



MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Winter 2003/2004

COULD SCHIAVO HAPPEN IN MARYLAND?

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During the height of the news reports on the Florida "right to die" case involving Terri Schiavo, I was asked by several reporters and colleagues whether what happened in the Schiavo case could happen in Maryland. Schiavo, 39 years old, has been in a persistent vegetative state since 1990, when a heart attack cut off oxygen to her brain. Her husband, Michael, believed that she would not want to be kept alive any longer with artificial nutrition and hydration. Her parents opposed the termination of her life support, arguing that she was not in a persistent vegetative state and that she would have wanted to be kept alive under these circumstances. The case went to court. While the courts, on several occasions, upheld the determination of Terri's diagnosis and her husband's substituted judgment, last fall, the Florida legislature passed a narrow law overriding the court decisions by allowing the governor to issue a "one-time stay to block the withholding of nutrition and hydration under circumstances tailored to the Schiavo case."¹

My initial reaction to the questions about whether Schiavo could happen here was, "no, of course not . . . the Maryland legislature is an enlightened one. It reacted quickly to the Mack case, a 1992 Maryland case similar to that of Schiavo, by passing the Health Care Decisions Act (HCDA), a comprehensive law providing guidelines for when life support may be

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Diane E. Hoffmann, JD, MS
Editor

terminated from someone in a persistent vegetative state." But, that quick conclusion led me to look at what type of law Florida had on the books regarding end of life care.

I was surprised to find that the Florida law is very similar to the HCDA. Definitions of such key terms as "advance directive," "close personal friend," and "life pro-longing procedure" are almost identical. Moreover, the Florida statute, as does the Maryland law, considers termination of life support at

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The information in this newsletter is not intended to
provide legal advice or opinion and should not be acted
upon without consulting an attorney.

NETWORK NEWS

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

On December 12, 2003,
MHECN and Franklin Square
Hospital co-sponsored the
conference, "Not in my ER, Not in my
Nursing Home: Regulatory, Legal, and
Ethical Insights about Dying in
Institutions." Over 100 people
attended the conference. This
conference was sparked by
discussions in meetings sponsored by
MHECN to address problems when
patients are transferred from nursing
homes to emergency rooms at the end
of life.

On November 6, 2003, members
attending the MHECN Journal Club,
hosted by Kennedy Krieger Institute,
took part in an insightful discussion of
the book, "The Spirit Catches You
and You Fall Down," (Fadiman,
1998). If any member institution is
interested in hosting a Journal Club
discussion, please contact the
MHECN Coordinator.

MHECN is planning a Spring dinner
and lecture on the topic of sex and
ethics in health care and is in the
planning phase of a fall 2004
conference on issues related to do-
not-resuscitate orders.

For more information, contact
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THE METROPOLITAN WASHINGTON BIOETHICS NETWORK

The MWBN continues to
collaborate with its members in
co-sponsoring various ethics
events. For example, the Network
helped coordinate a series of
upcoming lectures in March and April
offered by faculty of the Center for
Clinical Bioethics at Georgetown.
Other upcoming events include the
Health Care Ethics Semi-Annual
Short Course at Walter Reed Army
Medical Center, the Harvey
Lectureship in Health Care Ethics at
Georgetown, the Annual Faith, Ethics
and Health Care Conference at
Georgetown, and the Leikin Memorial
Lecture at the Children's National
Medical Center (*see* Calendar for
details).

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Could Schiavo Happen in Maryland?

Cont. from page 1

the request of a surrogate (proxy) appropriate in three circumstances – the patient is terminally ill, is in a persistent vegetative state, or has an end stage condition. The term “end stage condition” was defined and used for the first time in a state statute regarding end of life care when the Maryland legislature passed the HCDA in 1993. It appears that the Florida legislature looked to Maryland’s statute for this term. The two statutes are also virtually identical in the list of surrogates who may make decisions for a patient lacking decision-making capacity and apply the same standards to the surrogate’s decision, i.e., it must be based on what the patient would have wanted or, if this cannot be determined, on what would be in the patient’s best interest. In Florida, the legislature also required that an institution’s bioethics committee review any decision to withhold or withdraw life-prolonging procedures from a patient in a persistent vegetative state who does not have a surrogate (proxy) and has not indicated his/her preferences for life-support. In Maryland, review of an ethics committee (patient care advisory committee) is not required in such circumstances but the HCDA specifies referral to an ethics committee if surrogates of the same class do not agree on whether to withhold or withdraw life support, or if a health care provider believes that a decision to withhold or withdraw life sustaining treatment would be inconsistent with “generally accepted standards of patient care.”

One feature of the Maryland statute that is not included in the Florida law is guidance on the factors that may be considered in determining what the patient would have wanted, e.g., prior statements, personal values, etc., or in determining what would be in the patient’s best interest (*see* Md. Health-Gen. §5-605 (c)(2) & §5-601 (e)).

Neither statute states specifically what would be in the “best interest” of someone in a persistent vegetative state and even the guidance included in the Maryland statute does not provide a clear cut answer to this question. In Maryland, it is up to the individual decision-makers

(guardian, agent or surrogate), in each case, to determine whether “the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from the treatment” (HG §5-601). Factors listed in the Maryland statute for decision-makers to consider in deciding “best interest” allow for some discretion recognizing that those legally vested with the ability to make such decisions are in most all cases those who have the best interest of the patient foremost in mind.

