

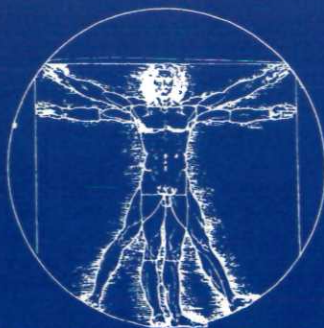
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Summer 1994

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia

Published by the Institutional Ethics Committee Resource Network

Law & Health Care Program

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ETHICS COMMITTEES: TIME TO EXPERIMENT WITH STANDARDS

Ethics committees for patient care issues have become a fixture in hospitals in the United States. In the area of patient care, ethics committees were established in some institutions in the 1970s in response to recommendations by the New Jersey Supreme Court in the Quinlan case,¹ and later, in response to recommendations of a President's Commission² and the "Baby Doe" guidelines.³ A few states have passed legislative mandates. In Maryland,⁴ for example, all licensed hospitals and nursing homes must have a "patient care advisory committee." In New Jersey,⁵ hospital-licensing standards include a provision that a hospital have either an ethics committee or a prognosis committee. New York State has legislation⁶ pending that would mandate the establishment of committees. Recent legislation has even stipulated that certain types of cases or disputes be taken to these committees. For example, the recently enacted Maryland Health Care Decisions Act⁷ requires that if a disagreement exists among family members of the same class (for example, the patient's children) about termination of

Letter From the Editor

In this issue of the Newsletter our focus is on the changing role of ethics committees as shaped by recent state statutes and what this means for ethics committees in terms of structure and process—should members of ethics committees be required to go through some type of training, should standards be established for case consultation? The lead article in this issue, reprinted from a recent issue of the *Annals of Internal Medicine*, addresses some of these questions. This issue is also the last in which I will appear as editor, at least for the next year. I will be taking a research leave beginning this summer. While I am away, Janice Rosenzweig, a practicing health law attorney in Baltimore will edit the newsletter. Please feel free to contact Janice with any ideas, articles or suggestions you have for future issues. She may be reached at (410) 825-0552; Fax (410) 825-9373. Enjoy the rest of your summer!

Diane E. Hoffmann

life support, the dispute must be referred to the institution's ethics committee; the health care provider may follow the recommendation of the committee without fear of liability for

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NETWORK NEWS

Baltimore Area Ethics Committee Network (BAECN)

The Baltimore Area Ethics Committee Network held its last meeting on May 26th at Good Samaritan Hospital. The topic for the session was: Where do we go from here? In advance of the meeting, participants were sent a brief Survey of Interests and Needs. Included in the survey was the question: "What do you see as the major purposes of regularly scheduled network meetings?" Respondents were asked to check up to three of the following options: a) sharing information about ethics committee issues; b) formal continuing education for ethics committees by experts in the field; c) a forum for joint formulation of policies and/or procedures; d) a clearinghouse for policies and/or procedures; e) a forum for community education; f) a forum for setting procedural guidelines for ethics committee case consultation process; g) a forum for setting suggested educational standards for ethics committee members; h) a forum for external review of hospital or nursing home ethics consultations; i) a mechanism to influence public policy on health care issues in Maryland. Respondents were most in agreement on options a and b. There was also considerable interest in serving as a way to influence state health care policy. Whether the Network should get involved in drafting suggested educational standards for members or procedural guidelines for case consultation was debated at some length by those in attendance. At the end of the meeting there was some consensus that the Network should change its structure from its rather informal organization to a more formal entity with officers and working groups. A working committee was established to draft a mission statement and operating procedures for the Network. The committee will meet during the summer and prepare the draft documents for review by other Network participants in the fall. For more information about the Network contact Henry Silverman at 410-706-6250.

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Washington Metropolitan Bioethics Network (WMBN)

Plans for the September meeting of the Washington D.C. Network include a panel discussion by members from several active ethics committees in the area. Focusing on what makes a successful ethics committee, the panel hopes to assist health professionals who are now developing committees in their own institutions.

Looking farther ahead, plans for the Network's October meeting include an examination of the changes in Emergency Room Medicine given the number of patients with DNR orders. Guest speakers will address this topic in light of legal reform in Virginia and a recent opinion by the attorney general in Maryland regarding DNR orders in response to questions raised under the new Maryland Health Care Decisions Act (see article in this issue).

For more information about Network activities contact Joan Lewis at the District of Columbia Hospital Association (202) 682-1581.

