Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee Newsletter, Summer 1996

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ETHICS COMMITTEES AND THE COURTS

In the ideal world, ethical disputes in medical decision making that occur within a health care institution are brought to the attention of and resolved by the institution’s multidisciplinary ethics committee. The ideal is just an ideal, however, and the resolution of ethical disputes, therefore, is sometimes sought in court, in some cases after an ethics committee has made its recommendation. Recognizing that such situations pose unique questions about the roles of committees and courts in medical decision making, the Federal Judicial Center, a federally funded agency that supports federal and state court judges through educational programs, included a session on ethics committees as alternative dispute resolution bodies in its June 1996 conference on health law issues. This article summarizes points made at the session and describes how courts have viewed the recommendations of ethics committees in cases that have come to trial after being heard by a committee.

While a 1992 study by the National Center for State Courts estimated that 7,000 cases involving termination of life support had come to the trial courts, very few cases have come to the courts after actually having been reviewed by an ethics committee. In most cases, the court has ignored the ethics committee’s recommendation or has treated it simply as a confirmation of the treating physician’s decision, but in a few cases the court has given the ethics committee some deference as an expert body on matters of ethics. One of the oldest court cases involving an ethics committee’s decision is In the Matter of the Guardianship of Eberhardt, in which the parent guardians of a mentally retarded young woman sought court approval of their
**Network News**

**Baltimore Area Ethics Committee Network (BAECN)**

The BAECN’s June meeting was devoted to a final review and vote on the set of ethics committee standards the network’s Task Force on Standards for Education and Ethics Committee Qualifications has been developing over the past year. The standards were approved and will be available for public distribution in September. For further information, contact Jack Syme, M.D. at (410) 368-3020.

**Metropolitan Washington Bioethics Network (MWBN)**

At the request of Superior Court judges in the District of Columbia, WMBN, in cooperation with Iona Senior Services, the District of Columbia Hospital Association, and the District of Columbia Health Care Association, organized a half-day seminar for the judges on issues such as the withholding or withdrawal of artificial nutrition or hydration, Do-Not-Resuscitate orders, surrogate health care decision making and guardianship. For a review of this highly successful program, please see *Bioethics in Action* on page 10. A similar program was presented to the 21st Annual Judicial Conference of the District of Columbia Courts on June 21.

The June meeting of the WMBN was a cooperative venture with the Washington Hospital Center’s Bioethics Awareness Day. The program addressed the topic of organizational ethics and featured Paul M. Schyve, M.D., Senior Vice President, Joint Commission on the Accreditation of Healthcare Organizations (JCAHO). Dr. Schyve discussed some of the JCAHO’s initiatives in this area, with a focus on the major challenges facing health care institutions today in light of managed care and other environmental factors.

The WMBN will not meet over the summer but will resume its monthly meetings in September with a program on mediation in bioethics, followed by its October meeting on ethical issues in alternative therapies. For details about either of these programs, please consult the Calendar of Events.

**Virginia Bioethics Network (VBN)**

The annual VBN membership meeting will be held on October 18, 1996, in Richmond, Virginia, following a workshop on ethics in health care institutions sponsored by the Center for Bioethics on October 17 and 18 (for information on the workshop, see Other Announcements below). The membership will host a reception for representatives from Richmond area health care institutions, followed by dinner and presentations from area networks. Participants from the workshop are also invited. For more information or to register, please call (804) 924-5974.

**West Virginia Network of Ethics Committees (WVNEC)**

A Summer Intensive Course in Medical Ethics will be held July 25-27 at the Robert C. Byrd Health Sciences Center in Morgantown, West Virginia. Looking further ahead, mark your calendars for the WVNEC’s biannual forum, which will address the subject of “Complying with JCAHO’s Standards on Organizational Ethics.” The forum will take place on October 4, 1996, at the Days Inn in Flatwoods, West Virginia. For information about either of these events, call (304) 293-7618.

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consent to surgical sterilization of their daughter. The Supreme Court of Wisconsin ultimately refused to grant their petition, on the basis that the legislature, rather than the judiciary, was the appropriate body to declare public policy with respect to surrogate decision making of this kind. The majority opinion referred to the ethics committee’s role only parenthetically, indicating simply that the young woman’s physician had submitted the question of the propriety of her sterilization to the hospital’s medical ethics committee, which had approved the surgery. The committee was composed of physicians, psychiatrists, hospital administrators and representatives of the diocese in which the Catholic hospital was located.

The committee’s role was discussed in greater detail by several concurring and dissenting opinions. One judge interpreted the fact that the guardians sought judicial approval of surgery to the physicians’ desire to be insulated from legal liability should their judgment, the ethics committee’s approval notwithstanding, turn out to be in error. Since there was no statutory basis for judicial approval, however, the judge felt the court had no authority to provide such legal insulation. Although the ethics committee’s role was not discussed further, the logical corollary of this argument is that its determination was of no legal importance whatsoever. Only one of the dissenting judges found that the ethics committee’s approval of the sterilization, in addition to the concurrence of her guardians, her physicians, and her guardian ad litem, lent credence to the assertion that sterilization was in the young woman’s best interests, and that the court should have permitted the surgery to proceed on those grounds.

