

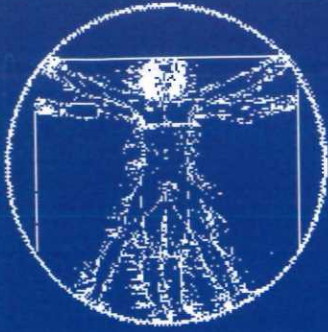
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2002*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2002

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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 Maryland Health Care Ethics Committee Network, the Law & Health Care Program,
University of Maryland School of Law

Fall 2002

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SPIRITUALITY AND RELIGION: WHERE DOES IT FIT IN ETHICS CONSULTATION?

Consider the following case. Mrs. Z. is an 83 year-old woman, widowed, with four children. She has a several-year history of chronic obstructive pulmonary disease and coronary artery disease. About four months ago she had a stroke, after which she entered a long-term care facility for rehabilitation. However, over the past two months while in the nursing home she has been deteriorating, both in physical and cognitive function. Six days ago she was transferred to the hospital after developing sepsis (systemic infection) following a urinary tract infection. Her respiratory status requires placing her permanently on a ventilator. After five days of antibiotic therapy she develops acute renal failure. The prognosis for Mrs. Z. is very poor—survival to hospital discharge is not expected. At this point her attending physician, concurring with another physician, decides that initiating kidney dialysis or attempting CPR would not be medically effective, as these would only, at best, prolong Mrs. Z's inevitable death. She has no written living will nor has she appointed a health care agent. (Mrs. Z. is not responsive and is not receiving paralytic agents, so there is no option of "waking her up" to see what she would want.) The health care team meets with the children to explain the situation.

The Mid-Atlantic Ethics Committee Newsletter is published by the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. 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.

Diane E. Hoffmann, JD, MS
Editor

Now, consider two alternative scenarios. In the first, the second of the four children insists that "everything be done" to keep the patient alive. His older sister confides to a nurse that her brother feels guilty about not having been involved in his mother's care, and for past irresponsible behavior, and that this is what is prompting him to request life-prolonging therapy for their mother. Yet, the other siblings are inclined to agree with their brother's demands to "keep the family peace."

NETWORK NEWS

The Mid-Atlantic Ethics Committee Newsletter

is published three times per year by the
Maryland Health Care Ethics
Committee Network
Law & Health Care Program
University of Maryland School of Law

500 West Baltimore Street
Baltimore, MD 21201
410-706-7191 or 410-706-5369

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

The Metropolitan Washington Bioethics Network (MWBN)

In October, the Metropolitan Wash-
ington Bioethics Network presented a
session on ethics at the D.C. Superior
Court-sponsored training program for
court-appointed guardians. The
Network provided information about
bioethics in general, and more specifi-
cally, about the Bioethics Court Visitors
Program. In addition, the Network is
working with the Court to train guard-
ians and potential guardians about
bioethics issues through a series of
brown-bag lunches on such topics as
DNR orders, palliative care, withhold-
ing and withdrawing of nutrition/
hydration, etc. Also in October, the
Network sponsored a program on
"Research, Integrity, Conflicts of
Interest and the Commercialization of
Science" in conjunction with the
Georgetown Bioethics Colloquium. A
half-day program, "Making the Transi-
tion from Chronic to Terminal Care"
will be held on Monday, October 28 at
the Washington Hospital Center." For
more information contact Joan Lewis.

Joan Lewis, Coordinator
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Maryland Healthcare Ethics Committee Network (MHECN)

On September 3, the MHECN mem-
bership voted to transfer its operations
to the University of Maryland School of
Law's Law & Health Care Program.
Although MHECN has grown both in
membership and the services it has
provided over the years, the revenue
generated by membership dues and
conferences has been insufficient to
maintain the Network as an indepen-
dent entity. The change in status will
not change the mission or scope of the
services provided by the Network.
However, with the generous support of

the Law School, the Network will be
able to continue to provide comprehen-
sive services to its members without
increasing membership fees. In
addition, the tasks of the Executive
Director will now be performed by
Law School staff or contracted to
individuals outside of the Law School.
Governance and administrative deci-
sions will be made by the Director of
the Law & Health Care Program at the
School of Law, currently Diane
Hoffmann. Hoffmann will continue to
work with the Advisory Board (which
has recently been expanded) to deter-
mine Network goals and priorities. The
Network looks forward to continued
growth, and to that end, encourages
your suggestions and participation. We
thank Anne O'Neil for her countless
hours of dedicated service as Executive
Director, nurturing MHECN in its
formative years. Her faithful oversight
will be missed!

Upcoming MHECN educational
programs include the fall conference on
"Spirituality and the Role of Ethics
Committees," scheduled for October 28
and a meeting of the Journal Club on
November 12 (see Calendar for details
on both).

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GROUND ZERO— One Chaplain's Experience

The Rev. Dr. Bob Steinke, member of MHECN's advisory board and patient education committee, was asked to serve as a Volunteer Crisis Chaplain in New York City during the recovery work at Ground Zero. For several months he spent every other weekend at Ground Zero, ministering to those working and volunteering at the site. We asked him to recount some of his experiences for this issue of the Newsletter. This is an edited version of a longer article he wrote for another newsletter.