Virginia Bioethics Network (VBN)

The VBN continues to move forward with its goal to develop guidelines on the fairness of the processes used by ethics committees for case consultation. It hopes to have the guidelines out by October 1995. Undoubtedly, these guidelines will reflect VBN's philosophy which its Board President, Ellison Conrad, M.D. says "stresses local voluntary control of ethics activities in healthcare institutions, rather than centralized mandated control." As a result of these efforts, VBN hopes to become a model for many bioethics networks elsewhere.

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STATE NEWS

MARYLAND

State Attorney General Interprets Maryland's Health Care Decisions Act with Regard to DNR Orders

In response to questions raised by Senator Rosalie Abrams, Director of the Maryland State Office on Aging, on May 3, 1994, the Attorney General issued an Opinion on questions raised by the Health Care Decisions Act regarding Do Not Resuscitate Orders. In her letter to the AG, the Senator raised seven questions:

1. Under what circumstances, if any, may a "surrogate decision maker" consent to the withholding or withdrawing of a life-sustaining procedure or the entry of a "do not resuscitate" ("DNR") order on a chart of a patient?

2. Under what circumstances, if any, may a guardian consent to the withholding or withdrawing of a life-sustaining procedure or the entry of a DNR order on the chart of a patient?

3. What is the responsibility of the guardian when the patient's attending physician indicates that a life-sustaining procedure should be withheld or withdrawn or that a DNR order should be entered because such procedure would be medically ineffective?

4. Does a health care agent have authority to instruct that a DNR order be entered for a patient who has not been certified to be in a terminal condition, persistent vegetative state ("PVS"), or end stage condition?

5. What is the effect of a patient's advance directive on the physician's, surrogate's, or guardian's ability to authorize the withholding or withdrawing of a life-sustaining procedure or the entry of a DNR order?

6. What is the status of DNR orders currently in the medical files of patients in related institutions who have not been certified to be in a terminal condition, PVS, or end-stage condition?

7. May related institutions that handle chronic care cases require consent to the withholding or withdrawing of life sustaining procedures or the entry of a DNR order as a condition of admission to the facility?

Surrogate Decision-making

In general, the Health Care Decisions Act provides that a surrogate may only make a decision to withhold a life-sustaining treatment from a patient if the patient has a terminal or end stage condition or is in a persistent vegetative state. The Opinion points to two problems in the law with respect to this provision and the withholding of cardio-pulmonary resuscitation from an incapacitated patient. First, the definition of life-sustaining procedure in the Act appears to limit it to procedures that would "afford a patient no reasonable expectation of recovery from a terminal condition, persistent vegetative state, or end-stage condition." This interpretation of the statutory language would mean that in some cases, CPR was not a life-sustaining procedure, e.g. in those cases where someone was perfectly healthy but had a cardiac arrest. Given this illogical result, the AG concludes that it was the intent of the legislature to include CPR as a life sustaining procedure. Second, the limitation on a surrogate's ability to withhold CPR to those conditions where the patient is terminally ill, in a persistent vegetative state, or has an end stage condition, overlooks the fact that a cardiac arrest can drastically change an individual's health status. Some patients who do not fit into one of the three statutory categories prior to arrest would be considered terminally ill or in an end stage condition once they arrest. In these cases, their prognosis for recovery from the arrest is very small. The Opinion concludes, therefore, that if a surrogate is acting based on the wishes of the patient or in their best interest, they may authorize a DNR order even if the patient is not currently in one of the three statutory categories if two physicians certify that

the patient would be in one of the categories upon cardiac arrest.

Guardian Decision-making

The Opinion concludes that a guardian may consent to a DNR order for a patient only if "(i) the court has approved the decision, whether or not the patient has been certified to be in a terminal condition, PVS, or end stage condition; or (ii) under circumstances specified by law, the court has authorized the guardian in advance to make decisions concerning life-sustaining procedures and the patient has been certified to be in a terminal condition, PVS, or end stage condition."

When two physicians have determined that CPR would be medically ineffective under the law, it is the duty of the guardian to inform the court of that decision. The court may then, if it wishes, order the guardian to request a transfer of the patient to another health care provider who would be willing to resuscitate the patient.

Agent Decision-making

As long as an agent's authority to withhold or withdraw life-sustaining treatment on behalf of an incapacitated patient is not limited to those situations where a patient has a terminal or end stage condition or is in a PVS, an agent may authorize a DNR order for a patient even if the patient is not in one of these three conditions. The agent's decision, however, must be consistent with the patient's wishes or, if these are unknown or unclear, with their best interest.

