



# Ethics

## Children: Legal and Ethical Issues

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## Introduction

Parents clearly have an overwhelming interest in their child's life and well-being. However, as a society, we place limits on parental authority. This module examines healthcare decision making for minor children, and identifies some problematic issues for parental decision making. We also discuss other topics related to death and dying in children, such as premature infants, NICU, multiple pregnancy, and pain in children.

## Healthcare Decision Making for Children

Parents are expected to make healthcare choices that are in the *child's* best interests as opposed to their own interests, the interests of the extended family, or in another child's best interests. The opposite stance, both legally and ethically, would be to view children as the property of their parents and to give parents wide discretion in their child's healthcare decision making. In this property view, parents' choices for their children would face few societal limits. Instead, a child's future autonomy is viewed as held in trust by parents, healthcare providers, and society at large. Parents are held to a best interests standard because children typically do not have a history of prior choices that could be relied upon to make substituted judgments, the choice an autonomous person would make if able to choose for him or herself. Hence, parents are not allowed to make unusual, eccentric, or poorly reasoned choices for their children. For this reason, parents who are Jehovah's Witnesses or Christian Scientists are not allowed to refuse clearly beneficial medical therapy for their children. **Note:** See the Healthcare Decision Making module for additional discussion of standards for surrogate decision making.

Competent adults can make a wide range of choices for themselves – or direct their surrogate to do so if they become incompetent – but a parent cannot impose their religious beliefs, cultural norms, or personal choices onto their child if it means the child will likely suffer serious consequences such as disability, pain, or death. When healthcare professionals are concerned that parents are not acting in the child's best interests, they should respond first with understanding and respect, eliciting the parent's view of the child's illness and proposed treatments. Whenever possible, healthcare professionals should attempt accommodation of the parent's wishes. When this approach appears impossible, consultation should be sought from legal or ethics experts.

“The right to practice religion freely does not include the liberty to expose the community or child to communicable disease, of the latter to ill health or death.... Parents may be free to become martyrs themselves, but they are not free to make martyrs of their children.”  
Justice Holmes, *Prince v. Massachusetts*, 1944<sup>1</sup>

## Informed Consent

Healthcare decision making for minor children, as for anyone else, involves the process of informed consent. The elements of informed consent require professionals to:

- Provide information (e.g., possible therapies, risks, benefits)
- Assess patient's capacity and understanding of the information     AND / OR
- Assess surrogate's capacity and understanding of the information
- Assess that the patient or surrogate is not being manipulated or coerced.

## Parental Permission

In decision making for the pediatric patient, informed *consent* usually becomes a model of parental informed *permission* combined with the *assent* of the child. Parental permission includes all the elements of informed consent PLUS:

- decision must represent the best interests of child
- there can be wide discretionary authority on determining what constitutes best interests
- protection of the child from abuse or neglect is embedded into the assessment of all parental decisions.<sup>2</sup>

## Assent

Assent takes into account the developmental capabilities of the child. Hence for a 2-year-old toddler, assent might mean simple cooperation while for a 16-year-old teenager it could involve reasoned decision making.<sup>2</sup>

- Assent simply means trying to gain the child's cooperation and agreement as much as possible. It does not imply rational, autonomous, decision-making.
- Assent empowers children to the extent of their developmental capacity
- Assent includes:
  - developmentally appropriate awareness of condition
  - knowing what to expect with tests or treatments
  - assessing child's knowledge and response to tests or treatment
  - soliciting child's willingness; but if refusal will not be honored, child should not be deceived

While assent is the ideal for practice, it is the standard in research with children. This concept is very important since many seriously ill children are involved with research at some point in their treatment. **Following are the Rules of 7s regarding age and formal assent and consent guidelines for research with minor children:**

- 0-7 years - Seek informed permission of parents (or legal guardians) and gain the cooperation of the child to the extent possible.
- 7-14 year - Seek informed permission of parents PLUS assent of child (research protocols may include written assent forms that the child signs)
- 14-21 year - Seek informed permission of parents PLUS consent of child (both parties would sign formal consents)
- 21+ year - Seek informed consent of patient

Cardwell v. Bechtol, 724 S.W 2d 739 (Tenn. 1987)

## Problems with Parental Decision Making

Whose interests count? Parental decision making, like surrogate decision making, makes the false assumption that persons can set aside their own interests or the interests of others under their care and love, to make choices for another person. In reality, this assumption is impossible. A parent cannot temporarily suspend the need to consider the well being of other children when making choices for an ill child. Generally, this problem is not serious because the interests of one child will not directly compete with the interests of another child. But in the case of serious, debilitating, chronic illness, parents may be faced with making choices for one child that will

impoverish their other children's futures, and possibly their own. In particular, with the current healthcare financing for chronic illnesses, this issue may be overwhelming for many parents.