On September 11, 2001, I spent the afternoon and the following day providing spiritual and emotional support to recovery workers and Emergency Services personnel at the Pentagon. My wife, Millie, and I live only 60 miles from where the plane came down in Pennsylvania. Wednesday evening, the day after the 9-11 attacks, the call went out asking for available Crisis Chaplains to come to Shanksville, PA, so I spent Thursday working with recovery workers there. Everything then seemed to quiet down and I returned to work as Director of Pastoral Care and Hospital Chaplain of Frederick Memorial Healthcare Systems.

In October, as a member of the Maryland Critical Incident Stress Management Team, I received a call as to my availability to respond to needs coming out of New York City. My hospital has been very generous and supportive of my involvement. After arranging for appropriate Pastoral coverage at the hospital, I traveled to New York City, where I spent two days working at the Land Fill (Killing Fields) located on Staten Island. I then went to lower Manhattan and worked at both Ground Zero (T-Mort) and at St. Paul's Chapel, "the Chapel that survived." Since October I have been traveling to New York every other weekend and ministering at both St. Paul's Chapel and Ground Zero. In March, my wife, Millie, was able to

accompany me and volunteer at St. Paul's Chapel. She has since returned twice. This has really helped in enhancing our relationship through sharing such a meaningful experience.

I remember feeling the butterflies start stirring in my stomach the first time I toured Ground Zero and T-Mort with Tom, the T-Mort Chaplain Coordinator. When we approached the barricaded entrance, it was as if someone knocked the wind out of me. I just couldn't seem to catch my breath sufficient to say anything. I found I was totally unprepared for the scene that was being played out before us. Never had I been witness to such utter devastation. Nothing in all my experience serving multiple tours of combat duty in Vietnam in the Marine Corps could compare with the carnage and destruction that towered before me. I don't know whether it was the sheer magnitude that was so overwhelming or the density of the air filled with smoke and the pungent odors associated with death that continued to rise out of the bowels of the debris. The majority of people do not know the fires continued and were not completely extinguished until the 20th of December; 3rd months after the attack and 3rd months after the fires began. Rays of sunshine would attempt to break through, creating dark pockets and shadows that appeared to shift and move like dancing silhouettes of sadness. After giving me a moment to catch my breath, Tom asked me, "Are you ready to go?" I timidly assured him I was. We both donned our respirators and held up our credentials for the NYPD Officer on watch to observe and pass us through. It truly felt like entering Danté's *Gates of Hell*. This analogy would later strike me as ironic. In the lobby area of Cantor Fitzgerald, bronze masks depicting faces from scenes taken from Danté's *Gates of Hell* were placed on pedestals, some of which survived and are now being stored in locked containers at the Fresh Kills land fill.

St. Paul's was a respite center for those involved in the recovery effort at "The Pile." As such, it was closed to the public. Volunteers manned the

different stations located inside St. Paul's for 12 hour shifts. Each station offered different supplies and/or food and beverage. Chiropractors and Massage Therapists volunteered their services. Each afternoon volunteer musicians would come to St. Paul's from the Juilliard School of Music and offer their talents for the benefit of the recovery workers. The entire inside of the Chapel was adorned with posters, letters, cards, and a wide array of messages of encouragement and greetings from children around the world. Each pew contained a blanket, pillow, and Teddy Bear at either end. (The Teddy Bears were sent by the people of Oklahoma City for use by those wanting to either sit quietly or lie down and rest.) The upstairs balcony, on one side, contained boxes and boxes of stacked supplies such as helmets, socks, rain gear, respirators, shirts, gloves, everything any of the recovery workers might need to replace without having to leave the area. The other side of the balcony contained a row of about eight cots where tired workers could sleep with little disturbance. Working as a Chaplain meant being available to talk with anyone expressing a need or interest, praying with and offering blessings to those who desired such assistance. I got to know some of the EMT's and firefighters. Some wanted to share their experiences, others had questions about how God could allow such a tragedy to occur. Most were really more in need of venting, so I mainly listened and prayed, sometimes lighting a candle in a place provided adjacent to the altar at St. Paul's.

One incident for which I am extremely thankful is being able to actually identify a specific individual over whose remains I offered prayers and a blessing. I was never on duty when identified remains were discovered. I was never on duty when entire bodies were recovered from "The Pile" or "The Pit." Very few of us were. The majority of occurrences involved the discovery of small pieces or minute fragments of what once was

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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 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. Baltimore St., Baltimore, MD 21201-1786.

Physician Duty—Minor Patient Not Complying With HIV Regime

Dr. Wilson, an HIV expert, was having difficulty with a minor patient and the patient's aunt, who was caring for the patient. The patient, 2-1/2 year old Brianna, was developing resistance to her HIV medication. Brianna's aunt, 19 year old Kimberly, had volunteered to take care of Brianna when Brianna's mother (Kimberly's sister) died of AIDS. Brianna was just 2 weeks old at the time of her mother's death. Kimberly, by all reports, is generally an excellent caregiver, and developed a close bond with Brianna. She thinks of Brianna as her daughter and would like to adopt her. However, she has had great difficulty getting Brianna to take her medication. The child would often spit out her medicine when Kimberly tried to give it to her, and, even after Dr. Wilson's staff offered suggestions, the child was still often uncooperative. Although Kimberly claims that things are getting better and the child is now getting her medication, the pharmacy has informed Dr. Wilson that prescriptions are not being filled on time.