Status of DNR Orders

Executed Prior to New Law

In cases where a DNR Order was written and entered into a patient's chart prior to the effective date of the new law (Oct. 1, 1993), the Order remains valid, if executed based on the law at that time. The law, prior to the enactment of the new law allowed a physician to enter a DNR order for a patient only at the instruction of a

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ETHICS COMMITTEES

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failure to obtain the appropriate consent. The Arizona Living Wills and Health Care Directives Act⁸ permits that if a listed surrogate cannot be located, the patient's attending physician may make health care treatment decisions for the patient after consulting with and obtaining the recommendations of an institutional ethics committee. The proposed New York State legislation, similarly, would allow a physician to rely on the advice of an ethics committee for a patient who has no agent or close family members, thus avoiding guardianship proceedings.

In 1991, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) mandated⁹ the establishment of a "mechanism" to consider ethical issues in patient care. However, it has not issued guidelines for what satisfies this bare rule. This "notably vague"¹⁰ requirement allows for vast diversity among institutions to address ethical issues in patient care.

A recent survey of committees¹¹ showed that their three most common tasks were educating clinical staff and patients about ethical issues in patient care, developing institutional policies, and providing consultative services on request. Despite this general agreement on tasks, little consensus exists about standards for education and skills necessary for membership on a committee, or for the internal operations of committees, for providing consultation as a committee member, or for procedural guidelines for the conduct of consultations.

We have given a major part of our careers to work with ethics committees in the Mid-Atlantic states. With some important exceptions, most members of ethics committees engage in little or no serious study of clinical ethics or related topics. In practice, each member tends to maintain his or her own personal concept of ethics, which is rarely examined in serious debate. In many places, committee members begin to serve without even a modest orientation to the committee's tasks.

Moreover, we have seen committees, which are confused about their advisory role, make decisions "behind closed doors"¹² at the request of clinicians who approach the committee without notifying the patient or surrogate decision makers. Standards of due process are not followed and may even be unknown to the committee. Inattention to procedural due process raises concerns that the rights of caregivers, patients, and patients' families are possibly being compromised or violated.^{10, 13} The degree of respect for confidentiality is difficult to judge, but patient's charts are easily obtained by consultants whose participation in care is unknown to the patient. Some committees also call on the services or advice of external consultants who have no locus of accountability in the institution. In short, we worry that an "ethics disaster" is waiting to happen.

"An ethics committee that becomes a forum for risk management has abdicated its mission."

Even at their best, ethics committees are not well used by clinicians or patients and surrogates. Major causes include lack of knowledge about the committee's services, poor institutional support, and a lack of confidence due to the absence of research on the outcomes of consultations.^{14, 15} The literature on ethics consultation consists of collections of case reports^{16, 17} and evaluations focused on physicians¹⁸⁻²⁰ who requested consultation. To our knowledge, no epidemiologic research exists on the efficacy of ethics consultations for specific decisions made in patient care.

The absence of such studies has lowered expectations of committees and has increased physicians' skepti-

cism about contacting them in ethically troubling cases.²¹

Another source of confusion stems from role conflicts among the ethics committee, legal officers, and risk managers. When committee members are unsure of their mission and administrators are overly concerned about protecting the institution, legal and risk management concerns can easily displace the committee's authentic role. An ethics committee that becomes a forum for risk management has abdicated its mission.²²

Hospitals that invest in the education of resource persons for committees can point to some progress in remedying these major problems.²³ Good multi-institutional epidemiologic studies of the process and outcomes of ethics consultations depend on agreeing on the goals of consultation,²⁴ on strengthening an educational and training infrastructure for ethics consultation, and on experimenting with standards. Wide diversity in consultation practices now presents major obstacles to such studies. For example, crucial data are missing because some committees or consultants do not enter chart notes or submit reports of their work to review committees.

Where do we go from here? The time for a laissez faire approach to ethics committees is long past. Some form of regulatory oversight is to be expected because the activities of ethics committees bear directly on patients' rights and enable life-and-death decision making. Committees are also aiding institutions in the dialogue about medical futility and rationing of efficacious treatments in the face of economic scarcity.²⁵ Although self-regulation is preferable, if it fails, committees potentially face regulation by the JCAHO,²⁶ state or federal agencies, or court-imposed practices.

In response, we strongly recommend a period of experimentation with standards aimed at raising the level of accountability in practices of committees. Such standards should address: 1) access to the committee and its services; 2) education and training of committee members; 3) case consulta-

tion procedures; 4) documentation of consults; and 5) review of committee processes and recommendations.¹⁰

As to standards for appropriate education and training, more consensus is needed on what new and continuing members should learn about ethical concepts and approaches to ethical problems in patient care. We recommend that standards be structured in two tiers, one minimal and one exemplary, and that the locus of judgment about satisfaction of educational standards remain in each institution as it presently does for other hospital committees. At a minimum, new ethics committee members ought to receive a thorough orientation to the history and literature of ethics committees and to the specific mission and duties of their own committee. New members should also engage in a course of study of ethical concepts, types of ethical problems most frequently faced by clinicians and patients, and methods of ethical decision making. Relevant health law and differences between legal and ethical considerations need to be stressed. This minimal standard should be satisfied before new members are given full committee assignments.

