Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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MID-ATLANTIC ETHICS COMMITTEE NEWSLETTER

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

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Inside this issue:

Letter From the Editor

This issue of the Newsletter marks the beginning of a column called "Moral Musings" by Evan DeRenzo that will appear periodically in future issues. The Column will take the topic of the case study in the issue as its jumping off point. Thus, this issue's topic is about Hospice care and how we can get dying patients into a Hospice sooner. Also in this issue, is information about two resources in the area that some of you may be interested in: The Center for Improvement of Care for the Dying, in Washington, D.C. and the Institute for Bioethics at Johns Hopkins University. Please share with us your thoughts and comments on our new column as well as suggested topics for future issues. We look forward to making the newsletter more responsive to your needs.

Diane E. Hoffmann

MORAL MUSINGS: SEEKING HOSPICE QUICKER

How can we get better at calling Hospice sooner? I think that's the right question for ethics committees to be asking. Certainly it's not "Why don't we call Hospice sooner?" The answer, albeit obvious, is too metaphysically complex to be sufficiently amenable to procedural or policy intervention to be profitably addressed. That is, it's fairly clear that the earlier we call Hospice the earlier we have to admit that we, or someone we love and/or are caring for, is dying. Given that dying is something we don't like and that makes us sad, we avoid it. Ergo, although the answer to the "Why?" question is quickly given, knowing the answer doesn't really help us formulate policies and procedures for encouraging that call to Hospice.

But if we approach that call to Hospice from the "How" direction, we can make more progress towards developing institutional means of assuring that the call gets made and that it gets made sooner, rather than later. To begin with, framing the question procedurally allows us to, a priori, take several issues off the table. That is, by accepting that we need to develop procedures to assure a call to Hospice is made in a timely fashion, we are already saying that we:

1. believe that Hospice ought to be called more often and more quickly than we now do,
2. see Hospice, at least in an abstract sense, as ordinarily assistive to dying patients, their families and their medical care providers,
3. are confident that Hospice provides a standard of care with which we are comfortable, and
4. accept, philosophically, that Hospice offers an appropriate alternative

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NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHCECN)

Since the last issue of the Newsletter, the Baltimore Area Ethics Committee Network has become the Maryland Health Care Ethics Committee Network. Over the summer, interested individuals in Maryland met at the University of Maryland School of Law to discuss the change. There was agreement that given the additional responsibilities placed on ethics committees by the Maryland Health Care Decisions Act and the changing nature of the health care system as a result of managed care, there was a need for a new Network. The new Network will have a statewide focus and have a broader conception of the needs of ethics committees and the types of organizations needing assistance with ethical issues. Thus, it will not only work with hospitals and nursing homes, but also with home health agencies, hospices, and managed care plans. The Maryland Network now has an Executive Committee composed of six individuals from around the state and an advisory committee composed of approximately 30 individuals. Subcommittees have also been established for Membership, Policy Clearinghouse, Case Consultation, Education, and Fundraising. The Network will be co-sponsoring a continental breakfast at the upcoming bioethics conference in Baltimore on November 8th. (See Calendar - November 5-9 - "Visions.") To learn more about the new Network or to become a member call Diane Hoffmann at 410-706-7191.

Virginia Network of Ethics Committees (VNEC)

The Virginia Center for Biomedical Ethics announces a new Center Director: Jonathan D. Moreno, Ph.D. Dr. Moreno graduated from Hofstra University in 1973 with the highest honors in philosophy and psychology, and received his doctorate in philosophy in 1997 from the Washington University in St. Louis. Dr. Moreno has held full-time faculty positions in philosophy departments at Swarthmore College, the University of Texas at Austin, and George Washington University. He has worked on the staff at the Hastings Center and was a philosopher in residence at the Children's National Medical Center. Dr. Moreno currently is a Faculty Associate at the Center for Bioethics at the University of Pennsylvania, and directs that Center's project on Human Research Ethics. He is a Senior Research Scholar of the Kennedy Institute of Ethics at Georgetown and a Fellow of the New York Academy of Medicine, an Adjunct Associate of the Hastings Center, and a member of the Board of Directors of the American Society of Law, Medicine and Ethics. Dr. Moreno has published over 100 papers and book chapters, has written several books and is a member of the editorial boards of *Bioethics, The Journal of Clinical Ethics, and the Health Care Ethics Committee Forum*. He is expected to begin his appointment as Kornfeld Professor for Biomedical Ethics and Director of the Center for Biomedical Ethics in June of 1998.

Bioethics on the Web

Information on bioethical issues, networks and resources can now be found on the internet. There are over 10 web sites devoted exclusively to bioethics in general, with at least 20 more covering specific areas ranging from topics such as health law and policy to euthanasia and hospice care. In the Mid-Atlantic area, the University of West Virginia and University of Virginia both have web sites for their bioethics programs, and these sites like many other bioethics web sites provide links to other related sites and sources. In addition, there are several data bases available providing a host of information and literature on bioethical issues. Two of the more prominent include the National Library of Medicine's Bioethics Database, and Physician's On Line Health Database.