In Florida, the statute was not the problem. The courts applied the statutory standards and upheld the finding, attested to by several medical experts, that Terri Schiavo was in a persistent vegetative state and that her husband² could terminate her life sustaining treatment based on clear and convincing evidence that this is what she would have wanted. In Maryland, the HCDA similarly would allow a court to come to the same conclusions (although it is possible a court could weigh the evidence differently).³ Rather, the problem in Florida was with the legislature which sought to overturn the court’s determination that the standards of the statute were met. It is not entirely clear whether the Florida legislature no longer believes in the procedure it set up in its statute and will seek to change the existing law or whether it simply does not agree with how the court weighed the evidence presented regarding Terri Schiavo’s medical condition or her wishes. There is some evidence of the former. According to one report, a bill was introduced in Florida that would not allow life sustaining treatments to be withheld or withdrawn from individuals in a PVS unless they have stated in writing, through an advance directive, that that is what they would want.⁴ Because the bill apparently faces much opposition it is more likely that the majority of the Florida legislators simply disagreed with how the courts weighed the evidence in the Schiavo case. However, such action, as has been reported in the media, raises constitutional issues regarding the separation of powers between the judiciary and the legislature and the

ability of the legislature to usurp the authority of the courts in their role of applying the law to the facts of a case. The Florida legislature’s actions in passing the statute that prohibits the withdrawing of life support from Terri Schiavo has been challenged as a constitutional violation and we will need to await the decision of the courts as to what will ultimately happen in that case. The outcome of that decision will determine whether Maryland or any other state legislature could succeed in a similar action.

In the meantime, the moral of the Schiavo case is to prepare an advance directive (particularly, one expressing your wishes regarding tube feeding), share it with your loved ones, and make sure that your physician has a copy!

Diane E. Hoffmann
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Notes

¹ “*ACLU to Challenge Law Allowing Governor to Stay Court Order to Remove Feeding Tube*,” *BNA Health Law Reporter*, Vol. 12, No. 43 (Oct. 30, 2003).

² *Mr. Schiavo was also his wife’s judicially appointed guardian.*

³ *Under the Maryland HCDA, the courts would apply a “preponderance of the evidence” standard to the determination of Schiavo’s diagnosis, see HG §5-612(b), but would apply a “clear and convincing” evidence standard to the substituted judgment of Schiavo’s husband, see E&T §13-712(b).*

⁴ *See Florida Senate Bill 692, the Florida Starvation and Dehydration of Persons with Disabilities Prevention Act.*

SANCTIONS FOR FAILURE TO HEED WRITTEN DIRECTIVE

The following is a summary of a case in which the Office of Health Care Quality (OHCQ) of the Maryland Department of Health and Mental Hygiene found a Maryland nursing home deficient in honoring the advance directives of a resident in its care. OHCQ levied a \$10,000 fine against the nursing home for the deficiency. This case was presented at the December 12, 2003 MHECN conference, "Not in my ER, Not in my Nursing Home . . ." by Bill Vaughan, RN, BSN, Chief Nurse of OHCQ.

Jane Doe was an 83 year old female when she was admitted to [a Maryland nursing home] on February 26, 1998. Almost a year prior to her admission, while still living in the community, this resident wrote certain instructions related to her health care. These instructions were contained in a document entitled "Advance Health Care Directive for Jane Doe." The resident signed this document on March 19, 1997, and two individuals witnessed the signing.

Mrs. Doe's advance directive instructed her healthcare providers to withhold or withdraw life-sustaining procedures if she met any one of the following criteria:

1. "If I am suffering from a terminal condition and if my death is imminent..."
2. "If I am in a persistent vegetative state..."
3. "If I have an end-stage condition ..."

Mrs. Doe, in her advance directive, specifically addressed the issue of artificial nutrition as follows:

"I direct that no nutrition or sustenance be administered to me artificially, such as the insertion of a feeding tube; and, I direct that upon finding that I am as described [as either terminal, in a persistent vegetative state or in an end-stage condition] that any

such artificial administration be terminated immediately ..."

Mrs. Doe had been at [a Maryland nursing home] for 18 months when on August 23 and September 20, 1999, two physicians certified that her medical condition was end-stage due to dementia. On July 17, 2000, two physicians again certified that her condition was end-stage secondary to dementia. At that time, the physicians also noted that tube feeding this resident, i.e. providing nutrition via a tube placed into the stomach, would be "medically ineffective."

Mrs. Doe experienced a gradual decline in her overall condition, and during the first several months of 2001, it became apparent that her oral intake of food and fluids was becoming inadequate. Her capacity to make medical decisions and her ability to communicate had become severely impaired, and due to her dementia, she was no longer able to participate in decisions related to her health care. On April 5, 2001, she was admitted to [a Maryland hospital] for the third time in the preceding six months due to dehydration. Despite Mrs. Doe's clear advance directives to the contrary, a feeding tube was surgically placed into her stomach during this hospitalization at the insistence of her son. The house staff at the hospital administered fluids and nutrition through the tube.