The medication regimen for individuals with HIV is extremely

demanding, e.g., three different drugs, three times a day, some to be taken with food, some without, etc. For the drugs to be effective, the patient must be extremely compliant with the regimen. Anything less than 95 to 100% compliance will result in the drugs becoming less effective. In addition, and perhaps most importantly, being less than fully compliant will mean that the patient will develop resistance to one or more of these drugs (and the whole class of drugs to which this drug belongs) meaning that the drug will no longer work for the patient in the future, dramatically reducing the patient's long term treatment options. These drugs often have side effects that can interfere with an individual's day-to-day sense of well being, including diarrhea, nausea, fatigue, neuropathy, etc.

Dr. Wilson consults the ethics committee for advice. He wants to know whether he should report Kimberly to the Department of Protective Services for child neglect. He thinks that Kimberly is somewhat immature and may not have the skills necessary to adequately care for Brianna's medical needs. He doesn't think Brianna should necessarily be taken away from Kimberly, but he hopes that with the help of Protective Services, Kimberly might receive the help that she needs. If reported, Kimberly's name would appear on a child abuse/neglect registry and she would be prevented from adopting Brianna.

Response From a Health Care Attorney

Though it might be legally appropriate for the physician in this case to make a report to the Department of Social Services (DSS), it may not be the most effective course of action in protecting the child's best interest. Less dramatic measures should be attempted to address this situation before making such a report. In a situation involving alleged medical neglect, a DSS report should generally be used only as a last resort, if other efforts to address the non-adherence problems have failed. This is true both because of the impact such a report is likely to have on the medical provider's ability to work with the family and the potential trauma to the child of the threatened removal from her family. In addition, as a practical

matter, the Department of Social Services is likely to get involved only if the staff is persuaded that the child is at substantial risk of harm and that reasonable attempts by the medical provider to remedy the situation have failed.

The statute regarding the reporting of abuse or neglect by healthcare practitioners provides that: "notwithstanding any other provision of law, including any law on privileged communications, ... each health practitioner acting in a professional capacity, who has reason to believe that a child has been subjected to . . . neglect shall notify the local department."¹ Section 5-701 (P) defines neglect as "the leaving of a child unattended or other failure to give proper care and attention to a child by any parent or other person who has permanent or temporary care or custody or responsibility for supervision of the child under circumstances that indicate that the child's health or welfare is harmed or placed at substantial risk of harm."

In this case, it is unclear if Kimberly is neglecting the child's needs, or if there are other barriers to the child's receiving appropriate medical care. The Ethics Committee should explore these issues with Dr. Wilson. The committee might ask Dr. Wilson to consider what barriers may exist to Kimberly's being willing to disclose ongoing difficulties in getting Brianna to take her medication. For example, is it possible that Kimberly simply doesn't understand the importance of getting 95 to 100 percent of the medication into Brianna on a precise schedule? In many other areas, 80 percent compliance is considered to be adequate. While that is clearly not the case with HIV medication, it takes many families time to fully understand the unforgiving nature of HIV treatment.

On the other hand, is it possible that Kimberly is simply afraid to disclose her difficulty with the medication because she fears that Dr. Wilson may take the action he is contemplating involving a child neglect report? Kimberly is only 19 years old and may feel that covering up her difficulty is her best course of action. This may be tied with some lack of trust in her relationship with Dr. Wilson that may also need to be addressed.

Because of the recognition of the difficulty of managing HIV infection in children as well as adults, the NIH has

published guidelines for the use of antiretroviral agents (in pediatric HIV infection) which specifically recognize that “effective management of diverse and complex needs of the HIV infected infants, children, adolescents and their families require a multidisciplinary team approach that includes physicians, nurses, social workers, psychologists, nutritionists, outreach workers and pharmacists.” This may be an appropriate juncture at which to involve other members of the multidisciplinary team to attempt to address whatever barriers to treatment may exist.

In addition, it will probably be useful to explore in more detail why Brianna is so uncooperative in taking her medication. For example, is it simply that the medication tastes bad and this could not be effectively addressed? Palatability is a major issue with HIV medication, though progress has been made in this area. Is it possible that Brianna has had unpleasant or uncomfortable side effects from some of the medications that she has been asked to take? If so, this may be affecting her willingness to take it.

In Maryland, the statute mandating the creation of ethics committees specifically provides that, in appropriate cases, the committee should consult with the patient and other family members as well as with the petitioner, in this case, the physician. I would suggest that a member of the committee meet with Kimberly and any other involved family members, as well as with members of the treatment team, to attempt to identify what the barrier is to treatment. The ethics committee may be able to identify the barrier(s) and help the physician and the patient’s family successfully address them.

If attempts to communicate with Kimberly and identify the barriers to delivering medication to Brianna are unsuccessful, a medical neglect report to the Department of Social Services may be necessary. However, the important thing here is not to do more harm than good by making such a report. The case study identifies Kimberly as an excellent caregiver separate from the medication issue, and indicates that she is interested in adopting Brianna and has developed a very close and loving relationship with her. It is in the child’s best interest to try to preserve this relationship. This must be

considered in determining when the situation has reached the level of such potential detriment to Brianna that a medical neglect report can not be avoided.