Moral Musings: Seeking Hospice Quicker

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to hi-tech, aggressive medicine when aggressive intervention is no longer appropriate.

And although one can quibble with my wording of these assumptions, the literature points to general consensus on these issues.

Yet still we resist - as the clock ticks away.

Procrastinating on making a call to Hospice, however, has very different implications than procrastinating about other things. Just in the last month I have had three separate reminders of how dragging one's feet to make that call removes the opportunity to have some of the burdens of dying relieved.

> ***"Procrastinating on making a call to Hospice, however, has very different implications than procrastinating about other things."***

The first reminder was a case I recently reviewed in preparation for a talk. The case was of a 31 year old man dying of AIDS. Hospitalized a half dozen times the year he died, he and his mother could not be convinced to contact hospice, or agree to have the hospital make the initial contact for them, until the very end. This man had been in Hospice care less than one month when he died.

The second reminder was the case in the July, 1997 issue of *Medical Ethics Advisor*. This was the story of a 57 year old woman with diabetes who was left permanently vegetative from a cardiac arrest. She was transferred often from nursing home to hospital for treatment of infections. Ultimately, renal failure resulted in her transfer to three different hospitals as the family sought dialysis. Finally, the third hospital's ethics committee forced the issue, in what seemed to me from the printed case as a less than optimal process, and the patient was transferred to a Hospice unit, where she died 48 hours after admission.

The final reminder is my own aunt. In decline the last two years, she had a stroke this summer that left her unable to move and virtually without speech. Even in the face of a joint decision with my aunt, her only daughter, her physician and me not to pursue further aggressive care, there was confusion about accessing Hospice services. By the time the call was finally made the clock had ticked too long. The Hospice nurse arrived just in time to arrange my aunt's body for transport. She had died a few minutes before.

These stories just don't make good sense. I have never heard anyone say that Hospice care made things worse. Rather, the comments about Hospice are invariably that they reduced the patient's and family's suffering and stress. But Hospice can only help if they are given the chance. Coming in hours, days, or even only weeks, before a death gives Hospice precious little time to assist.

Clearly it's not that these patients weren't dying long enough. Persons who die of acute conditions are not usually appropriate candidates for Hospice by virtue of the speed of the disease process. Rather it is those slower, but reasonably well delineated diseases, such as cancer or certain cardiac and pulmonary disorders, that result in a dying process that is optimally managed by Hospice. But how can we get better at calling Hospice more quickly when we have gotten so miserable at deciding when someone is beginning to die? Herein lies my procedural suggestion.

As Dan Callahan points out explicitly in his book *The Troubled Dream of Life* (a must read for ethics committee members and any clinician caring for patients who die), we simply no longer know when someone is dying. Because we are so good at treating, and even sometimes curing, horrible, lethal diseases, we have a very difficult time agreeing on just exactly when a particular individual has started his or her death trajectory. Making the judgment more complicated is that it is not merely a physiological matter, but includes psychological and temperamental factors, as well.

So my suggestion for one procedural change that might help get that call to Hospice made sooner is for clinicians, ethics committee case consultation teams, and hospital discharge planners to ask explicitly, "Has this patient started dying?" when discussing care plans for patients with diagnoses of lethal diseases. It's not that I think asking the question is going to result in agreement on an answer. Quite the contrary. What probably will happen is that everyone will start recognizing how differently each person answers that question for a particular patient or patient population. But by getting the disagreements out and on the table, the promise of compromise is greater and thus is the possibility that that call to Hospice will be made just a little bit sooner than we make it now.

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

Case Study From a Maryland Hospice

Ms. M was admitted to hospice with end-stage breast cancer. We were called into the home by the patient's mother who reported that her daughter had just been told that there was no other treatment available to her. The mother reported that she was physically and mentally unable to take care of her daughter and that the patient's partner would be the primary care giver in the home. The patient's mother and the patient's partner were present when the admission nurse was sent into the home.

Upon arrival the admission nurse asked to speak to the patient. The patient's partner refused to allow the nurse to assess the patient unless the nurse promised not to identify herself as a hospice nurse. The partner then added the threat of legal action if the nurse or any other hospice staff member tried to discuss hospice care with the patient.

The nurse agreed to remove her name tag. She and the patient's partner visited with the patient. The nurse assessed the patient to be alert and oriented and able to make her own medical decisions. The hospice nurse was unable to persuade the family to allow her to discuss hospice with the patient. The patient was not admitted at that time and the nurse reported the case to the members of the interdisciplinary team. The nurse felt that the patient and the patient's family were in critical need of hospice services but that she could not deceive the patient about who she was and the services she was going to offer.