She returned to [the nursing home] on April 13, 2001. The clinical staff at the nursing home, including the attending physician, medical director, numerous members of the nursing staff, the administrator, the social worker and a corporate nurse who was a member of the facility's patient care advisory committee, all agreed that administering tube feeding to this resident would be against her wishes. Therefore, Mrs. Doe received only water and medications through the feeding tube. The facility's decision not to administer nutritional tube feeding per the resident's advance directive was communicated to the resident's family.

On April 14, 2001, the attending physician visited the resident and wrote the following progress note: "... G tube [feeding tube] is placed against living will ...". The attending physician next visited Mrs. Doe on April 16, 2001, and wrote: "Pt [patient] had PEG [feeding tube] placed for nutritional purposes against the wishes of the patient. I personal [sic] do not recommend G tube

[feeding tube] placement, I want to respect patient's wishes ... continue G-tube [feeding tube] flushes [water only] no nutrition ..."

Three days later, on April 19, 2001, the attending physician again came to the nursing facility and wrote: "Tried for family discussion with her son and daughter-in-law. Looks like they have contacted the attorney and made the decision if patient is not fed they will sue us ..."

From the time Mrs. Doe was readmitted to the nursing facility on April 13, 2001, until the physician wrote her last note on April 19, 2001, all the resident had received was water and medications through her feeding tube. As her attending physician had, on two previous occasions, declared her to be in an end-stage condition (due to dementia) and her own physician had deemed that providing nutrition via a feeding tube would be "medically ineffective," the decision to withhold nutrition was completely in accordance with her advance directive. However, after the resident's family made threats of legal action, the physician, on April 20, 2001, ordered the nursing staff to begin administering nutrition via Mrs. Doe's feeding tube. The nursing staff of the facility complied with this order and from April 20, 2001 through May 2, 2001 administered tube feeding formula to her daily. On May 2, 2001, the resident became acutely ill, was hospitalized, and did not return to the facility.

In summary, it is clear that the staff at the nursing facility was not responsible for the placement of the feeding tube. That act, in direct contrast to the expressed wishes of the resident, was performed at the hospital. The staff at the nursing facility was, however, required to honor the instructions set forth by Mrs. Doe in her advance directive. Those instructions carried the same weight as if Mrs. Doe had spoken them herself during April and May of 2001. Despite clear misgivings on the part of the nursing and clinical staff, who were personally familiar with Mrs. Doe's wishes, the facility failed to allow this resident to exercise her right to refuse treatment, specifically the right to reject the artificial administration of sustenance. Instead of honoring the very clear and concise directives of Mrs. Doe,

the facility inappropriately followed the wishes of her family, which were in absolute contradiction to her expressed wishes.

The Office of Health Care Quality considers the rights of patients to be paramount in any healthcare institution and will continue to monitor the response of facilities to this issue.

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Note: The nursing home appealed the deficiency and sanction (\$10,000.00 fine) to the Maryland Office of Administrative Hearings. A redacted version of the judge's decision in this case is available online at www.dhmd.state.md.us/ohcq/download/alert2/pdf.

Was the hospital off the hook?

The staff of OHQC also conducted an investigation into the care Mrs. Doe received at the hospital where the feeding tube was inserted. The hospital was seemingly unaware that a feeding tube had been placed in this patient against her expressed wishes. The Office of Health Care Quality issued a deficiency to the hospital for failing to provide care in compliance with a patient's advance directives.

Of note is that the patient's attending physician and family chose to institute treatments that were not only against Mrs. Doe's wishes (as stated in her written advance directive) but that were determined by two physician certifications to be medically ineffective.¹

Were actions consistent with hospital policies?

A review of hospital policies revealed that Hospital Policy Number RJ10 defines medically ineffective treatment and end-stage condition. Enacted in order to "foster respect for the inherent dignity of each person," this policy allows a health care provider to withhold or withdraw life-sustaining procedures provided that the patient's attending and a second physician have certified the patient as having a terminal condition. The certifications (noted above) predated this hospital admission by nearly one year and verified that the patient's condition

was "severe and permanent deterioration indicated by incompetence and complete physical dependency [and] treatment of the irreversible condition would be medically ineffective." Despite this fact, the G-tube was inserted.

In addition, Hospital Policy Number RI8 states that to "avoid conflicts of interest and/or the appearance of conflict," the hospital must "assure that the care provided each patient is appropriate" and "ensure the integrity of clinical decisionmaking..." This policy states that it is in place to "promote employee and medical staff sensitivity to the full range of such needs and practices [physical, psychological, social and spiritual needs and cultural beliefs and practices]." There was no documentation to indicate that the physician, surgeon, anesthesiologist or other healthcare providers or administrative staff voiced the conflict between the patient's advance directive and the insertion of a feeding tube by invoking the hospital's "specific mechanisms or procedures to resolve conflicting values and ethical dilemmas among patients, their families, medical staff, employees, the institution and the community" as identified in Policy RI8.

A review of the hospital's Ethics Committee meeting minutes revealed that the hospital has a functioning system for the review of cases where there are conflicts regarding a patient's treatment, family wishes or advance directives. However, there was no documented evidence that the conflict between this family, the provider and the patient's advance directives had been referred to the hospital's Ethics Committee or for an ethics consult. Hospital staff interviewed on October 10, 2001 indicated that neither the physician nor the family referred this patient's case for an Ethics Consult. In response, the hospital revised its policies and implemented staff training to ensure that advance directives are followed.
www.dhmd.state.md.us/ohcq/download/alert2/pdf

Note

¹ Medically ineffective treatment refers to treatment that would not alter the patient's deteriorating health status nor prevent her impending death.

