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Termination of Life Support After Severe Child Abuse: The Role of a Guardian ad Litem

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ABSTRACT. Discontinuation of life-sustaining interventions often raises ethical concerns. In cases of severe child abuse with poor prognosis for recovery, accused parents may have a conflict of interest regarding medical decision-making for their child, because the outcome of such decisions may impact legal charges filed against them. The recently issued American Academy of Pediatrics guidelines for addressing such cases recommended the appointment of a guardian ad litem for medical decision-making. We present the case of an 8-month-old infant who was abused severely by her father, resulting in a persistent vegetative state. We describe our experience with appointing a guardian ad litem and the ethical issues involved. *Pediatrics* 2004;113:e141–e145. URL: <http://www.pediatrics.org/cgi/content/full/113/2/e141>; *child abuse, medical ethics, guardian ad litem.*

ABBREVIATIONS. AAP, American Academy of Pediatrics; CT, computed tomography; CPS, Child Protective Service.

In cases of severe child abuse resulting in serious neurologic damage and a poor prognosis for recovery, the accused parents or guardians may have a conflict of interest regarding medical decisions for their child. The parents may be asked to make decisions that then have an impact on the legal charges filed against the alleged abusive parent. Withholding and/or withdrawing life-sustaining interventions may result in the child's death, changing the legal charge from one of felony child abuse to manslaughter or even murder. When the parents' ability to make medical decisions is compromised, health care providers may turn to the courts. Confronted with situations in which medical technology can prolong the lives of children even in persistent vegetative states, many judges are reluctant to make decisions to withdraw life-sustaining treatment. Consequently, gravely injured victims of child abuse may be maintained in foster home nursing or convalescent hospitals, where they may live for months or

even years before they eventually succumb to infection, pneumonia, or other complications.

Significant advances in medical technology have enabled more patients to survive serious trauma and other life-threatening conditions. Their quality of life, however, is often low, with many patients in vegetative or minimally conscious states and needing supportive technology such as ventilation, tube feeding, and assistance with most activities of daily living.¹ Recent studies^{2,3} have shown that, after an initial period of risk, the life expectancy of children in vegetative states is longer than previously thought. For example, for children who were 3 years old at the onset of the persistent vegetative state, 63% were still surviving 8 years later. Few, however, had regained consciousness, and only 12% were functioning with better than minimal consciousness 3 years after onset of the impairment. A 1994 report published by the Multi-Society Task Force on Persistent Vegetative State⁴ estimated that the cost of caring for patients in persistent vegetative states in skilled nursing facilities ranged from \$126 000 to \$180 000 per year. The financial and emotional impact on the siblings and parents of such impaired children is harder to quantify but is clearly significant.

In 2000, the American Academy of Pediatrics (AAP) issued recommendations regarding the decision to forgo life-sustaining medical treatment for victims of severe child abuse.⁵ The AAP recommended that such decisions be made by using the same criteria as would be used for any other critically ill children. Thus, the primary concern should be determining what is in the "best interest of the child after weighing the benefits and burdens of continued treatment." If the parents seem to have a conflict of interest and do not seem to be acting appropriately on the child's behalf, physicians should seek consultation from an ethics committee. It may be necessary, however, to seek a court hearing, given that parents typically retain legal custody and the right to make medical decisions even when they are accused of child abuse and do not have physical custody. Because termination of parental rights typically requires a judicial process, in many cases, legal decisions regarding parental rights may drag on, and the timeliness of medical decisions may be delayed. Therefore, in all cases of severe child abuse requiring life-sustaining medical treatment in which the accused parents may have a conflict of interest, the

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AAP recommends that a guardian ad litem for medical decision-making be appointed. In California, a guardian ad litem is an attorney who is assigned to advise the court on actions that should be taken in the child's best interest. In some states, a guardian ad litem may be a social worker or another professional that has been trained to assist the court on matters involving minors or other incapacitated individuals, whereas in other states such as North Carolina, a guardian ad litem is a trained volunteer who is appointed by the court to advocate for the best interests of abused or neglected children.