All the team members agreed that the patient and the family would benefit from hospice and a decision was made to admit the patient to the hospice. Concerns regarding the legality of allowing the patient's mother to sign the admission paperwork were raised and discussed. A nurse and social worker were assigned. Both felt comfortable and confident that the situation would change once hospice services were initiated.

Follow-up: The social worker came to understand that the patient already knew we were hospice workers and that she was dying. She wanted her family and her partner to make whatever decisions needed to be made. Midway through her hospice stay, the patient's partner suggested a "final try" of chemotherapy. The primary nurse discussed the decision with the physician who agreed to administer the chemotherapy. He agreed that it would offer no medical benefit to the patient but that he didn't want to be the one to take away "all of their hope." The patient died in our program before receiving the chemotherapy. The patient and the partner grew distant throughout the last days of the dying process as the patient, her mother and the hospice staff prepared for her death.

Case Discussion: Comments From a Hospice Administrator

Professional duties, contractual obligation, truth-telling and informed consent are the standard ethical issues in this case. However, there are fuzzier issues, too: access to hospice, the therapeutic nature of hope and the hospice standard of treating the family rather than just the patient as the unit of care.

Despite years of public advocacy for enhanced patient self-determination, many patients want others to make choices for them. Law and regulation may require informed consent for admission to hospice, but neither this patient nor those who most loved her valued the explicit level of information presumed necessary for adequate consent. Even the hospice workers, agents of a licensed health care facility, saw the consent forms as "paperwork" and for the time at least, allowed the wrong person to sign it so that the patient/family could get the hospice care the team thought was critically necessary.

This case raises a variety of troubling questions.

- Was the physician who initially disclosed to Ms. M. that she had no other treatment options the one who was willing to give her chemotherapy without medical benefit so he would not have to "be the one" to take away her family's hope? The patient may have deferred decisions to her family, but she, not they, was still the primary subject of his care and professional obligation.
- Was the physician going to bill the patient's insurance for this medically unwarranted chemotherapy? Was he planning to falsely attest to its medical necessity so the bill would be paid?
- Did the physician plan to treat the patient without explanation? Would he have withheld from her his opinion of its futility so that her hope would remain intact?
- What would the chemotherapy have cost the patient? Money? Inconvenience? Discomfort?
- Had the hospice Medical Director discussed the proposed chemotherapy with the physician and had the nurse reported to the patient her physician's opinion?
- Earlier on, had the primary physician recommended hospice when it became an appropriate treatment option? Perhaps he wanted the hospice team to facilitate family communication or wanted the nurse to teach the patient, help her confront the reality of the prognosis and act as her advocate. Or, did he just not give much thought to hospice as an available "treatment." Possibly he even withheld information about hospice, believing such a suggestion would erode hope.

- Initially Ms. M's mother reports her own physical and mental incapacity to care for her daughter. Did the doctor and admitting nurse perceive a similar incapacity in Ms. M. such that she appeared initially incapable of handling the truth about her prognosis?

- As it appears, was hospice care started without the patient's signed consent or were pre-admission visits for information just extended for a time until proper consent was given? If hospice care started on the mother's consent alone, what reason was written on the consent form explaining the reasons for the mother's signing in lieu of the patient? Did a member of the hospice team go so far as to sign as witness to a lie? Is this a hospice with such hubris that it believes it is above the law?

- Is hope so powerfully therapeutic that its benefits override honesty and accountability? On the face of it, neither physician nor patient appears to have wanted accountability for treatment decisions. Both seemed to have opted for the gray zone of knowing and yet not knowing so that hope would not flee. In our lived experience, this gray zone is familiar territory.

Good health care law and ethical analyses are meant to clear up this murkiness. During the second half of this century we ardently strove to clarify patient's rights and to enforce respect for them. Physicians were often portrayed as paternalistic enemies of these rights routinely withholding information, ordering futile treatment, participating in conspiracies of silence. Then laws changed. Informed consent became the rule. Patient choice prevailed. But this recognizable hospice case reveals a continuing disparity between patient wishes and prevailing opinion, between life's ambiguities and our yearning for clarity.

The characters in the case are little antiheroes. A competent patient foists her treatment decisions on others. A mother is just not up to the physical and mental challenges of her last remaining mothering opportunities. A physician lacks the courage to profess his calling, in this case to "be the one" to inform his patient that a requested medical treatment is medically hopeless. He also presumably lacks the honesty to square with the people who will pay for it. A partner bars open communication by aggressively and prematurely threatening legal action. A nurse removes her name tag. A health care administrator allows someone without legitimate authority to sign consent forms.