INTERVIEW WITH PHIL PANZARELLA, MD, ETHICS COMMITTEE CHAIR, FRANKLIN SQUARE HOSPITAL

This article is part of a series featuring interviews with health care ethics committee chairs about how their committee was established and operates.

By Samantha Freed
MHECN Research Assistant
(edited interview)

SF: When was your ethics committee formed and what prompted its formation?

PP: 1982. Dr. Lewis Breschi, who is still on the medical staff, formed the committee. He was interested in medical ethical issues at a local and regional level with the state medical society and the AMA. He was getting questions about these issues, and because he was interested, he brought the idea of the committee to the medical executive committee. He saw a need for it. It was a much smaller committee then and he was the first chair.

SF: Could you describe how your ethics committee is structured?

PP: It's a medical staff committee, but because we do organizational ethics and not just clinical ethics, it's also a hospital committee. The committee chair and members are elected by the medical staff president. The chair is someone who has been a member for a long time and has a lot of experience and training. I am only the fourth chair in 24 years. Committee members are appointed – if committee members are going off the committee, we look at the needs of the committee and present [candidates for membership] to the medical staff president.

SF: How does the opinion of the committee get reported?

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Interview with Phil Panzarella, MD
Cont. from page 5

PP: Summaries go to the medical executive committee board of directors of the hospital and the CEO.

SF: Is there a budget and if so, under what department?

PP: There's not a formal budget. Some money comes from conferences we've done. There's a budget so our meetings are catered and any other ad hoc request comes from me up through the VP of Medical Affairs and goes from there. We also have a budget line to support an ethics consultant, Evan DeRenzo. She's been effective and important to our committee and very helpful.

SF: What is Evan's background and what does she do for the committee?

PP: She has a PhD, she's an ethicist with a background in research. She worked at NIH for a number of years. She was on their IRB and did research ethics. From there, she worked in clinical ethics and is a member of the Center for Ethics at Washington Hospital.

SF: How many members does your committee have and what are their professional backgrounds?

PP: About 30 members. It's a fairly large committee, which is good because of everyone's schedules. We can't get everyone at the meetings, but we usually get at least 20 people at every meeting. Committee members come from every part of the hospital - case management, pastoral counseling, nursing, dietary and nutrition, physician assistants, ethicists, administrative members, physicians and nurses. We do have legal counsel. He doesn't come to the meeting but he's available when we need him. He'll be on the speaker phone during a consultation if needed. We have residents that come through as part of their rotation. Everyone signs a confidentiality agreement. We've had nurses who are in training or interested in ethics, and I make sure this experience is appropriate for them. So, these aren't permanent members but we learn from them as well.

SF: How does one become a member of the committee?

PP: Some people will approach me and I will ask them why they are interested and about their background. We also try to recruit members. We try to make sure they are willing to make a three year commitment. Sometimes, people will come up to me and recommend someone who has just joined the staff. So it goes both ways. Once we feel it's a good fit, we submit a recommendation to the medical staff president. It's not a big deal to add new members to the roster.

SF: How did you get to be Chair of the Committee?

PP: I have been a member since I came here to Franklin Square in 1991. I have a background in ethics and in the history and philosophy of science. I served as a member. When the last chairman was leaving, he approached me and asked me to be the chairman. It was also done with a lot of due diligence on my part and deliberation. I asked, "Why me? What are the challenges and what are the rewards?" Being a member, I already had some ideas of the answers.

SF: How do staff and families know about the ethics committee?

PP: The staff learns about it during [professional staff] orientation and through educational conferences (or committees). We have conferences at least once a year. They learn through our consults, and our members tell their colleagues. In April, we are planning a series of Ethics Town Hall Meetings to bring in issues informally that staff has seen on the floor. We see this going in a lot of different directions. All sorts of issues could be brought to us. As for families and patients, patients get a statement of their rights and responsibilities when they enter the hospital. This includes patient and family access to the ethics committee.

SF: How does a referral for a consultation get to the committee?

PP: We have five people who actually run the consult and we rotate every

month. The social worker does the formal intake. If there is a request [for a consult], that information gets to the consult team members in a number of ways. Either another physician will be called or I'll be called. Sometimes it's a policy issue, but sometimes it can be resolved with a few phone calls. We do try to be careful that we aren't out there individually answering questions, and we try to err on getting more people involved.

SF: Tell me more about the consultation process.

PP: ... If the social worker decides there is a need for a meeting, she arranges one. Then the doctor in charge looks at the chart and sees what else is going on and what else he needs to find out. If possible, we may interview the patient. The consult is called and basically our role is an advisory one. We are here to facilitate discussion and communication and decision making. We aren't here to see that a particular decision is made (although in situations of [granting] immunity to physicians, we are put into positions that aren't just advisory). Then, we have our usual deliberation after the consult. When we're done, the person running the consult writes a summary. At the committee meeting, we will go over the consults we've had since the last meeting. We may role play, and try to review the consults we've had and determine whether the advice was reasonable, what other people would have done. It is expertise by committee, and it certainly has a formal piece to it.

