

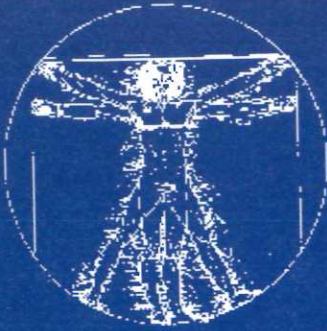
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2000*

Mid-Atlantic Ethics Committee
Newsletter, Summer 2000

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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
School of Law, University of Maryland at Baltimore

Summer 2000

THE IMPERATIVE OF TRAINING FOR ETHICS CONSULTATION

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As you know, Maryland has unique laws calling for mandatory ethics committee consultation. While I urge you, especially committee chairpersons, to read these laws carefully, the laws, per se, are not the point of this article. They are merely the hammers that bang home my point—ethics committee members who perform clinical ethics consultations had better be well trained.

Very often, ethics committee consults involve difficult end-of-life decisions. That means that when the ethics committee is called, it is usually about somebody getting dead, somebody wanting to get dead or somebody being dead. Now nobody likes getting dead. So when it is about somebody getting dead, it is, at a minimum, sad. When it is about somebody wanting to get dead, or somebody wanting somebody else to get dead, it is usually sad and conflicted. When it is about somebody who is already dead, you can be sure things are very, very conflicted. Need I point out that any one of these scenarios requires skill and knowledge if the ethics committee consultation is to result in a good outcome.

What I mean by a good outcome is to have the consultation, whether the patient dies or not,

The Mid-Atlantic Ethics Committee Newsletter is a publication of the University of Maryland School of Law's Law & Health Care Program and is distributed in cooperation with the Maryland Health Care Ethics Committee Network. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

- 1) increase patient and family trust in the medical system;
- 2) strengthen the ability and confidence of participating clinicians to make sound, prudent, and explicitly justified ethical judgments in the future;
- 3) train clinicians to more comfortably use the language of death and dying;
- 4) model a deliberative process that builds respect for ethical analysis and ethics committee participation; and,

The Mid-Atlantic Ethics Committee Newsletter is published three times per year by the Maryland Health Care Ethics Committee Network

Individual Subscriptions/\$35 per year
Institutional Subscriptions/\$90 per year (up to 20 copies)

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NETWORK NEWS

Regional Network News

On June 23, 2000 representatives from the Metropolitan Washington Bioethics Network (Joan Lewis and Andrea Sloan), Northern Virginia Health Care Ethics Network (Elizabeth Bray and Jim Fletcher), and Maryland Healthcare Ethics Committee Network (Anne O'Neil) met to discuss the background, mission, and activities of each group. The most important question addressed was how the Networks can support one another as they provide educational programs, resources, and support for their own members. The June meeting was an excellent start. Representatives from these groups hope to be able to attend the September meeting of NOVAHEN (see Network News, page 4).

Maryland Health Care Ethics Committee Network (MHECN)

Over 50 participants attended an evening dinner program (I Don't Want to Die Today: Complexities of Advance Directives) sponsored by MHECN and Medstar at Harbor Hospital on June 1, 2000 (see article, page 9). The program was preceded by a roundtable discussion led by Anita J. Tarzian, Chair of the Education Committee.

Plans are now being finalized for a half-day workshop this fall on communication and ethics consultation. Members who are part of MHECN's e-mail distribution list will be sent more details about the workshop as soon as they are available. Brochures will be out in early September. Members who have not been receiving e-mails from the Network should contact Anne O'Neil (aoneil@law.umaryland.edu) to be added to the list.

MHECN is also planning a half-day workshop in early winter 2001 on hospital policies related to the work of

ethics committees. The workshop is an initiative of the Network Policy Committee chaired by Evan G. DeRenzo. Other members of the committee include Karen Caffi-Lalle, Phil Panzerella, Pat Brown, Dennis Dupont and Bob Steinke.

The Committee recently sent out a survey to learn about member needs related to ethics-relevant policies in their institutions and ethics committees and is working on the upcoming Policy Workshop.

For more information about the Committee or if you have thoughts about the upcoming workshop, contact Evan DeRenzo at ederenzo@worldnet.att.net.

Metropolitan Washington Bioethics Network (MWBN)

The DC Network is continuing to serve the DC Superior Court as Bioethics Visitors. Two interesting orders have been written recently by a probate judge and will be reported on further in the next issue of the Mid-Atlantic Ethics Committee Newsletter.

The Network has a program planned for September on medical genetics (see Calendar for further details). Another program is being planned for mid-October. The speakers will discuss cases and issues in the daily care of patients with dementia/Alzheimer's or other cognitive problems. This program will be held at IONA Senior Services, 4125 Albermarle Street, NW. To receive information on either of these programs please contact Joan Lewis at jlewis@dcha.org or at 202-682-1581.

Northern Virginia Health Care Ethics Network (NOVAHEN)

Northern Virginia Health Care Ethics Network was founded on May 5, 2000 at a meeting at the home of Linda

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The Imperative of Training

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5) enhance appreciation for, and humility in the face of, the complexities, ambiguities, and metaphysical nature of death.