Three years after *Eberhardy*, the Supreme Court of Minnesota adopted a very different position on the role of ethics committees, in the case of *In re Torres*. In *Torres*, the court-appointed guardian for a middle-aged man who had suffered irreversible cessation of nearly all brain functions sought the court’s permission for the removal of his ward’s respirator. After a full evidentiary hearing, the trial court granted the guardian’s petition, but the patient’s court-appointed attorney appealed. In the supreme court’s opinion affirming the lower court, the court repeatedly mentioned the involvement of several biomedical ethics committees, all of which concurred in the treating physicians’ recommendation that the respirator be removed.

In a footnote, the court stated that a court order was necessary in this case because a guardian was statutorily required to obtain court permission to withdraw or withhold life-sustaining treatment. Such an order was, however, not required for the removal of life support systems following agreement between the attending physician and the family and approval by the hospital ethics committee. Several judges on the court took exception to this unqualified endorsement of non-judicial end-of-life surrogate decision making and argued that in recognition of the state’s interest in the safety of its citizens, the withdrawal of life support systems should not occur without approval by a court in a judicial proceeding, regardless of unanimity between the family, physicians, and ethics committee.

The Superior Court of New Jersey, in *In the Matter of Clark*, took a more moderate approach and included the opinion of a hospital’s ethics (optimal care) committee as evidence in its deliberation over what was in the patient’s best interest. This case involved a middle-aged man who had very low cognitive ability as the result of a stroke and had been admitted to the hospital for malnourishment and dehydration caused by his incapacity to eat sufficient amounts of food. Based on their perceptions that the patient was awake, had some ability to interact with others, was not in apparent pain, not on life support systems, and not about to die, his physicians and the hospital’s optimal care committee (a group of physicians who made recommendations regarding further therapy or choice of therapy) recommended that an entero- stomy be performed in order to provide him with sufficient nourishment. His siblings, however, refused to consent to performance of the surgery, based on their evaluation of his quality of life and perceived level of suffering and the very low likelihood of any neurological recovery.

The court reviewed substitute decision making standards enunciated in two earlier state cases and found that the procedures those cases had outlined for health care institutions deciding whether to provide or withdraw life support could not be followed in this case. When, as in this instance, there was not complete concurrence among the patient’s family, the attending physicians, and the hospital’s ethics or prognosis committee, court involvement was required. The court heard testimony from seven of the patient’s siblings and several physicians. Dr. Richard Spence testified on behalf of the optimal care committee. He stated that because the patient was not in pain, the entero- stomy would prolong the patient’s life not his suffering. Based on a best interest test, the court ultimately decided that the entero- stomy should be performed. The decision was consistent with the recommendation of the optimal care committee and that of at least one physician who testified in the case.

Nearly ten years after its decision in *Eberhardy*, the Wisconsin Supreme Court displayed a far more positive attitude towards the involvement of ethics committees in medical decision making for incompetent persons. In *Phillips*, the institutional guardian of an elderly, mentally ill man in a persistent vegetative state petitioned the court for permission to consent to withdrawal of all life-sustaining medical treatment. The patient’s guardian ad litem appealed the court’s decision granting the institutional guardian such authority. The supreme court affirmed, stating that in the absence of evidence of a patient’s wishes, the guardian had a duty to determine what course of treatment would be in the patient’s best interest.

The court then listed the factors it believed a guardian should consider in making this determination. Referring to the fact that the hospital’s ethics committee in this case had unanimously concluded that removing life support was appropriate where the patient was
Ethics Committees and the Courts

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in a persistent vegetative state, the court indicated that the guardian should request review by an ethics committee (if available) and consider its opinion in determining the patient’s best interest. In addition, the court found that the ethics committee’s approval functioned as a confirmation that the physicians’ actions in requesting the guardian’s consent to withdraw treatment was consistent with current medical ethics. Nonetheless, despite the court’s favorable mention of the value of an ethics committee recommendation, it remained merely one of many factors the guardian was to consider.

Perhaps the most well-known recent case involving a hospital ethics committee’s recommendation is In the Matter of Baby K. This case involved a hospital’s decision to withhold respirator treatment from anencephalic infant with virtually no brain function. The hospital argued that since no treatment existed for the child’s condition, no therapeutic or palliative purpose was served by continuation of her ventilator treatment, and the treatment was therefore medically unnecessary and inappropriate. Nonetheless, the baby’s mother refused to give her consent to discontinue ventilator treatment. The hospital then sought the help of its ethics committee, and the ethics committee concluded that the ventilator treatment should end. The mother rejected the ethics committee’s recommendation and continued to insist on her daughter being maintained on the respirator. When the hospital sought judicial resolution of this impasse, the court agreed with the mother, finding that the hospital would be in violation of a number of federal and state laws regulating the provision of medical treatment should it refuse to provide the infant with necessary treatment. The ethics committee’s recommendation in this instance was clearly overruled, and the court gave it no further notice.