SF: Do you have subcommittees?

PP: There are two subcommittees. One is an education subcommittee that works on the regional conferences that we put on for the hospital. We have an educational session at the beginning of the meeting for about 25 minutes, and the subcommittee brings topics that people want to hear. We coordinate the Ethics Town Hall meetings. We also have an end-of-life care committee, which I am chair of, but it may get its own life and legs, far from the ethics committee. We used to have an executive committee and a

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IN RE SOPHIA E. FOLEY: FOLLOW-UP

In the Summer 2003 edition of this publication, we reported on the case of *In re Sophia E. Foley*, 373 Md. 627 (2003). This article briefly summarizes the Court of Appeals decision in the case and describes a subsequent trial court opinion.

In *Foley*, the Circuit Court of Anne Arundel County, Maryland, issued an order for a physical examination pursuant to a discovery request filed by the petitioner for guardianship (Mrs. Foley's sister). The order was issued over the objection of Mrs. Foley's husband and health care agent, despite the acknowledgement by the court that: (i) Mrs. Foley had executed a valid advance directive in 1992; (ii) that Mr. Foley was his wife's designated health care agent; (iii) that, as the health care agent, Mr. Foley was granted "broad powers;" (iv) that the purpose of the advance directive was to permit Mr. Foley to manage his wife's

health care; and (v) that Mr. Foley was trying to follow his wife's doctor's orders "as best he can." Regardless of these findings, the trial court held that a "reasonable health care agent" ought to have the tests performed.

On appeal, Maryland's intermediate appellate court vacated that order; however, that ruling was overturned by the Maryland Court of Appeals, which held that the trial court's discovery order was not subject to appeal. The Court of Appeals specifically indicated that the ruling was not based on the subject matter of the appeal, but was based on a procedural issue. After a petition for review was denied by the United States Supreme Court, and the case sent back to the trial court, Mr. Foley requested that the trial court reconsider its original opinion, an opinion that effectively granted Mrs. Foley's sister the relief

sought in the guardianship case (i.e., a physical exam including a test for Lyme disease) without appointing her guardian.

The trial court granted Mr. Foley's motion for reconsideration, and dismissed the guardianship petition. In its opinion, the trial court, for the first time, incorporated the three-step, decision-making process set forth in Maryland's Health Care Decisions Act (HCDA) into its determination of whether a guardian should be appointed when a valid advance directive is in existence.

The decision-making process of the HCDA provides, as a first step, that medical decisions are to be made in accordance with the expressed wishes of a competent individual in a written (or oral) advance directive. If the declarant did not specifically address a particular situation in his advance directive, then decisions are to be made in accordance with the HCDA's considerations for determining a patient's wishes. Lastly, if the wishes of the patient are unknown or unclear, decisions shall be based on the best interest of the patient, as defined in the HCDA.

The court stated that although Mrs. Foley had not expressed her wishes regarding her examination, testing, and treatment for Lyme disease, which were requested by her sister, Mrs. Foley did not have to provide such specificity in her advance directive. The court went on to state that Mrs. Foley's advance directive, specifying her husband as her health care agent, "should end the inquiry." Based on the record before it, the court held that Mrs. Foley's sister had not met her burden to prove that Mr. Foley was not acting in accordance with his wife's best interest, and, therefore, it was not necessary for the court to superintend and direct Mrs. Foley's care through a guardianship.

Although this opinion has no precedential effect beyond the *Foley* case, it is the first time that a Maryland court, at any level, has incorporated the decision-making process of the HCDA into a determination of under what circumstances a health care agent or surrogate could be overruled by a court. Further, this decision places the burden squarely on a challenger to prove that a health care agent or surrogate is not

"FAST FACTS" – PALLIATIVE CARE KNOWLEDGE THAT'S EASY TO DIGEST

Organizational change theorists know that it takes more than improving knowledge to effect change in an institution. That is, knowledge is not sufficient, but it *is* necessary. To address deficiencies in palliative care knowledge among health care professionals, the National Residency End-of-Life Curriculum Project (funded by the Robert Wood Johnson Foundation) created "Fast Facts." These are one to two page summaries of palliative or end-of-life care facts or concepts that are distributed by e-mail every two weeks. (See box for examples). They are also available for downloading at www.eperc.mcw.edu. To subscribe or download, you must register at the site, but registration is free.

Selected "Fast Facts & Concepts"

Treating Terminal Delirium	Determining Prognosis in Advanced Cancer
Converting To-From Transdermal Fentanyl	Palliative Chemotherapy
Syndrome of Imminent Death	Constipation
Death Pronouncement	Conducting a Family Conference
Treatment of Nausea and Vomiting	Patient-Centered Interviewing:
Delivering Bad News Part I	Understanding The Illness Experience
Depression in Advanced Cancer	Oral Opioid Dosing Intervals
Morphine and Hastened Death	Taking a Spiritual History
Hospice & Palliative Med. Certif. Exam	Opioid Dose Escalation
Tube Feed or Not Tube Feed?	Hope and Truth Telling
Delivering Bad News Part II - Talking to Patients and Precepting Trainees	Writing a Condolence letter
Myths about Advance Directives	DNR Orders in the Hospital—Part 1
	DNR Orders in the Hospital—Setting—Part 2
	Opioids and Nausea

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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 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 about 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, 500 W. Baltimore St., Baltimore, MD 21201, or dhoffman@law.umaryland.edu.