Granted, this is a tall order. But when an ethics consultation is done well, these outcomes are achievable and observable. When consultations are done poorly, however, the miserable results are obvious, too. And the cost to patients and clinicians of consultation failure defies calculation. A poorly conducted consult results in professional paralysis in ethical decision-making, reductions in patient quality of care, and leaves a nasty residue about the ethics committee, at the very least.

What causes such miserable consultation outcome? My unscientific answer is half-baked ethics analysis. Thinking through ethics issues is horrendously complex. Although there are those who may still think otherwise, they are misguided, ignorant and/or excessively egotistical. Whatever the source of ethics consultation incompetence, it all ends up the same—posing grave risks of harm to patients, clinicians, and to trust in the health care system.

What is required to achieve excellence in ethics committee consultation? For starters, just knowing how to spell “respect for persons,” “beneficence,” “nonmaleficence,” and “justice” doesn’t cut it. Unfortunately, that is the level at which many ethics committee consultants are when they start doing consultations. Worse yet, lacking appreciation of one’s own ignorance often means that consultants do not get past this paucity of skill in ethical analysis. If you think I’m simply being flip, think again. The frequency with which I find, for example, those who should but don’t know that the principle of respect for persons carries a two-part meaning and who cannot articulate the implications of both parts is positively frightening. That many consultants lack the most basic ability to apply ethical justification structures is even scarier.

No one should be doing ethics consultations who has not taken a substantial health care ethics course.

Since the Maryland law went into effect many years ago, it is likely that many committees have been doing consults untrained. It is now time to fix things. Committees need to take stock of what education their members have and how long ago it has been since they took such a course. If any members have not taken such a course, or have not in a long time, they should. Committees also need to develop an on-going self-education program that must be attended by those members doing consultations. This can be done by establishing a brown bag ethics education series or by having an annual committee retreat that is at least a half-day of education.

The American Society of Bioethics and Humanities has developed core competencies for health care ethics consultation that should be used to build your own committee’s ongoing committee and consultation service education program. Once the curriculum is set, a process for apprentice consulting needs to be established.

Book learning is insufficient to give one the full range of skills and abilities to do consults well. That is because in addition to the core competencies, there are important process issues. For one, lone ranger consults, especially lone ranger consults by physicians, are a bad idea. Given that all persons carry moral filters that shade their recommendations, and that most persons require assistance in seeing their own filters, the quality of most consultations (excluding bona fide curbside consults – a topic for a future article) is strengthened by having more heads than one.

Minimally acceptable consultations require good team process. If you think me harsh in singling out physicians, I do so for a functional reason. Physicians hold the highest rung on the medical power hierarchy. Because of this power position, and because they often lose sight of the distinctions between their responsibilities as an ethics consultant and their persona as physician, that power can wreak havoc on good consultation process and result in lasting harms. Further, given that Maryland law requires that the hospital’s administrative leadership be on the committee, if that person is on the consultation team

and is also a physician, the power and role confusion issues can become overwhelming. Even when the physician and/or physician-administrator is him – or herself able to keep fully separate in his or her own mind the distinctions among these roles, such analytic precision is too great to expect from others.

Physicians also have to get over the notion that their medical degree makes them automatically qualified to do ethics consultation. Whether one has a medical degree, a nursing degree, a social work degree or any other degree, we have all gone into health care because we are decent, moral people. But innate goodness and compassion do not equate into good ethics consultants. There is no such innate ability. Ethics consultation requires proper training and development of analysis and communication skills.

Finally, let me address the need for addressing these sensitive and prickly issues as part of the training process. An inability to speak openly about these ethics consultation complexities is a sign that we are not yet sufficiently skilled at the process of ethics consultation to be conducting any.

As I noted at the outset of this article, given that the majority of consults are about death and dying, such cases involve sadness, loss and conflicted emotions. There are rarely any clear-cut moral answers, but instead, a range of ethically permissible options, depending on how one justifies the various possible actions. Identifying the full range of possible options and engaging in a process of sound deliberation and justification demands a competent group of well-trained and emotionally mature ethics consultants. The alternative is disaster. And the only way to prevent dangerous incompetence is to get serious about training committee ethics consultants. If we don’t, besides exacerbating the risk of harm to patients and clinicians, one of these days, Maryland law, which demands excellence in ethics committee consultation, will come down hard on us all.

By Evan G. DeRenzo, Ph.D.
Center for Ethics
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Network News

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Brown, RN, MA. NOVAHEN hopes to serve its region, as do other networks especially in identifying resource persons among its members to provide education and training for ethics committees in the area. Also discussed was the hope to do a project with the judiciary in Northern Virginia similar to Andrea Sloan's work in the District courts. Co-conveners of NOVAHEN meetings are Elizabeth Bray, RN, JD, MA (braveliz@aol.com) and James Fletcher, PhD (jfletche@gmu.edu). Interested persons are invited to contact either of them for information about the next meeting, which will begin with a potluck dinner on Friday, September 15, at 6:00 pm at Elizabeth Bray's home. Please contact her for address and directions.

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. 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: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 515 W. Lombard St., Baltimore, MD 21201-1786.

Case Study From A Virginia Hospital

The patient is a 6 month old female delivered at 29 weeks gestation to a 17 year old mother. Baby Carol was a breech birth at home. The rescue squad arrived within 10 minutes of delivery. Carol required intubation en-route to the hospital. She was admitted to the neonatal ICU and was immediately diagnosed with respiratory distress syndrome. Her hospital course has been complicated by patent ductus arteriosis, pseudomonas pneumonia, retinopathy of prematurity, and oxygen dependency. Her current diagnosis is severe BPD (bronchopulmonary dysplasia) a condition caused by her medical treatment.