The following case describes the involvement of an ethics committee, guardian ad litem, and juvenile court officials in resolving a conflict between parents and the medical team in treatment for a victim of severe child abuse.

CASE REPORT

Initial Presentation

Infant Jane*, an 8-month-old female, was found pulseless and lacking respiratory effort by paramedics called to her home. Her father claimed that he had shaken the infant to stimulate breathing after she had an episode of choking during feeding. Paramedics resuscitated the infant, intubated her, administered epinephrine and intravenous fluids, and transported her to the hospital. In the emergency department, she was found to have a stable heart rate and mean arterial pressure of 70 to 80 mm Hg. She had some agonal breathing and made no spontaneous movements. Her initial Glasgow Coma Score was 3. She was admitted to the intensive care unit, where she was placed on a ventilator and had central and arterial lines placed.

Initial Examination and Findings

Her physical examination was notable for an abrasion over the forehead and nose, as well as contusions in the right mandibular area and beneath the chin. Contusions also were noted on the back and left thigh. There were abrasions around the perineal body and possible contusions of the perineum and around the anus. An ophthalmologic examination revealed bilateral retinal hemorrhages. The head computed tomography (CT) scan findings at admission were consistent with old subdural effusions bilaterally and a new subarachnoid hemorrhage. Loss of gray-white-matter differentiation was consistent with brain swelling. A lumbar puncture was performed and showed bloody cerebral spinal fluid with xanthochromia. Skeletal survey showed a right humeral fracture, ~1 week old, and multiple old fractures. The initial chest radiograph was normal. The abdominal CT showed no organ injuries. The state Child Protective Service (CPS) was notified in accordance with our mandatory obligation to report suspected cases of child abuse and neglect. CPS evaluated the case and felt that the physical findings were highly suggestive of severe and chronic child abuse.

Past Medical History

Infant Jane was born after an uneventful pregnancy and labor. Her married parents were both in their mid-20s and had no other children. Infant Jane was diagnosed with congenital pneumonia at birth and required a 6-day stay in the neonatal intensive care unit. She was discharged from the hospital to her father and mother. Two days after discharge, she was brought to the emergency department with sudden-onset bleeding from her mouth. Her face was also bruised. The father ultimately admitted that the bleeding was due to his use of excessive force while trying to use a bulb syringe. During the hospital admission, Infant Jane was evaluated for nonaccidental trauma; all studies, including head CT, skeletal survey, and ophthalmologic examination, were negative. On the night before the scheduled day of discharge, she had a second

episode of bleeding, with ~15 mL of blood suctioned from the back of her mouth. The father admitted to again aggressively suctioning the infant. Infant Jane was discharged from the hospital under the supervision of CPS.

When Infant Jane was 27 days old, she was seen in the emergency department for the second time. Her parents reported that she was not moving her left leg. An evaluation for nonaccidental trauma was repeated and revealed 4 metaphyseal fractures including both distal femurs and both proximal tibias. Radiograph findings were also consistent with a recent refracture of the left proximal tibia. There were skin injuries in a grasp pattern on the left arm and leg. Although the ophthalmologic examination was normal, a head CT showed interhemispheric, right posterior, and tentorial subdural hemorrhage, consistent with head trauma. A work-up for possible bleeding disorders was negative. After extensive questioning of Infant Jane's father, the treating staff felt that the child's injuries were accidental, caused by clumsiness rather than malice. Nonetheless, Infant Jane was diagnosed with battered-child syndrome, CPS was contacted, and she was discharged to foster care.

After foster placement, Infant Jane had no hospital admissions or significant medical illnesses until the present admission. She had begun seeing her parents through the family reunification program. The visits had progressed gradually from brief supervised visits to unsupervised overnight visits. Two weeks before the present admission, after Infant Jane's second unsupervised overnight visit with her parents, the foster mother noted bruises on the right arm and shoulder, which she reported to the CPS worker. It is unclear why no medical examination or investigation was conducted at that time; however, the worker in charge was later demoted, in part because of her negligence in this case. The episode leading to the present admission occurred during Infant Jane's fourth unsupervised overnight visit with her parents.