CASE STUDY FROM A MARYLAND HOSPITAL

Mr. Y. is a 25 year old East Asian man who came to the U.S. from his home country (on a limited family-based immigrant visa) to live with his sister. He had been receiving dialysis in his home country, and because he has no health insurance, he went to the emergency room of a Maryland hospital seeking dialysis. Because he had complications from not receiving dialysis for about a week, he was admitted and received dialysis. Now, three months later, he is still an inpatient because the hospital is unable to discharge him without adequate plans for outpatient dialysis. They cannot find any outpatient dialysis facility that will take unfunded patients. Mr. Y applied for Medicaid, however, because he is young and relatively healthy (no acute care needs if he

receives dialysis), staff suspect the physician may not declare him to be disabled for at least a year (and thus he may not qualify for Medicaid). A staff member tells the patient's sister that she must have her brother go back to his country to receive dialysis until it is known for sure that he will qualify for Medicaid. Someone asks a member of the ethics committee what the "ethically ideal" thing to do would be in this case.

RESPONSE FROM A NURSE ETHICIST

The ethical issues associated with the provision of health care to non-citizens are complex and cannot be fully addressed in a brief discussion. However, we can address what I consider to be the central ethical concern in this and similar cases: is withholding lifesaving therapy from someone who can clearly benefit from it ever justified? The ethically ideal response is no, unless there are extenuating circumstances such as the proposed treatment must be rationed due to scarce supply. There is support in the literature for this position. The Renal Physicians Association (RPA) addressed the issue of provision of kidney dialysis for non-citizens in the United States in 2000 and offered guidance to their members. The primary question they asked was should a provider of dialysis services deny care to an individual based on that person's citizenship status? Their response was clear. "Without imposing an unreasonable burden on themselves or others, all health care professionals and health care systems have an obligation to treat the sick" (RPA; 2000). Of course the question that lingers is, what constitutes unreasonable burden?

The RPA made additional equity related recommendations due to the fact that non-citizen dialysis care falls most heavily upon the health care systems of a few states, such as New York, Texas, and Florida, primarily border states or those with international points of entry. The RPA recommended distribution of the cost of non-citizen dialysis care across the fifty states and further stated that the federal government should be the primary payer through the use of emergency Medicaid funds. Even without the proposed distribution of the financial

burden, the RPA was clear that there is an ethical obligation to treat (dialyze) based on need. I agree. However, it is undeniable that in states with high immigrant health demand, the provision of dialysis care is becoming preemptively expensive. Federal legislation has been proposed but not enacted to avert what can only be referred to as a tragedy in these cash strapped states as providers notify their non-citizen patients that they will not be treated and so must go home to their native countries presumably to die (Neumann; 2002).

Nickel offers a humanitarian argument for providing non-citizen health care. He describes denying medical care that is life saving as analogous to the state taking no steps to prevent starvation or murder of a non-citizen. Nickel states that *all* persons have moral claims against others to needed assistance in obtaining the requirements for survival and that the use of citizenship as a criterion for the provision of lifesaving therapy is not ethically justified if universal humanitarian claims are taken seriously (Nickel, 1986)

From an ethics perspective the foundation for the RPA's and Nickel's recommendation is the bioethical principles of beneficence and non-maleficence or the obligations to do good and avoid harm. Although not referred to directly as beneficence/non-maleficence the obligation is clearly alluded to in the RPA position paper when the authors state that "...there is a humanitarian claim that society is responsible for caring for those among us in need." It is clear that in this case the patient at issue has a medical need that can be successfully treated and, according to the RPA, should be treated. Again, I agree. The clinicians involved have a moral obligation to provide their patient access to life saving kidney dialysis. They may pursue the least expensive option, but the option selected must meet standards of practice to be ethically acceptable.

Who should be responsible for providing aid in a particular case? Whoever is best able to do so. In this case, if dialysis care is truly available in the patient's home country, once Mr. Y feels well enough, returning home to receive needed therapy is not an unethical option. Another alternative is that the hospital itself could pay for Mr. Y to receive outpatient dialysis care. Doing so

would be less expensive than continuing to treat him as an in-patient. In general, the state and federal governments are certainly in a better position to provide care than private individuals or groups as government entities are able to spread the burdens and costs of doing so over a larger number of people through the use of tax revenues. In a related discussion, Slifkin and Charytan urge the federal government to take responsibility for the problem and write that "in the absence of societal or governmental policy, in states where there is no provision to finance renal care for non-citizens the decision to deny care or face financial insolvency is left to the nephrologist or the administrator." They find this unacceptable, unethical and unwise (Slifkin and Charytan, 1997). When this occurs providers must make decisions that protect and value life even when those decisions are conflicted and administratively unpopular.

*Lynn Randolph Noland PhD APRN, BC
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Notes

Neuman ME. "Nowhere to go... immigrants waging seesaw battle over coverage for dialysis care in the West, Southwest." Nephrology News & Issues. 2002 July; 16(8): 11.

Nickel JW. "Should undocumented Aliens be entitled to health care?" Hastings Center Report. 1986 16: 19-23.

RPA position on dialysis for non-citizens. Renal Physicians Association. Clin Nephrology. 2000 Sep;54 (3): 253-4.