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School of Law

1. Family Law Section 5-704, Maryland Annotated Code 2001.

Response From a Pediatric Physician

Advances in HIV treatment are greatly benefitting HIV-infected children in the United States and elsewhere.¹ Combination therapy with a minimum of three antiviral medications is now recommended as the standard of care for HIV-infected children for whom treatment is indicated. Current published consensus guidelines state that all HIV-infected children under 12 months of age and those over 12 months of age with clinical symptoms or immune suppression (low CD4⁺ cell count or percent) should be treated, although treatment may be postponed until adherence barriers can be addressed.²

Unfortunately, these pediatric treatment guidelines, developed as a consensus document, fail to reflect clinical evidence that the risk of disease progression or death among HIV-infected patients, including children, may differ depending upon viral load (the number of virus particles in the blood stream) and degree of immune suppression (or decrease in the CD4⁺ cell count or percent). Disease in HIV-infected children generally progresses more rapidly than adults. Children under one year of age have a 25% risk of progression to a serious infectious or neurologic complication with no marker of risk for this ‘rapid progression’. However, higher risk children over the age of 12 months can be identified. In one study that followed HIV-infected children for an average of five years, the risk of death for those with a viral load ≤ 100,000 copies/ml increased from 15% to 63% based on CD4⁺ cell counts.³ Thus, it would be important to know Brianna’s viral load and CD4⁺ cell counts to inform decisions about the degree of harm that

is threatened by her not taking the antiretroviral medications prescribed.

In addition, combination antiretroviral therapy is not without risk. There is little ‘reserve’ in potency of regimens currently available, and non-adherence leading to drug resistance is well-established as a major correlate of clinical failure. Because there is a strong potential for cross-resistance among some of the drugs, the efficacy of future treatment options could be severely compromised for Brianna by inadequate adherence. Regarding side effects, while benefits undoubtedly outweigh risks for most patients, long-term complications of this therapy that have been seen in adults include cholesterol/lipid problems, fat distribution abnormalities, and increased risk for diabetes. Some of these problems are beginning to be reported in children.

These issues must be carefully weighed by Dr. Wilson as he considers treatment options for Brianna. Depending on the child’s risk of progression and the particular circumstances, possible options include working with Brianna’s aunt to overcome the adherence problems with the current regimen, changing to a more palatable and easier to give but less potent regimen, prescribing a ‘drug holiday’ for Brianna while adherence problems are addressed, or discontinuing antiretroviral therapy and monitoring Brianna’s viral load and CD4⁺ cell count/percent while off the drugs.

For physicians and other health care providers with experience caring for chronically ill children, a medical neglect report to Protective Services is resorted to only after many services have been offered to assist the family and failed. In Brianna’s case, her aunt may benefit from working with a pediatric psychologist or other child development expert to formulate a management plan for Brianna’s oppositional behavior, which is normal for her age. Nurses, preferably visiting in the home setting where medicine is administered, can help Brianna’s aunt incorporate medication dosing into her daily routine and devise strategies to address palatability problems such as mixing bad tasting medicine in chocolate syrup. A social worker can help Brianna’s aunt identify and address other adherence barriers that may be present, such as housing instability, non-disclosure of

Cont. on page 6

Response From a Pediatric Physician

Cont. from page 5

Brianna's diagnosis to others in the household, mental health, or addictions issues. A peer outreach worker can provide social support and help Brianna's aunt develop a more effective working relationship with the health care team. If medicine palatability is the sole problem, some parents of young children and even some older children have opted for placement of a 'button' gastrostomy tube. This temporary device is placed through the abdominal wall during minor surgery and allows squirting medicine directly into the child's stomach using an adaptive tube and syringe.

In spite of maximum support of the family, there are HIV-infected children at high risk for disease progression whose parents or substitute caregivers are not meeting their medical needs. In these cases, a formal report of medical neglect is legally mandated and ethically justified. Should the caregiver be the biological parent, such an action can be therapeutic, resulting in even more "intensive" support services for the parents, or helping parents address an adherence barrier such as addiction, which has not been previously possible. Since Brianna is not living with a biological parent, it is likely that an alternative placement would be sought. In this difficult situation, I find the viewpoint of Dr. Howard Dubowitz, a national expert on child abuse and neglect at the University of Maryland, helpful. Neglect should be considered from the child's perspective, and one should acknowledge without blaming parents that many risk factors may be responsible. For the sake of argument, if Brianna could somehow become capable of adult decision-making, would she choose to be raised by an aunt who loved her very much but was unable to meet her medical needs, placing her at risk for disease progression and death?

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1. *N Engl J Med* 2001;345:1522-8

2. *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*; <http://www.hivatis.org>

3. That is, those with a viral load $\leq 100,000$ copies/ml with a CD4⁺ cell percent $\geq 15\%$ had a 15% risk of death, while those with the same range of viral load and a CD4⁺ cell percent $< 15\%$ had a 63% risk of death. *J Infect Dis* 1997;75:1029-38.

4. *Pediatr Rev* 2000; 21:111-16.

Spirituality and Religion

Cont. from page 1

In the second scenario, the children insist that the doctors must do everything possible to keep Mrs. Z. alive—to do less would be "playing God," and they have faith in God's greater plan. They describe their mother as a devout Baptist, and they believe that, although she never talked about being in the state she's in, she would want to be kept alive as long as possible.