Everyone subscribes to the principle of muddling through. The nurse reports her physical and psycho-social assessment to the interdisciplinary team. Doubtless having experienced countless similar situations, they anticipate that in their own time and way the patient, her mother and her partner will eventually talk openly about the prognosis, acknowledge facts and share feelings. Soon the social worker discerns the patient's awareness of and tacit consent for a hospice plan of care. The antagonistic partner eventually trusts the nurse to communicate his wishes for a "final try" of chemotherapy with the physician. The physician never actually performs the futile treatment. The family realigns. The mother rises to the occasion of her child's dying and becomes the primary caregiver. The patient prepares for her own death. Correct legal and ethical form may be absent but the "hospice effect" takes.

"But this recognizable hospice case reveals a continuing disparity between patient wishes and prevailing opinion, between life's ambiguities and our yearning for clarity."

I do not wish to suggest that the end justifies the means. But I do want to explain some of the factors which complicate cases like this. One is the hospice standard (and regulation) to consider not just the patient but also the family as the unit of care. A whole person is dying; the family is integral to that person. This is why hospice care in the form of bereavement support continues after the patient dies.

Consistent with this holistic theme, a patient's psychological disposition, perceived spiritual dimension and personal history along with his social relationships are supposed to be featured in the care plan written by the interdisciplinary team. From the U.S. hospice movement's beginnings in the mid seventies until this day, care of the whole dying person has been the rationale for the medically directed and nurse coordinated hospice interdisciplinary team of professionals and trained volunteers. National professional standards and federal regulations stipulate that this team minimally include nurse, doctor, pastoral counselor, social worker and volunteer.

Having such a group from various professions develop a realistic, attainable care plan with consideration to the patient's and family's physical, social, psychological and spiritual needs is no small challenge. (A physician pioneer of the hospice movement, Balfour Mount, once remarked on film to anyone claiming to work on an interdisciplinary team: "Let me see your scars!") Yet ethicists, courts and insurance companies typically view only the patient as the unit of care.

Even health care plans with hospice benefits referring to the patient and family as the "unit of care" consider the beneficiary a discrete unit. They require a competent beneficiary's own signed authorization for payment to health care providers. They require that treatments be medically necessary. They establish contracts with both beneficiaries and health care providers to which all three are legally bound. Courts view patients as citizens with legal rights not to be compromised by the arbitrary wishes, traditions, and inclinations of family and community. Despite concessions that accountability may be modified by social circumstance, typical legal and ethical analysis focuses on individuals.

Hospice values on the other hand are largely communitarian. Although patients' rights to know their terminal condition, to refuse treatment, to choose dying at home rather than in a hospital, and even their

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"right to die" energized the US hospice movement of the 1970's, much of its imagery and lore reveals pre-modern images of patients. We continue to refer to our medieval roots as a place of refuge for travelers on life's journey. We urge communities to embrace and cherish these travelers, recognizing that we are all on the same journey from one life to the next. While advocating advanced pain control techniques we also value compassion—shared suffering. We say "hospice is a caring community" or "hospice is a special kind of caring" or "volunteers (community) are the heart of hospice." Our brochures and posters depict hearts, trees of life, hands clasping, poignant embrace, and silent but warm communication.

Like hope, the imagery is a powerful force. Hospice ideals probably motivated this team to muddle through. Sometimes a world in which knowing is reduced to information, a world of consent forms, unequivocal statements, logical analysis, and contracts seems especially strange.

Nevertheless, this hospice and its agents are obliged to respect the law and tell the truth while remaining faithful to their ideals and sensitive to the suffering.

Marion F. Keenan
President, Coastal Hospice
Salisbury, MD and
President, Hospice Network
of Maryland

Case Discussion: Comments From a Bioethicist/Hospice Chaplain

It happens more often than we'd like. The patient is terminally ill. The patient and family or supporting community need medical expertise, and physical, emotional, and spiritual help to keep the patient comfortable at home. Hospice provides all of this plus particular skills and experience in caring for the dying. Perhaps the patient is covered by Medicare, and is eligible for the Hospice Benefit under Medicare, which covers 100% of diagnosis - related costs for care managed by a Medicare - certified hospice. So Hospice is called in, and then comes the sticking point. The family doesn't want the patient to know that she is terminally ill. The "D" word is forbidden. The family expresses concern for the patient and fear that the patient will give up hope. Therefore the "H" word - Hospice - is also forbidden and the nurse is asked to remove her badge before seeing the patient.

What's a hospice worker to do? You believe strongly that the patient would benefit from your services. There are many signs indicating, in fact, that both the patient and the family are desperate for your services: pain is out of control. Nausea or mental status changes have brought on a crisis. Family members are exhausted. The house is a mess. You have the skills and the support of an interdisciplinary team to turn the situation around and provide comfort for the patient, which is your primary goal. Furthermore, you have a mission, both personal and institutional, of providing hospice care to all who want it and are eligible for it. Why let a badge or name tag get in the way of doing such an obvious service?

The case we have here follows this pattern. It is complicated by the presence of the patient's partner, someone with whom she has a committed but not legally recognized relationship, and by the partner's threat of undefined "legal action." The partner and the mother may have been in disagreement about calling for hospice services. The hospice nurse is stuck in the middle. What she is dealing with is a proposed violation of the patient's autonomy.