Carol is now in the pediatric ICU (PICU), with a tracheostomy tube in place, chemically paralyzed and sedated, and mechanically ventilated. She was transferred to the PICU from the NICU due to possible isolation requirements for a staph infection. The PICU team has called for an ethics consult because of a potential conflict with the parents regarding the treatment plan.

Carol has both her birth mother and her adoptive parents. Arrangements were in place before the birth for the birth mother to relinquish all care and decision making to the adoptive parents, but at this time, six months after the birth, the papers have not been formally signed. One reason for this is that if the papers are formally signed, Carol would have to be transferred to a facility 120 miles away due to requirements of the HMO to which the adoptive parents belong. The adoptive parents do not want to transfer her because of the excellent care little Carol is receiving at the present hospital.

The adoptive mother feels that Carol is suffering greatly. She has seen her go through "spells" where she turns blue and requires even more high-technology medical support to allow her lungs to recuperate. However, the hope is that they may attempt to wean her from the ventilator at a later date. The adoptive mother is not sure if Carol experiences pain, but the numerous spells over the hospital course have left her unsure if she should continue to let Carol be treated. She is asking about withdrawing the ventilator from Carol and allowing her to die peacefully.

The medical team feels that withdrawing life support is premature. The PICU attending physician and the pediatric pulmonologist agree that Carol has a severe form of BPD, but they feel that in about 3 years she can successfully have the tracheostomy removed and with aggressive pulmonary rehabilitation, she can lead a relatively normal life. The physicians have told the adoptive parents numerous stories of children who have gone through this and are leading relatively healthy and normal lives. They cited a program in Los Angeles that has an 80% success rate once the child enters into the rehabilitation phase. There is a 40-50% chance that Baby Carol will be able to enter the rehab program. They state she needs at least 2-3 more years of mechanical ventilation and oxygen therapy before they can prognosticate better. A recent CT scan of the chest revealed normal tissue, which is an encouraging sign. The spells Baby

Carol has are considered normal for her disease process and she will continue to experience more spells before she begins to outgrow them. The medical team is requesting time so they can better evaluate Baby Carol and see where her disease course leads before they will consider withdrawing life support.

The major voice in the case is the adoptive mother. The birth mother has visited rarely in the past few months, but is contacted and comes to the hospital when Carol seems near death. The adoptive parents do not feel they should have to watch Carol suffer. The mother speaks eloquently of both parents' commitment to Carol despite her medical problems. They have been building a house in the area, near relatives, so baby Carol can have 24 hour family support when she gets out of the hospital. They have recently adopted another child from Russia.

Despite the new addition, the adoptive mother states that she is fully committed to Baby Carol. However, she feels there is nothing more medicine can offer the child. She understands the wait period, but also feels that it should not be a blanket license to "do whatever they want to her just so she can have a heartbeat." The parents describe themselves as Christians who feel that it is in God's hands now. Medicine has reached the end of its road. The adoptive mother asks, "so we get over this spell. What happens when the next one comes, and the next? Do we just keep doing this to her? We are not sure she is not in pain, you said that yourselves. I just want the suffering to stop. We are not allowing her to die. We keep doing hurtful things to her. I just want her to be comfortable. Please!"

The adoptive parents are upset at the transfer to the PICU. Complicating the matter is their continued contact with the neonatal ICU staff about Baby Carol's care. The PICU and NICU staff have different views on the future course of care and this difference is not helping communication issues. The PICU attending called the ethics consult service for help. He asks, "Do we have to honor the parent's wishes? What about my role as the medical authority?"

I think we can get her through this and I do not feel the parents have a right to ask for this." The parents are asking, "If we are supposed to make medical decisions, why not this one? We feel our baby is suffering and this is cruel to continue to do this to her each and every time she has a spell. Why are we not allowed to make this decision when we feel it is in her best interests?"

The ethics committee is addressing the following questions: 1) What is the legal right of the adoptive parents to speak for Baby Carol?; 2) Is this a case for lawyers or ethicists?; 3) What is the place of the birth mother in these deliberations?; and 4) Is negotiation possible with the sides so far apart?

Response From a Bioethicist

This situation is among the unhappiest in medicine. Making matters worse, a cloud of legal uncertainty hovers over who can act as the baby's parents. This very sick but not yet dying premature infant has adoptive parents who now want to discontinue life support so that she can die. They believe that continued treatment is causing the baby to suffer intolerably and invoke their religious beliefs. PICU intensivists and the pulmonologist want to continue treatment. They appeal to data regarding successful treatment and rehabilitation of similarly affected infants. Baby Carol's prognosis is grim at times, but the data show that with perseverance Carol has an almost even chance of making it to the rehabilitation stage of her illness. The process of intensive care, home care, and rehabilitation could take three or four years. Very few, if any, parents are prepared for the perilous course of hospital and home treatment of bronchopulmonary dysplasia.