The exemplary standard would be applied to members who plan to participate in clinical ethics consultations or for members responsible for training others in case consultation procedures. A 1988 conference sponsored by the Society for Bioethics Consultation²⁷ concluded that education and training of bioethics consultants required in-depth work in biomedical ethics, health care law and public policy, clinical medicine and decision making, cultural and religious traditions and their effects on health care decisions, and psychological and interpersonal knowledge and skills. These areas also appear appropriate for ethics committee members engaged in case consultation.

Several local or regional networks of ethics committees or "bioethics networks" have evolved.²⁸⁻³⁰ We believe that such networks are good settings in which to debate, plan, and implement a trial period for standards

because of the prevailing diversity of committees.

Institutions and ethics networks desiring to improve quality in bioethics services and in the education of ethics committee members³¹ can forge cooperative educational and training relationships. A newly formed, statewide network in Virginia has recently embarked on the task of defining how education and training will be organized and delivered.

Ethics committees are no longer in their infancy¹³—they are aiding decision makers to make important

***"Where do we go
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life-and-death choices. We agree that a great need exists for epidemiologic studies and evaluative research on ethics committees; this must continue to take place. But we cannot wait for the definitive study to begin to experiment with minimal standards for these committees.

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Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region 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 Maryland Hospital

A five year old girl developed a brain tumor while living in Alaska. Her family, with the support of their church, embarked on a series of homeopathic and natural forms of treatment throughout the country before presenting to an Arizona hospital where the tumor was judged too large to be surgically removed. Radiotherapy was begun with encouraging results, but the family abruptly left the area before it had been completed and were not seen again until they asked for consultation at a Baltimore hospital.

On evaluation, the child was found to have a large tumor mass which, after consultation with the Arizona hospital, appeared to have grown significantly. Nevertheless, the oncologic and surgical team assessing the patient, thought that there was a twenty-five percent chance of curing the child with aggressive surgery and chemotherapy. This information was presented to the parents. While both appeared to have a genuine concern and love for the child, the mother wished to consult her church leaders and appeared to feel that

alternative forms of therapy may be more appropriate than traditional medical care. The father was receptive to the idea of surgery and chemotherapy.

One day the parents abruptly told the health care team that they had decided to take their daughter to a hospital in Seattle, Washington. The medical care team asked if they had made any arrangements for the child to be seen at the Washington hospital. When the parents said no, the surgical team arranged for the child to be seen by an eminent Washington State surgeon. In spite of this, one of the surgical team remained suspicious that the parents would not keep the appointment.

The surgical team requested an ethics committee consultation and asked what their obligations were to the child in light of their suspicions.

The ethics committee met with the surgical staff and the parents. After much discussion and reassurance by the parents that they had the child's best interest at heart, the ethics committee saw no compelling reason to suggest to the surgical team that they try to restrain the parents from taking the child out of the hospital.

A week later, one of the ethics committee members called the Washington State hospital to see if the child had been seen at the appointed time. The surgeon stated that the child had not been brought to the appointment nor had the parents called to arrange for another appointment. The ethics committee, in the process of completing the consultation, had obtained a number of phone numbers of individuals in the family's church community who routinely knew the family's whereabouts. The question arose then as to what the committee's obligations were to pursue this matter further.

Case Discussion: Comments From a Nurse/Attorney

This child unfortunately suffers from a life-threatening physical condition and must endure the behavior of

parents who fail to provide necessary medical care. The actions of the parents seem to belie their verbal assurances of maintaining the best interest of the child. Since the child was originally diagnosed with a brain tumor while the family was living in Alaska, they migrated to Arizona, Maryland and finally Seattle, Washington. Despite reasonable offers of medical care and treatment throughout their journey, the parents relied heavily on alternative and unconventional forms of therapy which were supported by their church. All of this seems to suggest that for whatever reason the parents do not appreciate the seriousness of the child's condition and the effect their attitude has on the health of their daughter. There are a number of issues that arise in this situation:

- What are the obligations of the parents, the health care providers and Ethics Committee of the Baltimore Hospital?
- Does the behavior of the parents amount to child neglect?
- Have the parents received all of the information they need to make an informed decision regarding the care and treatment of their child?

What are the obligations of the parents?