Slifkin RF, Charytan C. "Ethical issues related to the provision or denial of renal services to non-citizens." Seminars in Dialysis. 1997 May-June; 10(3) 173-5.

We welcome comments to this case study, including how cases such as this are handled at your institution. Please e-mail your comments to MHECN@law.umaryland.edu."

LIVING-RELATED ORGAN DONATION WITH SURROGATE CONSENT

At their March meeting, ethicists from the United Network for Organ Sharing (UNOS) will be discussing a topic that is just beginning to gather attention: living-related organ donation from patients expected to die but not within the window of time allowed by non-heart-beating organ donation protocols. A case that sparked discussion among bioethicists and transplant specialists involved a 20-year-old firefighter treated at UCLA. Three weeks after he suffered massive bleeding into the brain, the man was not technically brain dead, but neurologists determined he had no chance of recovering and would probably die if removed from life support, though not immediately. His parents believed he would have consented to organ donation because he had "dedicated his life to helping others," according to a report on the case by Dr. Neil Wenger, chairman of UCLA's ethics committee, and Wenger's colleagues.

Organ donation guidelines say living donors must be competent to give consent. Because the firefighter's organs would have deteriorated if he had been taken off life support and allowed to die first, family members asked doctors to let them speak for the patient and give consent for a living donor kidney transplant. The kidney would go to the firefighter's cousin.

The doctors gave their OK. Though they believed the firefighter could not feel pain, they treated him during and after surgery as they would any other living donor, and he began healing quickly from the operation. Four days afterward, doctors removed the man from a ventilator, and he died a day later. The cousin is now healthy, Wenger said.

Though such circumstances are rare, the UCLA ethics group agreed that guidelines are needed, and should require that in cases where a patient has not given consent, the family members designated to speak for him "should derive no benefit from the organ

donation." Also, surgical procedures that probably would severely endanger the patient's health, including removing vital organs, should be prohibited, the group said.

A similar 1998 case involved a patient who had been in a coma for three weeks. He was registered in Ohio as an organ donor. The patient was 51 at the time and was comatose following a heart attack. The judge ruled one kidney could be removed and given to the patient's brother who was on the transplant waiting list. The court's rationale was that the comatose patient's condition was irreversible, he could still live (comatose) with one kidney, and there was prior evidence that the patient wanted to be an organ donor.

NIH ethicists David Wendler and Ezekiel Emanuel said that allowing family members to decide whether to take organs from a living but incapacitated relative should be discouraged and should be permitted only for patients who are in a persistent vegetative state. Immediate family members, they assert, should not get the organs.

The practice risks undermining public trust in the organ donation process, Wendler said. "If people start thinking they can take your organs if you're not feeling very good and your spouse thinks it's OK, that's going to cause more problems than it solves," he said.

"I don't know of any professional organization that has addressed this," said Dr. Mark Fox, head of the ethics committee at UNOS. "It's certainly a topic that warrants discussion," which is what Dr. Fox and colleagues will be doing at their meeting this March.

Adapted from a story by Lindsey Tanner of ©The Associated Press.

In Re Sophia E. Foley: Follow-Up Cont. from page 7

acting in accordance with the decision-making processes set forth in the HCDA.

By Angela Grau
Attorney at Law
Davis, Agnor, Rapaport & Skalny,
L.L.C.*

**The firm represented Mr. Foley in the litigation.*

Interview with Phil Panzarella, MD

Cont. from page 6

policy committee but as we've developed, they really aren't committees anymore. As part of the charter, we review policies but we don't have a separate committee anymore. And the executive committee, which used to talk about consults, isn't really necessary anymore.

SF: How many ethics consults come to the committee each month, on average?

PP: Formal consults, we get about two or three. More informal ones, probably four or five. This includes individual questions.

SF: Do you allow for anonymous consults? If so, has this ever happened?

PP: We do allow them but I'm unaware that we've ever had one. Anyone can pick up the phone to contact the committee.

SF: How often does your committee meet?

PP: Once a month for about one and a half hours or longer. The education subcommittee meets for an hour before the committee meeting and the end-of-life care committee also meets for an hour once a month.

SF: Do you offer formal or informal education sessions that each member must attend?

PP: We give all our members copies of the clinical ethics book that comes from our budget. We ask them to be familiar with the basic sections and to bring in for discussion any questions they have. In terms of other requirements, no.

SF: How does the opinion of the committee get reported?

PP: We write-up the whole consult which goes in the patient's file and a copy goes to the medical staff office. What's reported in our minutes, which is a truncated summary, goes to the medical board. It may just say what the case was

about with no patient information. It includes the major issues but we keep it as generic as possible. We want to show that we deliberated and if someone wants more information, he/she can come and ask us.

SF: What would you say is most satisfying about your work with the committee?

PP: A number of things: seeing another dimension of patient care. What attracted me to this area was seeing medical situations in their social context, with issues of values. Embedded in what we do are lots of assumptions. I like to talk about it and hear what others have to say about it. I learn a lot from the members of the committee. I like educating others about it. It's good to have a forum for medical staff to come talk about these issues. Also, I get to meet other people outside of the hospital, find out what other people are doing, like Diane (Hoffmann) and Jack (Schwartz). This is an important part as well.

