Panel Discussion

End-of-Life Issues at the Beginning of Life

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End-of-Life Issues in Pediatric Patients

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Abstract:

Dealing with end-of-life issues in pediatric patients is difficult due to their young age, the complexities of situations leading to illness, and the multiple decision makers that exist in addition to parents and guardians. Pediatric patients do not have living wills addressing specific instructions for how long to continue life support systems such as a ventilator or a G-tube (gastrostomy tube for feeding). The dying pediatric patient also has typically not consented to organ donation either. The burden of decision making lies with the parents, guardians, and health-care providers of the dying child. This paper deals with these complexities and reflects the author's own experiences over nearly four decades of dealing with pediatric patients in her practice.

Key words: Informed consent, end-of-life care, do not resuscitate (DNR), brain death, cardiac death, organ donation.

When a terminally ill or critically ill pediatric patient is admitted to a neonatal or pediatric intensive care unit (NICU or PICU), it is important that the primary care doctor continue to be the connecting link between the patient, family, subspecialists, and other health-care providers.

The health-care team, of course, should care for the child and family with an enormous amount of empathy and compassion. The team should have many "care conferences" with the family, wherein all the facts about the patient's serious illness and critical health are explained in detail to the family. These conferences should occur at each stage of the child's illness to better prepare the family for what may be a difficult outcome.

It is vital that the ethnicity and religious preference of the pediatric patient be identified. If there is a language barrier between the health-care providers and the patient's family, an interpreter's help should be sought to ensure proper care management.

Informed consent for procedures such as a tracheostomy and insertion of a gastrostomy tube must be obtained from the family or legal guardian and a review of the possible complications related to these procedures must be shared. Again, if there is a language barrier, the assistance of an interpreter should be utilized to ensure that the family or legal guardian is fully apprised of the situation.

Informed consent is also needed from a parent or guardian for withdrawal of life-sustaining treatment such as hydration, nutrition, ventilator support, and for "do not resuscitate" (DNR) orders.[1] When the health-care provider recognizes the futility of a treatment -- for example continuing invasive measures to save life in cases such as asphyxiating thoracic dystrophy, where there is a small thorax, and hypoplastic or poorly developed lungs -- the health-care provider must inform the patient's family or legal guardian of the poor prognosis for life, even with continued ventilator treatment or life-saving measures.[1]

When dealing with cases such as trisomy 13, trisomy 18, and anencephaly, the health-care provider must clearly explain the patient's poor prognosis for life and functioning to the family or legal guardian, and they must decide for themselves as to the future management of their child.[1] The health-care team must continue to be very supportive of the family or legal guardian's decision, whatever it may be.

It is the author's experience, when given all the facts, the family members or the legal guardian are usually able to make the right choice for further management of their child. They, like the health-care provider, would like to make the child's final journey as pain free and comfortable as possible and often choose not to prolong the child's suffering by keeping the child on a ventilator. Parents and family

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can also suffer immensely by seeing their child on a ventilator for prolonged periods of time.[1] Acceptance of a DNR order is easier when parents are given all the facts about their child's poor prognosis for life or functioning, depending upon the severity of the cases discussed above.[1]

In some cases when parents are perhaps responsible for the child's injury, such as in shaken baby syndrome, which leads to brain hemorrhage, blindness, and death in some cases; severe burns; or even drowning due to lack of supervision or abuse, the parent or guardian will not accept the DNR order or have the child taken off the ventilator, even if the child is already brain dead or has a poor chance to live. Parents, family members, and legal guardians in such circumstances refuse to accept the futility of treatment as they are afraid of the consequences and implications when the child is pronounced dead.[2-4]

In such cases a great deal of time has to be spent with the pediatric patient's parents, family members, or legal guardian to explain the poor prognosis, even if all the supportive treatment for life is continued. Such interactions will involve the entire health-care team, legal services, and even religious leaders and clerics such as a priest, chaplain, imam, or rabbi to help the family understand the prognosis and make the best choice or decision on behalf of the dying child.[4]

Religious leaders or clerics can offer comfort to the parents of the dying child, assist the child in the PICU or NICU, and perform last rights. When life-sustaining treatment is removed, the religious leader or cleric can recite prayers or the "shahada" in the ears of a dying Muslim child. This is comforting to distraught parents and family members who are agonizing over the death of their precious child.

Organ donation is still a controversial topic for families of different faiths. In general, most families are not comfortable dealing with the topic of organ donation at the time the child is dying. On rare occasions, a family may realize their dying child could give life and good health to another child and actively seek to allow for the child's organ donation.

Organ donation is still a rarity, although several pediatric centers are actively pursuing organ donation after cardiac death (DCD), when cardiopulmonary functions have stopped, especially for the purpose of kidney donation. Many controversies and issues are involved with organ donation in relation to brain death, i.e. when the cortical and brain stem functions have clinically ceased. Dialogue regarding this will continue to evolve in the future.[5-7]

Conclusion

Dealing with a dying pediatric patient and comforting the grief-stricken family is a very difficult task for physicians and health-care professionals. It requires a team of concerned physicians, primary care physicians, specialists, nurses, case managers, interpreters, social workers, legal services, and religious leaders to provide optimum care to the dying patient and his or her family.

Great professional skills along with compassion, empathy, counseling, and support are essential ingredients to the successful management of the end-of-life dilemmas of pediatric patients.

Muslim families find comfort in the Holy Qur'an, which states:

> It is He who gives life and death and when He
> decides upon an affair, He says to it; be it and
> it is.[8]

Another Qur'anic verse states:

> No soul can die except by God's permission,
> the term being fixed by writing.[9]

When a child dies, parents and families of the departed child find comfort in each other, friends, and health-care providers. Yet, their religion may provide the most comfort. They seek the ultimate strength from their faith in order to deal with the child's situation and move on. Muslims believe that this life is temporary and there is a hereafter. In situations of a child's death, it is this belief that is most comforting to a Muslim family.

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