Parents are, by law, considered the joint natural guardians of a minor child and are individually and jointly responsible for the child's support, care, nurture and welfare. This includes necessary medical care and treatment. Generally, a minor cannot consent to treatment and so the health care provider must obtain the consent of the parents. In cases where parents fail to provide children with necessary medical care, the state can limit the autonomy of parents. When children are in need of lifesaving or life-preserving treatment, courts may, in certain situations, order the necessary treatment despite parental objection. The ability of a court to do this is based upon the state's interest in preserving

life. In some cases, such action can be taken by the state even when the parental objection stems from religious beliefs.

In this case, the child's condition was becoming progressively worse given the significant growth of the tumor. In addition, it appears that the alternative natural forms of treatment, as recommended by the church, were unsuccessful. Delaying appropriate medical treatment by moving the child to a hospital in Seattle, Washington does not appear to be in the best interest of the child. The child's father was prepared to proceed with the recommended surgery and chemotherapy, yet the mother wished to continue with the alternative forms of treatment in consultation with her church leaders. This dispute, as with any dispute among surrogate-decision makers, can be referred to the hospital's Patient Care Advisory Committee, also known as the Ethics Committee, for a recommendation.

What are the obligations of the Baltimore Hospital

As mentioned above, the state has an obligation to preserve the health and life of a child. Such an obligation is usually exercised through court actions brought by a health care provider for that child seeking appropriate necessary medical care. In this situation, the hospital could have petitioned a court for a determination as to whether the decision of the parents was consistent with generally accepted standards of medical care. An alternative, to petition the Patient Care Advisory Committee for a recommendation regarding the appropriateness of the decision of the parents, was chosen in this case by the surgical team. The facts of this case as presented to the Ethics Committee, must have been sufficient to support the decision permitting the parents to remove the child from the hospital. Unfortunately, it was not until a week after the consultation with the Ethics Committee, that the hospital learned that the parents had not kept the appointment in Washington nor scheduled another one. Upon learning these facts, the Ethics

Committee questioned its obligations with respect to pursuing the matter, with perhaps some concern about confidentiality issues surrounding its deliberations and proceedings.

In Maryland, the proceedings and deliberations of the Advisory Committee are considered confidential and the advice of the committee becomes a part of the patient's medical record. Although there are many limitations with respect to the disclosure of confidential medical information, there is an exception for purposes of an investigation in the case of suspected child abuse or neglect. In addition, the child abuse and neglect reporting requirements permit certain disclosures, despite well-established privileged communications occurring between specific individuals. Information could be disclosed to the local Department of Social Services for purposes of investigation into suspected neglect. Any other disclosures to third parties would need to be evaluated on a case-by-case basis.

Does the behavior of the parents amount to child abuse?

Child neglect is defined as the failure by a child's parents or legal guardian to give proper care and attention to that child under circumstances which suggest that there is significant harm or risk of harm to that child's health. Health practitioners, social workers and any other individuals who believe that a child has been subject to neglect are required to report the situation to the local Department of Social Services. Specific information includes the whereabouts of the child.

Given the facts of this case, probably the safest method for reporting such a situation is through a health care provider, such as a physician, nurse or social worker. Unfortunately, in this case some of the information the Department of Social Services requires, such as the whereabouts of the family, is not known. A number of individuals in the family's church community knew of their location, and the success of the investigation will depend upon the cooperation of such individuals. Unfortunately, the

minister or clergymen of the church could attempt to avoid providing information on the basis of privileged communications with the parents. In any event the health care providers at the hospital can initiate the investigation, by making the original report to the local Department of Social Services.

Was there adequate information provided to the parents to allow for informed consent?

Given the parents' interstate travels with the child, it is impossible to assume they were well informed regarding the child's condition. It is therefore necessary for the surgeon at the Baltimore hospital to conduct a thorough assessment of the child, and based on those findings, explain the recommended treatment, such as surgery and chemotherapy, to the parents. In addition, the surgeon would need to explain the material risks and complications, the expected outcome, the probability of success, and alternative procedures or treatments. Regarding material risks, one must determine what facts the parents might consider important in their decision about whether to forego the surgery and chemotherapy. As far as alternative procedures, only those generally recognized, accepted or considered reasonable by a patient (or parent) need be disclosed. In this case we know that the mother relied on her church for direction with respect to alternative forms of treatment. If such alternative treatments are not generally recognized within the medical community, then this is something the physician needs to discuss with the parents, explaining the probability of success with these.

We do not know why the parents journeyed from state to state or why they rejected the recommended surgery and chemotherapy for the child. They might have benefited from an opportunity to speak with a multidisciplinary team at the hospital consisting, perhaps, of representatives from pastoral care, social work, the Ethics Committee, and the surgeon, in an effort to answer their questions and alleviate any fears they might have had.