Perhaps the most recent case to address the role of ethics committees in medical decision making is Liddington v. Burns. The court in this case clearly recognized the importance of an ethics committee’s recommendation, not so much as an example of alternative dispute resolution but rather as a major influence on the decision making process of an individual patient examining different medical treatment options. In Liddington, a severely deformed infant’s parents brought a medical malpractice action against a physician, alleging that he negligently informed the mother after ultrasound that the fetus was “probably” normal after two failed termination attempts by another physician, and that he failed to order repeat tests that would have revealed those abnormalities at a time when the mother could have legally terminated her pregnancy. The defendant argued that any negligence on his part was superseded by the mother’s failure to obtain a third trimester abortion after a third physician detected the abnormalities, particularly since the first physician’s wife had informed the plaintiff of a physician in another state who performed third-trimester terminations in cases involving danger to the mother or the fetus.

The appellate court affirmed the lower court’s holding that the mother’s conduct did not relieve the physician of liability for any medical negligence. The third physician had consulted his hospital’s ethics committee regarding the permissibility of a third-trimester termination and had informed the mother of the committee’s determination that she could not legally obtain an abortion at that time. It was entirely foreseeable, the court said, that the mother would follow the advice of her third physician, who had conferred with the hospital ethics committee, over the advice of the first physician’s wife. Under the law of superseding cause, the defendant therefore could not be insulated from liability for his negligence.

These cases demonstrate how widely courts differ in their attitudes towards the role and importance of ethics committees in medical decision making. They also point to some of the reasons why the adoption of a consistent approach to ethics committees is likely to be impossible. One reason is that ethics committees differ in composition, structure, function and procedures. In Clark, the ethics committee (also called an optimal care committee or prognosis committee) was composed entirely of physicians whose purpose was to evaluate the need for further therapy and choices of therapy, whereas in Eberhardt, the committee’s membership was far more diverse, containing physicians, administrators, and religious representatives.

Another way in which ethics committees differ is the lack of due process protection in how many of them proceed in their deliberations. In some cases, patients are not notified of the committee’s review of their case and have no input into its process.

Because of the lack of uniformity in their composition and procedures, courts are justified in reviewing ethics committee determinations on a case-by-case basis. In reviewing cases that come to trial that have been reviewed by ethics committees, the courts may want to consider:

1. Whether the ethics committee members have had any training in bioethics or law;
2. Whether the committee includes community representatives or other individuals who espouse values that may not be the same as those of health care providers or institutions;
3. Whether the committee followed minimal elements of due process, including providing notice to the relevant parties, providing an opportunity for each of the parties to be heard, displaying evidence of diverse committee participation in the deliberative process, and providing a rationale for its final recommendation that is supported by relevant ethical and societal norms.

If these criteria are met to the court’s satisfaction, a court may want to give considerable weight to the ethics committee’s recommendation. So long as a committee’s composition and procedures do not meet these criteria, however, courts will need to continue to take a critical stance towards the quality of the committee’s
recommendation and the value of the committee’s role as an alternative dispute resolution body.

Submitted by:
Andrea Imredy, JD Candidate
University of Maryland School of Law
and Diane E. Hoffmann, MS, JD
Assistant Professor of Law
University of Maryland School of Law

2. 102 Wis. 2d 539, 307 N.W. 2d 881 (1981).
3. In the Matter of the Conservatorship of Torres, 357 N.W. 2d 332 (Minn. 1984).
I.E. Phillips Career Dev., Ctr., 167 Wx. 2d 53, 482
N.W. 2d 80 (1992).

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to:
Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Study From a Hospital in the Washington, D.C. Area

Ryan is a three week old baby who was diagnosed with complex congenital heart disease (Epstein’s anomaly) during the prenatal period. At birth he was aggressively managed with pharmacologic, ventilatory and hemodynamic support. A central shunt was inserted and post-operatively the baby developed capillary leak syndrome, acute renal failure, and hemodynamic instability. After two weeks of intense intervention, the family approached the care team about their concern that their baby was experiencing tremendous suffering and that his condition was not responding to the aggressive interventions. The family requested that no further aggressive treatment be initiated and that she not be resuscitated should she arrest. The cardiologist team was hesitant to agree to the parents’ request because they believed that the baby had a reasonable chance for a good outcome and that his condition was reversible. An ethics consultation was requested.

Case Discussion: Comments From a Nurse Ethicist

The central ethical issue in this case involves determining what will promote Ryan’s well being. The primary goal of medical and nursing care is to do good and avoid harm. Choices among alternative treatments should therefore benefit the infant and clearly outweigh the associated burdens and harms. A moral tension exists, however, between benefiting Ryan by sustaining his life with aggressive interventions and avoiding, or at least minimizing, the burdens that may accompany the treatments necessary to do so. Searching for a clear understanding of what Ryan’s interests are and how to promote them should be based on the best information that is available at the time. Questions such as the following may be useful in clarifying the range of options and the values that underlie the pursuit of each option.