What about parents who are not "ideal"? Not all parents are perfect caregivers. This fact creates dilemmas for healthcare providers caring for a vulnerable child whose primary support system – the family – is fractured, dysfunctional, overwhelmed, or negligent or abusive. To care for the child, many healthcare professionals find themselves also needing to care for the family. While from an ethical perspective, this approach is justified, appropriate and even laudatory, from a clinical perspective it is increasingly difficult. Parents may need healthcare themselves in order to be able to care for their children, yet they may lack the resources to obtain that care and social welfare programs are often inadequate. Similarly, for parents with limited resources and low-paying jobs, the struggle to obtain childcare for an ill or disabled child, take their child to a myriad of appointments, and maintain their own employment may prove impossible. If healthcare providers suspect that parents are negligent or abusive to their child, they are required by law to report the situation to the state agency that protects children's welfare (e.g., Child Protective Services). But many of the situations encountered in the care of chronically ill children do not meet the threshold for reporting. They include frequently missed appointments, inadequate compliance with a complex care regimen, or obvious exhaustion, depression, and stress. In these situations, healthcare providers need to establish mechanisms to work with parents, to create support services for them (e.g., through a hospital guild or other resource), and to provide expert testimony to policy makers to ultimately improve the services available to ill children and their families.<sup>3</sup>

Who is the child's surrogate decision maker when the parent cannot be? This question is complicated and is dependent on individual state laws. If parents have relinquished their parental rights, then the child's adopted parents or legal guardian would make healthcare decisions. However, if the child is in foster care, the situation may be very complex. Foster parents do not have unlimited decision making authority. In some cases, the biological parents retain healthcare decision making rights even when a child has been removed to foster care; in other cases, the state child welfare worker or an appointed guardian acts as the child's surrogate. When legal guardianship and healthcare decision making is in question for a very ill child, seek guidance from legal counsel or other resources.

Coping with the range of parental preference for aggressive therapy when a child is dying. Losing a child is widely recognized as the most difficult and painful type of loss. It is no wonder then that many parents respond to serious illness in their child by seeking aggressive curative therapy. The hyperbole about miracles that often accompanies advertising for pediatric hospitals may contribute to parent's expectations that anything can be cured or overcome. Also, parents may not receive accurate or consistent information about their child's condition. Oftentimes this misinformation occurs because care providers try to assuage the parents' pain by not providing honest and candid information, unintentionally offering false hope.

Parents who demand more therapy than healthcare professionals feel is appropriate are likely to be confronted with two arguments. The first argument is that treatment is futile, that is the requested therapy will be ineffective in restoring or maintaining organ function. The second argument is that the child is suffering and that the parents' demands for therapy are hence, cruel. Both of these arguments may backfire if the parents lack trust in the healthcare providers, have

received conflicting information, or if their child either does not appear to be suffering or does not appear to be suffering any more than when care providers were treating the child aggressively. Conversely, parents who opt to withhold or withdraw aggressive therapy sooner than healthcare professionals believe are warranted often have their love for their child called into question. The parents may be threatened with referral for medical neglect or have healthcare professionals suggest medical foster home placement. Parents who defend their decision with statements that indicate strong religious beliefs may be suspected of acting on eccentric religious beliefs.

Parental preferences for aggressive care fall somewhere along the continuum represented by these two extremes. Preventative ethics for these situations involves the need for:

1. Consistent, frequent, and honest communication with parents – healthcare providers need to guard against protecting parents by limiting information or making the child appear comfortable when in fact they are suffering. Rather, parents need accurate, honest information provided in a compassionate manner.
2. Resources to support the parents during crisis periods (such as volunteers, a grief counselor, social worker, or chaplain)
3. Parents to be presented with more than one medical treatment option whenever possible (indicating which is the recommended option).
4. Continuity of care by both nurses and physicians.

Professionals need to recognize that death in children often elicits strong emotions in the healthcare providers. This response may make it difficult to respond empathetically to parents because to put oneself into the parents' position is to open oneself to the unspeakable pain of losing a child. Some facilities find that it is helpful to have two sets of caregivers for dying children, one for the family and one for the child. This approach allows each group to focus their empathy and support more clearly.