Autonomy, often stated as "patient choice," is a core foundational principle for the hospice philosophy, coming from a history in which a patient had to make an assertive choice to be cared for and to die at home with hospice services, rather than to die in a hospital. As frequently happens, autonomy is pitted here against beneficence, the professional's desire and even obligation to act in the patient's best interest and benefit. As the case unfolds, the staff clearly recognized the threatened violation of the patient's autonomy, as seen by the nurse's refusal to admit the patient under these circumstances. This patient has the right to make decisions regarding her treatment, a right that clearly will be violated if the hospice provides care which is palliative, rather than curative, without the hospice staff, the physician, or the family providing her with the information which she needs to make that choice. Furthermore, she has the right to know who is providing her care, to know that the nurses treating her are hospice employees. To do otherwise is as deceptive as taking her to be admitted to Hospital "A" while telling her that she's actually in Hospital "B."

> ***"Therefore the "H" word - Hospice - is also forbidden and the nurse is asked to remove her badge before seeing the patient."***

In order for Ms. M. to make these decisions she must be capable of understanding the appropriate information provided to her and the consequences of the available choices. I would not quarrel with the nurse's removal of her badge in order to determine that she was indeed alert, oriented, and capable of making medical decisions. Had she been reasonably assessed as incapacitated, and had no durable power of attorney or written legal proxy, her mother would have been the one to make decisions for her under Virginia law. The presence of the partner, without marriage, is an emotional complication but not a legal one.

Without an Advance Directive naming him or her as decision-maker, s/he has no rights to determine Ms. M.'s treatment or care provider, even if Ms. M. were incapacitated. The threat of legal action is an empty one, unless s/he owns the home and wants to accuse the hospice nurse of trespassing.

But Ms. M. is clearly capable of decision-making, and has not, in the narrative as written, asked anyone else to speak for her. If she were hospitalized in an emergency situation the partner would not call the shots. The realistic difference in hospice is one of turf. It is unrealistic to try to provide honest hospice care to the patient against the wishes of her partner in a home she willingly shares with the partner. If the partner is making threats it may also be unsafe for staff.

It was appropriate to refuse to admit the patient. The concerns about the signing of the paperwork were also appropriate; the consent to admit to hospice care, acknowledging the understanding that the goal of the treatment provided will be comfort and not cure, must be signed by the patient unless s/he is clearly incapacitated. The decision by the team to admit the patient, even though based on good intentions and a desire to help, was inappropriate. Even with good intentions, medical care forced on someone against his or her will or without his or her consent has long been determined to be battery.

What are the effects of this well-intentioned deception, of providing care without being clear up front with the patient about the identity of hospice staff? Deception is an assault on trust. I remember hearing in a team meeting once about a family who didn't want to take away Grandpa's "hope," and therefore had told him that the nurses who would be visiting were "the nice ladies who are coming to make you better." When Grandpa doesn't get better, he has good reason to mistrust the competence of the nurses. If Grandpa eventually discovers the identity of the nurses who have been lying to him, how can he trust their truthfulness in other care-related matters? Such a deception is also an assault on the integrity of the hospice professional, who is forced to continue to lie to the patient about the purpose of the visits. The decision to admit based on the confidence that the patient and family can be "brought around" is paternalism at its worst.

The deception also causes harm to the family unit. Unable to be honest with one another, and to share their grief and other emotions around the coming death, they are robbed of intimacy and openness with one another. The perpetuated falsehood hiding the terminal prognosis isolates the patient, and robs her of the chance to make plans, arrange her affairs, say her goodbyes. This is not to say that everyone must face death openly and with acceptance, in some kind of "hospice-approved fashion." But it is one thing to choose to be in denial, to insist that one will still "lick this disease no matter what the doctor says." It is another thing never even to know what the doctor says. Gentle truthfulness, given in a sensitive and compassionate manner with the promise of continued presence and support, respects the patient's autonomy. It is also respectful of her autonomy to allow even the capacitated patient to designate others to make decisions for her, as this patient ultimately did. But to do that, she must know enough to acknowledge that she is in a situation where decisions will have to be made, and she must make that designation clear to her professional care providers.

Finally, the muddle of providing care without shared acknowledgment of the goal of the therapy led to the agreement to provide the "final try" of chemotherapy, a treatment certainly not known to enhance physical comfort, despite the agreement by all except the partner that the treatment would be futile, of "no medical benefit." The narrative does not even indicate that Ms. M., herself wanted, asked for, or agreed to this chemotherapy. Was it agreed upon for her benefit, or to support her partner's denial? Did the primary nurse discuss it with the physician because she thought it was in the patient's best interest, or because she still feared the partner and his or her threat of "legal action"? One can be grateful that the patient died before receiving this "treatment," which would have been an abuse of resources, a detriment to the goal of comfort, and emotionally fraudulent.