I. What is known about the treatment and prognosis for Ryan’s cardiac lesion?

Epstein’s anomaly is an uncommon cardiac defect but Ryan’s particular cardiac malformation was extremely rare. The outcome of treatment ranges from early death to survival following several surgical reconstructive procedures. None of the survivors reported in the literature with anatomy similar to Ryan’s have reached adulthood yet and the degree of morbidity associated with the treatment is described as moderate to severe.

II. What medical and non-medical goals are possible for Ryan?

The range of medical goals may include: 1) aggressive stabilization in preparation for a staged surgical reconstruction of the heart, including interventions to reverse the complications that occurred following cardiac surgery (acute renal failure, capillary leak syndrome, hemodynamic instability) in an effort to maximize survival and positive outcome; 2) maintain the current level of support and treat complications with standard therapies but not pursue invasive interventions such as dialysis or resuscitation; or 3) allow Ryan’s underlying disease process to take its course and promote a peaceful death. Other relevant goals may include relieving pain and suffering, maximizing opportunities for interaction with family and others, or promoting parent infant bonding and family integrity.

III. Based on the goals that are possible for Ryan, what is the range of outcomes that could be expected in relation to each goal and what is the likelihood of each?

Given the medical goals described above, it is important to determine the probable outcomes of pursuing each goal. For example, how likely is it that the proposed treatment will be effective? What degree of risk, intrusiveness or discomfort is associated with the proposed treatment? Will the proposed treatment alter the natural course of the disease? Is the patient experiencing pain? Is the patient dependent on respirator or other technology or treatment for survival? Does the treatment prolong dying? What is the patient’s capacity to experience and enjoy life? If the complications are reversed what is the likely outcome of each reconstructive surgical procedure? What would
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happen if treatment was not escalated or withdrawn?

Evaluating the possible goals for Ryan also involves important values about what makes life meaningful and what sorts of burdens are acceptable in order to achieve those goals. This case highlights the differences in values between the parents and treatment team about how to promote Ryan’s interests. The treatment team values the possibility, however small, to promote survival and therefore they have a high threshold for the burdens they will tolerate in order to give Ryan a chance for life. They believe that the multiple organ system dysfunction is reversible and because the complications are unusual for this type surgery, aggressive intervention is warranted.

The parents, in contrast, also value giving Ryan a chance for life but their threshold for reasonable burdens to give him a chance for life are somewhat different. They believe that the burdens of his current treatment and the possibility that even if he does survive his life may continue to be significantly burdened is disproportionate in relation to the chance that he may survive now and to adulthood.

A secondary issue concerns whose values are to count in determining what will be done for Ryan. Even though infants are not autonomous or self-determining, an element of respect is still required since the lives of children also have unique meaning. To treat patients with respect is to acknowledge and value who they are outside of a medical context, rather than to treat them only according to how professional goals and values are advanced. To respect a child is to acknowledge the importance of his or her world and the relationships that are central to it.

Based on the moral framework of shared decision-making it is necessary for someone to represent the interests of the child. There is a strong presumption that parents should make judgements about what is in the best interest of their child. Parents are identified as appropriate surrogates because strong bonds of affection and commitment are likely to yield the greatest concern for the well-being of their children. Parents are obligated to protect their children from harm and to do as much good for them as possible.

While there are compelling reasons to extend parental decision-making authority, such authority is not absolute. The interests of the parents and the family must take a high priority but do not override the fundamental respect for the best interest of the infant or child. Parents should be decision makers for their infant unless they are disqualified by decision making incapacity, or unresolvable discontentment between them, or their choice of a course of action that is clearly against the best interest of the infant.

When parental decision making is questioned, it is crucial to assess whether the parents are capable of serving as the child’s surrogate and/or whether their position is morally defensible. The following questions may assist in such an assessment:

- Do the parents meet the standard of reasonable parents? (Do the parents have the capacity to understand the information relevant to the decision? Are the parents capable of making a reasoned decision in accordance with their values and beliefs? Are the parents able to put their child’s interests above all others? Are there any serious conflicts of interest that may bias their decision making?)

- Is the parents’ request within the range of morally acceptable action? (see range of goals described above)

- What evidence is there that the parents should be disqualified as the decision maker for their child?

- Are there actions that could be taken to enhance the parents’ ability to act as the child’s surrogate?

In Ryan’s case his parents clearly met the criteria of reasonable parents and it could be argued that given the uncertainty surrounding his prognosis their request to forego any further aggressive intervention was a morally acceptable option. Professionals must be cautious however not to base their decision to disqualify a parent as a decision maker merely on the basis that they disagree with the recommendations of the health care team or that they must be protected from future guilt or responsibility.