Is there a difference in how an ethics consultation team might approach these two scenarios? If yes, why? Ethicists advocate gathering all the facts about and information related to a case, including the beliefs and values of those involved that likely prompt behaviors and decisions related to the situation at hand. Religious and spiritual beliefs and practices should be elicited as part of this process. Yet, in my own experience, validated by anecdotes from other ethics consultants, reveals a tendency for discussion to broaden in the first scenario, where religion/spirituality are not at the forefront, and for discussion to become more narrow in the second scenario. There seems to be less aversion to probing motivations for decisions or behaviors that ethics committee members suspect are rooted in emotional or psychological distress, or family discord, than those rooted in spiritual angst or confusion about the interpretation of religious mandates.

There are various possible objections to advocating exploration of religious/spiritual input into ethical dilemmas that come before ethics committees. Here are a few:

1. *Religious beliefs are non-negotiable and thus are not open to being explored or questioned*

One obvious counter to this is that the process of gathering relevant information in an ethics consultation

cannot reasonably exclude information about a person's religious beliefs and practices – it's imperative that, during an ethics consult, ethics committees identify what underlying values and beliefs are driving a patient's/family members' decisions or requests for medical treatment. This involves more than making assumptions about a patient/family member's spiritual beliefs and values based merely on their religious affiliation (or lack of one).

Furthermore, there are times when patients or family members are confused about the mandates of their religion. They may, for example, be unaware of interpretation of their religious doctrine that allows the hastened death of a dying patient by withdrawing a ventilator or withholding kidney dialysis. Exploration of religious beliefs may also uncover other reasons motivating their request for treatment deemed medically ineffective, such as feelings of guilt or the burden of feeling complicit in their loved one's death—issues that may have been missed had the ethics consult team not probed beyond initial proclamations of religious proscriptions. Identifying all beliefs that contribute substantially to a patient/family member's treatment request—religious beliefs notwithstanding—is a necessary component of how the ethics committee advocates for the patient during a consultation. Moreover, probing religious beliefs that seem incongruous with other religious doctrine or its interpretation may also be appropriate, but this raises other concerns, such as, who should be allowed to do such probing?

2. *Religion and spirituality fall under the expertise of the clergy and not ethics committee members—even those trained as chaplains may not be authorities on a particular patient's faith tradition, and should not pretend to be.*

Assuming one agrees with the counter-arguments under Objection #1, various questions follow, including: (a) if assessing and perhaps even probing further into a patient's/family member's spiritual and religious beliefs is necessary for some ethics consultations to be effective, who should take on this role? (b) isn't it dangerous to

permit, let alone encourage, every ethics committee member to function in this capacity?

(c) Wouldn't it be more appropriate to invite a clergy member or representative from the patient's faith tradition to fulfill this role? I would answer: (a) "I don't think just one person," (b) "maybe," and (c) "yes, but not exclusively." Consider a situation in which the religious beliefs of a patient (or the family member(s) of a decisionally incapacitated patient) are a key component of the ethical dilemma or issue that prompted the ethics consult. The chaplain on the ethics committee seems like the most likely person to make inquiries and assessments in this area. But what if an ethics consultation is performed without a chaplain present? Isn't it necessary for others on the consult team to be able to address these issues, at least in an information-gathering way? Such an assessment might reveal that further religious/spiritual clarification or guidance is needed, at which time a religious leader from the patient's faith community could be invited. But not all patients for whom religious beliefs are influencing their medical decision-making are involved in a religious community. For patients who may be confused and/or not tapping into their own spiritual support community, what's the best way to advocate on their behalf? I don't have a definitive answer here, but I think it would probably better serve patients and family members if ethics committee members were educated about the interplay between health care decision-making, spirituality, and religion, and skilled in the basics of how to apply that knowledge to ethics consultations.

3. Religious and spiritual beliefs of individual ethics committee members often bias how they see a case, and to protect against this, it's best to exclude

those views entirely from ethics committee case consultations.

This follows on the heels of Objection #2 – the criticism being that ethics committee members not only lack the knowledge and skills necessary to effectively assess how spirituality and religion might be motivating a patient's decisions or behaviors, but that they also lack self-awareness of their own biases in this domain. Individuals are often unaware of how their own beliefs may cause them to make assumptions and judgments about others' behavior. In the realm of ethics, there's a danger of religious beliefs creeping in, perhaps unknowingly. That may relate to the overlap between ethics and religion—that is, both ethics and religious doctrine have to do with determining which actions are considered morally good or right and which are considered morally bad or wrong. At the same time, in this pluralistic society where functions of Church and State are kept separate, there's an expectation that specific religious viewpoints will be respected, but that no one religious viewpoint will be endorsed in public venues. Religious viewpoints may become "secularized" in public discourse. So, individuals whose morality is heavily shaped by their religious affiliation (or lack of religious affiliation) may perceive and judge others through their own religious (or secular) viewpoint, but not be aware that they're doing so because of social pressures to keep religious views private (for example, separate from ethical discourse). While I think this dynamic may be a real threat to effective ethics consult deliberations, I don't think the answer is to exclude religious viewpoints from case consultations. Rather, I think ethics committee members should be encouraged to examine their own biases and be provided with opportunities to discuss how their

biases may influence their participation in ethics case consultations.