It is not clear from the narrative whether the patient grew distant from the partner, or the patient and her partner grew distant from the staff. Either situation is the usual result of this kind of deception, as the patient begins to recognize that she is indeed growing worse and approaching death, that those around her know it and are lying to her, and that their denial is blocking her final communications. The gift that hospice can give to a dying patient is the promise to be present, to be open, to listen to her story, and to do all that is possible to provide physical comfort and emotional/spiritual support. We cannot do this if we have helped to create an environment without trust in this most intimate of times in someone's life.

Hospice has to be willing to help all patients who want us, but not against their will or knowledge. We are not the only ones who can provide home care for the dying; it is arrogant to think we are. In this case, once the admitting team had provided assurance of the positive aspects and necessity of being honest with the patient about hospice services, and tried to convince the family of their sensitivity and gentleness, it would have been better to have facilitated admission to a home health agency until such time that hospice care was the patient's informed choice.

Jeanne Brenneis, Chaplain
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CENTER TO IMPROVE CARE OF THE DYING

As medical technology advances, people are living longer and healthier lives. Yet, we all still die. Though it is true American health care has seen great development in many areas, the system has done very little to meet the needs of those who are dying. The Center to Improve Care of the Dying (CICD) at George Washington University was established to help fill this void. The Center is dedicated to having people confident of a meaningful and comfortable time as their lives come to a close.

CICD opened September 1, 1995 at the George Washington University Medical Center in Washington, DC. It is a unique, interdisciplinary organization committed to research, education and advocacy to improve care of dying patients and those suffering with severely disabling diseases. Its broad perspective is achieved by the incorporation of insights and experiences from social sciences, humanities, law, epidemiology, health services research and ethics.

The Center's promise, " to care always " embodies the sentiment and commitment of its staff, headed by Dr. Joanne Lynn. Dr. Lynn is a nationally known physician whose career has been devoted to very old, disabled and dying persons. She has been a hospice and nursing home physician and is a respected ethicist. In addition, CICD has a multi-disciplinary staff working to further the Center's promise.

From a broad perspective, CICD furthers its goal by moving in multiple arenas, hoping to effectuate change. Improving end-of-life care needs to be made a national priority. Several current projects at CICD encourage the development and realignment of healthcare funding mechanisms to provide the most relevant care. Staff speak to a variety of groups and sit on various committees and task forces to ensure a wide audience for the message of the Center to Improve Care of the Dying.

One of the most visible projects CICD completed in the last year was an amicus brief to the U.S. Supreme Court on behalf of the American Geriatrics Society for the cases involving physician-assisted suicide. The brief was quoted in the oral arguments before the Court in January of 1997. The Court subsequently decided in June that the right to assistance from physicians in hastening death was not a fundamental right guaranteed by the U.S. Constitution. Instead, the issue of legalization will now go to the state legislatures and may be a "hot" topic this year in upcoming legislative sessions.

In anticipation, staff at CICD is working to publish a guide for citizen-advocates who are looking to enter the debate and perhaps influence state legislators on this question. The guide will discuss the present state of end-of-life care, proposals on how to improve it, and difficult issues surrounding death. There is also a parallel book being drafted at CICD which will be geared toward legislators and their staffs.

Another main project at CICD is the development of a proposal called "*Medicaring*." This project extends the concept of hospice to include a broader population of terminally ill individuals than currently benefits from the Medicare hospice program. *Medicaring* would provide comprehensive, supportive, community-based services that meet personal and medical needs, enhance the priority given to patient autonomy and preferences, provide good symptom management, and ensure family counseling and support. Among other things, *Medicaring* will define financing strategies, recognize family role, and identify appropriate limits on medical interventions. *Medicaring* envisions a delivery system that tailors services to the last phase of life and pays for them in a way that encourages excellence (capitated payment to a multidisciplinary team).

The Center to Improve Care of the Dying also seeks to examine contemporary challenges to both the practice and policy of ethics. Decision-makers at all levels need to be made aware of all of the issues surrounding care at the end of life and ethical dilemmas abound when a family member or close friend is close to death. At CICD, we hope to engender more understanding of what a "good" dying might be and what cultural expectations need to be reshaped before we can arrive at a better level of care.

The Center to Improve Care of the Dying (CICD) was founded in the belief that life under the shadow of death can be rewarding, comfortable and meaningful for almost all persons—but achieving that goal requires real change in the care system.

Janet Heald Forlini, J.D.
Center To Improve Care of the Dying
Washington, D.C.