Treatment and Hospital Course

Shortly after admission, a pediatric neurosurgeon drained the patient's subdural effusions and placed an external ventricular drain. Mechanical ventilation was continued, and Infant Jane eventually developed acute respiratory distress syndrome. This resolved over time, and ventilator support was decreased. Initially, she had poor cardiac function and required vasopressors and inotropic support. This, too, gradually improved over several weeks. She was fed through a nasojugal tube.

A neurologic examination conducted 1 month after admission revealed findings consistent with severe encephalopathy. Pupillary reflexes were marginally preserved, but cranial nerve reflexes were absent. There was no response to painful stimuli. Extremities were spastic. At this evaluation, Infant Jane was considered to be in a coma, because she did not have the intact sleep-wake cycles or normal respiratory function required for the diagnosis of vegetative state.¹ The diagnosis of coma is associated with a higher fatality rate than less-impaired states of consciousness including vegetative state. The neurologist concluded that, if extubated, the patient might gain some respiratory effort and might progress to a vegetative state. A second neurologic evaluation, 2 months after admission, found no improvements in her neurologic status. She had no gag reflex or cough, and she did not respond to noxious stimuli. Her limbs were flaccid. She was described as having extremely severe cortical and cerebellar injury with minimal brainstem functioning. The consensus from the neurology service was that she had a high probability of evolution to a persistent vegetative state, with "absolutely no hope for any meaningful recovery" to even a moderate level of disability. A repeat head CT at this time showed cerebral atrophy, subdural fluid collection, and increased ventricular size.

Ethics Team

One month after admission, the hospital staff caring for Infant Jane requested a bioethics consultation to help resolve a growing conflict that had arisen between the staff and Infant Jane's parents regarding appropriate medical interventions for the infant. The parents desired continuance of aggressive medical intervention for Infant Jane, including life-sustaining treatments such as tracheostomy, placement of a gastrostomy tube, and fundoplication. In contrast, the medical staff felt that such interventions would not be efficacious given Infant Jane's current state and bleak prognosis. The staff had informed the parents that aggressive interven-

*The child's name and other identifying facts have been changed to conceal the child's identity.

tions would only prolong her present state, without hope for cure or recovery of neurologic functioning. However, the family insisted that all measures be taken, asserting that they were religious and believed that a miracle might occur.

The ethics team, consisting of a physician, nurse, and hospital chaplain from the hospital's Ethics Committee, was consulted in an effort to resolve the conflict between the medical team and the family. The ethics team obtained information regarding the child's medical condition and prognosis and assessed the parents' understanding of the child's prognosis and anticipated quality of the child's of life without additional recovery. The ethics team also reviewed the parents' preference for treatment options. Next, the team determined the range of ethically appropriate options considering quality of life, parental preferences, and best interests of the child (see "Discussion"). They met with the medical team and parents to discuss their findings and recommendations and attempted to reconcile differences between the medical recommendations and the parents' wishes. The ethics team sought to ensure that Infant Jane and her parents were treated with compassion and respect, because some staff members expressed feelings of negative transference toward Infant Jane's parents. The ethics team wanted to be sure that Infant Jane was not in acute pain and were reassured to learn that she had been maintained on intravenous pain-relief medications, which were subsequently weaned and replaced by a patch containing sustained-release analgesics. Finally, the ethics team provided ongoing support and consultation to the parents and medical team as the recommendations were conducted.

