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SUFFER THE LITTLE CHILDREN

Doctors and patients have come to expect a cure for most every illness and condition. Unfortunately for both groups, this is not always possible. When faced with the prospect of the imminent death of a patient, doctors may exhibit curative attitudes and perform interventions which may not be in the best interest of the patient. Referral to palliative care may become the only appropriate avenue of treatment, yet it may never be offered. Nowhere is this seen more clearly than in the treatment of a dying child. The lack of healing services provided to terminally ill children is alarming. This dearth of pediatric palliative care stems from the history of palliative care, societal attitudes about dying children, the current standard of medical education, the limited experience of pediatricians with death, and the issues of required parental consent. These factors cumulatively affect the interactions between doctors, parents and children faced with a terminal illness.

The World Health Organization has defined pediatric palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and families (1)." Contemporary society is obsessed with curative treatment. The last one hundred years have seen a dramatic increase in medical technology. Many once-fatal diseases are now mere inconveniences and science has given doctors incredible tools to eradicate illness and death. With respect to children, world mortality rates have been declining steadily. The chance of a newborn dying before its fifth birthday is seven percent, down from 25 percent in 1950 (2). This decrease is due largely to advances like pre-natal care, antibiotics, immunizations, and surgical repair of anomalies.

Before the many scientific advances, a physician's role was fundamentally different. Without the many curative measures that we have today, death was much more common and different skills were in demand. Because of their inability to cure, doctors used a palliative approach to comfort and ease the burden of death on patients and their families. Today the curing role has superceded this healing role because science has given us the opportunity to do so.

The ability to cure has changed the focus of medicine. With all the life-saving measures that exist, it is difficult for many to believe that nothing curative can be done. While the ability to prolong life may be possible, it is questionable whether or not it is advisable. In medicine, curing has been associated with life while palliative care has been linked with death. One reason why these associations exist: it seems to be easier for physicians and family to accept that a person died because heroic measures failed.

This direct association of palliative care with death makes its implementation an uncomfortable decision when children are concerned. Dying children defy the natural order (3). While elderly individuals and their families may be more open to palliative care, parents and doctors of children seem to be reluctant to implement it. Those who have lived a long life are more apt to accept its final, inevitable, conclusion. Since they hold out no hope for a permanent cure, palliative care can be a desirable option for terminally ill adults. The Institute of Medicine states that a "decent or good death is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and is reasonably consistent with clinical, cultural, and ethical standards (4)." This is the goal of palliative care.

However, the goals of palliative care have not been entrenched in pediatric situations. One reason is lack of pediatric palliative care training and education. Training programs in the United States, like those offered by the American Academy for Hospice and Palliative Care, focus primarily on adults. There are no established national standards for pediatric palliative care curriculum (5). As a result, only 10 percent of pediatric oncologists have had formal courses and only 2.2 percent have undergone a clinical rotation in palliative care (6). In addition, undergraduate medical education in the United States has focused predominantly on palliative care for adult and geriatric patients (7). Therefore, the established adult model of seeking a cure, then palliating until death, is being applied to children. This model does not necessarily fit the situation experienced by caregivers of children. In what has been called the Persephone syndrome, a course of disease that is fraught with rebound-relapse episodes may lead family and other care providers to be more persistent in pursuing aggressive therapy for prolonged periods of time in hope of yet another astonishing recovery (8). Because the adult model is cure or palliate, these children never receive palliative treatment. They are perceived as being perpetually in the cure stage, despite terminal illness. The logical conclusion would indicate to use both curative and palliative treatments, but, because of current educational practices, the combination of potentially curative and palliative medicine currently escapes us (9). Even the World Health Organization's definition of pediatric palliative care as quoted earlier in this paper seems to artificially separate curative and palliative efforts.

Further complicating the issue, pediatricians are relatively inexperienced with death. On average, a general pediatrician will come into contact with 3 children per year who will die (10). This limited exposure has two major effects: first, pediatricians lack experience dealing with the complex emotions related to death; and second, they report feeling a sense of guilt about their inability to cure. As a result, a common reaction is to separate themselves emotionally and physically from the dying children and their families (11).

Although adults involved in the medical care of family members want dying parents not to suffer, they expect their children to outlive them. When families are faced with the terminal illness of a child, they are presented with many challenges, some of which the medical system imposes upon them. They receive an overwhelming amount of technically complicated information from which they must make difficult decisions about the fate of their child. They may feel that an incorrect choice will cause undue suffering or death. As a result, families in these situations prefer to be guided by their practitioners (12).

Unfortunately, this creates a situation where pediatricians may influence parental attitudes and behavior. The feeling that the inability to cure a child is a personal failure, combined with a lack of education in pediatric palliative care, makes pediatricians reluctant to provide palliative care as an option. Even those pediatricians that do receive adult palliative care training are reluctant to turn care over to another clinician because of their strong relationship with the patient and his or her family (13). This makes the family see only one course: cure or nothing. This is unfortunate, because the decision of when to provide end-of-life care is paramount. Delay causes difficulties in tailoring treatment and exacerbates feelings of vulnerability and helplessness in the family and patient (14). Because of the issues previously discussed, doctors are waiting for the family to decide to stop the curing process while the family is expecting the doctor to inform them when curative treatments should be abandoned. As a result, neither party actively initiates the discussion of terminal care. This can lead to prolonged suffering. "The need to do everything is a powerful force. This is relevant when interventions focused on cure are no longer reasonable and may well be harmful (15)."

In a Wisconsin study of dying children whose parents had received a palliative care consultation, they found a significant decrease in the administration of blood tests, central lines, feeding tubes, gastrostomy tubes, endotracheal tubes, x-rays, and paralytic medications compared to children whose parents had not (16). This study suggests that once palliative care is introduced as an option, invasive medical procedures with limited benefit are refused.

Misconceptions about children needing protection from pain, assumptions about their ability to understand, or the thought that they are too young to be affected continue today (17). In one study of dying hospitalized children in Edmonton between January 1996 and June 1998, only one child among 77 was documented as being specifically told that they were dying (18). Though legally unable to give informed consent, the "assent" of sick children may be weighed heavily by parents and doctors in deciding a course of treatment. When children are not informed that they are dying, they cannot make any direct contributions to their care. Because the parents and the child are not both directly included, they have no opportunity to work together in deciding the best course of action (19). Therefore the patient's best interests may not be met.

The combination of these factors explains the lack of palliative care options offered for pediatric cases. Parents are dependent on the pediatrician to help make choices about end of life care. The pediatrician is not trained in offering such options, and the child is essentially uninvolved in the process. Since parents are not presented with the option to provide palliative care, they see stopping curative treatment as stopping all treatment for their child.

There is some academic work being done in the area. Some schools, like The Johns Hopkins Children's center, offer a one day seminar to residents (20). Several articles have been written recently (21,22,23) which show that awareness of the problem is growing. The issues at hand are: does medical intervention really lead to an improved quality of life for children? Are the necessary facilities and training available to residents and students to assist them in this aspect? Can doctors make better use of facilities and training that already exist? These are issues that must remain in the spotlight. Only by focusing on them will palliative services for children become more utilized in the future.

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