanding or insight into the severity of illness and proposed treatment, that complicates any refusal of care on their part and should prompt a multidisciplinary effort to ensure that the best decision is reached for the well-being of the child while still respecting parental autonomy. However, in the end, we have both an ethical, and, in every state, a legal obligation in this case to ensure that the child receives the potentially life-saving treatment she needs.

In summary, this case presents a not-infrequently encountered issue of parental refusal of care for their child. Legally and ethically, parents are allowed a great deal of discretion, including making decisions for their children that may not be in the child’s best interest but is not causing immediate harm. However, in a case such as this, where the parental refusal of care can result in serious consequences to the life and well-being of the child, the health care provider needs to act in the best interests of the child, even if that runs counter to parental wishes, and involve the proper agencies if needed to protect the child. ▀