These are just a few questions that are raised when considering the issues of spirituality, religion, and the role of ethics committees. Other questions include, "Is it okay to pray with a patient or family if it's discovered in a case consultation that they would be comforted by prayer?" "How should parents' religious beliefs be accommodated when they may endanger the physical health of a child? and "How should an ethics committee respond to a demand for medically ineffective therapy based on a hope for a miracle?"

Anita J. Tarzian, PhD, RN
Chair, MHECN Education
Committee

One Chaplain's Experience
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a living, breathing body. In just one incidence of discovery with which I was involved, we were able to discern, after the fact, the identity of the remains. We were able to do this because the experts determined the remains were from a female. Additionally, the remnants of a Port Authority Police Department (PAPD) Captain's uniform were imbedded within the badly decomposed tissue. As a result of this information, I was later able to find out her identity because there was only one female PAPD Captain who had perished in the collapse of the Twin Towers: Captain Kathy Mazza. I will retain a picture of her in my mind for the remainder of my life.

From the end of October through the last two weeks of June, I spent every other weekend as a Volunteer Crisis Chaplain in New York. Just as my life changed and became renewed through the tragic circumstances of Vietnam ... so too has my life been changed and become renewed through the tragic circumstances of 9-11. I am simultaneously overwhelmed with feelings of sadness and grief and, at the same time, feelings of being blessed beyond measure. The intensity of intimacy and the fulfillment of meaning arising from the contact available to us as human beings during times of overwhelming tragedy is nothing short of a beautiful gift; a gift I believe offered and made available to each of us from our loving Creator, God Almighty.

The Rev. Dr. Robert E. Steinke
Hospital/CISM/Police Chaplain
Director of Pastoral Care
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Interview with Judy Levy—Ethics Committee Chair at Kennedy Krieger

(Interview conducted by J. Anne O'Neil, PhD, RN, in March 2002; edited version)

Anne: Judy, can you explain how your ethics committee is structured?

Judy: We report directly to the hospital Board and the management team. The minutes go to the Vice President for Clinical Affairs and also to the Board through the representative of the Board, who is on the committee. My office takes care of typing the minutes, and there is some additional money in the Social Work budget for in-service activities, paying speakers, and buying food for meetings.

Anne: How did you get to be Chair of the committee?

Judy: I was on the committee. In 1987 or 88 I was asked to be the Chair by the President of Kennedy Krieger and I said yes. It was pretty simple. ... I was surprised because I hadn't developed any focused interest in it like I have now, but that's what has developed over the years. I was glad to be given the opportunity to do it. ...

Our ethics committee was originally called The Human Rights committee, and that just came from the background of human rights violations regarding people with disabilities, you know, institutionalization, over-zealous use of restraints, medical sterilizations, and so on. ... It was only ten years later, after I became the Chair, that we changed the title of the committee to "ethics committee." We realized that the issues we were dealing with were much broader than just human rights violations. We were talking about treatment issues and sometimes end-of-life issues for people with disabilities. We were meeting the requirement of JCAHO for ethics committees, and we were meeting the legal requirements for a patient care advisory committee in Maryland, so it just made sense to change the name.

Anne: Is the emphasis still on human rights?

Judy: I think it's much more medical now. Part of the reason I think that is the field has changed. In the beginning when Kennedy first started, this was really a hospital where people came for evaluation and to reach goals related to their maximum adaptive potential. That's still true, but now there's more complexity to their medical situation. We are keeping more people alive—babies who are born with disabilities, older people, children, and young adults who have traumatic injuries who would have died years ago. And they all have very complex medical situations. The degree of complexity and need among the patients who get admitted to our hospital in the first place is greater than in the past. So what we are dealing with is just different. And so I think the emphasis for the committee has changed somewhat also. And of course we have a myriad of outpatient issues that come up that are very much the same.

Anne: What would you say is the professional background of the committee members?

Judy: ...Nursing, medicine, social work, psychology, and neuro-psych. The latter two are both psychologists, but they do very different things and it's important to have them both there ... We have the risk manager on the committee who is also a nurse. And we have community members. We have *always* had people with disabilities on the committee, or their parents or their family members. We have one member who has been on the committee for a really long time and his son has a disability and he is also an attorney, and that's a good thing. And right now we have a woman who is a board member and also a mental health professional, and that's been interesting because she brings a different perspective to the discussion. But right now [interviewed Spring 2002] we need a clergy person, because the one we did have had competing demands. We are taking a two-pronged approach to finding a replacement, because we also have a commitment to having a community member who represents the community we re-

side in. So we are searching for an African-American minister. ... And we also need more consumer members—individuals with disabilities.

Anne: How many members does your committee have?

Judy: Right now we have fifteen members. At times we have had over 20. One of the reasons we have tried to keep it that large is because there are so many times people have competing responsibilities and can't be at the meetings. One of the biggest issues we face here at Kennedy is patient transportation, and one of our longest serving members is a young man with disabilities who we have known for many years, who is now in his thirties. He lives in Salisbury and we have paid to have one of the caregivers where he lives bring him to our meetings. Of course, they have to get up at the crack of dawn to get here. I'll bet for about 10 years he has come ... it was important for him and certainly for us to have that perspective in our deliberations. And we had a wonderful woman on the committee who was in her 60s and had cerebral palsy. Overall we have a pretty good track record, but right now the population we serve is underrepresented.

Anne: How do you get to become a member of the committee?