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Case Comments

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Conclusion

These facts present a difficult situation for the Ethics Committee and surgical team. The Ethics Committee consultation was certainly appropriate and the members had no way of knowing at that time that the parents would fail to keep the appointment at the hospital in Washington State. Reporting the matter as a case of suspected neglect could have initiated an investigation by the local Department of Social Services. The person notifying the authorities would have immunity from civil liability or criminal penalty. Alternatively, the hospital could have petitioned a court of competent jurisdiction while the family was still in Maryland. However, reassurances by the parents that they had the child's best interest at heart would have, more than likely, led the court to reach the conclusion that it was appropriate for them to move to Washington. Perhaps the court would have required certain actions on the part of the parents to confirm that follow-up treatment had been provided.

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Baltimore, Maryland

Case Discussion: Comments From a Physician

This case raises a number of important issues concerning the role of ethics committees and the limits of surrogate decision-making. First, the case concludes with the implication that the role of the ethics committee includes activities that transcend articulation of recommendations. For example, the question implicitly asked at the end of the case was whether the ethics committee should contact the parents via the family's church community. Such a role for ethics committees is

inappropriate. First and foremost, ethics committees should try to forge a consensus from among the different parties involved in a particular case. If this is not possible, e.g. due to the unavailability of relevant parties, then the ethics committee should make recommendations based on their evaluation of the contextual aspects of the case. Subsequently, it is the care providers' decision to follow any of the suggestions offered by that committee. Hence, in this case, the ethics committee could either advise the members of the medical team to contact the family, using the information obtained from the family's church community, or recommend that the medical team alert the appropriate authorities (e.g. child protection agency).

Should, however, the ethics committee become actively involved in the case (i.e. alert the authorities themselves) if the medical team fails to act on the recommendations of the ethics committee? This question brings us to the larger issue in this case—the limits of surrogate decision-making, i.e. how much discretion should surrogates have in making decisions for members of their family? Implicit in the deliberations of this case is the belief that any decision not to treat the child with “aggressive surgery and chemotherapy” is unreasonable and inappropriate. Does the option not to treat represent an unreasonable decision or does it reflect the inherent (and probably unconscious) bias of the medical profession *and* the members of the ethics committee towards preserving life at all costs?

A careful reading of the case reveals that a decision not to treat may not be unreasonable. For example, the initial evaluation by the Arizona hospital was that the tumor was too large to be surgically removed. However, at the Baltimore hospital, surgery is now considered a possibility, although it appeared that the tumor had “grown significantly.” Furthermore, according to the medical opinion, there was a twenty-five percent chance of curing the child. Are these odds such that refusal of therapy is unreasonable?

(Notice that the medical profession *frames* the risk in terms of cure, not death. The effects of such framing may influence the determination, in our final decisions, as to what is reasonable.) Finally, even if “aggressive surgery and chemotherapy” is regarded by most members of our pluralistic society to be the best decision in this case, the more fundamental question is whether a decision not to treat would be considered, by most, as unreasonable. In other words, surrogates are not obliged to select what is considered the “best decision.” Rather, they should be able to select from a broad range of reasonable decisions. In the context of our pluralistic society, determining what may be the best decision is difficult. Given the particular medical facts in this case, the decision not to treat may not be unreasonable.

Finally, the possible reasons for the family's refusal of therapy was not addressed explicitly in this case. For example, did confusion caused by the differing medical opinions interfere with the family's ability to make a competent and autonomous decision? Alternatively, were transcultural factors present which might explain the family's different beliefs about health and disease? Essentially, an evaluation was needed to determine whether the family was giving an *informed* refusal, i.e. were they making a decision with a full understanding of the information, free from internal and/or external coercion? To determine the adequacy of informed consent, one needs to explore the family's value systems and their reasons for their decision. This determination falls within the ethical obligation of ethics committees.

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Medical System

ETHICS COMMITTEES

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Statutory Recognition of Ethics Committees in Health Care

As indicated in the article by Fletcher and Hoffmann (page 1), in recent years state legislatures have recognized the role of ethics committees in the health care setting and have statutorily delegated various duties to them. The most typical uses of ethics committees in this area are as dispute resolver between patient and health care provider, and as advice giver when difficult ethical issues arise dealing with life and death matters. The following is a brief discussion of several state laws which recognize and create specific roles for ethics committees.