The legal issues are impressive. The adoptive parents are not yet legally authorized to give proxy or substituted consent for the child. Their good intentions have won them moral standing to carry out the legitimate role that parents have in medical care of imperiled newborns and children, i.e.,

to participate in decision making and to give or refuse permission for treatments. The adoption process has been interrupted by the illness and further delayed by reluctance to transfer Baby Carol to a facility much further away to satisfy HMO requirements. The birth mother is the only parent with legal standing, but she rarely visits and then only when the baby seems near death. Her potential to change her mind about the adoption is real but seems to be minimal. The PICU staff has rightly chosen to interact with the adoptive parents, whose commitment to the baby's well being is clear. However, the PICU doctors are in serious disagreement with them over the course of treatment, and this disagreement itself could become an even larger legal issue than uncertainty about the status of the adoptive parents as legally authorized decision makers for the infant.

A further complication in the dynamics is that the adoptive parents are hearing two messages. Evidently, the NICU staff supports their outlook and differs with the PICU's position on long-term aggressive treatment and rehabilitation. The PICU physicians are committed to stay the course and have new data derived by CT scan showing normal tissue in the chest.

There are good reasons for the ethics committee to provide *ethics* consultation, but the legal issues need referral to the hospital's attorney and possibly other authorities. All concerned need assurance that there is no illegality involved in proceeding with the consultation with the adoptive parents in a provisional parental role. Time is of the essence and while the legal situation needs to be worked out, this need should not deter the more urgent need to address the ethical issues and decide on a course of care in the baby's best interest.

The consultants' tasks are to provide a good process for ethics consultation with the key decision makers and to prepare for any and all opportunities to educate about the ethical issues. This means preparation to clarify the ethical

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Response From a Bioethicist

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problem(s) in the case, to teach about the key ethical concepts involved, and to help the decision makers explore ways to resolve the problems. Some issues about the process need resolution. The birth mother deserves to be notified about the consultation. She is still Carol's parent until the adoption process is completed. She can decide about participation. The issue of the adoptive parents continuing contact and reliance on the NICU's views of the case needs to be addressed. That question will turn on whether they develop trust in a new set of doctors and accept their recommendations about long-term hospital and home care treatment.

The ethical problem in the case is a dispute about continued treatment between the PICU physicians and the adoptive parents. What are the morally acceptable options? What the physicians want to do is clearly morally acceptable, but to do it with parental permission, they need to persuade the adoptive parents that the benefits outweigh the burdens.

The option of withdrawing life support is morally acceptable if the burdens of continuing outweigh the benefits. At this stage of the illness, this option is controversial and dubious. The key questions are prognosis, pain, and suffering. Given the large experience in developed nations of treating premature infants with this condition, the physicians will likely have reasonable responses to these issues. Their task, not the consultants' task, is to persuade the parents that Carol is not suffering in an inhumane sense. There is a struggle with every oxygen-dependent infant with maintaining sufficient levels of oxygenation. If Carol's treatment is effective, these episodes will decrease but not disappear for some time.

The adoptive parents also need to understand the future difficulties of extended home care and the social and economic costs to the family. None of these goals can be accomplished in a single meeting, but some groundwork

can be laid. A satisfactory outcome at this stage might be that the adoptive parents were unconvinced but open to permit treatment to reach some specific milestone.

The prevailing morality in our society is to give seriously ill newborns the benefit of the doubt and to treat until it is clear that further efforts are unjustified. Physicians have a socially constructed imbalance of power and authority in this situation and imperiled infants are protected against premature decisions to stop treatment by federal and state laws. (Another way to view the case is that if the facts were that Carol had biological parents, they would have no more power or legitimate authority to override the physicians' position than the adoptive parents have.) Cases in the NICU and PICU are marked by struggles for power and authority between unequals. Our society bestows equality when the clinical facts show that continued treatment would not benefit the infant. Predictably, the consultation will not yield happiness, but it may begin a process of shared understandings and trust that can benefit Carol, if she survives this disease.

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Your Comments . . .

We would like to know others' thoughts on this case. Please email comments to Anne O'Neil at aoneil@law.umaryland.edu We will summarize them in the next newsletter.

LEGAL BRIEFS

I. A Case from the D.C. Courts

In light of our case discussion in this issue involving a child with broncho-pulmonary dysplasia, we report on this recent D.C. case regarding a child with the same disorder.

In Re K.I.

As a consequence of premature birth at twenty-six weeks gestation on June 15, 1997, K.I. developed a number of serious medical problems including broncho pulmonary dysplasia, an abnormal condition of the lung cells requiring the child to use oxygen; hemoglobin SC disease, a blood disease similar to sickle cell disease; and reactive airways disease, a condition characterized by wheezing. In addition, the child suffered gastro-esophageal reflux, cerebral palsy, and sepsis.

Following the child's release from the neonatal intensive care unit in November 1997, the child's biological mother (B.I.), and K.I. stayed with K.I.'s putative father (D.M.), in an apartment in northwest D.C. K.I. was required to wear heart and apnea monitors, take medication for her lungs, and use oxygen continuously.

On December 28, 1997, D.M. reported to Howard University that B.I. had left the apartment with K.I., but failed to take the child's oxygen. Thereafter, the Department of Human Services (DHS) filed a neglect petition against B.I., and based on the testimony of the DHS representative and D.M., the court held that K.I. was a neglected child under the D.C. Code. The court found that B.I. was unable to discharge her responsibilities to K.I. because her drinking compromised her ability to care for the child, and furthermore, she had placed K.I. at risk by removing the child's required monitoring and oxygen devices on several occasions.