Judy: We interview potential members—one other person and myself—to get a feel for how it looks for a fit ... and then the Kennedy president appoints him or her. Everyone gets a letter every year which says, "I am reappointing you for the next year."

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

Judy: Yes, usually we have done in-service training for committee members in the past, and we are planning to do another one with MHECN. But what I would like to have is an educational program with some sort of regularity, and to have some kind of package for new members when they come on. That's a future project I'd like to get done. We have a new member packet with the [ASBH Core Competencies for Ethics Consultations] booklet in it, but

is it the right sort of material for a new member? I'm not sure.

Anne: Is a portion of your meeting dedicated to education?

Judy: It's rare that we don't have something to discuss that fills up the whole two hours ... Lots of times we are reviewing policy kinds of things, or I may go over a consult we had that everyone wasn't able to attend. So you might consider that an educational component of the meeting.

Anne: What else do you do at your meetings?

Judy: Well, recently we have had two visits from the director of the neurobehavioral unit educating committee members on how the unit functions, what their policies and procedures are, what their evaluations are like because the kids and young adults that are admitted have very self-injurious or aggressive behavior. When you start thinking about what they are dealing with you realize it's one of the most intense kinds of work you can do, with a lot of ethical and human rights issues involved.

Also, I might tell the committee about Ethics Rounds, because not everyone on the committee is able to come to the Ethics Rounds ... on the first Tuesday of every month at noon. We discuss a case and/or an article ... At the last Ethics Rounds we discussed the question of parents with limited mental capacity making a decision about treatment of their child on the neurobehavioral unit who has pretty serious behavioral issues. During the consult we found out the mother had been diagnosed with mild mental retardation and schizoid affective disorder and that she hallucinates. So we really talked about how you ascertain capacity. ... All the evidence pointed to the fact that the mother did actually do a good job with him. He got to school, he was fed, and he was clean. So just because she hallucinates, does that mean she cannot make a decision about his treatment? We didn't make a decision about that at Ethics Rounds, we just discussed how you approach that kind of situation.

... We actually have fewer consult requests now, and I think Ethics Rounds has something to do with that, because

there is just more opportunity to talk about issues and concerns than there ever was.

Anne: How often does your committee meet?

Judy: We meet for two hours every other month. We tried meeting every month and that lasted about four months and everyone said let's go back to every two months.

Anne: Do you have sub-committees?

Judy: You know, that's been really hard to do. I don't know how others do it, because people are *so* busy. That's an issue for me as Chair and for committee members—how to devote more time than the committee meetings. There are certain people who are able to carve out time, but it's hard, and I don't press, because I am just happy they are coming to the meeting, or, if we have a consultation request, that they attend.

Anne: So the whole committee does consultations?

Judy: The whole committee may do a consultation, but who shows up or is able to make it is another question. We don't have a sub-committee in charge of consultations.

Anne: And who gets the initial call requesting a consultation?

Judy: It comes to me—if I'm not here, [another] social worker on the committee is kind of the second in charge and the call would go to her. I usually talk to the person calling and make some determinations about whether or not we should get together and really review it. Sometimes the situation doesn't require that and I can redirect the person, but if it needs our attention then I generally ask the person that called me who should be at the consultation meeting and what's the best time for them. I know what it's like with all these various disciplines and trying to find a time and if there is a family member coming in and the patient is to be invited. Sometimes with some of our patients it's not a good idea because the patient may not really understand anything, but we always try to invite the patient and the family. We try to work out a

Interview with Judy Levy

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mutually convenient time knowing that families have to come from their jobs or from where they live, which may be at a distance. We try to do it as soon as possible. My secretary sends out an e-mail to everyone on the committee that has e-mail and calls those who don't and says we are meeting at this time for a consultation. Generally we get about five people, which is fine. When we get together we first ask for standard patient information and then we ask everyone who's there (all the patients here have a team, so you can have a lot of people at a consult), we ask the team and family members to tell us what they would like to say about the issue that has been brought to the committee. Then we kind of go over the principles so we understand who's making the decision, what the benefits and risks are. We try to cover all of those bases, and then what we usually do is tell people we are going to discuss it as a committee by ourselves. Then I write the summary and give it to them. Of course, sometimes there is a need to get the recommendations immediately. In those cases, I'll e-mail the person who requested the consult the results of our discussion and let them also know that within 48 hours they will get a hard copy of our recommendations.

... When there is a formal consult we ask for follow-up from the people who originally asked us. So a copy goes to the person who requested the consultation, to the family member involved, a copy is put in the medical record, and I keep a copy in the ethics committee file.

Anne: Are you involved in any community education?

Judy: Recently we did something that included the whole community and I am hopeful we can do more things like this. We invited one of the Kennedy Attorneys, Carol Jacobs, to talk about people with limited capacity giving consent. We talked about guardianship, surrogacy, everything. We searched for ev-

eryone in the last year who had come to Kennedy who was over 18, and we sent an announcement to their parent or guardian. And we invited them all to come. That probably is the most community education we have done, but I think we will be doing more of it. This program really touched on the need of our population of patients for information, because people whose children have always been unable to make these decisions go forward past the age of 18 with their parents thinking that they are still responsible for decision-making, whereas by law they are not. The parents are scared to let go, and guardianship is a big deal to obtain and to even contemplate. So actually surrogacy is a good thing for them to know about.