Health care professionals (HCPs) involved in the care of infants such as Ryan may be confronted with conflicting values and obligations. HCPs have a duty to benefit others and prevent and remove harmful conditions. In the care of infants, HCPs must attempt to provide them with the opportunity to become autonomous adults who will realize their own unique life goals. Yet the very interventions that sustain life may also cause significant burdens to the patient.

HCPs also have obligations to families. A moral framework for shared decision-making requires the balanced involvement of both parents and HCPs. Both are committed to the goal of patient well-being and both must have enough information from the other to accomplish this goal. As responsible parties in the health care setting, HCPs are obligated to facilitate and support a collaborative process of care-giving and decision-making. Parents are obligated to continue their care-giving role within the critical care setting, and to work with HCPs to establish the scope of parental care giving including decision-making.

As advocates for patients and families, HCPs must have a clear understanding of the facts of the case, the context of the decision, family values and goals, and the family’s understanding of their child’s condition. HCPs must also clarify their own values and possess an adequate understanding of the ethical dimensions of decisions such as this one. Their advocacy can be enhanced by having mechanisms for resolving disputes, support systems that facilitate advocacy efforts, and direct access to ethics consultants and ethics committee consultation.

Submitted by:
Cindy Hylton Rushston, DNSc., RN, FAAN
The Johns Hopkins Children’s Center
Baltimore, MD

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Case Discussion: Comments From a Health Law Attorney

It is the unusual case that presents such a clear conflict between the desires of parents, (who are usually held by both statute and judicial decision to be the proper agents to give or withhold consent to medical treatment for their minor children), and the best medical chance for their child's survival. Since the medical providers cannot, absent consent, proceed with further treatment, the first question in this case is whether and how that consent can be obtained from someone other than the parents. The available procedural alternatives in turn raise the question of what legal duty the providers have to seek such alternative consent.

Alternative Consent

In 1980, Adam L. was born in the District of Columbia. Less than three months later he was diagnosed as suffering from patent ductus arteriosus. Corrective surgery was recommended by several physicians, but Adam's parents consistently refused to give consent, citing their financial obligations to Adam's five siblings, a desire to wait until Adam was old enough to participate in the decision, and optimism based on the father's good health despite an uncorrected congenital heart defect. On September 28, 1982, Adam was brought to a local emergency room with symptoms of cardiac enlargement, heart failure and possible viral pneumonia. When Adam's parents again refused to consider surgery and attempted to remove him from the hospital, officials called the Metropolitan Police who intervened and brought in the Child Protective Services unit of the local court. A temporary “shelter” order kept Adam at the hospital until a hearing could be conducted on the District of Columbia's petition asking that he be declared a “neglected” child and continued in shelter until necessary medical treatment had been provided.

The Honorable Frank E. Schwebel, then sitting in the local trial court, determined that within the definition of the D.C. child abuse and neglect statute, Adam was "neglected." He found that although parents have a primary right to raise their children according to their own consciences and their decisions deserve great deference, this prerogative may give way when there is a conflict between their decisions and their child's best interest. He noted:

"parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves." The surgery was ordered, Adam survived and was returned to his parents.

Notably, the decision in Adam did not rest on a determination that the boy's parents had intentionally failed to care for or love him. Instead, it focused on the Court's determination, as parens patriae, of what course was "rationally" in Adam's best interest. The Court's decision was clearly influenced by medical testimony which characterized the risks of the proposed procedure as "very slight" and "99.5%" likely to be successful in so young a child. The sole medical witness also emphasized that the operative risks would increase as Adam grew older and opined that non-performance of the surgery would likely lead to progressive development of the defect, heart failure and possibly death. Finally, officials of the hospital which reported Adam to child care authorities testified that the surgery would be performed without regard to Adam's parents' resources.

Adam is not a unique decision, but there is no clear line determining when a court in a particular jurisdiction will or will not order a particular treatment. The invasiveness of the proposed treatment, the potential risks with and without it, and the basis of the parent's objections will all likely be considered. Although there is an even greater reluctance expressed in the decisions to overrule a parent's objections based on religious belief, where the danger of inaction to the child's survival or health is sufficiently grave, even those objections have been overruled. In this case, the risk of inaction is the death of the child. This would be weighed against the "reasonable chance" of a favorable outcome, the likelihood of a reversal of his condition and, given the apparent lack of religious objection, might well persuade a court to order further treatment, particularly if assurance could be given that the baby would not be subjected to intense pain.

The Duty to Obtain Alternative Consent

Given the alternative of obtaining consent from a court or other agency, the question arises as to what legal duty, if any, the providers have to seek such consent.

At least one commentator has suggested that physicians who do not seek alternate authorization for medical treatment they believe necessary to preserve their minor patient's life could be subject to criminal penalties. In practice, however, whatever their theoretical foundation such prosecutions are unlikely to be either instituted or successful.