K.I. was taken from B.I.'s custody and hospitalized and a guardian was appointed to make medical decisions for the child. Her condition worsened over the next several months and on July 21,

1998, K.I. went into cardiac arrest. She was without a heartbeat for approximately 25 minutes, causing prolonged hypoxia. The following day, she experienced a seven-hour seizure, which doctors relieved by inducing a coma. K.I.'s doctors described her condition as "neurologically devastated" and stated that her chances of regaining cognitive ability were virtually nonexistent. Further, any extraordinary attempts toward resuscitation would likely be highly invasive and painful.

Because of K.I.'s persistent and severe medical problems, K.I.'s court appointed medical guardian requested issuance of a DNR (do not resuscitate) order at a hearing in the Superior Court of D.C. The trial court granted the DNR order, holding that where a child has been found neglected, and one or both of the child's parents takes a position clearly inconsistent with her best interests or displays judgement that is contrary to all competent medical evidence, the Court must act in the child's best interest. The trial court further held that the issuance of a DNR order must be predicated upon a finding by "clear and convincing evidence" that it is in the child's best interest to forego aggressive revival measures and that the parents' or guardian's refusal to consent to the DNR order is unreasonably contrary to the child's well-being.

K.I.'s biological mother appealed the decision of the trial court claiming (1) that as K.I.'s parent, she had the right to decide whether or not to request a DNR order, and the trial court should have applied the "substituted judgement" test instead of the "best interest of the child" standard, and (2) that the trial court applied the wrong evidentiary standard.

The Appeals Court Decision

The Appeals Court upheld the DNR order, affirming the judgment of the trial court.

In cases involving minor respondents who have lacked, and will forever lack, the ability to express a preference regarding their course of medical treatment, and where parents disagree as to the proper course of action, the

Appeals Court said that the "best interest of the child" standard shall be applied to determine whether to issue a DNR order. The "substituted judgement" doctrine is generally invoked in cases of adults who at one time were competent but later became incompetent. The Court further stated that the standard of proof necessary for issuance of a DNR order in the best interests of a child is "clear and convincing evidence."

II. Maryland AAG Opinion Letter

In response to a request to clarify the distinction between a patient's exercise of informed consent and the creation of an oral advance directive, Jack Schwartz, Maryland Assistant Attorney General and Director, Health Policy Development, issued a letter opinion on April 25, 2000. The opinion relies on reasoning in the recent case, *Wright v. Johns Hopkins Health Systems Corp.*, 353 Md. 568 (1999). The following is a brief summary of Mr. Schwartz's opinion. (The full text of the opinion may be found at <http://www.oag.state.md.us> and click on health policy.)

Maryland court cases make clear that the informed consent doctrine concerns decisions about *specific* diagnostic or treatment procedures. A competent patient may give informed consent "...when the physician and patient together can explore, in meaningful detail, the risks and benefits of, and alternatives to, the proposed treatment given the patient's diagnosis and prognosis." In general, informed consent is given or refused where there is a highly detailed clinical context, a patient is already experiencing a disease, the treatment issue is immediately at hand, and the patient's decision addresses the current health care team only.

The procedures for documenting informed consent decisions are those of ordinary medical practices. For surgery and certain other procedures, the patient's consent is reflected in a signed document; for clinical procedures, the patient's consent may be noted in the

chart or simply inferred from participation in the procedure.

By contrast, the oral or written advance directive, a mechanism created by the Maryland Health Care Decisions Act, (the "Act") gives effect to health care decisions that are anticipatory, contingent and more open-ended. An advance directive has the following general characteristics: the clinical context is abstract or hypothetical, the patient is not currently experiencing the disease to which the advance directive relates, the treatment issues are remote and speculative, and the patient's decision addresses unknown health care providers.

In Maryland, a written advance directive must be dated, signed by or at the express direction of the declarant, and subscribed by two witnesses. An oral advance directive "...must be made in the presence of the attending physician and one witness, and then documented as part of the patient's individual medical record. The documentation shall be signed and dated by the attending physician and the witness."

An example of an advance directive is a "living will" that refers to an individual's desire not to receive life-sustaining procedures that would only prolong an inevitable dying process. In Maryland, in order to legally implement a patient's advance directive stating a decision to forego life-sustaining treatment, the patient must be certified to be in a terminal condition, end-stage condition, or persistent vegetative state (conditions defined in the Act).

The following examples illustrate the distinctions between giving informed consent and stating health care preferences in the form of an advance directive:

1. A patient with severe renal disease who is thinking about whether to decline further kidney dialysis is told by the attending physician that discontinuing dialysis would quickly result in death and that no alternative to dialysis is available. The patient decides to decline further dialysis. This is an example of informed consent, not an oral advance directive.

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2. A renal disease patient who is continuing on dialysis has decided that, in the event of future cardiac arrest, CPR should not be attempted. The patient's preference about CPR, which is intended to affect an open-ended period of time and is not dependant on a particular clinical encounter, is an exercise of patient self-determination that can be reflected in an advance directive, following the procedures of the Act.