Arizona recognizes the use of ethics committees to assist physicians in making health care treatment decisions for patients who are unable to communicate and the physician cannot locate a designated surrogate.¹

Colorado requires that a health care facility's medical ethics committee give assistance to any proxy decision maker who requests that assistance when they are considering or have made a decision to withhold or withdraw medical treatment from a patient over whom they have decision making authority.²

Georgia requires that a physician consult with an ethics committee and gain the committee's concurrence before a do not resuscitate order is issued for a patient, when that patient cannot make that choice themselves, and when other authorized persons who could make that choice for the patient are unavailable.³

Hawaii statutorily recognizes ethics committees and defines them as "a committee that may be an interdisciplinary committee appointed by the administrative staff of a licensed hospital, whose function is to consult, educate, review and make decisions

regarding ethical questions, including decisions on life-sustaining therapy."⁴ While immunity is granted to members of ethics committees, it is unclear as to what role, if any, they would play in a patient-physician dispute or exactly what role they are to play in life-sustaining treatment issues.

Maryland has been among the leaders in recognizing and requiring the use of ethics committees. In 1987, Maryland required all hospitals to establish 'patient care advisory committees.' These committees are to offer advice as to options for individuals with life-threatening conditions, as well as educate hospital personnel and patients as to individual rights. They may also review and recommend institutional policies concerning the withholding of treatment.⁵

Under the Maryland Health Care Decisions Act,⁶ ethics committees are also used as a dispute resolution mechanism when surrogates with equal decision making priority disagree on what form of treatment to follow for an incapacitated patient⁷ and when a health care provider believes that an instruction to withhold or withdraw a life-sustaining treatment from a patient is inconsistent with generally accepted standards of patient care.⁸

New Jersey recognizes ethics committees as a means of resolving disputes between patients and health care providers concerning the patient's decision making capacity or the interpretation and application of the terms of the patient's advance directive.⁹

There is also proposed legislation in a few states that would give ethics committees more authority. The New Hampshire House of Representatives has proposed a statute that would use ethics committees to review the decision of a terminally ill individual who requests a physician to prescribe medication which will control the time, place and manner of the individual's death.¹⁰

In the state of New York, proposed legislation drafted by the Governor's Task Force on Life and the Law makes explicit a number of roles of bioethics

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Statutory Recognition

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committees. Under the proposal (Program Bill.#69), a bioethics review committee must consider any health care matter presented to it by a person connected with the case. The committees' response to a health care matter may include:

- (i) providing advice on the ethical aspects of proposed health care;
- (ii) making a recommendation about proposed health care;
- (iii) providing assistance in resolving disputes about proposed health care; or
- (iv) discussing a matter without making a recommendation.

The proposal further specifies certain types of situations in which the committee must be consulted. These include cases involving (1) emancipated minors and the withholding or withdrawal of life sustaining treatment, and (2) incapacitated adult patients without surrogates and the withholding or withdrawal of life sustaining treatment. In both of these cases the bioethics committee must approve a decision to withhold or withdraw life support before a physician may carry out the decision. The proposal further provides that disputes between an attending physician and a consulting physician over major medical or life sustaining treatment for an incapacitated patient without surrogates must be referred to the bioethics review committee, if it cannot otherwise be resolved.

Finally the bill requires that bioethics review committees "routinely review, on a retrospective basis: (i) committee approvals or disapprovals of decisions to withhold or withdraw life-sustaining treatment for an emancipated minor patient or for an adult patient without a surrogate or in a residential health care facility for decisions by a surrogate to withhold or withdraw life-sustaining treatment for a patient who is not terminally ill or permanently unconscious; and (ii) decisions by surrogates to withhold or withdraw life-sustaining treatment for general hospital patients who are not terminally ill or perma-

nently unconscious, except for decisions to withhold CPR."

These roles for ethics committees undoubtedly shape their authority and jurisdiction. They also affect the character of the committees—elevating their status and making them, at least for some types of ethical dilemmas, dispute resolution bodies.

1. A.R.S. §36-3231 (1993).
2. C.R.S. §15-18.5-103 (1993).
3. 1994 Georgia Law Act 974 (S.B. 580), to be codified at O.C.G.A. §31-39-4.
4. H.R.S. §663-1.7 (1993).
5. See Md. Health-Gen. Code Ann. §19-370 *et seq.* (1990 and Supp. 1993).
6. Md. Health-Gen. Code Ann. §5-601 *et seq.* (1994).
7. Md. Health-Gen. Code Ann. §5-605(b) (1994).
8. Md. Health-Gen Code Ann. §5-612(a) (1994).
9. N.J.S.A. §26:2H-66 (1994).
10. See 1993 NH H.B. 395. (Re-referred to committee on January 6, 1994).

Submitted by:
Timothy Burch, J.D.

NETWORK NEWS

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Incorporated within the last year, as the result of state-wide institutional support, this Network believes that its new member recruitment efforts will raise membership to thirty (30) members by October of this year.