## **Ethical issues for children who are dying**

### **Palliative Care**

Since we are uncomfortable with death in general, and dying children in particular, there are relatively few services available to support the care for dying children. For example, many communities do not have home hospice services for children, in-patient hospice units that accept children, or hospital palliative care services for children.<sup>4-8</sup>

### **NICUs and Very Low Birth Weight Babies**

NICUs and the care of low-birth weight babies often elicit strong positive or negative feelings. For some parents, NICUs represent places where miracles occur – perhaps where a sibling was saved. For other parents NICUs epitomize excessive medical care and are targeted as a way to reduce overall healthcare spending. Yet, the issue of NICUs is more complicated. Many babies born prematurely and very small survive with few or no complications due to NICU care. But others are saved only to face shortened lives of chronic illness. For others, the NICU only forestalls their death briefly perhaps offering parents time to bond and then say goodbye. How much say should parents be given in decision making for their premature infants? Since parents will bear the financial burden of treatment of severely compromised children, should they have complete authority over treatment decisions?

- **Baby Doe Regulations.** These federal regulations require states to create a mechanism to facilitate reporting situations where medical care is not being provided based on a child's mental or physical disabilities (i.e., situations where the same treatment would have been given to a normal child but is being withheld from a disabled child). These regulations had a chilling effect on healthcare decision making in the NICU where the risk of serious neurological disabilities is high due to infant's extreme prematurity. The regulations were widely over-interpreted to mean that treatment could not be withdrawn from children until it was medically ineffective, regardless of the child's prognosis for quality of life. Most experts agree this interpretation was not the intent of the regulations and that it is acceptable to withdraw or withhold medical therapies in the NICU based on the prognosis for serious physical or neurological disability.<sup>9-11</sup>
- **NICU survival rates:** The outcomes for very low birth weight infants have been the subject of many research studies. However, this area is one of rapid technological development where survival rates have steadily improved in the last decades.<sup>12-14</sup>

### **Infertility, In Vitro Fertilization (IVF), and Multiple Pregnancy**

Another topic that often arises around pediatrics is the issue of multiple pregnancy, meaning more than three fetuses. Because many multiple pregnancies end in fetal death or premature birth, this issue is relevant to end-of-life issues for children. There is a great deal of misunderstanding about the clinical reasons for the increase in multiple births. Some experts believe that all women on fertility drugs should be monitored monthly by ultrasound monitoring to assess how many eggs are maturing. During cycles when more than two or three eggs are mature, women would then be counseled to avoid becoming pregnant due to the high risk of multiple pregnancy. Similarly, some experts advise that IVF clinics set limits on how many fertilized eggs are implanted to avoid supernumerary pregnancies.<sup>15, 16</sup>

### **Pain in the Very Young Child**

While pain management in adults is often considered to be lacking, pain management for infants and very young children may be appalling. Historically, neonates received little or no analgesia for painful procedures to the extent that open-heart surgery to repair defects was done using only paralytic medications. Studies showing that infants who received pain medication had better outcomes ended this horrific practice, but pain management is still lagging for the myriad of procedures the very ill child may encounter. The reasons for this lagging practice are many:

- fear that the child physiologically cannot handle narcotics or other pain medications;
- the mistaken belief that children are small, therefore they have small pain;
- a belief that the child will not remember (and therefore will not unduly suffer from) a painful procedure;
- the child cannot describe the pain verbally.

In fact, very small children appear to experience pain more acutely than adults do and to have long term consequences from unrelieved suffering. Dying children in particular need to have their pain assessed and treated aggressively to prevent unnecessary suffering.<sup>17-20</sup>

## Cultural Differences in Child-Rearing

When children are ill and dying, cultural issues may arise that present dilemmas for care providers. For example, alternative health beliefs may be employed in an attempt to supplement Western medicine. Some of these practices may appear to be abusive such as moxybustion. Moxybustion is the application of heat and herbal therapy to acupuncture points by burning herbs near the acupuncture point. Yet are they any worse than the painful procedures we submit children to in the name of helping them (e.g., chest tube placement, injections). In addition, when a child dies, there may be special rituals that should be performed or adhered to for the family to feel that the death was meaningful. Nurses and others may need to seek consultation from cultural experts and talk with the parents and other family members to ensure that culturally sensitive care is provided.

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