The ethics team approached this dispute by using the best-interest standard as recommended by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Biobehavioral Research.⁶ In determining the best interests of the patient, the ethics team took into account those factors that any surrogate decision-maker should consider: "(1) relief of suffering; (2) preservation or restoration of functioning; and (3) the quality as well as the extent of life sustained." The ethics team found that Infant Jane's neurologic evaluations showed severe neurologic damage with no hope for meaningful recovery and that she suffered from severe physical debilitation and irreversible loss of sensory and intellectual activity. Surgeries for a tracheostomy, gastrostomy tube, and fundoplication would provide long-term maintenance of her medical care and nutritional needs but would not improve her overall prognosis. They concluded that restoration of neurologic functioning was not possible but that relief of suffering was paramount. The ethics team recommended that the child's best interest was served by forgoing further surgeries and life-sustaining treatments and instituting "do-not-attempt-resuscitation" orders. They also recommended that Infant Jane receive palliative care for relief of suffering and that comfort and compassionate care be provided. They recommended ongoing neurologic evaluations to monitor her progress. These evaluations would be useful for reassessing the appropriateness of her medical treatment. Finally, after examining the potential sources for the parents' disagreement with the medical team, the ethics team noted the potential for a serious conflict of interest in parental decision-making for their daughter given the prospect of criminal consequences, should she succumb rather than persist in a vegetative or comatose state.

In an attempt to resolve the conflict between the medical recommendations and the parents, the ethics team worked with the parents to ensure that they had sufficient information and understanding to determine the best interest of the child and make an appropriate decision. The ethics team repeatedly tried to educate the family about Infant Jane's condition and her prognosis. Although the parents missed multiple follow-up appointments to meet with the ethics team, they were able to meet with the team on several occasions, and eventually, Infant Jane's parents seemed to comprehend the information about the seriousness of their daughter's condition and the likelihood that she would not improve. The parents made clear statements that they did not want their child to continue in her current state but paradoxically demanded all medical interventions that would prolong her life and refused to consent to any efforts to withhold or withdraw life-sustaining treatments. The parents were able to meet with both the hospital social worker assigned to this case and the pastoral service, but such counseling did not modify their wishes for their daughter.

At this point, the ethics team recommended that the juvenile court be petitioned to appoint a guardian ad litem to serve as a

surrogate decision-maker for Infant Jane. The petition for termination of parental rights and appointment of a guardian ad litem was initiated by the hospital social worker familiar with the case and submitted to the court ~2.5 months after Infant Jane's admission to the hospital. The judge acted on it expeditiously, removing parental rights regarding medical decision-making, given their potential conflict of interest, and appointing an attorney to evaluate the patient's clinical condition and report back to the court regarding Infant Jane's best interests.

In the jurisdiction in which this case took place, a minor's counsel is appointed for virtually all children under the supervision of CPS. Infant Jane had an attorney representing her from the onset of her involvement with CPS when she was <2 weeks old. However, Infant Jane's counsel felt that, as her advocate, he was conflicted in making a recommendation to the court to discontinue life-sustaining treatment that may result in her death. He agreed with the ethics team that the appointment of a guardian ad litem, who had no previous history with the child or her parents, to make recommendations for medical treatment would be in the best interests of the child.

Guardian ad Litem

In this particular jurisdiction, the guardian ad litem is an attorney chosen to ascertain and advocate for the best interest of the child and functions as an agent of the presiding judge. Such individuals, theoretically, are unbiased by either parental or staff views and can ascertain the best interests of the child more clearly when conflict arises and the parents may possess a conflict of interest in their decision-making process. Although the court has the ultimate authority to decide whether to order or oppose the life-sustaining surgeries or therapies, the guardian ad litem is responsible for collecting and summarizing all medical data, research, and case law relevant to the case. The guardian ad litem in Infant Jane's case observed the patient, reviewed her medical records, and interviewed the medical, nursing, and social work staff. In drafting her findings and recommendations, the guardian ad litem synthesized the medical and legal information and brought an educated layperson's perspective to the case.