CALENDAR OF EVENTS

MARCH

- 18 "Clinical Futility - Families that Just Won't Listen," Speaker: Edmund Pellegrino, MD, Professor Emeritus of Medicine and Ethics, Georgetown University Medical Center. Zamoiski Auditorium at Sinai Hospital, Baltimore, MD (9A-10A, free).
- 19 "Priorities for US Health Care," Participative Seminar for the Public sponsored by Georgetown's Community for Health Care Justice. Speaker: Jack Glaser, STD, VP St. Joseph Health System, Orange, California, Director of the Center for Health Care Reform. Georgetown University Medical Center, Building D (4000 Reservoir Rd, Washington, D.C.), Warwick Evans Room. (9A - 11:30A). RSVP to: omearad@georgetown.edu, 202-687-1122.
- 24 Harvey Lectureship in Health Care Ethics, Sponsored by the Center for Clinical Bioethics, Georgetown University, Speaker: Cardinal Eugene George, Archbishop of Chicago, Washington, D.C. 7:00 pm. Contact: Joan Lewis, JLewis@dcha.org, (202) 289-4923.
- 25-27 Ethics and epidemics: An international conference on the ethical dimensions of epidemic control. Albany Medical College. Contact: www.amc.edu, e-mail amccme@mail.amc.edu, or call 518-262-5828.

APRIL

- 2 "Choosing our Health Plan All Together," Participative Seminar for the Public sponsored by Georgetown's Community for Health Care Justice. Speaker: Marion Danis, MD, Head, Section on Ethics and Health Policy, NIH. Georgetown University Medical Center, Building D (4000 Reservoir Road, Washington, D.C.), Warwick Evans Room. (9A - 11:30A). RSVP to: omearad@georgetown.edu, 202-687-1122.

- 7 Annual Leiken Memorial Lecture, The Non-Heartbeating Organ Donor in Pediatrics: Ethical Issues. Speaker: Professor Robert Veatch. Sponsored by the Ethics Program at Children's National Medical Center, Washington, D.C., Children's Hospital Auditorium. (8:00 AM, free). Contact: Joan Lewis, JLewis@dcha.org, (202) 289-4923.
- 15 University of Maryland Medical Humanities Hour: Ethics of Human Subject Research. University of Maryland Medical Campus, Shock Trauma Auditorium, Baltimore, MD. Speaker: David Wendler, PhD, Dept of Clinical Bioethics, NIH. (5-6 PM, free).
- 15-17 Justice and Health through Creative Technologies: Saris, "Whistles" & Buckets. Creighton University, Omaha, NB. Contact: www.justiceandhealth.org, or call (402)280-2017.
- 16-17 ASBH & American Medical Informatics Association's Spring Meeting: Ethics and Health Information. Miami Beach, FL. Contact: Ken Goodman at kgoodman@miami.edu or 305-243-5723; www.miami.edu/ethics.
- 21 Annual Faith, Ethics and Health Care Conference - Topic: Spirituality and Aging, Sponsored by the Center for Clinical Bioethics, Georgetown University, Washington, D.C. Contact: Joan Lewis, JLewis@dcha.org, (202) 289-4923.
- 21 Ethics Annual Symposium: Informed Consent. Sponsored by The Inova Fairfax Hospital/Inova Fairfax Hospital for Children Ethics Committee. Physicians Conference Center, Inova Fairfax Hospital, Falls Church, VA. (5:30-8:00 PM, free). To register, call: 703-204-3333.
- 21 Spirituality and Aging. Sponsored by the Georgetown University's Center for Clinical Bioethics and Center for Population and Health – The Initiative on Aging. (all day, \$25 registration fee). Register at: <http://clinicalbioethics.georgetown.edu>.
- 28-30 Mobilizing Trust to Reduce Disparities in Health Care, Boston, MA. Sponsored by Harvard School of Public Health & the Harvard Trust Initiative. Contact: mwilson@hsph.harvard.edu; 617-384-8679; www.hsph.harvard.edu/trustinhealthcare/agenda_disparities.htm.

MAY

- 24-26 Friends Research Institute's Sixth Annual Ethics Conference: The Ethics of Human Cloning. The Argonaut Hotel, San Francisco, CA. Contact: www.friendsresearch.org/Ethics2004/SaveDate3.htm, 410-763-7620, or friconferencediv@friendsresearch.org.
- 25-27 Conference on Ethics and Epidemics: An International Conference on the Ethical Dimensions of Epidemic Control. Albany Medical College and Union College, Albany, NY. Contact: www.bioethics.union.edu, bioethics@union.edu, www.who.int/ethics/events/date/2004/03/ethics_epidemics/en/.

JUNE

- 8-13 Kennedy Institute of Ethics Intensive Bioethics Course, Georgetown University, Washington, D.C. Contact: www.georgetown.edu/research/kie/site/index/htm.
- 11-12 Beyond the Bungled Transplant: Jessica Santillan and High-Tech Medicine in Cultural Perspective. Rutgers, State University of New Jersey, New Brunswick, NJ. Contact: kwailoo@history.rutgers.edu.
- 17-19 Conference on Ethics and Aging, Sponsored by the Center for Clinical Bioethics, Georgetown University, Washington, D.C. Contact: clinicalbioethics.georgetown.edu/ethicsandaging.html.

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