In conclusion, Mr. Schwartz acknowledges that the distinction between informed consent and advance directives is not always crystal clear. He suggests imagining an informed consent/advance directive scale, in which 1 = archetypal informed consent (i.e., a renal disease patient who declines dialysis scheduled this week despite having been informed by the attending physician that a discontinuation of dialysis will result in death and no alternative treatment is available) and 10 = an archetypal advance directive (i.e., a healthy 40 year old who wants to decline life-sustaining treatment whenever he or she happens to become terminally ill, which actuarially would not be for decades). Based on the *Wright* case, oral statements must be assigned a 2 or a 3 to count as informed consent. The more that an oral statement tends toward the "10" end of the scale, the more important it is to follow the Act's requirements for an oral advance directive.

ETHICS NETWORKS FROM AROUND THE WORLD

In the next few issues we will be reporting on ethics networks from different areas of the United States and the world. We hope you will find this of interest and thought-provoking as MHECN enters a new growth phase in its history.

New Jersey Nursing Home Network

New Jersey is in the midst of both organizing and educating regional ethics committees to serve the over 400 nursing homes and assisted living residences in the state. This project is funded by the Robert Wood Johnson Foundation, NJ Health Initiatives and the Louis & Bessie Stein Foundation under the auspices of the New Jersey Office of the Ombudsman for the Institutionalized Elderly. The mission of The New Jersey Stein Ethics Education & Development Project (NJ SEED) "is to establish an educational forum, bringing together health care providers for the thoughtful resolution of ethical dilemmas arising in long term care settings."¹ Linda O'Brien, RN, MA of The Cooper Health System is Co-PI and Project Director for this large project.

As stated in the NJ Seed brochure "ethics committee members typically are called upon to assist with staff education, case consultation and policy development. While, however, such committees can prove to be an invaluable resource to staff members, residents and their families, little opportunity exists for formal education of committee members."² It is the NJ Seed Project's goal to insure that every long-term care facility in NJ has access to sophisticated bedside ethics consultation and policy development. To accomplish this goal, a total of 12 regional ethics committees are in the process of being formed. Eleven committees have already been formed and, of these, eight are doing ethics consultations on a regular basis. The

NJ SEED Project is a membership organization. Membership dues are \$200.00 per institution, which covers three institutional representatives. The fee also includes a year long educational program. At this time, over 100 long term care facilities have completed the ethics seminar series.

Part of the grant funds will also be applied to evaluating the success of the education and consultation services provided. More information may be obtained by calling Linda O'Brien at 856-963-3714.

¹ A Matter of Ethics, Vol. 1, Number 1, 1999. Published by the NJ Seed Project. Copies may be obtained from Linda O'Brien, The Cooper Health System, Department of Medicine, Three Cooper Plaza, Suite 220, Camden, NJ 09103.

² The NJ SEED Project: Building an Ethics Network for Long term care. Copies may be obtained from Linda O'Brien at the above address.

Development of a UK Network for Clinical Ethics Committees

Clinical ethics committees (hospital ethics committees) in the UK are a recent phenomenon. To date, there are about 20 established committees and an additional 20 committees in the development stage. There has been a recent increase both in the number of committees and in hospitals expressing an interest in establishing one.

The Centre for Ethics and Communication in Health Care Practice (CECHCP) at the University of Oxford has conducted a national study into clinical ethics support for health professionals within the UK. The study included a questionnaire survey sent to key post-holders (Medical Director, Director of Nursing, Chief Executive, and Chairman of Hospital Trusts) in every National Health Service Trust (NHS Trust) in the UK.

NHS Trusts are the providers of the majority of secondary health care in the UK. A Trust may be a single large hospital, a group of smaller hospitals or a group of community based services. Primary Care services (general practice) are a separate part of the health

service. There are 418 Acute and Community NHS Trusts in the UK and a response was received from at least one key person in 417 Trusts.

As a result of this study, CECHCP identified all existing clinical ethics committees and those institutions planning to set up a committee. The study also identified other mechanisms, both formal and informal, of ethics support for health care professionals in clinical practice.

It became clear during the study that there was a need among members of clinical ethics committees and others interested in the provision of clinical ethics support, for education, training, and, above all, a support network to assist in the future development of such committees. A workshop was held in Oxford in January 2000 to which all chairs of clinical ethics committees (and potential clinical ethics committees) were invited. It was agreed at the workshop to set up a national network of clinical ethics committees. The network is co-ordinated in Oxford, but the plan is for a rolling program of meetings in different regions of the country together with a regular newsletter to which network members will contribute.

The first network newsletter was distributed in May, and as a result of this, CECHCP has had inquiries about the network from several other medical centers keen to establish ethics support in their institution. One of the suggestions at the original workshop was to circulate within the network a list of issues addressed and guidelines produced by network members. Thus, a committee asked to consider a particular issue could refer to the list and see if any other committees had addressed the same issue. They could then make contact and benefit from the experiences of other committees. This circulation list is currently being compiled and CECHCP plans to update it with each newsletter.

The Centre has also held two one-day courses for members of clinical ethics committees which were well received and these will be repeated, initially in Oxford, but hopefully in the future in other regions of the UK. The network

is also used to inform members of events of interest and relevance to clinical ethics committees, both nationally and locally.

The network is very much in its infancy but it has received widespread and enthusiastic support from clinical ethics committees and other health professionals. The next few years should be an interesting and exciting time for the development of both the network and of clinical ethics in the UK.