The guardian ad litem's report identified one facet of Infant Jane's case that contributed an element of uncertainty regarding her prognosis. The issue concerned the relatively short period of time that had transpired since Infant Jane's initial injury and how that impacted on the ability of her physicians to be certain of a poor long-term outcome for her. By the time the guardian ad litem saw Infant Jane, it had been almost 3 months since her admission to the hospital. Because she did not demonstrate cyclic sleep-wake cycles, Infant Jane was considered to be functioning at a level slightly below "vegetative state." As noted above and in the guardian ad litem's report, research on children in persistent vegetative states caused by trauma shows that recovery after 3 months is possible but after 12 months is extremely rare. For example, data reported by the Multi-Society Task Force on Persistent Vegetative State,⁴ which pooled the results from several previous studies, showed that, of 106 children who were in a persistent vegetative state 1 month after a severe head injury, 24% regained consciousness within 3 months and 62% regained consciousness within 1 year. None regained consciousness after 1 year. Of those who recovered consciousness, 11% made a "good recovery," whereas the remaining 82% were considered moderately or severely disabled. Earlier recovery was associated with higher functional outcomes. Coma patients generally have poorer prognoses than those with less severely impaired consciousness.⁷ Although Infant Jane's functioning was actually below that of the subjects of studies of persistent vegetative state, it was felt that using this research-based information provided the most optimistic estimate of her prognosis and gave her the benefit of the doubt in terms of expected outcome. Thus, uncertainty remained, and although remote, the guardian ad litem noted that it was possible that Infant Jane might have a late recovery.

The medical staff pointed out that research findings relevant to Infant Jane's prognosis and likelihood of recovery have shown that long-term survival in a persistent vegetative state requires preservation of basic autonomic functions. Dependence on ventilators and gastrostomy feeding have repeatedly been shown to increase mortality risk.^{1,3,8} Also, most surviving patients have preserved gag, cough, sucking, and swallowing reflexes^{1,9}; Infant Jane, however, had none of these. Consequently, she was at in-

creased risk of serious complications such as airway occlusion and aspiration pneumonia. In summary, the weight of the clinical findings suggested that Infant Jane's chances of recovering a conscious life were close to zero.

The guardian ad litem noted that no previous legal cases in California addressed the removal of life-sustaining treatment from a child in a persistent vegetative state by parents, guardians, or conservators. However, 2 similar cases from Ohio addressed situations in which the guardian of a child made a decision to withhold life-sustaining treatment. In one case,¹⁰ the child was severely impaired with no detectable cognitive functioning for >5 years because of viral encephalitis when the parents sought to discontinue treatment. The court concluded that it was in the patient's best interest to let her die "peacefully, painlessly, and with dignity." In the second case,¹¹ a minor child had been in a persistent vegetative state for ~3 months when the court was asked to make a decision. The court decided that there was no utility in waiting until a year had elapsed (the required period of time specified by Ohio law for a decision to withdraw life-sustaining treatment), because the patient's condition did not seem to have any chance of improving. The court found that, although death unquestionably would result when medical intervention was removed, the alternative of continuing in a persistent vegetative state was less beneficial. The court also found that removal of nutrition and hydration would be humane, despite the fact that the process of death might take as long as 2 to 3 weeks, as long as efforts were made to minimize discomfort. The court concluded that "a three week dying process, under those conditions, does not outweigh the years of inhuman and tortuous existence in a vegetative state with a certain dying process of unknown duration at its end."

Regarding Infant Jane's condition, the guardian ad litem concluded that the patient seemed to have no chance of recovery of any cognitive function and noted that it is both humane and legally permissible to withhold life-sustaining treatment to permit such patients to die peacefully. The judge concurred with the findings of the guardian ad litem and ordered the discontinuation of life-supporting interventions, giving the parents 15 days to file a writ or appeal of his decision. The parents did not file an appeal. After being hospitalized for >3 months, Infant Jane was moved to a hospice, where she was extubated and treated palliatively.¹² Her parents were allowed to spend time with their daughter. Infant Jane died 2 days after extubation, 1 day before her first birthday. Her father was arrested after the funeral. He pleaded not guilty but was convicted of "assault on a child under 8 causing death" plus 3 counts of felony child abuse and sentenced to 42 years to life in prison.