A more likely source of legal obligation is the child welfare statutes of the particular jurisdiction. For example, in the District of Columbia, the statute's definition of a "neglected child" includes one who is not receiving "necessary" medical care. The statute also requires that physicians, nurses and others who know or "have reasonable cause to suspect" that a child is "in immediate danger of being...a neglected child [as defined in the statute] shall" (emphasis added) report the child to either the Metropolitan Police or Child Protective Services. "Willful" failures to report may subject the individual to either fine or imprisonment. In a case such as the one presented, the proposed interventions appear to be "necessary" for the child's survival and an argument could certainly be made that under this statute the physicians have an obliga-

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welfare may range from a parent’s resigned acceptance, as in the case of Adam L., to a contested “battle of experts” before a court or even a decision by the parents, for emotional or financial reasons, to give up all claims and custody of the infant. Absent repeal of such “Baby Doe” requirements, however, the health care providers whose knowledge and skill places them in conflict with parental decisions denying “reasonable” treatment have little choice but to set the series of events in motion, however it ends.

Submitted by:
Martha Ann Knutson, JD
Gilberg & Kurent, Washington, D.C.

2. D.C. Code Ann. §16-2301(b)(B) defines a neglected child, in part, as one who is “without...care or control necessary for his or her physical, mental or emotional health...”
8. D.C. Code Ann. §2-1353(a) and (b) (1994).
11. Id. §1340.15(2).
12. Id.

Case Discussion: A Rebuttal to the Legal Analysis

Cases like Ryan’s rely on predictions about prognosis and recovery. Such predictions necessarily involve value judgments by parents and physicians. The physician’s claim that the baby has a “reasonable” chance for a good outcome may be based on his assessment that his current complications may be reversible and that he could survive for some time with palliation until the first surgical correction could be undertaken. Parents are likely to focus on what his life will be like now and during the time until surgery is performed, the burdens of the surgery and beyond. Unlike the case involving Adam L. (patent ductus arteriosus), where treatment itself involves reasonable risks and the chance for complete correction is expected, Ryan’s defect is much more complex and the outcome quite uncertain. With so few cases to base any prediction about outcome, predictions become less precise. Under such conditions of uncertainty about the success of the corrective surgery, it would be hard to argue that any attempt at surgical correction would unequivocally result in survival or improved function. Using the language of the Baby Doe Regulations, one could argue that the continued treatment and the proposed surgical interventions may not “completely ameliorate or correct [life-threatening] conditions” and therefore are not obligatory. One must be cautious about interpreting the Baby Doe regulations so literally, however, because they deliberately contain ambiguous language. For example, the regulations state that appropriate hydration, nutrition, and medications must be provided—it does not specifically state that “under no case can nutrition, hydration or medication be withdrawn.” The interpretation of the meaning of “appropriate” within the
context of a particular case must therefore be explored.¹

Although there are cases where the courts should appropriately be involved, cases such as this one are best resolved within the context of the provider/parent relationship. Unless it is evident that the treatment refused by the parents is clearly beneficial as in the case of Adam L., it is prudent to advocate for open, respectful communication, and opportunities for honest acknowledgment of the differences in values among providers and parents, and institute a process that is fair and responsive. Often ethics committees can play an invaluable role in facilitating this process. Routinely taking such cases to the courts seems unjustified and may create unnecessary and detrimental adversarial relationships.

Cindy Hylton Rushton, DNSc., RN, FAAN


THE NEW JCAHO ORGANIZATION ETHICS STANDARDS

For several years, the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) has required healthcare organizations to demonstrate compliance with its Standards for Patient Rights and Ethics in order to qualify for accreditation. These standards have focused on patients’ rights to treatment, to be involved in all aspects of their care, to give or refuse consent to medical treatment, to be fully informed about the risks and benefits of and available alternatives to recommended treatment, and to protection of patient confidentiality, privacy, security, and autonomy. They also address patient participation in medical research, the use of advance directives, end-of-life decisionmaking, and the use of life-sustaining treatment.

In 1995, the JCAHO added a section called “Organization Ethics” to its Patient Rights and Ethics Standards. These provisions require that a healthcare organization operate

according to a code of ethical behavior that addresses marketing, admission, transfer and discharge, billing practices, and the relationship of the hospital and its staff to other health care providers, educational institutions and payers. Although the new standards are expressed in very general terms, they have far-reaching implications for the operations of health care organizations, both internal and external.

In its explanation of Organization Ethics, the JCAHO states that a hospital must have and operate according to a code of ethical behavior (not necessarily a single document) that ensures that the hospital conducts its business and patient care practices in an “honest, decent and proper manner.” The JCAHO provides the following examples of such conduct in the various areas addressed by the standards:

**Organizational Relationships:**
- proposed contractual relationships with providers of goods or services are evaluated and chosen on the basis of best-bid practices and the potential for conflict of interest;
- governing board members sign conflict of interest statements;
- investment in or ownership of other health care service providers, such as a home health agency or medical equipment supplier, is disclosed to the patient and the patient is given a choice among such providers;

**Marketing:**
- marketing materials reflect only the services the hospital can presently provide as opposed to services it is planning to provide in the future or refers to other providers;
- marketing materials state the actual level of licensure and accreditation;

**Billing/Billing-related Disputes:**
- initial patient billing is itemized and includes dates of service;
- a formal process exists for expeditious review of patient or other payer questions about hospital charges and for courteous and non-threatening discussion and resolution of disputes;
- the number of patients or insurers who come back and dispute the bill is tracked and used to improve billing practices;

**Admission/Transfer:**
- admission and transfer policies are not based on patient or hospital economics;
- the only basis for diversion or transfer of a patient to another hospital is the inability to safely treat the patient’s specific condition or disease.