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MHECN SPONSORS CASE PRESENTATION DISCUSSION

“I Don’t Want to Die Today”

On Thursday, June 1, at Harbor Hospital, MHECN sponsored an evening of provocative discussion surrounding a case drawn from the television drama “ER.” Moderator Evan DeRenzo directed participants to act as an ethics committee at the hospital where the following scenario took place. Here we review the facts of the case, and the discussion that ensued.

Case Presentation

A young woman (Amy) is dying from end-stage cancer, which has spread to her brain. She has fluid in her lungs and is short of breath. Her father brings her to the ER to get some relief from her increased pain and shortness of breath. He tells the ER physician (Dr. Carter) that Amy has an advance directive that prohibits the use of aggressive life-sustaining procedures, that a Do Not Resuscitate (DNR) order has been written, and that he is her health care agent. Dr. Carter assures

him he can make Amy more comfortable. He drains a large amount of fluid from her lung and administers oxygen and morphine. After the father leaves Amy’s bedside to make a phone call, she regains consciousness long enough to emphatically plead with Dr. Green (Dr. Carter’s superior): “Please, help me. I don’t want to die today.” Amy is very short of breath. Dr. Green asks Amy if she would like some morphine to make her more comfortable, but she repeats her request. He asks if she wants to be put on a breathing machine, informing her that if she is put on a ventilator she “might never come off,” and she nods affirmatively. Shortly after that, her respiratory status worsens. Dr. Green revokes Amy’s DNR order, intubates her, and puts her on a ventilator. A power struggle then ensues between Dr. Green and Amy’s father, and between Dr. Green and Dr. Weaver (Dr. Green’s superior). Dr. Weaver tells Dr. Carter that Amy’s DNR order is reinstated. Dr. Green tells Dr. Carter that Amy is now a “full-code” patient. Moreover, Dr. Green tells Dr. Weaver that if she forces him to withdraw from the case or prevents him from administering cardio-pulmonary resuscitation (CPR), he will resign from the hospital. In the end, Amy’s heart goes into a fatal rhythm and Dr. Green insists on attempting CPR, to the reluctant acquiescence of Dr. Weaver. CPR fails, and Dr. Green pronounces Amy dead.

Relevant Facts

DeRenzo began the discussion by asking the audience as an ethics committee what factual issues need clarification. The first issue identified was Amy’s decisional capacity. Was she competent and/or did she have decisional capacity at the moment of her voiced “wish”? What about at the time the DNR order was originally made? Criteria for decisional capacity were reviewed (able to communicate a choice, able to give reasons for evincing a choice, and able to understand the

Cont. on page 10

MHECN Sponsors Case

Cont. from page 9

consequences of complying with a given choice). Evidence that was mentioned as relevant to this issue included Amy's shortness of breath and confusion, brain metastases, poor oxygenation, and that she was receiving morphine. In addition, the fact that Amy spoke to the doctor after her father left the room led some to wonder whether the father, in controlling Amy's care, was making decisions with which Amy did not agree. Others felt this was reading too much into the case.

A second issue raised was, if Amy was competent, what exactly did she want? Did her statement literally convey her wishes or was she expressing a "primal feeling" of not wanting to die? What was the meaning of her statement "not today"? Did that mean tomorrow might be okay?

A third issue raised was Dr. Green's ability to be objective. This is his first case after returning from his mother's funeral.

A fourth issue was who has or should have decision-making authority. Several power issues were identified that relate

to this question. As a young adult who has been suffering from a terminal illness since before she reached the age of 18, Amy has experienced increased parental dependence compared to other women her age. Her vulnerability is highlighted in the ER scene—some mentioned that her speaking to Dr. Green was the only way she could exercise any power. Her father may also be acting out of his own grief rather than what is in Amy's best interest. Dr. Green has an obvious power conflict with Dr. Weaver. Was Dr. Green's ultimatum—to attempt CPR on Amy or to quit—a measure of his commitment to advocate for his patient, or a struggle for power? What implications are there in Dr. Weaver's response to back down and allow Dr. Green to perform CPR?

Ethical Principles

A discussion of the ethical principles at stake in this case ensued. DeRenzo reminded participants that everyone prioritizes these principles differently, which influences the judgments and recommendations made. In the United States, the principle of autonomy often

takes priority. This requires us to protect a patient's right to self-determination, as well as to protect vulnerable persons from avoidable harm. Which of these two components of autonomy is operating in this case depends on Amy's decisional capacity when she voiced her request to Dr. Green, as well as when her advance directive and original DNR order were discussed. It was pointed out that no advance directive document had been produced, and that an attempt should have been made to check the records for documentation of a previous DNR discussion. Again, *what* she was requesting is also important. Does the principle of autonomy require that a health care practitioner comply with *any* patient's or family member's request?

Nonmaleficence (avoiding harm) and beneficence (seeking the good) were discussed in relation to this case.

