

Virtual Mentor

American Medical Association Journal of Ethics
July 2010, Volume 12, Number 7: 564-568.

HEALTH LAW

Legal Restrictions on Decision Making for Children with Life-Threatening Illnesses—CAPTA and the Ashley Treatment

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The purpose of palliative care is to provide comfort rather than cure an illness or prolong life [1]. Palliative care can be delivered in a number of clinical circumstances. Patients with life-threatening illnesses can receive palliative care at the same time they are undergoing medical treatments intended to cure the disease. In other cases, palliative measures enhance the quality of life of patients with incurable medical conditions that may or may not be life-threatening. And in still other cases, palliative care is the only type of treatment provided to patients with life-threatening medical conditions when treating the condition is deemed futile or inhumane.

Parental preference for palliative care is often honored when the benefits of continued treatment are uncertain and the burdens of medical treatments and the illnesses themselves seem great [2]. Nevertheless, physicians, parents, and other decision makers who are considering palliative measures rather than aggressive treatment or resuscitation on behalf of pediatric patients should be aware of federal and state statutory and case law that may restrict such decision making.

Two important examples of legal restrictions on decisions involving pediatric palliative care are the federal Child Abuse Prevention and Treatment Act of 1996 (CAPTA) [3] and Constitutional and case law restrictions on sterilization surgery such as the Ashley Treatment in disabled children.

Palliative Care for Infants under CAPTA

Most states have adopted the federal government requirements for states that receive grants under CAPTA [4]. To be eligible to receive the grants, a state's child protective services must have and exercise the authority to initiate legal proceedings to prevent medical neglect—which may include withholding of medically indicated treatment from disabled infants with life-threatening conditions—and to provide medical care or treatment for a child when necessary to prevent or remedy serious harm to the child.

Under CAPTA, failing to provide appropriate nutrition, hydration, and medication to any infant with a life-threatening condition always constitutes “withholding of medically indicated treatment.” The same holds true for failing to provide such an infant with a treatment that, in the physician's reasonable medical judgment, is most

likely to ameliorate or correct the condition, *unless* at least one of the following exceptions applies:

- A. The infant is chronically and irreversibly comatose;
- B. The provision of such treatment would
 - 1. merely prolong dying;
 - 2. not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or
 - 3. otherwise be futile in terms of the survival of the infant; or
- C. The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. [3]

Several court cases have applied CAPTA restrictions to medical neglect.

Montalvo v. Borkovec

In the Wisconsin case of *Montalvo v. Borkovec* [5], the court held that, due to CAPTA and other legal requirements, the parents of a premature newborn were not entitled to the opportunity to give or withhold their informed consent to resuscitation of the infant.

Emanuel Vila was born prematurely by cesarean section at 23 and 3/7 weeks' gestation and weighed 679 grams. At birth, Emanuel was handed to a neonatologist who successfully performed resuscitation. The baby's parents and guardian *ad litem* sued, alleging violation of informed consent and negligence. The plaintiffs charged that the parents, rather than the physicians, should have decided whether extraordinary measures were to be taken, and that the physicians and hospital were negligent in resuscitating Emanuel without his parents' informed consent. The plaintiffs alleged further that the parents should have been given statistics regarding Emanuel's risk of developing a disability had he lived and the opportunity to withhold life-saving measures immediately after his birth.

The trial court dismissed the lawsuit, and the Wisconsin Court of Appeals affirmed the dismissal. Among other reasons for its decision, the court stated that the parents' informed consent was not sought because, under CAPTA provisions, there was no lawful alternative to resuscitation. Wisconsin receives federal CAPTA funds, so medically indicated treatment could not be withheld from this disabled infant with a life-threatening condition.

In the Matter of AMB, Minor

In the Michigan case titled *In the Matter of AMB, Minor*, [6] the court found that the decision to terminate life support and provide comfort care did not violate CAPTA because the treatment that was being provided to the patient was futile and inhumane.

AMB was born 5 weeks prematurely and had a poor prognosis for long-term survival. Her heart was missing a septum, two of her heart valves were deformed, her

aorta was very small, and the size of her heart had forced her left lung into partial collapse. She had a possible problem with her intestines, as well as hydrocephaly and other brain abnormalities suggesting corpus callosum agenesis.