On the regional level, the Bioethics Network of Southeastern Virginia has an ambitious schedule of events planned for the coming year. In addition to its regular monthly meetings, a Saturday morning in September (see Calendar) has been set aside for a special neonatology ethics program. Sessions led by prominent local health professionals and ethicists will focus on the benefits and harm of the allocation of resources to and the medical decision-making for neonates of 24-25 weeks gestation.

STATE NEWS MARYLAND

Cont. from page 3

competent patient after informed consent, with the consent of a health care agent, or with the consent of the patient's family if the patient was terminally ill or would be terminally ill upon arrest.

DNR order as a Condition of Admission

The Opinion makes clear that nursing homes may not require the entry of a DNR order as a condition of admission to the facility.

Need for Witnesses for DNR Orders When Patient is Competent

Finally, the Opinion addressed the question of whether or not DNR orders must be witnessed as other oral advance directives must be. The AG concludes that in certain circumstances, i.e., when the patient's expressions to a physician are of a "generalized open-ended desire" the conversation must be considered an oral advance directive and must be witnessed to be valid. However, if the instruction to the physician is "the product of informed consent about contingencies in the discrete context of a discussion of 'a future course of treatment'" then the discussion is similar to other informed consent discussions and need not be witnessed.

VIRGINIA Local Government Invests in Nursing Home Ethics Program

The Board of Supervisors of Nelson County, Virginia sponsored three local health care professionals to attend the program "Developing Nursing Homes Ethics Program" (DNHEP), which was held in July at the University of Virginia's Center for Biomedical Ethics.

Nelson County, a small rural community in central Virginia (population 13,000), anticipates that by the year .

2000, twenty percent of its citizens will be over age 65. In recognition of this, local officials there have made a commitment to educate the community to the sensitive issues surrounding long-term care. It is expected that the persons who attended the DNHEP Program will serve as resources to the Board of Supervisors, hosting a community workshop on nursing home ethics issues in association with the

local Lovingson Health Care Center.

While details for this workshop, to be held in late fall, are still in the planning stages, discussion topics probably will include: Advanced directives, DNR decisions, living wills, economics of long-term care, future planning, and the idea of a "moral community."

In addition to the involvement of the local government and the community

health center, the Center for Biomedical Ethics has pledged to provide resource persons to assist with these efforts. The outpouring of enthusiasm and support for this upcoming workshop from the citizens and community organizations in Nelson County bode well for the success of this "cutting edge" cooperative program.

CALENDAR OF EVENTS

AUGUST

- 15th-20th "Developing Hospital Ethics Programs," (DHEP) A residential course designed to facilitate or strengthen the implementation of an ethics program within health care institutions. For further information call: Center for Biomedical Ethics at the University of Virginia Health Sciences Center, Charlottesville, VA (804) 924-5974.
- 31st Ethics Grand Rounds, Topic: "Resource Allocation in the Intensive Care Units: Neonates are a Much Better Investment Than the Elderly," John D. Lantos, M.D., University of Chicago, at Robert C. Byrd Health Sciences Center of West Virginia University. For more information contact Cindy at (304) 293-7618.

SEPTEMBER

- 6th Bioethics Network of Southeastern Virginia Meeting, 7:00 p.m., Auditorium, Hofheimer Hall, Norfolk General Hospital, Norfolk, VA. Topic: "Ethics and Cultural Diversity."
- 16th "The Medical Humanities Hour," Topic: TBA, sponsored by the Program in Clinical Ethics, University of Maryland Medical System, 1:00 p.m. - 2:00 p.m. in the Shock Trauma Auditorium. For more information contact Henry J. Silverman, M.D. at (410) 706-6250.
- 20th Washington Metropolitan Area Bioethics Network Meeting, 4:00 p.m., Panel Discussion by Members of Several Ethics Committees regarding "guidelines" for successful decision making. For location and further information contact Joan Lewis at (202) 602-1581.
- 23rd "Decisions Near And At The End Of Life," 6th Annual Bioethics Conference sponsored by the Shore Memorial Hospital Ethics Committee, The Flander's Hotel, Ocean City, N.J.
- 23rd West Virginia Bioethics Forum, "Developing Expertise in Ethics Consultation, Part II-The How of Ethics Consultation" at The Days Inn, Flatwood, West Virginia. Contact Cindy at (304) 293-7618 for more information.
- 24th "Saturday in Bioethics," a conference on the impact of the allocation of resources and medical decision-making in Neonatology for neonates of 24-25 weeks gestation, sponsored by the Bioethics Network of Southeastern Virginia, 8:00 a.m.-1:00 p.m. at the General Education Building, 1060 First Colonial Road, Virginia Beach, VA. For more information contact Julia West, M.D. at (804) 548-2911.

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