Potential harms to Amy that were considered include her experiencing unrelieved suffering, for example, from unrelieved pain or shortness of breath, or psychological/spiritual distress that was not adequately recognized or addressed. From a legal perspective, concerns for Amy's family would have a minimal impact on decisions about her care. This differs from an ethical analysis, particularly one situated from a care perspective, which acknowledges the impact of illness on close friends or family members—particularly in end-of-life care. Potential harms to Amy's father and other family members that were mentioned include emotional distress, complicated grieving, physical caregiving burden, and additional financial burden if Amy was resuscitated and survived in a comatose or vegetative state. The perception that withdrawing care (in this case, ventilator support) would violate the principle of nonmaleficence and is "complicated" or ethically more questionable than withholding it in the first place was exposed as a myth.

Issues of equal access to palliative and hospice care for those who need it encompass not only the principles of beneficence and nonmaleficence but justice as well (i.e., in a *just* society, those in need of palliative and/or hospice care can actually get that care). Inad-

DEVELOPING DHEP

From the Center for Biomedical Ethics, University of Virginia Website

For the tenth consecutive year, the Center offered its intensive course, Developing Healthcare Ethics Programs, from April 24-29, with more than 40 students in attendance and over a dozen faculty. DHEP has been the centerpiece for the Center for Biomedical Ethics' outreach efforts.

The Program has evolved over its ten year history. The most prominent change in DHEP this year was the introduction of three specialized tracks: clinical ethics, organization ethics, and research ethics. As the field of healthcare ethics has become more complex the demands have diversified. Clinical ethics can no longer be the sole focus of a well-designed educational program. As managed care places greater pressures on the moral standing of the organization as a whole we must be "at the table" when critical resource decisions

are made. And, as the human protections system seems to be up for change, including the likely accreditation of IRBs, training in research ethics will have to be offered by the major centers, including our own. Next year, to reflect the growing breadth of our offerings, Paul Lombardo will join Ed Spencer and Ann Mills as the leadership team for DHEP. Paul brings long experience in health law and ethics and a strong reputation as an effective teacher. Those of you who have suggestions and questions about the next DHEP, which will be held in Charlottesville the week of March 5, 2001, are invited to contact us.

Jonathan D. Moreno, Director
The Center for Biomedical Ethics
<http://www.med.virginia.edu/medicine/inter-dis/bio-ethics>

equate palliative care by the ER staff was identified as a problem needing attention. One question that arose was why Amy had not been followed by a home hospice team. If that had happened, most likely the family issues would have been addressed earlier, her wishes would have been clarified, good communication would have been prioritized, and morphine would have been available in the home (along with nursing support) for the relief of pain and shortness of breath.

Consideration of the principle of justice encompasses the question of whether Amy was requesting "futile" care. If one defines futility as implementing means that cannot achieve an identified goal, then one needs to consider the goal. For example, if it was Amy's parents' wedding anniver-

sary and she wished to spare them the memory of dying on their anniversary, then keeping her alive on a ventilator for one day would not be futile if it accomplished that goal.

Implications

Implications for hospital policy and staff education were discussed based on the case. Poor communication between staff and between patients/families and health care practitioners should be addressed, particularly communication surrounding end-of-life issues and advance directives. This would most likely require staff, as well as community, education. The issue of late or low rates of referral to hospice should be addressed, and written protocols or policies may need to be implemented, including for example, a palliative care

policy that would apply hospital-wide (including in the ER).

In summary, the ethics committee's job is to deliberate and discuss the ethical issues at stake in such cases, rather than to quickly rush to conclusions about what to do or what should be done, or base decisions merely on what the law mandates. This case points out how a legal document (an advance directive) does not ensure that the "ethically right thing" is done. The latter requires active thought and questioning, reflection, discussion, and knowledge of basic ethical concepts and principles.

Anita J. Tarzian, Ph.D., R.N., Chair
MHECN Education Committee

CALENDAR OF EVENTS

August

- 18 "Making Decisions for Incapacitated Patients: The New WV Health Care Decisions Act," Days Inn Conference Center, Flatwoods, WV. Sponsored by the West Virginia Network of Ethics Committees. For further information contact Cindy Jamison at cjamison@hsc.wvu.edu

September

- 1 - 3 "World Conference on Assisted Dying" Boston, Massachusetts. Sponsored by the Hemlock Foundation for the World Federation of Right to Die Societies. For further information call Nan Owens at 800-247-7421 or email world@hemlock.org.
- 11 "Genetics" Georgetown University Hospital, Washington, D.C. Sponsored by the Georgetown Clinical Bioethics Center and the Metropolitan Washington Bioethics Network. 4 - 6 p.m. Speaker: Father Kevin Fitzgerald. For further information, contact Joan Lewis at jlewis@dcha.org or 202-682-1581.
- 15 "Summit to Improve End-of-Life Care" Days Inn Conference Center, Flatwoods, WV. Sponsored by the West Virginia Network of Ethics Committees. For further information contact Cindy Jamison at cjamison@hsc.wvu.edu.
- 15 - 16 "Power Over Information, Power to Decide: Paternalism and Autonomy in Health Care" Charleston, South Carolina. Sponsored by the Medical University of South Carolina and the Institute of Human Values in Health Care. For further information Robert Sade, MD, or Jason Arnold, JD, MPH, at 843-792-5278 or values@musc.edu.
- 25 - 26 "Doctors, Death & Dignity III: Holding our Ground" Chautauqua, NY. Sponsored by The Hamot Second Century Fund and The Center for Hospice and Palliative Care. For further information call Hamot Medical Center CME Department at 800-352-2553 or visit their web site at www.hamot.org.

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