The organizational ethics standards also address the issue of patient rights to perform or refuse to perform tasks in or for the hospital in hospitals with longer lengths of stay.

While organizational ethics is an uncharted ethical territory for most businesses, difficulties in developing appropriate ethical standards for business practices are compounded for healthcare institutions by the unique challenges of a healthcare system that has undergone sea changes in how care is organized, delivered and paid for. In response to the JCAHO’s addition of its new standards, ethics programs are taking the initiative and organizing seminars and workshops addressing this topic. The goals of these sessions are to help healthcare institutions understand the new standards and to assist the individual organization in developing an appropriate strategy for response. As a result, the individual institution should not only be able to meet the letter of the law but incorporate a spirit of ethical conduct into all of operations.

OTHER ANNOUNCEMENTS

Responding to the JCAHO Organizational Ethics Standards:

**A Workshop**

In 1995, the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) added a section called “Organization Ethics” to its Standards for Patient Rights and Ethics. (See article this page.) Depending on interpretation and implementation, these new standards could well become the framework for assuring oversight of the managed care revolution. But whatever their role in the future of healthcare management, these standards are a part of the JCAHO’s requirements for accreditation, and HCCs will need a plan for response.

The Center for Biomedical Ethics at
Other Announcements
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The University of Virginia has developed a two-day intensive workshop to address this subject. The goals of the workshop are (1) to help HCOs (particularly hospitals and nursing homes) understand the new standards, and (2) to help the individual organization develop an appropriate strategy for response.

The program, “Responding to the JCAHO Organization Ethics Standards: A Workshop,” is scheduled to be held in Charlottesville, Virginia, November 14 and 15, 1996. Paul Schyve, M.D., Senior Vice President for Standards at the JCAHO, will discuss his ideas on the direction of the JCAHO at dinner on November 14. The program requires that two persons attend from each organization: an administrator and one other, preferably an ethics committee member.

For further information or to register, please call (804) 924-5974.

Developing Hospital Ethics Programs (DHEP)

The Developing Hospital Ethics Programs (DHEP), presented by the Center for Biomedical Ethics at the University of Virginia, is a unique six-day course of study for healthcare professionals from hospitals and other healthcare facilities. The course is designed to help these professionals start or strengthen ethics committees within their institutions. The program is limited to 24 participants.

The next DHEP session is scheduled from August 19 to 24, 1996. For information or to register, please call (804) 924-5974.

For announcements of upcoming workshops in the Mid-Atlantic area, please refer to the News and Calendar sections of this newsletter.

BIOETHICS IN ACTION

A recent study in hospitals throughout the country showed that many physicians simply do not follow the explicit wishes of their patients even when these are in writing and forcefully presented. One reason often cited for this behavior is that doctors fear legal and legal liability. To help the legal and the medical professions better understand each other, the Metropolitan Washington Bioethics Network, Iona Senior Services, the District of Columbia Hospital Association and the District of Columbia Health Care Association jointly presented a precedent-setting seminar for the judges of the District of Columbia Superior Court and District health professionals on the biomedical and legal issues affecting patients, hospitals, nursing homes, other healthcare facilities, and the courts. Held as part of the District of Columbia Courts’ Judicial Education Conference on April 27, 1996, the seminar was titled “Is Death an Option?”

Among the 100 participants were judges of the D.C. Court of Appeals and the D.C. Superior Court, City Council Members Linda Cropp and William Lightfoot, physicians, attorneys, nurses, social workers, bioethicists, clergymen, and hospital and nursing home executives. Except for brief opening remarks, there were no speeches. The unique seminar centered around two mini-dramas entirely written and acted by health care facility staffs.

One mini-drama concerned the problems and suffering of an elderly woman in a nursing home who wishes to die but is transferred to a hospital where she is force-fed and restrained against her will. When her condition deteriorates further despite treatment, the doctors and nurses go through complex procedures to obtain a do-not-resuscitate order to end her suffering.

The second mini-drama was a heart-rending monologue, written by a bioethicist, of a three-year old born with mental retardation and cerebral palsy, who spends her life between the hospital’s intensive care unit and a long-term care facility, abandoned by her teenaged parents and comforted only by a volunteer.

After the panel discussion, the audience broke into ten small groups composed of judges and health care professionals to analyze and discuss the issues further. This was an excellent opportunity for judges and health care professionals to ask questions of one another and exchange perspectives.