DISCUSSION

Discontinuing life-sustaining interventions in cases of sudden serious injury often gives rise to disagreements among health care providers, between health care providers and family, between minor and parents, or among other family members. Disagreements between providers and parents over the care of a child may arise from numerous sources, eg, parental frustration with the health care system, cultural differences, insufficient information or understanding, or potential conflict of interest. In a pediatric hospital that has a family-centered care ethic, the health care providers rely on parents, as natural guardians of their child, to know and make decisions in their child's best interest. However, the presumption that parents are best able to consider the best interests of the child may be weakened when the parents' ability to make decisions for their child is compromised by either insufficient understanding of their child's condition, refusal to acknowledge the seriousness of their child's condition, or a potential conflict of interest. Difficulties in decision-making may also arise when there are disagreements be-

tween the parents or when the parents themselves are minors.

In this case, the medical team recognized early that the parents' ability to make decisions for their child might be compromised by any 1 of these factors but especially the potential for conflict of interest. The medical team consulted with the ethics team to utilize all internal mechanisms to assess the parents' ability for decision-making and to resolve the disagreement between the parents and the medical team regarding Infant Jane's interests. In addition, the ethics team served the important function of reviewing the decision-making process by confirming that the medical team was using the best information it had available, that the medical team's recommendation was appropriate, and by attempting to resolve the dispute by improving communication and understanding between the medical team and the parents.⁶ In many situations, the involvement of the ethics team is able to resolve these types of disputes, and judicial involvement is unnecessary. Although judges and courts are reluctant to enter into the realm of family decision-making,¹³ when the parties become irrevocably deadlocked, it may be appropriate to seek judicial intervention.¹⁴ It became clear over a period of time that this dispute was irresolvable, and judicial involvement was necessary.

The involvement of a disinterested, compassionate guardian ad litem was key to the judge's understanding of the issues involved in determining Infant Jane's best interests. She actively sought the information about the relevant legal, medical, and ethical issues involving life-sustaining treatment. The guardian ad litem sought to gather all the information and present a recommendation to the judge in a comprehensive, reasoned manner. The medical team gave whatever time and information was necessary to the guardian ad litem to assist her in understanding and preparing her recommendations to the judge.

In analyzing ethical issues in pediatric health care, parental autonomy is often considered to be of paramount importance. However, Sklansky¹⁵ and others have noted that paternalism, motivated by beneficence and nonmaleficence, may trump patient autonomy in neonatal and pediatric medicine. As an infant, Infant Jane lacked the ability to make decisions autonomously, and her surrogate decision-makers (her parents) seemed unable to make decisions that were in their daughter's best interest. As might be expected, Infant Jane's parents were conflicted about their goals for their child. They stated that they did not want to prolong her suffering in a severely disabled state and yet insisted on medical interventions that would do just that. Because Infant Jane's parents faced potential criminal liability for their role in her injuries, it was difficult to adequately assess their decision-making ability for their child even after extensive counseling and education was undertaken. Thus, it was necessary to seek judicial involvement to assess the benefits and burdens of continuing medical interventions in the face of an extremely poor prognosis.

As an ethics team at a large, tertiary care, pediatric

referral center, each year we see approximately half a dozen cases of child abuse as severe as Infant Jane's. For >15 years, we had not been successful in either terminating parental rights to medical decision-making or petitioning for the withdrawal of life-sustaining interventions in cases of severe child abuse. We are aware of 1 adolescent patient in a convalescent facility who has been in a permanent vegetative state for more than a dozen years since he was severely beaten by his parents. For several years, while both parents were imprisoned for their role in his abuse, each medical decision required getting consent from both incarcerated parents. In most cases, of course, severely abused children do not survive for so long.

The AAP's recommendations regarding the decision to forgo life-sustaining treatment in cases of severe child abuse are useful guidelines available to caretakers when confronted with such difficult cases. They remind us to focus on the medical issues of victims of severe child abuse as one would any similarly critically injured child and to seek the appointment of a guardian ad litem and judicial involvement when necessary to resolve intractable conflicts around life-sustaining interventions for any child.

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