THE JOHNS HOPKINS BIOETHICS INSTITUTE

Whether providing ethics case consultation for patient care, conducting focus groups for research on topics such as genetics and privacy, or working with state agencies on ethical legal issues to improve care for terminally ill patients, faculty of the Johns Hopkins Bioethics Institute share a similar philosophy: bioethical issues transcend narrow disciplinary concerns, and fruitful discourse requires an interdisciplinary approach and broad based scholarly exchange. This approach is reflected in the unique structure of the Bioethics Institute. Established in 1995 as a University-wide endeavor, it provides an intellectual home for faculty in all divisions of the University and Health System whose research advances bioethical inquiry. The mission of the Institute is to bring the moral dimensions of medical care, health policy, and the biological, behavioral and social sciences to the forefront of scholarship and practice.

Ruth Faden, PhD, MPH, is director of the Bioethics Institute and the Philip Franklin Wagley Professor of Biomedical Ethics at Johns Hopkins. Appointed by President Clinton to chair the Advisory Committee on Human Radiation Experiments, Dr. Faden is a senior research scholar at Georgetown University's Kennedy Institute of Ethics, a fellow of the American Psychological Association, a fellow of The Hastings Center, and a member of the Institute of Medicine. She is the author and editor of numerous books, including *A History on Theory of Informed Consent* (with Tom L. Beauchamp) and *Ethical Issues in Social Science Research.*

The Bioethics Institute's mission includes education, research and service to the wider community. It intends to be a vital force for raising the level of public discourse about the bioethical dilemmas that beset contemporary American society.

The Bioethics Institute builds on the existing ethics courses and educational programs in the Johns Hopkins Schools of Arts and Sciences, Medicine, Nursing, and Public Health. (Hopkins is one of the few universities in America with all three health divisions.) Bioethics Institute faculty hold faculty appointments in these schools, where they teach ethics courses, conduct seminars, and lead "ethics rounds." Their goal is to see that all Hopkins students acquire skills for examining the moral dimensions of professional work and for fulfilling lifelong civic responsibilities.

Two educational programs provide unique interdisciplinary opportunities for the study of bioethics. A combined JD/MPH degree program offered jointly by the Johns Hopkins School of Public Health and the Georgetown Law Center prepares students for careers at the nexus of law, ethics, public health, and medicine. The Greenwall Fellowship Program in Bioethics and Health Policy, also jointly administered by Johns Hopkins and Georgetown Universities, provides intensive two-year postdoctoral training and includes an internship at a government agency, Congressional health committee or private institution involved in health policy.

The Bioethics Institute is dedicated to the scholarly study of complex moral and policy issues and facilitates interdisciplinary research and collaboration among philosophers, social and behavioral scientists, biomedical scientists, nurses, physicians and public health professionals. Research falls into five broad categories: the ethics of public health policy, the ethics of health care delivery, the ethics of clinical care, the ethics of biomedical research, and the ethics of genetic science. Questions of policy are a priority of the Institute.

Areas of faculty research include AIDS, advance directives, reproductive rights, privacy and advances in genetics, managed care issues, the rationing and allocation of resources, and research ethics. One current policy initiative is a joint project with the Maryland Attorney General's office to assess the impact of the legal system in Maryland on care at the end of life. Led by Ruth Gaare, JD, MPH, associate director of the Bioethics Institute, the Robert Wood Johnson-funded initiative seeks to encourage coalitions among government officials, health care professionals and facilities, health care funders and patients to identify educational efforts and policy reforms that promote better care for terminally ill patients.

LETTER TO THE EDITOR

"Bioethicists as Philosopher Kings"

In continuing the Newsletter's reflections on Ruth Shalet's critique of bioethicists, I want to comment on some emerging problems of bioethics consultants as expert witnesses.

Bioethics consultants usually work in a multidisciplinary institutional committee environment where members, drawn from different relevant fields and walks of life, are each considered a potential contributor to resolving the particular dilemma in patient care presented to them. Any one of them, in consulting on a case involving a contentious difference of opinion, could theoretically be asked to serve as an expert witness, in a court proceeding.

There, their unfamiliar bioethics profession, qualifications, and subject matter are likely to be questioned. And the recently heightened judicial caution in accepting expert testimony could subject their testimony to further scrutiny. This caution flows from the Supreme Court decision in *Daubert v Merrell Dow Pharmaceutical, Inc.* (1993), giving judges a "gatekeeper" role in judging the admissibility of "novel or scientific" evidence in a given case.

To explore this situation, we can briefly consider two possible gatekeeper questions addressed to the bioethics consultant community.

1. What or who is a bioethicist? Compared with the rather clearly established specialties of traditional scientific and medical experts, the bioethics expertise of philosophers, pastoral counsellors, or community members who serve for years on bioethics committees and consider themselves bioethicists appears difficult to specify for judicial proceedings. On this account, Douglas B. Mishkin, an attorney-member of two hospital ethics committees, faults the bioethics community for not generating "any formal guidance" for judges on the nature of bioethics expertise. Warning of "heightened attention to the issue of standards for the admissibility of bioethics expert testimony," he suggests that the community call itself "experts in bioethics" rather than bioethicists. (1)

Mishkin's alert is important, although he appears to be unaware of the existence of the Society for Bioethics Consultation and its ongoing collaboration with the Society for Health and Human Values to develop standards for bioethics consultation.