Physicians administered prostaglandin intravenously to open her ductus arteriosus to help circulate oxygenated blood through her body. She was intubated and placed on a ventilator. AMB was conscious and not sedated.

The baby's mother was allegedly mentally impaired and the putative father was in jail. The child protective services agency sought temporary custody and petitioned family court for a decision regarding AMB's best interests. AMB's neonatologist testified that the baby was experiencing physical distress and that there was no hope of her surviving independent of the life support. The ventilator did not improve the baby's chances for survival because her heart lesions were not compatible with long-term survival, and without the prostaglandins and ventilator she could live for hours, days, or months.

The neonatologist recommended stopping the prostaglandins, removing the ventilator, and providing palliative care such as fluids, heat, warmth, monitoring of heart rate and vital signs, and possibly a feeding tube. The neonatologist believed that medical care was futile because there was no treatment to offer. She thought the medical care being provided was inhumane because it intensified AMB's suffering and failed to solve her health problems. The neonatologist believed further that AMB suffered from the ventilator, the tube in her throat, and the IVs, and partly because they made it difficult to hold AMB and impossible to feed her.

In proceedings that the Court of Appeals characterized as "unredeemably flawed," family court issued what appeared to be an order authorizing the hospital staff to remove life support equipment and medication and provide comfort care. Medical personnel implemented the order 6 days prior to its effective date, and AMB died soon thereafter.

AMB's appointed attorney appealed the family court decision to the Michigan Court of Appeals, which found that, although the CAPTA exception that allows withdrawal of life support had not been satisfied because AMB was not "chronically and irreversibly comatose" (she was, in fact, conscious and not sedated), AMB's case satisfied each of the other CAPTA exceptions. No available treatment would have cured or alleviated her life-threatening heart problems, and maintaining her on a ventilator and providing prostaglandin would only temporarily delay her imminent death. Thus, as the neonatologist had testified, these treatments were futile and inhumane. Therefore, because the child protective services agency's request did not constitute medical neglect as defined under CAPTA, the agency did not violate any CAPTA duty when it requested the family court to determine what would be in the baby's best interests.

The Ashley Treatment: Sterilization of a Disabled Child

At the age of 1 month, Ashley displayed symptoms of hypotonia, feeding difficulties, choreoathetoid movements, and developmental delay. She was eventually diagnosed with “static encephalopathy with marked global developmental deficits” [7]. Ashley could not sit up, walk, or use language. In the opinion of her physicians, her cognitive ability and neurologic function were unlikely to improve significantly.

Ashley’s parents wished to continue caring for her at home, but were concerned that her continued growth would make it difficult for them to attend to her needs. When Ashley was 6 years old and exhibiting early pubertal development, her parents consented to several medical interventions intended to increase her comfort and improve her quality of life: growth attenuation through high-dose estrogen, hysterectomy, and surgical removal of the breast buds [7, 8].

The treatment was widely debated in the legal and ethics communities. The Washington Protection and Advocacy System investigated all those involved in Ashley’s treatment and surgery and released a report finding that, due to a communication breakdown, the hospital had violated state law and Ashley’s constitutional and common law rights by performing the hysterectomy without a court order [8]. The hospital acknowledged that a court order was required under Washington law and entered into an agreement with WPAS to take corrective action to assure that a court order would be obtained for any future sterilization of a child with a developmental disability [8, 9].

Conclusion

While parents often have legal authority to make decisions regarding pediatric palliative care, federal and state statutory and case law imposes significant restrictions on the decision-making authority of parents and physicians. Two important examples of such law involve CAPTA restrictions on medical neglect and the requirement to obtain a court order authorizing the sterilization of a disabled minor.

States receiving CAPTA grants must restrict the withholding of medically indicated treatment from disabled infants with life-threatening conditions unless (1) the infant is chronically and irreversibly comatose; (2) the treatment would merely prolong dying, would not ameliorate or correct all of the infant's life-threatening conditions, or would otherwise be futile in terms of the survival of the infant; or (3) the treatment would be virtually futile in terms of the survival of the infant and the treatment itself would be inhumane.

Surgical sterilization of a severely disabled child as a means of palliative care may require court order to protect the child’s constitutional and common law rights.

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