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

Judy: We have a fact sheet about the ethics committee that is posted in all the various locations by the registration desks. The Patient's Bill of Rights is available at the same location, and has information about contacting the ethics committee. We have, but not consistently, put out ethics newsletters. And periodically we have done two things: 1) we have gone out to various departments as a twosome (members of the committee) and given them an update on the committee—we explain what we do and ask what kind of concerns they might have; 2) we've asked various department and program directors to come and talk with the committee about what they do and what ethical concerns they see in their practice. And then sometimes I am asked to talk to groups, that's becoming a little more common. I think maybe Ethics Rounds has something to do with that increase. For example, just recently I went to talk with our rehab team, they asked me to come and talk about some aspect of ethics. I spoke about values and how our own values influence our ethical opinions and how we can't get away from that, and how sometimes that is at the very root of our disagreements with one another, families and patients and such.

Anne: Do you educate new employees about the ethics committee at their orientation?

Judy: During the orientation day they learn that there is a committee and how to access it.

Anne: What would you say satisfies you most about the work of your committee?

Judy: I think that people are taking this seriously; committee members and other staff are seeing it as a useful committee. I'm really happy about that. I am worried that we aren't getting as many consultation requests, but some say with education, that people learn to deal with ethical issues without coming to the committee. ... But in general I think the committee is a much more vibrant group that's accomplished a lot of growth and development. I think we are coming along. I think our strength has always been having the community and consumer members. And yet I still think we are a fledgling committee. Some of the questions you are asking about are ones I know we need to work on, like having some standard method of educating new members. The problem I see, which I think is a problem in every hospital, is the magnitude of the work that needs to be done and the time and resources allotted to do this work with ethics.

Anne: Well, I think you are doing very well. I thank you for taking the time to do this interview.

Judy: You're welcome.

Kennedy Krieger Institute provides interdisciplinary care for children and adolescents with disorders of the brain, either of congenital onset or acquired through injury or illness.

CALENDAR OF EVENTS

October

- 24** "Caring for Children at the End of Life: Can We Do Better?," lecture by Joanne Wolfe, MD. Fifth Annual Lecture Series in Palliative Care, Hurd Hall, Johns Hopkins Hospital (free for no credit, \$25 for credit for physicians/allied health professionals). For further information call 410.955.3169.
- 5:30 PM**
- 24-27** The Fifth Annual Meeting of the American Society for Bioethics & Humanities, The Wyndham Baltimore Inner Harbor Hotel, Baltimore, Maryland. Registration fees vary. For more information call 847.375.4745 or visit www.asbh.org.
- 28** "Spirituality, Health Care, and the Role of Ethics Committees," co-sponsored by MHECN, The Law & Health Care Program at the University of Maryland School of Law, and Franklin Square Hospital. Franklin Square Hospital, Baltimore, MD, 8:30 AM-4:15 PM. Registration fees vary (maximum \$90). For more information call 410.706.4457 or aoneil@law.umaryland.edu.

November

- 4** "Spirituality in Palliative Care," lecture by Christine Puchalski, MD, Fifth Annual Lecture Series in Palliative Care, 5-6P, Hurd Hall, Johns Hopkins Hospital (free for no credit, \$25 for credit for physicians/allied health professionals). For further information call 410.955.3169.
- 7-8** "Ethics in Healthcare Institutions: New Issues, Controversies, and Practical Considerations," sponsored by the University of Virginia Center for Biomedical Ethics, Jordan Hall Conference Center, Charlottesville, VA. For more information call 434.924.5974, contact cg2b@virginia.edu, or visit hsc.virginia.edu/medicine/inter-dis/bio-ethics.
- 12** MHECN Journal Club discussion at Shady Grove Adventist Hospital. Topic to be announced.
- 7:00 PM** For more information, call 410.706.4457.
- 15-16** "Doctoring in Hard Times," sponsored by The Acadia Institute & The Center for Bioethics, University of Pennsylvania. Will examine the profession of medicine and physicians' careers in an era of dramatic change and challenges. University of Pennsylvania Medical School Campus Biomedical Research Building II/III, 421 Curie Boulevard, Philadelphia, PA. Seating is limited, pre-registration is advised. Visit <http://www.med.upenn.edu/bioethic/events/20021115/registration>. call the Center for Bioethics at 215.898.7136 or e-mail doctoring@savage.med.upenn.edu.
- 18** "State Efforts to Expand Health Care Coverage: Current Realities and Future Possibilities," co-sponsored by the Law & Health Care Program, University of Maryland School of Law and the Johns Hopkins Bloomberg School of Public Health. For more information call 410.706.4128.
- 21** Briefing on The President's Council on Bioethics' recent report, "Human Cloning and Human Dignity." Panelists include Council members Leon R. Kass, MD, PhD, Rebecca S. Dresser, JD, MS, and Paul McHugh, MD. Co-sponsored by the Law & Health Care Program, University of MD School of Law and the Johns Hopkins Bioethics Institute. University of MD School of Law (free). For more information call 410.706.4128.
- 3-4:30 PM**
- 21** "What Research Consents Say and Why it Matters," Medical Humanities Hour Lecture by Nancy King, JD, University of North Carolina. Shock Trauma Auditorium, University of Maryland Medical Center. (free).
- 5-6:00 PM**

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