2. What is the subject matter frame of reference on which a bioethicist

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draws for counsel and recommendations? It will require the utmost conviction and skill on the community's part to clarify, for the judges, the differences between ethical and clinical and overcome legal skepticism of the apparently "soft" principles and criteria undergirding ethical reasoning about dilemmas in medical care. Justices will have to be familiarized in some way with the generally accepted codification of ethical principles, obligations, rights, virtues, and ideals in order to understand how this can sharpen awareness of ethical values and bring orderliness into the expert's reasoning and presentation.

Two very different current activities may help judges better understand bioethics reasoning. One is a series of regional conferences for state and federal court judges on the analogous problem of clarifying the nature of evidence in cases involving genetics, molecular biology, and biotechnology. (2)

The second is the joint effort of the Metropolitan Washington Bioethics Network and the D. C. Superior Court which has created three ethics panels (from Network membership) to work with the judges on specific local cases, particularly those involving guardianship issues.

Kathryn S. Arnow, M.A.
Bioethics Task Force
Home Care Partners
Washington, D. C.

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(1) Mishkin, Douglas B. Profferring bioethicists as experts. The Judges' Journal. Vol. 36, No.3. (Summer, 1997). Chicago, American Bar Association. Pp. 50-51, 88-89.

(2) [Editorial] Genetics in the courtroom: an introduction. Ibid. P.1.

Errata

Judith Littlejohn, RN, MS is a Professional Staff Member to the Maryland Board of Nursing and **not** a Member of the Board as was stated in the Summer 1997 issue, "Case Discussion: Comments From a Nurse/Attorney and a Member of the Maryland Board of Nursing," on page 8.

CALENDAR OF EVENTS

OCTOBER

31 The Third John E. Jones Lectureship on Medical Education and Health Policy, 7:45 a.m. to 11:30 a.m., Main Auditorium, Robert C. Byrd Health Sciences Center, Morgantown, WV - "The Future of Medicine" - Co-sponsored by the West Virginia Rural Health Education Partnership and The Center for Health Ethics and Law.

NOVEMBER

1 "Assistance in Dying: Is it Ethical? Should Physicians Be Involved?," to be held at Anne Arundel Medical Center, 64 Franklin Street, Annapolis, MD. To register, or for more information, call 410-267-1732 from 9:00 a.m. to noon.

1 "Medicine and Science in the 21st Century: Bioethical Issues," to be held at the Virginia Biotechnology Research Park, Richmond VA. This conference co-hosted by the Science Museum of Virginia, United Network for Organ Sharing, Virginia Biotechnology Research

Park and Virginia Commonwealth University, will have various speakers who will be discussing the bioethics of defining death, organ transplantation, genetic counseling, clinical research, reproductive medicine, economic issues in health care and uses of biotechnology in the food industry. For more information contact the conference information hotline at 804-367-6795 for program information, or 804-330-8530 for registration information.

5-9 The American Association of Bioethics, the Society for Bioethics Consultation, and the Society for Health and Human Values present: "Visions for Ethics & Humanities in a Changing Healthcare Environment," to be held at the Marriott Inner Harbor Hotel in Baltimore, Maryland. For more information call 703-556-9222 or e-mail shhv@aol.com.

12 Wilhelm S. Albrink Memorial Lectureship in Bioethics, "The Patient in the Family: An Ethics of Medicine and Families," presented by Hilde Nelson, PhD, Director of the Center for Applied Professional Ethics at the University of Tennessee - Knoxville. This lecture, available for viewing over MDTV will be held in the Addition Auditorium of the Robert C. Byrd Health Sciences Center, Morgantown, WV. For more information contact Cindy Jamison at 304-293-7618.

DECEMBER

9 Ethics Grand Rounds (title to be announced) will be held at 12:00 noon, Addition Auditorium, Robert C. Byrd Health Sciences Center, Morgantown, WV - available for viewing over MDTV

9 The Metropolitan Washington Bioethics Network presents "The Last Mile of the Way: Ethical Right of Ethical Death." Speaker Helen Chapple RN, MA from the University of Virginia. For more information contact Joan Lewis 202-682-1581.

MARCH

23-28 The Center for Biomedical Ethics at the University of Virginia is presenting "Developing Hospital Ethics Programs," a unique six day course of study for healthcare professionals. This program offers CHE and CME hours. The course is designed to facilitate or strengthen the implementation of an ethics program within hospitals and other health care institutions. The DHEP program encourages discussion of the theoretical and practical aspects of a working program in patient care ethics and organizational ethics through a series of highly interactive sessions. For more information contact Ann Mills at 804-982-3978.

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