Both sides learned from the interchange.

Submitted by:
Vera Mayer, Senior Advocate
Iona Senior Services
Washington, D.C.

CALENDAR OF EVENTS

JULY
14-15 American Society of Law, Medicine & Ethics, “Contemporary Challenges and Controversies for Nurses: The Interface of Ethics, Law and Policy.” Co-sponsored by the Hospice Foundation of America, Janssen Pharmaceutica, the Johns Hopkins School of Nursing, and The Nursing Spectrum. At the Radisson Plaza, Baltimore, MD; registration fees are $125 (students), $235 (ASLME members), $285 (nonmembers). For information, contact the Meeting Registrar at (617) 262-4990 (tel), (617) 437-7596 (fax), or aslme@bu.edu (email).

25-27 West Virginia Network of Ethics Committees, Summer Intensive Course in Medical Ethics. July 25 - 2:00-6:00 p.m., July 26 - 8:00 a.m.-6:00 p.m., July 27 - 8:00 a.m.-12:00 noon, at the Robert C. Byrd Health Sciences Center, University of West Virginia, Morgantown, W.V. To register, contact Cindy Janson at (304) 293-7618 (tel), (304) 293-7442 (fax).
AUGUST
19-24 University of Virginia, Center for Biomedical Ethics. "Developing Hospital Ethics Programs (DHEP)." At the University of Virginia, Charlottesville, VA; course limited to 24 participants from hospitals and other health care facilities. For information or to register, call (804) 924-5974.

SEPTEMBER
24 Washington Metropolitan Bioethics Network Meeting. "Mediation in Bioethics," Coordinator: Naomi Karp, American Bar Association Commission on Legal Problems of the Elderly. 4:00 - 6:00 p.m., at the ABA Commission on Legal Problems of the Elderly, 15th and H Streets, Washington, D.C. For information, call (202) 304-7618.

26 University of Maryland Medical System, Medical Humanities Hour. "Ethics of Gene Therapy" 4:30 - 5:30 p.m., at the Shock Trauma Auditorium, University of Maryland Hospital, Baltimore, MD. For information, call Henry Silverman, M.D., at (410) 706-6250.

26-28 Tuskegee University, Conference on the Human Genome Project. At the Kellogg Conference Center, Tuskegee University, Tuskegee, AL; registration fees (before 8/1) are $75 (students), $120 (post-docs), $150 (academic/gov't), $400 (others). For information, contact Ed Smith at (334) 727-8028 (tel), (334) 727-8552 (fax), or edsmith@acd.tuske.edu (email).

TBA Baltimore Area Ethics Committee Network Meeting. Details TBA. Call Jack Syme, M.D., at (410) 368-3020.

OCTOBER
4 West Virginia Network of Ethics Committees, Biannual Forum. "Complying with JCAHO's Standards on Organizational Ethics." At the Days Inn, Flatwoods, W.V. For information or to register, contact Cindy Jamison at (304) 293-7618 (tel), (304) 293-7442 (fax).

10-13 The Society for Health and Human Values and the Society for Bioethics Consultations Joint Meeting, "Health Care Ethics and Humanities: From Our Roots to Our Shoots," Sheraton Cleveland City Center, Cleveland, Ohio. For information call Jackie Kenney at (703) 556-9222.

17-18 University of Virginia, Center for Biomedical Ethics' October Workshop. "Ethics in Healthcare Institutions: New Issues, Controversies, and Practical Considerations." At the Holiday Inn, Richmond, VA; registration fees are $75 (Center Fellows), $100 (others). For information, call (804) 924-5974.

18 Virginia Bioethics Network, Annual Membership Meeting. At the Holiday Inn, Richmond, VA, following the Center for Biomedical Ethics' October Workshop. For information, call (804) 924-5974.

29 Washington Metropolitan Bioethics Network Meeting. "Ethical Issues in Alternative Therapies." 4:00 - 6:00 p.m., location TBA. For information, call (202) 304-7618.

NOVEMBER
1-2 American Society of Law, Medicine & Ethics, "National Meeting on Legal and Institutional Issues in Pain Relief," Royal Sonesta Hotel, Boston, MA. For information call (617) 262-4990.

14-15 University of Virginia, Center for Biomedical Ethics. "Responding to the JCAHO Organization Ethics Standards: A Workshop," At the University of Virginia, Charlottesville, VA; registration fees are $1,000 (for required two participants per institution). For information or to register, call (804) 924-5974.


19 West Virginia Network of Ethics Committees, Wilhelm S. Albrink Lecture in Bioethics, "Overtreatment at the End of Life," Daniel Callahan, President, The Hastings Center. Time TBA, at the Robert C. Byrd Health Sciences Center, University of West Virginia, Morgantown, W.V. For information call Cindy Jamison at (304) 293-7618 (tel), (304) 293-7442 (fax).
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The Mid-Atlantic Ethics Committee Newsletter  
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